In-Home and Residential
Long-Term Supports and Services
for Persons with Intellectual or
Developmental Disabilities:
Status and Trends 2015



**Residential Information Systems Project** 



# In-Home and Residential Supports for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2015

### **Residential Information Systems Project Report**

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#### **University of Minnesota**

Sheryl Larson, Principal Investigator Heidi Eschenbacher, Lynda Anderson, Sandy Pettingell, Amy Hewitt

National Association of State Directors of Developmental Disabilities Services
Mary Sowers, Mary Lou Bourne, Subcontract Principal Investigator

#### **Human Services Research Institute**

Brittany Taylor, John Agosta, Subcontract Principal Investigator

#### National Residential Information Systems Project (RISP)

University of Minnesota: College of Education and Human Development Institute on Community Integration/UCEDD: Research and Training Center on Community Living 210 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455

#### 2015

This report is available online at https://risp.umn.edu/publications.

Contact the project through our email address, risp@umn.edu, to request a print copy or to request technical assistance to interpret or customize tables.

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Report layout and design by Sarah Hollerich

Project Technical Staff: Kristin Dean, Jonathon Waltz, Shawn Lawler, and John Westerman

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#### **PREFACE**

#### Note to Our Readers

The Residential Information Systems Project (RISP) at the University of Minnesota has reported the living arrangements of long-term supports and services (LTSS) recipients with intellectual and developmental disabilities (IDD) since 1977. It has fielded annual surveys of state IDD agencies since 1988 when the project was first funded by the Administration on Intellectual and Developmental Disabilities (AIDD, formerly ADD).

Between 1977 and 2015, the locus of Medicaid-funded LTSS for people with IDD shifted from large state-operated IDD institutions to services provided to people living in their own homes, with a family member, or in another home and community based setting. The proportion of Medicaid Waiver recipients with IDD living in the home of a family member first exceeded 50% in FY 2011. Acknowledging the increased role of families in supporting people with IDD receiving publicly funded LTSS, the Administration on Community Living funded an additional Data Project of National Significance to describe people living in homes of their own or with family members.

The Supporting Individuals and Families Information Systems Project (FISP) began in October 2011 and concluded September 2017. It was a partnership between the University of Minnesota, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI). Through the combined efforts of the RISP and FISP projects, we conducted several special studies on supports for families, expanded the annual survey of state IDD directors to include more information about people living with family members or in their own home, updated our data collection and dissemination platforms, and created several new products targeting families and family advocates. The last FISP project report (for FY 2014) was published at the end of calendar 2016.

Knowing that the FISP project was ending, we spent the last year merging the FISP and RISP project activities and products. We expanded this FY 2015 RISP report to incorporate key FISP findings. We modified or reordered several tables and figures and shortened the annual survey of Public Residential Facilities. We also moved the detailed annual state level data on Medicaid ICF/IID and Medicaid Waiver recipients and expenditures from the RISP report to the Chart Gallery section of the RISP.umn.edu website.

We hope you enjoy the updated RISP content and products. As always, if you have questions about the report or the findings please contact us at <a href="mailto:risp@umn.edu">risp@umn.edu</a>. We will continue to refine and expand our product offerings based on the requests and feedback we receive from readers.

Sherri Larson, RISP Principal Investigator



#### **A**CKNOWLEDGEMENTS

The RISP project conducts annual surveys of state IDD agencies and state-operated IDD facilities serving 16 or more people. We are indebted to the many people who returned FY 2015 surveys and responded to questions to clarify their responses. The RISP project would not be possible without their knowledge, expertise, and generous assistance.

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

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

Lisa Sinclair is the liaison between the RISP project and the Centers for Disease Control's Healthy People 2020 project. The authors thank the staff at the University of Minnesota's Institute on Community Integration, Human Services Research Institute and NASDDDS for their contributions to the FISP project special studies; and FISP and RISP data collection, product development and dissemination activities. The UMass Boston advisory committee also provided input about the FISP project products.

We thank Jennifer Johnson, Ophelia McClain and Katherine Cargill-Willis and their predecessors at the Administration on Intellectual or Developmental Disabilities and Dawn Carlson, at the National Institute on Disability, Independent Living and Rehabilitation Research at the Administration on Community Living for their ongoing support of the RISP project.

Finally, we thank the individuals, families, advocates, researchers, students, teachers, providers and policy makers who use RISP findings to inform policy and practices for proving supports to people with IDD and their families.

#### STATE CONTACTS

#### **Alabama**

Daphne D. Rosalis Andy Slate Courtney Tarver

#### Alaska

Duane Mayes Anastasiya S. Podunovich

#### **Arizona**

Maureen Casey
Patrick Hays
Benjamin Kauffman
Laura Love
Rebecca Lynch
Bruce McMorran
Nicholas Romani
Kim Simmons
Pat Volle

#### **Arkansas**

Tammy Benbrook Teresa Bailey Glenn Clark Theresia Keith Shenna May Ann Marie Hatcher Melissa Stone Jane Ziegler

#### California

Nancy Bargmann Steve Burke Jerry Curteman John Doyle Ryan Langen Carie Powell

#### Colorado

Domenica Blom Karen Briggs Craig Michele Chris Mueller Joshua Negrini Barbara Ramsey Tammy Pickup

#### **Connecticut**

Victoria Berman Tim Braziel Timothy Deschenes-Desmond Martha Donovan Kathy Hanewicz Morna A. Murray Berneda Powell Denise Riberio Josh Scalora Jordan Scheff Robin Wood

#### **Delaware**

Jill Rogers Valerie J. Smith Lennie Warren Adele Mears Wemlinger

#### **District of Columbia**

Olga Figuera Erin Leveton Laura L. Nuss

#### **Florida**

Susan Chen Cindy Millican Susan Nipper Barbara Palmer Tony Reed Holli Rutledge Heather Traylor Geraldine Williams

#### Georgia

Ginger Bowman Dan Howell Esther Park John Quesenberry Ronald Wakefield

#### Hawaii

Mary Brogan Wendie Lino Debra Tsutusi

#### Idaho

Toni Brinegar Arthur Evans Cameron Gililand Aaron Haws

#### Illinois

Tom Armitage Gregory A. Fenton Reta Hoskin

#### Indiana

Kylee Hope TG Williams

#### Iowa

Theresa Armstrong Linda Bailey Norm Edgington Melinda Hayes Suzanne Fross Linda Kellen Kim Rose Rick Shults

#### Kansas

Bethany Griffeth Brandt Haehn Tim Posch Bill Schneider George Van Hoozer Brent Widick

#### Kentucky

James Kimble Claudia Johnson

#### Louisiana

Kristy Flynn Beth Jordan Mark Thomas Jane Walker

#### Maine

Cindy Eurich Daniel Sylvester

#### Maryland

Shelley Amick Maryjane Osazuwa Bernard Simons Robin Weagley Bernard Zenis

#### **Massachusetts**

Bill Burke Elin Howe Kris Silverstein Hans Toegel Margaret Van Gelder

#### Michigan

Dick Berry Kathleen M. Haines Lynda Zeller

#### Minnesota

Alex Bartolic Patti Harris Melanie Fry Sarah Thorson

#### Mississippi

Steven Allen Renee Brett Lori Brown Deborah Etzold Leigh Evans Tina Hester Kevin Howell Beth Luper Beverly Magee Rinsey McSwain Penney Stokes

#### Missouri

Betty Coleman George Fizer Valerie Huhn Rebecca Post Gary Schanzmeyer Carmel Seal Tonya Piephoff



#### **Montana**

Karen Corpron Jennifer Finnegan Novelene Martin Tammy Ross

#### Nebraska

Anna Bromberg Brandon Clark Joe Dodlinger Yvonne Eckhoff Elton Edmond Brad Wilson Courtney Miller Scott Hartz

#### Nevada

Eddie Ableser James Cribari Kate McCloskey Matt Stolle

#### **New Hampshire**

Ken Lindberg Christine Santaniello

#### **New Jersey**

Husam Abdallah Diane Armstead Robert Armstrong Dwight Booker Patrick Boyle Anthony Brindis William Cooper Elizabeth Shea David Thomas

#### **New Mexico**

Christopher Futey Kathyleen Kunkel Cathy Stevenson Chloe Tischler-Kaune

#### **New York**

Christine Muller Kerry A. Delaney Laura D. Rosenthal Steve Segore

#### **North Carolina**

Anne Barker
Courtney Cantrell
Carol Donin
Monica Harrelson
Lisa Hinson
Jeff Holden
Vicki Houston
Nancy Hux
David Igram
Mya Lewis
Leon Owens
Jason Vogler

#### **North Dakota**

Tina Bay Cheryl Schrank Sue Foerster Brianne Skachenko

#### Ohio

Deb Bish
Casey Kummer
Frank Lengel
John L. Martin
Hope McGonigle
Scott McVey
Misty Rayburn
John Trevelline
Clay Weidner

#### Oklahoma

Marie Moore

#### Oregon

Vera Kraynick Christy Orcutt Lilia Teninty

#### Pennsylvania

David Chu Kevin Dressler Cindy Foster Jerry Goessell Holly Lynott Bryan Porter Kimberly Rupert Mark Sauro

#### Pennsylvania (cont.)

John Sloyer Nancy Thaler Joyce Wong

#### **Rhode Island**

Adam Brusseau Brian Gosselin Anne LeClerc Corinna Roy Kerri Zachi

#### **South Carolina**

Darby Anderson Beverly A.H. Buscemi Neshia Caesar Rebecca Hill John Hitchman Amy McLean Susan Simpson Richard Wnek

#### **South Dakota**

Barb Abeln Laura Ellenbacker Darryl Milner Alana Suiter

#### **Tennessee**

April Darby Patricia Dodson Melinda Lanza Debbie Payne

#### **Texas**

Janie P. Eubanks Sonja Gaines Amanda Klekar Julia Marsch-Klepac Vicky Vanhorn

#### Utah

Josip Ambrenac Tyler Black Josette Harding Chad Midgley Angela Pinna Paul Smith

#### Vermont

June E. Bascom Roy Gerstenberger

#### Virginia

Connie Cochran
Brenda Haley
Kevin Harkins
Angela Harvel
Rupinder Kaur
Kevin Meyer
Dennis Shrewsberry
Cheri Stierer

#### Washington

Marci Arthur
Tony DiBartolo
Mark Eliason
Tricia Flick
Dave Cook
Kristin Ohler
Evelyn Perez
Jill Sinsel-Mcpherson
Lynn Reedy

#### **West Virginia**

Steve Brady Beth Morrison Cassandra Toliver

#### Wisconsin

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

#### **Wyoming**

Lee Grossman Chris Newman Colleen Noon Stephanie Wright

#### TECHNICAL USER'S GROUP

#### **NASDDDS Research Committee**

The NASDDDS Research Committee serves as the RISP project's Technical Users Group (TUG). Its membership includes state IDD directors, NASDDDS staff, and consultants who are non-voting members. The TUG provides feedback on survey processes, data elements, and the project evaluation. They also consult with project staff on strategies to ensure that the information collected is relevant and responsive to changes in Federal Medicaid policies.

#### **Voting Members**

John Martin (OH) – Chair Nicole Norvell (IN, former) Bernie Simons (MD) Terry Macy (CT) Paul Smith (UT) Chris Adams (TX) Laurie Kelly (NY)

#### **Non-Voting Members**

Amy Hewitt PhD (UMN) Bill Kiernan PhD (UMass) Val Bradley (HSRI) Rick Hemp (UC)

#### **NASDDDS Staff**

Mary Lee Fay Mary Lou Bourne Mary Sowers

#### FAMILY ADVISORY COMMITTEE

The Family Advisory Committee for the Supporting Individuals and Families Information Systems

Project assisted staff to develop customized tools and products for families, family advocates and individuals with IDD.

Katie Arnold, Sibling Leadership Network

Betsy MacMichael, First in Family North Carolina

**Angela Martin**, Wayne State Developmental Disabilities Institute

Lisa Pugh, Disability Rights Wisconsin

**Michelle Reynolds**, University of Missouri Kansas City Institute for Human Development

Pat Volle, Arizona Department of Economic Security

**Robin Wood**, Connecticut Department of Developmental Services

Dana Yarborough, Parent to Parent of Virginia



#### **A**CRONYMS

ACL Administration on Community Living
AHCA American Health Care Association

AIDD Administration on Intellectual and Developmental Disabilities (formerly ADD)

**APDDA** Association of Professional Developmental Disabilities Administrators

**ASD** Autism Spectrum Disorder

**CASPER** Certification and Survey Provider Enhanced Reporting (CMS)

CEHD College of Education and Human Development (University of Minnesota)CMS 64 Centers for Medicare & Medicaid Services Quarterly Expense Report

**CMS** Centers for Medicare & Medicaid Services

**DD** Developmental Disabilities

**DNF** Did Not Furnish

**FFP** Federal Financial Participation

**FISP** Supporting Individuals and Families Information Systems Project (University of MN)

**FMAP** Federal Medical Assistance Percentage

**FY** State Fiscal Year (e.g., FY 2015 is July 1, 2014 to June 30, 2015)

**HCBS** Home and Community-based Services (Medicaid)

**HSRI** Human Services Research Institute

**ICF/IID** Intermediate Care Facility for Individuals with Intellectual Disabilities (formerly ICF/MR)

ICI Institute on Community Integration (University of MN)

**ID** Intellectual Disabilities

IDD Intellectual and Developmental Disabilities
IDEA Individuals with Disabilities Education Act

**LTSS** Long-term supports and services

**MA** Medical Assistance

MCO Managed Care OrganizationMFP Money Follows the Person

**NASDDDS** National Association of State Directors of Developmental Disabilities Services

**NASUAD** National Association of States United for Aging and Disabilities

NHIS National Health Interview Survey

**NHIS-D** National Health Interview Survey-Disability Supplement

**NIDILRR** National Institute on Disability, Independent Living, and Rehabilitation Research

**OBRA-87** Omnibus Budget Reconciliation Act of 1987

**OSCAR** Online Survey, Certification and Reporting System (Medicaid)

**PASRR** Preadmission Screening and Resident Review

**PD** Partial data reported by state

**PRF** Public residential facility (a state-operated IDD facility serving 16 or more individuals)

**QIDP** Qualified Intellectual Disability Professional

**RISP** Residential Information Systems Project (University of MN)

**RTC/CL** Research and Training Center on Community Living (University of MN)

SNF Skilled Nursing FacilitiesSSA Social Security Administration

**UCEDD** University Centers of Excellence in Developmental Disabilities

# Guide to the FY 2015 Tables and Figures (with Cross Listings for FY 2012 and FY 2014)

These charts list the FY 2015 report tables and figures along with the corresponding table and figure numbers from the RISP FY 2012 and FY 2014 reports. FY 2012 or FY 2014 tables or figures that were revised, expanded or otherwise changed are followed by the letter "R". Tables and figures that previously were in the FISP project reports start with the letter "F". Not Applicable (N/A) indicates a table or figure that was not published in a particular year.

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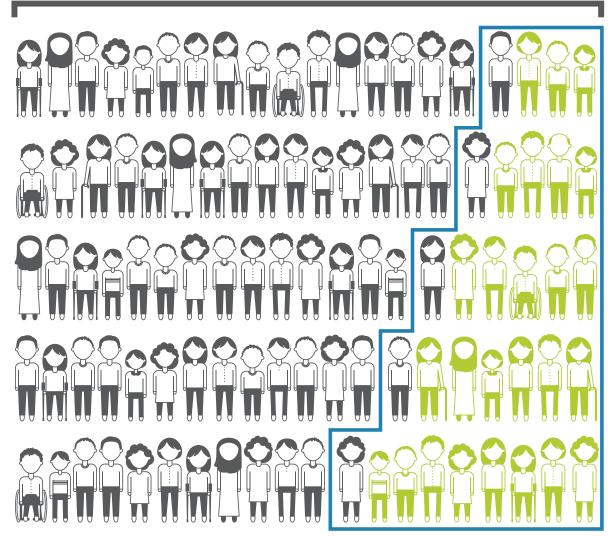
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#### **EXECUTIVE SUMMARY**

People with intellectual or developmental disabilities (IDD) 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. Most live with a family member and receive informal supports from family members and friends. Some also receive supports funded by

Medicaid or State funding authorities. This report describes long-term supports and services (LTSS) recipients with IDD and public LTSS expenditures for state Fiscal Year (FY) 2015 by setting type, setting size, funding source, state versus nonstate operation, and recipient age.

4.71 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2015



31% 1.46 million people with IDD were known to or served by state IDD agencies

26% 1.21 million people with IDD received long-term supports or services through state IDD agencies

Note: US IDD prevalance estimates from 1994/95 National Health Interview Survey Disability Supplement



#### Section 1 Summary: In-Home and Residential Support Settings

Section 1 reports the prevalence of IDD, the number of people with IDD known to state IDD agencies, the number of LTSS recipients with IDD and the living arrangements of LTSS recipients as of June 30, 2015.

How many people in the US had IDD were known to or received LTSS provided by or under the auspices of state IDD agencies on June 30, 2015?

An estimated 4.71 million people with IDD (14.6 per 1,000 of the population) lived in the United States on June 30, 2015 (using prevalence rates from the 1994/1995 National Health Interview Survey). The estimate increases to 6,360,551 if the 2000 DD Act definition is used to update the 1994/1995 NHIS estimate for children and to 6,452,964 if prevalence estimates for children from the 2014 NHIS are used (Zablotsky, 2015).

An estimated 1,464,459 people were known to or served by state IDD agencies (4.6 per 1,000).

- 39% (568,759 people) were 21 years or younger
- 61% (895,690 people) were 22 years or older

An estimated 26% (1,211,535 people) received LTSS provided by or under the auspices of state IDD agencies (3.8 per 1,000).

#### Where did people with IDD receiving LTSS provided by or under the auspices of state IDD agencies live?

Of the 1,211,535 people with IDD receiving LTSS provided by or under the auspices of state IDD agencies,

- 5% (61,715 people) lived in a host or foster family home
- 12% (139,985 people) lived in a home they owned or leased
- 26% (311,269 people) lived in a group home, ICF/IID or other group setting
- 58% (698,566 people) lived in the home of a family member

An estimated 24,284 people lived in psychiatric facilities or nursing homes. State IDD agencies served some but not all of individuals in psychiatric facilities or nursing homes.

#### How large were the non-family settings in which LTSS recipients with IDD lived?

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

LTSS recipients with IDD lived in an estimated 230,092 non-family settings, of which

- 84% (193,649 settings) served three or fewer people
- 12% (28,467 settings) served 4 to 6 people
- 3% (7,037 settings) served 7 to 15 people
- 0.4% (926 settings) served 16 or more people with IDD

#### How many people with IDD lived in non-family settings?

An estimated 512,969 people with IDD lived in non-family settings. Of those,

- 56% (287,136 people) lived with three or fewer people
- 25% (126,716 people) lived with 4 to 6 people
- 11% (56,627 people) lived with 7 to 15 people
- 8% (42,490 people) lived with 16 or more people with IDD

#### What was the average size of non-family settings?

The average non-family setting had 2.2 people with IDD in residence.

In nonstate-operated settings, there was an average of

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

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

- 5.5 people per group home (other than ICF/IID)
- 37.3 people per "other" group setting
- 62.1 people per ICF/IID

How many children and youth with IDD 21 years or younger lived in a congregate setting with shift staff? (A Healthy People 2020 indicator)

An estimated 13,754 children and youth with IDD 21 years or younger lived in congregate settings on June 30, 2015. Of those,

- 6% (821 children and youth) lived in nursing homes and
- 94% (12,933 children and youth) lived in other congregate settings

#### Section 2 Summary: Medicaid LTSS Recipients and Expenditures

Section 2 describes the Medicaid and state authorities through which people with IDD receive LTSS funding. 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 LTSS funding authorities were used by state IDD agencies to finance LTSS in FY2015?

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

In this report, we use the term "Medicaid Waiver" to refer to services funded through Medicaid 1115, and 1915 (a), (b), (b/c) or (c) waivers.

We use the term "Medicaid Home and Community Based Services (HCBS)" to refer to services funded through Medicaid 1115, and 1915 (a), (b), (b/c) or (c) Waivers or 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 2015?

Of the 1.46 million people with IDD known to state IDD agencies on June 30, 2015, 1,211,535 received LTSS through Medicaid or state funding authorities. Of the LTSS recipients,

- 53% (774,964 people) received LTSS funded by a Medicaid Waiver
- 29% (417,722 people) received LTSS through a Medicaid State Plan HCBS funding authority
- 18% (264,822 people) received state funded LTSS
- 5% (74,444 people) received supports in a Medicaid ICF/IID
- 13% (183,164 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, 2015?

An estimated 199,641 people with IDD were living with a family member and waiting for Medicaid Waiverfunded LTSS. Of those,

- 38% (76,682 people) were waiting to move from the home of a family member
- 21% (42,489 people) received Medicaid State Plan-funded Targeted Case Management services while waiting

Eleven 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 24% to serve every person on the waiting list.

#### Where did Medicaid Waiver recipients with IDD live on June 30, 2015?

Of the 774,964 Medicaid Waiver recipients with IDD

- 52% (401,967people) lived with a family member
- 27% (208,701 people) lived in a group setting
- 14% (110,340 people) lived in a home they owned or leased
- 7% (53,956 people) lived in a host or foster family home

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

- 25% (192,231 people) were 21 years or younger
  - 85% (162,523 people) lived in the home of a family member
  - 15% (29,708 people) lived in own home, host or foster family home, or a group setting
- 75% (582,733 people) were 22 years or older
  - 41% (239,444 people) lived in the home of a family member
  - 59% (342,289 people) lived in own home, host or foster family home or a group setting

There were 241 Medicaid Waiver recipients with IDD per 100,000 of the population.

- 211 people with IDD per 100,000 of the population were 21 years or younger
- 253 people 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?

- 79% (110,340 people) living in their own home received Medicaid Waiver-funded supports
- 58% (401,967 people) living in the home of a family member received Medicaid Waiver-funded supports

What were total Medicaid Waiver expenditures in FY 2015 for LTSS recipients with IDD? What proportion of Medicaid Waiver expenditures in FY 2015 were for adults 22 years or older?

Estimated Medicaid Waiver expenditures for people with IDD in FY 2015 were \$34.18 billion (\$106 per US resident).

- 10% (\$3.46 billion) was for people 21 years or younger
- 90% (\$30.72 billion) was for people 22 years or older

What were the average annual per recipient Medicaid Waiver expenditures for people with IDD in FY 2015? How did the average differ by age and type of living arrangement?

Average annual Medicaid Waiver expenditures were \$44,112 per year-end recipient with IDD in FY 2015. They were

- \$18,009 per recipient 21 years or younger overall
  - \$15,786 for people 21 years or younger living in the home of a family member
  - \$65,446 per people 21 years or younger living in other settings
- \$52,772 per recipient 22 years or older overall
  - $_{\circ}\,$  \$27,977 for people 22 years or older living in the home of a family member
  - \$68,952 for people 22 years or older living in other settings

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

#### How many ICF/IIDs were operating on June 30, 2015? How many people did they serve?

There were 6,396 ICF/IID on June 30, 2015. Of those,

- 5% (288 settings) were state-operated including
  - 24% (69) serving 6 or fewer people
  - 25% (71) serving 7 to 15 people
  - 51% (148) serving 16 or more people
- 95% (6,108 settings) were nonstate-operated including
  - 61% (3,734) serving 6 or fewer people
  - 33% (2,010) serving 7 to 15 people
  - 6% (364) serving 16 or more people

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

#### How many people lived in state or nonstate ICF/IID of various sizes on June 30, 2015?

An estimated 77,444 people lived in an ICF/IID on June 30, 2015. Of those,

- 28% (21,486 people) lived in a state-operated ICF/IID including
  - 1% (291) in a setting of 6 or fewer people
  - 4% (802) in a setting of 7 to 15 people
  - 95% (20,393) in a setting 16 or more people
- 72% (55,958 people) lived in a nonstate-operated ICF/IID including
  - 35% (19,399) in a setting of 6 or fewer people
  - 33% (18,313) in a setting of 7 to 15 people
  - 33% (18,245) in a setting of 16 or more people

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

There were 74,444 people living in an ICF/IID (24.1 people per 100,000 of the population) on June 30, 2015. Of those,



- 6% (4,942 people) were 21 years or younger (5.4 people per 100,000 of the population)
- 94% (72,502 people) were 22 years or older (31.5 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 42,490 people living in IDD settings of 16 or more people, 91% (38,638 people) lived in an ICF/IID. The proportions in ICF/IID settings were

- 99% (20,393 of 20,642 people) in state-operated IDD facilities
- 84% (18,245 of 21,848 people) in nonstate-operated IDD facilities

#### What were FY 2015 Medicaid ICF/IID expenditures?

Total ICF/IID expenditures in FY 2015 were \$10.43 billion (\$32 per United States resident).

Average annual ICF/IID expenditures were \$134,630 per year-end recipient. The average was

- \$108,896 for recipients 21 years or younger
- \$136,384 for recipients 22 years or older

### What proportion of combined Medicaid LTSS ICF/IID and Waiver recipients and expenditures were for people in ICF/IID settings in FY 2015?

An estimated 852,408 Medicaid LTSS recipients with IDD lived in an ICF/IID or received Medicaid Waiverfunded LTSS. Of those,

- 91% received Medicaid Waiver-funded LTSS
- 9% lived in an ICF/IID

Total Medicaid ICF/IID plus Waiver expenditures for people with IDD were \$44.6 billion in FY 2015. Of the total,

- 77% (\$34.18 billion) was for Medicaid Waiver recipients
- 23% (\$10.43 billion) was for people in ICF/IID

#### Section 3 Summary: Trends in Long-Term Supports and Services

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

#### How have the places in which LTSS recipients with IDD live changed?

Between 1998 and 2015, the number of LTSS recipients with IDD living in

- The home of a family member increased 115% from 325,650 to 698,566 people
  - The proportion receiving Medicaid Waiver-funded supports increased 407% from 80,799 to 401,967
  - The proportion not receiving Medicaid Waiver-funded supports increased 18% from 244,851 to 296,599
- A home of their own increased 115% from 62,669 to 134,719 people
- A non-family setting of three or fewer people increased 141% from 63,279 to 152,417 people
- An IDD group setting of four to 6 people increased 72% from 73,658 to 126,716 people
- An IDD group setting of 7 to 15 people increased 5% from 53,940 to 56,627 people
- An IDD facility of 16 or more people decreased 39% from 114,495 to 70,251 people

#### How have the number, size and type of operation of non-family IDD settings changed?

Between 1977 and 2015, the number non-family IDD settings increased from 11,008 to 230,092 settings.

The proportion of non-family IDD settings serving six or fewer people increased from 63% (6,898 facilities) in 1977 to 97% (222,129 facilities) in 2015.

- The proportion of nonstate-operated IDD settings serving six or fewer people increased from 65% (6,855 facilities) in 1977 to 97% (220,898 facilities) in 2015
- The proportion of state-operated IDD settings serving six or fewer people increased from 9% (43 facilities) in 1977 to 59% (1,231 facilities) 2015. However, this was a decline from 64% (1,637 facilities) in 2009.

Between 1977 and 2015, the proportion of non-family IDD settings operated by nonstate entities increased from 96% (10,543) to 99% (228,001). The proportion of non-family settings operated by nonstate entities

- Serving 6 or fewer people stayed the same at 99% between 1977 and 2015
- Serving 7 to 15 people decreased from 96% in 1977 to 90% in 2015
- Serving 16 or more people increased from 81% in 1977 to 84% in 2015

### How has the number of people with IDD living in nonstate settings of different sizes and types of operation changed?

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

- 6 or fewer people increased from 8% (20,400 people) in 1977 to 81% (413,852 people) in 2015
- 7 to 15 people increased from 8% (20,024 people) in 1977 to 11% (56,627 people) in 2015
- 16 or more people decreased from 84% (207,356 people) in 1977 to 8% (42,490 people) in 2015

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% (31,520 people) in 2015.
- The proportion in state-operated settings of
  - 6 or fewer people remained stable at 1% (216 people) in 1977 and 4,596 people in 2015
  - 7 to 15 people increased from 5% (950 people) in 1977 to 11% (6,282 people) in 2015
  - 16 or more people decreased from 75% (154,638 people) in 1977 to 49% (20,642 people) in 2015
- The proportion in nonstate-operated settings first exceeded the proportion in state-operated settings in 1987.

Between 1977 and 2015, the average size of all non-family IDD settings declined from 22.5 to 2.2 people per setting. The average size of

- State-operated IDD settings declined from 335.1 to 15.1 people per setting.
- Nonstate-operated IDD settings declined from 8.7 to 2.1 people per setting.

### How has the balance between Medicaid ICF/IID and Medicaid Waiver recipients, expenditures, and expenditures per person changed?

The number of people with IDD receiving Medicaid Waiver-funded supports increased from 1,381 in 1982 to 774,964 in 2015. The number of Medicaid Waiver recipients surpassed the number in ICF/IID settings in 1995.

Total Medicaid Waiver expenditures for people with IDD increased from \$2.2 million in 1982 to \$34.2 billion in 2015. Total Medicaid Waiver expenditures surpassed total ICF/IID expenditures in 2001.

Average annual per person ICF/IID expenditures increased from \$23,806 in 1982 to \$134,630 in 2015

Average annual per person Medicaid Waiver expenditures increased from \$1,624 in 1982 to \$44,112 in 2015

Average annual per person expenditures have always been higher for ICF/IID than for Medicaid Waiverfunded services.



- In 1984, there were 142,471 ICF/IID recipients and 17,972 Medicaid Waiver recipients with IDD. Annual per person ICF/IID expenditures (\$64,510 in 2015 inflation adjusted dollars) were 5.12 times higher than annual per person Waiver expenditures (\$12,604 in 2015 inflation adjusted dollars).
- In 2015, there were 77,444 ICF/IID recipients and 774,964 Medicaid Waiver recipients with IDD. Annual per person ICF/IID expenditures (\$134,630) were 3.05 times higher than annual per person Waiver expenditures (\$44,112).

There are important differences the types of expenses included in the cost of ICF/IID and Medicaid Waiver-funded services. For example, Medicaid Waiver expenditures exclude room and board costs while those costs 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 8% from 216,328 people in 2014 to 199,641 people in 2015.

How has the proportion of people living with family members who received Medicaid Waiver-funded supports changed?

- In 1998, 25% (80,788 of 325,650) of LTSS recipients with IDD living with family members received Medicaid Waiver-funded supports.
- By 2015, 59% (401,967 of 698,566) of LTSS recipients with IDD living with family members received Medicaid Waiver-funded supports.

# Section 4 Summary: Status and Trends in State-Operated IDD Facilities Serving 16 or More People (PRFs)

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

#### How did the population of PRFs serving people with IDD change in FY 2015?

The average daily PRF population in FY 2015 was 20,933.

The number of people with IDD living in a PRF on June 30 declined 7% from 22,271 in 2014 to 20,642 in 2015.

During 2015, PRFs had an estimated

- · 1,269 admissions or readmissions
- 2,126 discharges
- 702 deaths
- 957 short-term admissions (less than 90 days)

Average per person daily PRF costs were \$729 in FY 2015. Average costs were

- \$461 for Medicaid Waiver-funded PRFs
- \$747 for ICF/IID certified PRFs
- \$654 for non-Medicaid funded PRFs

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

Of the 374 PRFs operating between 1960 and 2015,

- · 219 closed before July 1, 2014
- 10 closed, merged, downsized to less than 16 people or converted to a nonstate facility between July 1, 2014 and June 30, 2015
- 145 were open on June 30, 2015

Of the PRFs open on June 30, 2015

- 12 anticipated closing by June 30, 2019
- 4 anticipated closing after July 1, 2019

On June 30, 2015, there were no PRFs serving people with IDD in 15 states: Alabama, Alaska, District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Vermont, and West Virginia.

#### How has the number of people with IDD in PRFs or state-operated psychiatric facilities changed?

The average daily PRF population declined from a peak of 194,650 in 1967 to 20,933 in 2015.

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 1,295 people on June 30, 2014, and 2,094 people on June 30, 2015.

The number of people in PRFs or state-operated psychiatric facilities declined at a rate of 1,900 people per year between 2010 and 2014, a 5.8% reduction. It declined by 530 people between 2014 and 2015, a reduction of 2.3%.

#### How has movement in and out of PRFs changed?

The number of annual admissions of people with IDD to PRFs was

- 18,078 (11% of the average daily population) in 1975
- 2,106 (5% of the average daily population) in 2005
- 1,269 (6% of the average daily population) in 2015

The number of annual discharges of people with IDD from PRFs was

- 16,807 (10% of the average daily population) in 1975
- 2,561 (6% of the average daily population) in 2005
- 2,216 (10% of the average daily population) in 2015

The number of people with IDD who died while living in a PRF was

- 2,913 (1.7% of the average daily population) in 1975
- 909 (2.2% of the average daily population) in 2005
- 702 (3.4% of the average daily population) in 2015

The proportion of PRF residents with IDD who were

- 40 years or older increased from 23% in 1977 to 77% in 2015
- 63 years or older increased from 4% in 1977 to 21% in 2015

#### How have average annual costs in large state-operated IDD facilities changed?

Average per person annual costs for people living in PRFs increased from \$45,188 in 1975, to \$183,097 in 2005 and was \$266,111 in 2015 inflation adjusted dollars.



#### What were the characteristics of people with IDD living in PRFs in 2015?

In 2015, 115 of 121 facilities in the sample frame serving an estimated 20,642 residents on June 30, 2015 returned PRF surveys. They reported that the number of

- People per facility ranged from 19 to 500 and averaged 173 people per facility (115 facilities reporting)
- Admissions or readmissions ranged from 0 to 93 and averaged 12 people (107 facilities reporting)
- Discharges ranged from 0 to 149 and averaged 17 (112 facilities reporting)
- Deaths ranged from 0 to 16 and averaged 6 (108 facilities reporting)

Of the 20,642 people with IDD living in PRF's on June 30, 2015 whose age was known, an estimated

- 4% (735 people) were 21 years or younger
- 19% (3,985 people) were 22 to 39 years
- 56% (11,594 people) were 40 to 62 years
- 21% (4,308 people) were 63 years or older

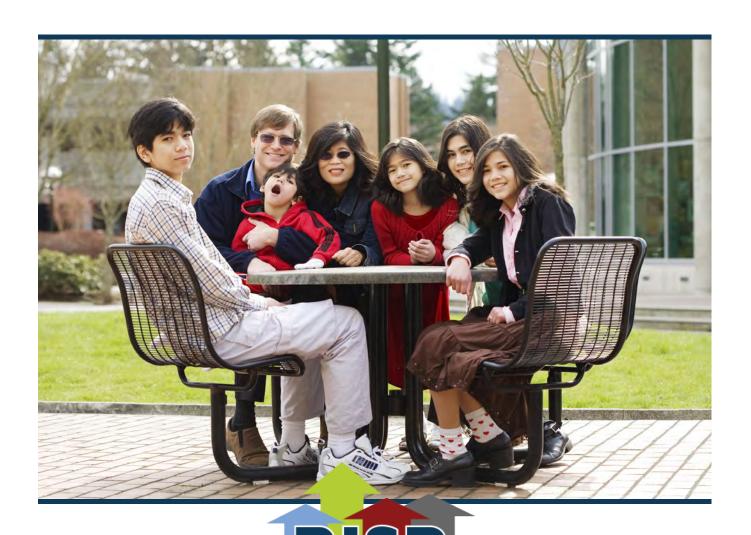
Of the 20,642 people with IDD living in PRF's on June 30, 2015 whose level of ID was known, an estimated

- 14% (2,790 people) had no ID or mild ID
- 14% (2,815 people) had moderate ID
- 16% (3,281 people) had severe ID
- 56% (11,444 people) had profound ID

#### How did the characteristics of people with IDD in PRFs change between 1977 and 2015?

As PRFs have downsized or closed, the age and level of IDD distributions of the people remaining changed. The following estimates exclude people whose age or level of ID was unknown.

- The proportion (and estimated number) of residents who were 21 years or younger on June 30 was
  - 36% (54,400 people) in 1977
  - 4% (1,306 people) in 2010
  - 4% (736 people) in 2015
- The proportion (and estimated number) of residents who were 63 years or older on June 30 was
  - 4% (6,044 people) in 1977
  - 15% (4,696 people in 2010
  - 21% (4,308 people) in 2015
- The proportion (and estimated number) of PRF residents who had profound ID was
  - 46% (68,886 people) in 1977
  - 59% (18,489 people) in 2010
  - 56% (11,620 people) in 2015
- The proportion (and estimated number) of PRF residents with mild or no ID was
  - 10% (15,700 people)in 1977
  - 12% (3,701 people) in 2010
  - 14% (2,833 people) in 2015



# Introduction

**FY 2015** 

### 



#### Introduction

Community living and participation means something different to each person. People with IDD, like those without IDD, live and participate in preferred communities in unique ways. People with IDD and their families increasingly expect that they will have the same opportunities as people who do not receive formal supports to participate fully in community activities, events, and organizations; interact with family and friends; and for working age people, work in a job earning at least minimum wage alongside people without disabilities. For people who receive publicly funded LTSS, however, opportunities to participate in preferred ways differ depending upon where the person lives and on the type and amount of supports they receive.

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

- Activities of daily living such as dressing, bathing and eating
- Household activities such as shopping, chores, and money management
- Developing and maintaining relationships
- Identifying and pursuing personal interests such as hobbies, sports, clubs or worship
- · Health (physical and emotional)
- Employment
- · Formal and informal learning opportunities
- Making decisions about where and with whom to live and about their schedules and activities
- Engaging in civic responsibilities such as voting and paying taxes

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

Full participation is affected by the availability and competence of paid and non-paid people who provide support, the design and funding of LTSS, the available supports, federal and state policies regarding oversight, operation, and funding of LTSS, and the extent to which services take into account the uniqueness of each individual in the context of their family, community, and culture. Most publicly funded LTSS in the United States for people with IDD are funded by Medicaid but some are funded by

state or local governments, or are purchased by the individual or family privately.

#### THE POLICY CONTEXT

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

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

On March 17, 2014, the Centers for Medicare and Medicaid Services (CMS) issued Home and Community-Based Services (HCBS) Rules establishing new guidelines for services and supports financed through several Medicaid LTSS funding authorities (Final Regulation CMS-2249-F/ CMS-2296-F; see the Medicaid Waiver webpage). The rules require person-centered planning and service delivery and prohibit conflicts-of-interest for those who develop plans of care. They require that recipients have full access to the greater community including competitive integrated employment; choice of services and service settings, daily activities, physical environments, and with whom to interact; freedom to exercise individual rights of privacy, dignity, respect; and freedom from restraint and coercion.

The "settings" section of the 2014 HCBS rule defines settings that qualify for Medicaid HCBS funding, and specifies requirements for Medicaid HCBS-funded provider-owned or controlled service settings. Medicaid HCBS 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. HCBS recipients must also have privacy in their sleeping or living units, control over their schedules and activities, access to food and visitors at any time, and live in settings that are physically accessible to them.

**Table A:** Long-Term Supports and Services Categories

Service Category	Brief description	Examples
Behavior Supports	Supports to prevent or reduce behavior-related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions	Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment
Employment and Day Services	Services provided to support participation in community-based activities, education, and employment	Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, early start programs
Environmental Modifications and Technology	Adaptive equipment, home modifications (e.g., ramps, bathroom modifications, etc.), modification or repair to a vehicle, adaptive equipment, augmentative communication devices, personal emergency response systems	Personal emergency response systems, 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 the individual for activities of daily living such as dressing and eating, instrumental activities of daily living such as cooking, cleaning, shopping, and money management, and developing and maintaining relationships	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 OT, PT, and speech therapies as well as in home nursing services for people who have ongoing support needs	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 services, or other community-based activities	Community transportation services, non-medical transportation

This table originally appeared in Anderson, L.L., Larson, S.A., Kardell, Y., Taylor, B., Hallas-Muchow, L., Eschenbacher, H.J., Hewitt, A.S, Sowers, M, & Bourne, M.L. (2016). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.



Most provisions of the regulation became effective on March 17, 2014. However, states have until 2022 to implement the settings portion of the rule. Between now and then each state must develop a state 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. More information is available at the CMS website in "Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers" and related guidance in the "Extension of Transition Period for Compliance with Home and Community Based Settings Criteria."

## The Supreme Court's Olmstead Decision Enforcement

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 continue to shape the

availability and delivery of HCBS. Notably, Rhode Island, Virginia, and Oregon agreements contain very specific requirements related to the nature and settings of services. The Department of Justice Olmstead website describes enforcement activities for residential institutions and sheltered workshops or segregated day services.

### State Litigation and Legislative Initiatives

Many states have been subject to individual or class action lawsuits related to reimbursement rates for Medicaid services, availability of Medicaid or state funded services and supports, or other elements of their LTSS systems. These cases influence state decisions regarding resources management, as well as the nature of services provided.

State legislation and policy initiatives also influence service delivery options. For example, some states are considering or have moved to using a managed care model for LTSS for people with IDD. Those states are learning to be more explicit in their performance expectations for Managed Care Organizations regarding person-centered planning, service delivery, and provision of information the



state needs to provide oversight, and to understand how services are affecting people and their families.

# 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 funds used, the characteristics and needs of service recipients, and of those waiting for services, and about individual and systems level performance outcomes. Information is needed about the extent to which funded programs support valued personal outcomes such as opportunities to build authentic relationships and to participate in and contribute to communities.

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

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

Medicaid LTSS programs have become more complex, offering new and different funding authorities requiring states who offer Medicaid-funded services to adhere to new program rules. Those complexities are important to consider when comparing states or interpreting data on service utilization or expenditures.

# **Factors to Consider When Comparing States**

Many complexities arise from the flexibility states have in how they administer LTSS for individuals with IDD and their families. Some of those complexities are described here.

Eligibility criteria. Medicaid eligibility is complex. States are required to cover certain groups of individuals in specific income brackets, but may elect to cover additional groups and/or income levels. For Medicaid Waiver programs, federal guidelines establish minimum eligibility criteria (e.g., institutional level of care requirements). However, states have the authority to apply additional requirements such as diagnostic, or age-related, eligibility criteria. For example, some states consider



family income when determining whether a child with a disability who resides in the family home is eligible for services while other states do not.

**Service definitions.** Service and program definitions vary from state to state. For example, many states offer a service called "Family Support." What is included under that label, however, can be very different (ranging from small family stipends, or limited respite, to intensive 24-hour in-home support). Adding to the complexity, states offering similar services may refer to them using different names.

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

**Data systems.** States differ in how they collect and maintain data about service recipients. Depending on the age and sophistication of the data management system, it may be difficult to identify people with IDD within Waivers serving multiple populations, or to report age and living arrangement sizes and types across funding authorities. In states using managed LTSS, some of the needed data is maintained by the managed care entities. Budget or staffing limitations can make it difficult to extract the information for the RISP report.

**Funding options.** Many Medicaid structures are available to states to finance services for individuals with IDD and their families, including state plan services, demonstration waivers, managed care waivers, and other waiver options. Information about Federal Medicaid funding authorities is available in the *Guide to Federal Medicaid Authorities Used in Restructuring Medicaid Health Care Delivery or Payment* http://www.medicaid.gov. States may administer services and programs in cooperation

with state or local governments and with the contribution of state and county dollars.

We encourage readers to review the data in this report in light of these complexities. Detailed information about the surveys and operational definitions used for the RISP project can be found in Appendix B. These documents are used to provide guidance to states specifying the operational definitions for each data element. The state notes section of this report provides key background information needed to interpret data for specific states accurately. RISP project staff members are available to assist you to understand the findings (email risp@umn.edu). It may also be helpful to check your state's DD agency website, or with the DD Agency director if you need further clarification of a specific finding for a specific state. Links to state specific information are available on the following websites:

- The National Association of State Directors of Developmental Disabilities Services (NASDDDS) website lists state IDD agencies.
- The National Association of Councils on Developmental Disabilities website lists state DD councils.
- The National Disability Rights Network website lists Protection and Advocacy (P&A) and Client Assistance Program (CAP) organizations.
- The Residential Information Systems Project website publishes fact sheets, data visualizations, state profiles, and other resources at http://risp. umn.edu.

# 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 Medicaid-funded 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 US states plus the District of Columbia.

The RISP project is housed at the University of Minnesota's Institute on Community Integration in the Research and Training Center on Community Living. RISP staff members are employed by the

University of Minnesota, the Human Services Research Institute (HSRI), or the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

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

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

In 1977 and 1982, the University of Minnesota participated in a census of all state and nonstate residential facilities for people with IDD (Bruininks, Hill & Thorsheim, 1982; Hauber, et. al., 1984). Trends in the use of public (state-operated) residential facilities serving 16 or more people have been included in annual RISP reports since 1983. Individual state profiles summarizing the status and trends in residential and community supports have been part of the report since 1995.

The annual RISP report has described LTSS for people with IDD funded through the Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) program, and Medicaid Home and Community Based (HCBS) Waiver funding authorities since 1982. As Medicaid added new LTSS funding authorities, the project adjusted the survey items to differentiate them in finer detail. At the request of AIDD and in consultation with state IDD agency directors, we began collecting and reporting more details about the age of LTSS recipients with IDD, and about services provided to people living in their own homes or 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. To respond to the Centers for Medicare and Medicaid Healthy People

2020 monitoring needs, we incorporated questions on children living in institutional settings into our annual data collection protocol. Finally, to respond to technical assistance requests from Federal and State agencies we added a table to the report showing the estimated US population with IDD by state.

This RISP report describes Medicaid and statefunded LTSS managed by, or under the auspices of, state intellectual and developmental disabilities (IDD) agencies in State Fiscal Year (FY) 2015 (July 1, 2014 through June 30, 2015) and examines trends across time. The RISP report describes six dimensions of LTSS:

- 1. Type of entity providing services (state or nonstate)
- 2. Living arrangement (own home, family home, foster or host family home or group settings)
- 3. Setting size (number of people with IDD living together)
- 4. Recipient age (child ages birth to 21 years or adults ages 22 years or older)
- 5. Funding authority (Medicaid, State, or other)
- 6. Time (fiscal year)

## STUDY METHODOLOGY

# Survey of State Directors of IDD Services (RISP Survey)

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

Prior to 2007, RISP data were collected via a paper survey. The first online survey was used from 2007-2012. The online data collection system was redesigned and new features were added in 2013. The new version automatically tracks edits or changes by date and the person who made or requested the change. State data providers and project staff can



view previous year's data for each data element, and can assign special codes to indicate estimates, external data sources used, data imputed by project staff, and alternative dates if data were not available for the requested date. State data providers may enter notes to help research staff and readers of the report to interpret the data correctly, or to record reasons for changes. Data proofing tools were added to online system for FY 2015 to assist states to identify possible arithmetic errors, inconsistencies within or across survey sections, and large year-to-year changes requiring explanation.

NASDDDS hosted a webinar for state IDD directors and designated data providers to launch the FY 2015 survey in February 2016. Most states submitted their surveys by September 2016. Preliminary state profiles were sent to states for review in April 2017. Requested changes were made and the final profiles were sent in August 2017. This report incorporates changes submitted by states through the end of August 2017. Corrections received after this date will be reflected in the online database and in products developed after that date.

# Survey of Administrators of State-Operated Residential IDD Facilities (PRF Survey)

Annual surveys of state-operated IDD facilities have been fielded since 1977 in cooperation with the Association of Professional Developmental Disabilities Administrators (APDDA). The sample frame was based on the 1977 census of Public Residential Facilities (PRFs). A few state-operated IDD facilities serving 16 or more people not in the original sample frame are not surveyed. PRFs in the sample frame that were open on June 30 of the fiscal year are surveyed. The final disposition of facilities that closed, were repurposed and no longer serve people with IDD, merged, or downsized to fewer than 16 people with IDD prior to June 30 are recorded in the annual report.

The PRF survey includes questions about facility closures and planned closures, number and age of people in residence on June 30, 2015, admissions, readmissions, discharges, and deaths during FY 2015, and average daily per person expenditures. Survey data were analyzed using Microsoft Excel and SPSS 21.0 software. Missing or

inconsistent responses are confirmed in follow-up communications with the survey respondents.

#### **DEFINITIONS**

**Caseload** is the number of people known to the state office who are receiving services, waiting for services, or known to the state IDD agency but not receiving services. In some states, people in psychiatric or nursing home facilities are included in the IDD agency caseload. In other states, an office other than the state IDD agency manages their care.

**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** include 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 either for prior or subsequent year, data from the adjacent year is used and are 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) notes instances when some, but not all, of the data elements required for a computation were furnished by the state.
- On the nursing home and psychiatric facility table, additional codes specify whether date were missing for state-operated nursing homes (b), or nonstate nursing homes (c) or both.

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

**Other Sources**. Appendix A references 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, 2015. 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 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 Waiver-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 2015 RISP survey and operational definitions documents are included in Appendix B. ■









**SECTION ONE** 

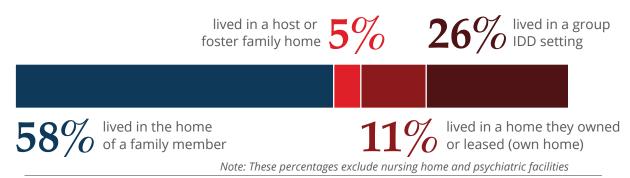
# In-Home and Residential Supports

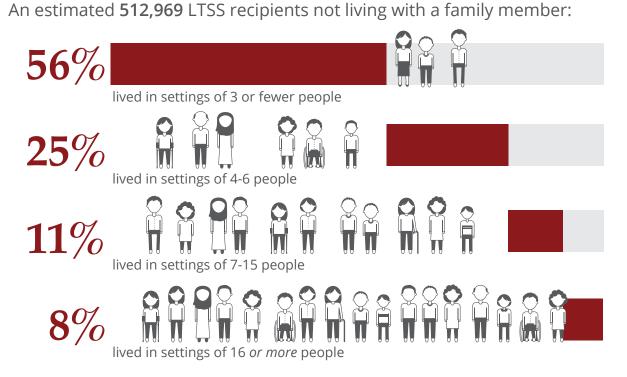
**FY 2015** 



# Where People Served by State IDD Agencies Lived on June 30, 2015

An estimated **1,211,535** people received long-term supports and services (LTSS) from state IDD agencies as of June 30, 2015:





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



# Section 1: In-Home and Residential Supports

# NUMBER OF PEOPLE WITH IDD IN THE UNITED STATES

Administrative records, public health surveillance, and nationally representative surveys can be used to estimate the total number of people with IDD in the United States. In this report, prevalence estimates are based on a population based survey, US Census Bureau data on the total population by age, and the number of people with IDD served by state IDD agencies.

## **Administrative Prevalence**

The number of service recipients can be estimated based using records from agencies providing or administering services. For the RISP project, state IDD directors report the number of people with IDD receiving LTSS through or under the auspices of state IDD agencies.

The U.S. Department of Education reports administrative data on children and youth ages 3 to 21 years who receive special education services by disability category. In the 2013/2014 school year, 1.51 million students with intellectual disabilities (ID), autism spectrum disorder (ASD), developmental delay, or multiple disabilities were educated in US schools. For every 1,000 students, 10.8 had ASD, 8.5 had ID, 8.2 had a developmental delay, and 2.6 had multiple disabilities (National Center for Educational Statistics, 2016).

Administrative data sets are also maintained by other federal or state agencies such as the Social Security Administration. Estimates from administrative records include people eligible for services but may not include people who do not qualify to receive services, and typically do not include people who have not applied for services.

#### **Public Health Surveillance**

In 2010, the CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) estimated that 13.6 per 1,000 8-year-old children had ID (Van Naarden Braun, et. al., 2015). In 2012, the CDC estimated the prevalence of Autism Spectrum

Disorder (ASD – a related condition in some states) among children aged 8 years to be 14.6 per 1,000 (Christiansen, et. al., 2016). The ADDM network tracks changes in prevalence rates for children from year to year. However, those estimates only include children, prevalence rates vary for children and adults (Larson, et. al., 2001), and the majority of people served by state IDD agencies are adults.

## **US Population Based Surveys**

Several US population-based surveys managed by the National Center for Health Statistics include questions that might be used to identify and describe people with disabilities. For example, the American Community Survey (ACS) asks if, because of a physical, mental, or emotional condition, a person has serious difficulty concentrating, remembering, or making decisions. While people with IDD would likely be among those reporting a cognitive limitation, in the ACS they are indistinguishable from the larger group of people who because of dementia, mental illness, other disabilities or physical illness had difficulty remembering or concentrating. Difficulty learning, one of the defining characteristics of intellectual disabilities, is assessed for children but not for adults in the ACS.

The National Health Interview Survey (NHIS) is an annual nationally representative survey of the civilian non-institutionalized US population. In 2014, the NHIS sample child survey asked parents whether a doctor or other health professional had ever diagnosed the child as having intellectual disabilities (ID), autism spectrum disorder (ASD), or other developmental delays. Among children ages 3 to 17 years, prevalence rates were 22.4 per 1,000 for ASD, 11 per 1,000 for ID, and 35.7 for developmental delay. Altogether 57.6 children per 1,000 of the population were estimated to have one or more of these conditions (Zablotsky, et. al., 2015). Like the ACS, however, the NHIS survey does not include questions that would allow reliable identification of adults with IDD. Furthermore, the term developmental disability as defined in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-



402), is not equivalent to term developmental delay as it is used in the NHIS sample child survey.

In 1994 and 1995, the National Center on Health Statistics with funding from several other federal agencies fielded a supplement to the annual NHIS survey with a robust set of questions that allowed identification of children and adults with a variety of disabilities including IDD. The NHIS Disability Supplement (NHIS-D) included an expanded list of questions about age-specific functional limitations, the severity and age at onset of those limitations, expected duration of the limitations, and the condition causing the limitation.

Researchers have used the 1994/1995 NHIS-D to describe the prevalence of and characteristics various types of disabilities including IDD (e.g., Barnartt, Altman, Hendershot and Larson, 2003). The University of Minnesota used the NHIS-D questions to create an operational definition of developmental disabilities using criteria from the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 1997 to identify people developmental disabilities and created an operational definition of intellectual disabilities using NHIS-D condition file records and other survey items (Larson, et. al., 2001). The prevalence of intellectual disabilities, developmental disabilities or both was estimated to be 38.4 per 1,000 for children birth to 5 years, 31.7 per 1,000 for children 6 to 17 years, 7.9 per 1,000 for adults 18 years or older and 14.9 per 1,000 for people of all ages in 1995 (Larson, et.al., 2001). The intellectual disability and developmental disability groups overlapped but were not exactly the same overall or for people in different age groups.

We attempted to update prevalence rates of IDD in children and adults using the 1997-2007 version of the NHIS survey but were unable to do so. The primary reason was that many of the NHIS-D items used to identify people with IDD were not available after the 1995 NHIS-D. A secondary issue was that the NHIS survey methodology prohibited proxy responses for adults for several years removing many adults with IDD from the samples (Hendershot, Larson, Lakin & Doljanac, 2005). For this report, we used the prevalence rates by age from analyses of the 1994 and 1995 NHIS-D

to estimate the number of people with ID, DD or both in the US population in 2015.

# Number of People with IDD in the United States

#### RISP 2014 and 2015 Estimates

The US Census Bureau estimated the total US population in 2015 was 23.9 million children ages birth to five years, 49.7 million children ages 6 to 17 years, and 247.8 million adults 18 years or older (See **Table 1.1**). Applying the prevalence rates from the 1994/1995 NHIS-D to the 2015 Census, we estimate there were 918,737 children ages birth to 5 years, 1,576,114 children ages 6 to 17 years and 1,957,412 adults with IDD in the 2015 US civilian noninstitutionalized population.

Because the NHIS sample frame specifically excludes people living in "group quarters" such as group homes, we used 2015 RISP data to estimate that there were 253,594 people with IDD estimated to be living in an IDD setting of four or more people or a nursing home or psychiatric facility in 2015. In total, we estimate that there were 4,705,856 people with ID, DD or both in the US in 2015 (14.6 per 1,000). State estimates ranged from 13.0 per 1,000 in Vermont to 16.3 per 1,000 in Utah. Using the same methodology, we reported that there were an estimated 4,680,606 people with IDD in the United States in 2014.

#### **Alternative Estimates**

The DD Act definition of developmental disabilities was updated in 2000 expanding the number of children ages 6 to 9 years who qualify as having DD. In a yet to be published manuscript, we reanalyzed the NHIS-D data using the revised definition to assess the impact of the change in definition of developmental disabilities (Byun, Larson & Lakin, 2015). When we updated the operational definition to reflect the 2000 change in the DD Act definition, our estimate of the number of children ages 6 to 9 years with DD increased 245%. The estimated prevalence of ID, DD or both across all ages increased 27% from 14.9 people per 1,000 to 19.0 people per 1,000. Applying the revised prevalence rate to the 2015 population would increase the estimated number of people

**Table 1.1** Estimated Number of People with IDD in 2015 by Age and State (Using 1995 NHIS-D Prevalence Rates)

	110	Population by	age s —			People	with IDD	
State		. opulation by	uge	Not in Cong	regate Settings	(NHIS-D) 1	In congregate	Estimated Total
	0-5 years	6-17 years	18+ years	0-5 years	6-17 years	18+ years	settings <sup>2</sup>	L3tilliated Total
AL	352,754	750,742	3,755,483	13,546	23,799	29,668	2,180	69,193
AK	65,870	120,396	552,166	2,529	3,817	4,362	214	10,922
AZ	517,199	1,105,651	5,205,215	19,860	35,049	41,121	1,392	97,423
AR	229,191	476,109	2,272,904	8,801	15,093	17,956	3,085	44,935
CA	3,007,598	6,113,318	30,023,902	115,492	193,792	237,189	22,371	568,843
со	405,279	851,786	4,199,509	15,563	27,002	33,176	1,365	77,106
СТ	226,945	537,114	2,826,827	8,715	17,027	22,332	3,845	51,918
DE	67,099	137,287	741,548	2,577	4,352	5,858	577	13,364
DC	50,940	67,167	554,121	1,956	2,129	4,378	462	8,925
FL	1,320,662	2,784,467	16,166,143	50,713	88,268	127,713	10,506	277,200
GA	796,792	1,707,380	7,710,688	30,597	54,124	60,914	2,577	148,212
HI	109,833	201,000	1,120,770	4,218	6,372	8,854	421	19,864
ID	136,791	296,046	1,222,093	5,253	9,385	9,655	924	25,216
IL	944,173	2,014,500	9,901,322	36,256	63,860	78,220	16,839	195,175
IN	504,906	1,074,550	5,040,224	19,388	34,063	39,818	5,913	99,182
IA	237,216	491,580	2,395,103	9,109	15,583	18,921	4,724	48,338
KS	237,681	481,876	2,192,084	9,127	15,275	17,317	1,980	43,700
KY	332,293	679,374	3,413,425	12,760	21,536	26,966	1,852	63,114
LA	371,687	743,126	3,555,911	14,273	23,557	28,092	10,137	76,058
ME	78,284	178,096	1,072,948	3,006	5,646	8,476	1,166	18,294
MD	443,350	904,876	4,658,175	17,025	28,685	36,800	2,833	85,342
MA	440,193	946,894	5,407,335	16,903	30,017	42,718	8,536	98,174
MI	688,381	1,518,923	7,715,272	26,434	48,150	60,951	12,821	148,355
MN	421,429	862,958	4,205,207	16,183	27,356	33,221	7,535	84,295
MS	231,834	495,014	2,265,485	8,902	15,692	17,897	3,245	45,737
МО	450,128	941,348	4,692,196	17,285	29,841	37,068	3,893	88,087
MT	74,380	152,040	806,529	2,856	4,820	6,372	1,583	15,630
NE	157,127	313,210	1,425,853	6,034	9,929	11,264	1,104	28,331
NV	214,028	455,136	2,221,681	8,219	14,428	17,551	965	41,163
NH	77,992	186,006	1,066,610	2,995	5,896	8,426	252	17,570
NJ	637,678	1,361,143	6,959,192	24,487	43,148	54,978	9,050	131,663
NM	162,323	334,585	1,588,201	6,233	10,606	12,547	1,300	30,687
NY	1,414,384	2,796,433	15,584,974	54,312	88,647	123,121	34,588	300,669
NC	729,114	1,561,454	7,752,234	27,998	49,498	61,243	6,595	145,333
ND	63,128	110,798	583,001	2,424	3,512	4,606	957	11,499
ОН	833,280	1,795,197	8,984,946	31,998	56,908	70,981	11,044	170,931
ОК	321,719	639,602	2,950,017	12,354	20,275	23,305	3,765	59,700
OR	278,600	584,256	3,166,121	10,698	18,521	25,012	2,671	56,903
PA	859,114	1,831,160	10,112,229	32,990	58,048	79,887	8,382	179,306
RI	66,134	144,910	845,254	2,540	4,594	6,678	1,157	14,968
SC	350,107	741,481	3,804,558	13,444	23,505	30,056	4,152	71,157
SD	73,218	138,106	647,145	2,812	4,378	5,112	1,405	13,707
TN	483,535	1,014,076	5,102,688	18,568	32,146	40,311	2,090	93,115
TX	2,384,563	4,827,208	20,257,343	91,567	153,022	160,033	15,525	420,148
UT	302,921	609,575	2,083,423	11,632	19,324	16,459	1,338	48,753
VT	36,626	83,297	506,119	1,406	2,641	3,998	116	8,161
VA	617,513	1,252,909	6,512,571	23,712	39,717	51,499	5,819	120,698
WA	538,979	1,072,863	5,558,509	20,697	34,010	43,912	3,109	101,728
WV	123,682	255,914	1,464,532	4,749	8,112	11,570	884	25,315
WI	410,394	884,232	4,476,711	15,759	28,030	35,366	3,812	82,967
WY	46,392	92,503	447,212	1,781	2,932	3,533	539	8,786
	23,925,439	49,719,672	247,773,709	918,737	1,576,114	2,222		4,705,856

<sup>&</sup>lt;sup>s</sup> U.S. Census Bureau, Population Division (2016). <sup>1</sup> Estimated prevalence rates from the 1994/1995 NHIS-D: 3.84% for people 0-5 years; 3.17% for people 6-17 years; and 0.79% for people 18+ years (Larson, et al., 2001). <sup>2</sup> Settings of 4 or more people, including nursing homes or psychiatric facilities. State estimates assume no state to state differences in prevalence of IDD. The estimated total with IDD would increase 6,360,551 if the 2000 DD Act definition was used instead of the 1997 DD Act definition of developmental disabilities.



with IDD in the United States from 4,705,856 to 6,360,551. If the prevalence estimate for children reported by Zablotsky (2015) based on analysis of the 2014 NHIS were used the estimated total would be 6,452,964.

In the FY 2013 RISP report, we estimated the total number of people with IDD in the United States to be 6,154,636. The prevalence rate applied for adults was based on the 1994/1995 NHIS-D (Larson et al., 2001). The prevalence rate applied for children ages 18 years and younger was based on the 2014 NHIS (Zablotsky et al., 2015).

# PEOPLE SERVED BY, OR UNDER THE AUSPICES OF STATE IDD AGENCIES

States reported the total number of children and adults who were served by, or known to, their state IDD agency. This number includes people with IDD who received LTSS or other services, people with IDD who had requested and were waiting for services, and people with IDD known to state IDD agencies, but not currently getting publicly funded LTSS. It does not include people with IDD served by other state agencies such as a department of education, vocational rehabilitation, corrections, or a state Medicaid office operating separately from the IDD agency unless those individuals are also served by or known to the state IDD agency.

Forty-nine states reported the number of people with IDD served by state IDD agencies. In addition, 48 states reported the total number of people served or tracked by age: children and youth (ages birth to 21 years) and adults (22 years or older).

In FY 2015, an estimated 1,464,459 people with IDD (31% of the total in the United States) were served by or known to their state IDD agency (See **Table 1.2**). The majority of people served were ages 22 years or older (61%, 895,690 people). The proportion of adults with IDD varied widely by state. States in which adults comprised 90% or more of the IDD agency caseload included Rhode Island (100%), District of Columbia (97%), Virginia (96%), and Alabama (91%). States in which fewer than half of the people with IDD served or tracked were adults included California (49%), Washington

**Table 1.2** Number and Percentage of People Known to or Served by State IDD Agency by Age on June 30, 2015

	30, 2013 Numbe	er of People Se	rved <sup>1</sup>	% of Peo	ple Served
State	Birth-21	22+ years	All Ages	Birth-21	22+ years
N States	48	48	49	48	48
AL	778	8,115	8,893	9	91
AK	1,104	1,689	2,793	40	60
AZ	23,255	12,430	35,685	65	35
AR	DNF	DNF	DNF	DNF	DNF
CA	126,361	123,282	249,643	51	49
СО	12,994	11,889	24,883	52	48
CT	4,062	12,266	16,328	25	75
DE	1,308	2,896	4,204	31	69
DC	69	2,156	2,225	3	97
FL	16,253	40,859	57,112	28	72
GA	3,991 <sup>e</sup>	12,585 <sup>e</sup>	16,576 <sup>e</sup>	24	76
HI	571	2,778	3,349	17	83
ID	3,694	3,699	7,393	50	50
IL	15,555	39,216	54,771	28	72
IN	8,520	18,894	27,414	31	69
IA	4,297	10,653	14,950	29	71
KS	4,069	8,062	12,131	34	66
KY	10,000 <sup>e</sup>	8,000 <sup>e</sup>	18,000 <sup>e</sup>	56	44
LA	25,088	23,217 <sup>e</sup>	48,305 <sup>e</sup>	52	48
ME	954	5,545	6,499	15	85
MD	5,534	19,377	24,911	22	78
MA	11,161	24,277	35,438	31	69
MI	12,504	32,611	45,115	28	72
MN	10,536	20,950	31,486	33	67
MS	1,908 <sup>e</sup>	5,232 <sup>e</sup>	7,140 <sup>e</sup>	27	73
MO	14,132	19,157	33,289	42	58
MT	587	2,608	3,195	18	82
NE	1,584	7,008	8,592	18	82
NV	2,531	3,801	6,332	40	60
NH	1,275	3,960	5,235	24	76
NJ	DNF	DNF	25,330	DNF	DNF
NM	4,967 <sup>e</sup>	6,361 <sup>e</sup>	11,328 <sup>e</sup>	44	56
NY	42,734	89,055	131,789	32	68
NC	12,743	21,715	34,458	37	63
ND	2,312	2,658	4,970	47	53
ОН	51,971	51,092	103,063	50	50
OK	5,475	8,334	13,809	40	60
OR	9,867	14,834	24,701	40	60
PA	17,647	44,066	61,713	29	71
RI	0	4,016	4,016	0	100
SC	16,258	18,115	34,373	47	53
SD	1,584	2,966	4,550	35	65
TN	5,460	16,339	21,799	25	75
TX	DNF <sup>d</sup>	DNF <sup>d</sup>	DNF <sup>d</sup>	DNF	DNF
UT	2,565	4,669	7,234	35	65
VT	1,372	3,036	4,408	31	69
VA	800 <sup>e</sup>	18,717 <sup>e</sup>	19,517 <sup>e</sup>	4	96
WA	21,800	20,574	42,374	51	49
WV	1,477 <sup>d</sup>	3,047 <sup>d</sup>	42,374 4,524 <sup>d</sup>	33	67
WI	13,029	27,978	41,007	32	68
WY					
Reported	631	1,479	2,110	30	70
Total	537,367	846,263	1,408,960	38	60
Estimated Total	568,769	895,690	1,464,459	39	61
	/ Llevelly Ave	ust 31 2015 or	- luna 20, 2017	I) e Estimato	DNE DIA

d Other date (Usually August 31, 2015 or June 30, 2014). Estimate ™ Did not furnish (missing value). Source U.S. Census Bureau, Population Division (2016). See state notes in Appendix. The caseload total includes people with IDD who recieve services, are waiting for services or are known to but not recieving services under the auspices of the state IDD agency.

(49%), Colorado (48%), Louisiana (48%), Kentucky (44%), and Arizona (35%).

Differences in the age distribution of the people served, or tracked by, the state IDD agency may or may not reflect differences in prevalence. Often, they reflect differences in which state agency manages LTSS for people with IDD, whether a separate Medicaid office administers Medicaid State Plan LTSS, and/or the use of Medicaid managed care.

## SIZE AND TYPE OF LIVING ARRANGEMENTS

The FY 2015 RISP survey captured information about the following residence types:

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.

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).

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 pwer year.

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

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

# **Groups of Settings**

Many tables in this report combine multiple residence types into larger clusters. The clusters include IDD group settings, IDD non-family settings, and all IDD LTSS settings (See **Table B**). Services are also grouped by type of operation. State-operated settings use employees who work for the state government. Nonstate settings are

**Table B:** Setting Clusters Used in this Report

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



staffed by employees who work for a nonstate agency or provider. Nonstate settings also include all own home, family home and host/foster family home settings.

LTSS Long-term supports and services

**Type of Operation** refers to whether services are operated by the state (using state employees) or by a nonstate entity (using staff employed directly by an entity other than the state).

**IDD Group-** This cluster includes all group and facility settings in which LTSS recipients served by or under the auspices of state IDD agencies live. Residence types in this cluster include IDD group homes (except ICF/IID), Intermediate Care Facilities for Individuals with Intellectual Disabilities, and other state or nonstate settings. This cluster does not include own home, family member, or host/foster family home settings.

**IDD Non-Family-** This cluster includes all settings in which people with IDD served by or under the auspices of state IDD agencies live except the home of a family member.

**All IDD LTSS Settings** -This cluster includes all residence types in which LTSS recipients with IDD served by or under the auspices of state DD agencies live. It includes own home, family home, host/foster family home, group home (except ICF/IID), ICF/IID, and "other" settings. It does not include nursing homes or psychiatric facilities.

# **Living Arrangement Types**

Of the 1,464,459 people served by state IDD agencies as of June 30, 2015, an estimated 83% (1,211,535 people) received publicly funded long-term supports or services (See **Table 1.3**).

Of those who received LTSS in known settings an estimated

- 97% (1,180,015 people) received LTSS from a nonstate entity. Their living arrangements included:
  - 58% (698,566) in the home of a family member,
  - 16% (192,738) in an IDD group home,
  - 12% (139,985) in a home they owned or leased,
  - 5% (61,715) in a host/foster family home,
  - 5% (55,958) in a nonstate ICF/IID, and

- 3% (31,053) in an "other" nonstate IDD setting.
- 3% (31,520 people) lived in a state-operated IDD setting. Their services were funded by
  - 1% (9,775) Medicaid Waiver,
  - 2% (21,486) ICF/IID, and
  - 0.02% (259) other types of funds.

In the 42 states providing complete setting type information, the setting type in which the largest number LTSS recipients with IDD lived was:

- Family home in 27 states (AZ, AR, CA, DE, FL, GA, HI, IL, IN, MI, MN, MS, MO, NV, NJ, OH, OR, PA, RI, SD, TN, UT, VT, WA, WV, WI, WY),
- Nonstate group home (except ICF/IID) in 8 states (AL, CT, DC, ME, MA, MT, NE, VA),
- Own Home settings in 4 states (AK, ND, CO and OK),
- Host/family foster home in 2 states (NH and TX), and
- "Other" Nonstate IDD setting in one state (MD).

### **Residence Size**

**Figure 1.1** shows living arrangements for people with IDD served by or under the auspices of the state IDD agency and/or living in a nursing home or psychiatric facility. The blue section shows people living in the home of a family member, the red sections show people living in non-family settings shared by one to three people with IDD, the green sections show people living in non-family IDD settings shared by four or more people and the black section shows people living in nursing homes or psychiatric facilities. On June 30, 2015 of the LTSS recipients with IDD:

- 56% lived in the home of a family member,
- 23% lived in a non-family setting of 3 or fewer people including
  - 11% in an "own home" setting,
  - 7% in an IDD group setting of 3 or fewer people, and
  - 5% in a host/foster family home.
- 18% lived in an IDD group setting of four or more people including:
  - 10% in an IDD group setting of 4 to 6 people,
  - 5% in an IDD group setting of 7 to 15 people, and
  - 3% in an IDD group setting of 16 or more people.
- 2% lived in a nursing home or a psychiatric facility.

**Table 1.3** Types of Living Arrangements for LTSS Recipients with IDD by Type of Operation and State on June 30, 2015

			Nonstate IDD S	Settings			State Op	erated IDD S	ettings	Estimated Tatel
	Family home	Own home	Host /Foster Family Home	Group not ICF/IID	ICF/IID	Other	Group Waiver	ICF/IID	Group Other	Estimated Total Recipients
N States	46	46	48	49	51	48	50	51	50	51
AL	480	96	175	3,230	14	0	0	0	0	3,995
AK	282	687	198	608	0	0	0	0	0	1,781
AZ	31,151	265	1,397	2,677	29	11	154	0	0	35,786
AR	1,973	616	542	1,107	526	0	0	913	0	5,682
CA	162,156	25,097	4,968	20,890	7,032	0	0	1,077	0	221,335
СО	4,483	4,799	2,710	796	20	1,267	116	155	0	14,345
СТ	1,516	1,131	442	3,752	364	0	326	468	0	8,012
DE	3,014 <sup>e</sup>	18	135	1,071	68	0	2	52	0	4,360
DC	799	13	83	953	329	17	0	0	0	2,194
FL	38,377	5,743	284	6,611	1,967	941	0	711	116	54,814
GA	3,105 <sup>e</sup>	1,156 <sup>e</sup>	1,235 <sup>e</sup>	2,877 <sup>e</sup>	0 <sub>d</sub>	33 <sup>e</sup>	0	267	0	8,697
HI	2,241	78	486	272	76	0	0	0	0	3,153
ID	DNF	1,483*	575	225	432 <sup>s*</sup>	0	0	24	0	6,897 <sup>i</sup>
IL	11,390	733	255	10,425	5,101	0	0	1,686	0	29,591
IN	12,756	5,936	221	637	3,319	0	0	0	0	22,869
IA	DNF	DNF	2	536	1,459	0	58	391	0	11,711 <sup>i</sup>
KS	DNF	DNF	DNF	DNF	138	0 <sup>d</sup>	0	312	2	9,971 <sup>i</sup>
KY	DNF	DNF	1,249	3,296 <sup>e</sup>	135	0 <sup>d</sup>	0	286	0	15,795 <sup>i</sup>
LA	13,870	2,408	DNF	DNF	4,242	0	0	497	0	30,404 <sup>i</sup>
ME	136	384	524	1,627	167	305*	0	0	0	3,143
MD	2,215	2,542	212	5,997	0	13,429	0	105	26	24,528
MA	6,948	2,551	2,074	9,740*	0	0	1,087	433	66	22,899
MI	25,780 <sup>d</sup>	6,980 <sup>id</sup>	474 <sup>id</sup>	10,334 <sup>d*</sup>	0	1,216 <sup>d*</sup>	0	0	0	44,784
MN	11,232	2,294	664	9,191	1,462	6,152	350	74	0	31,474
MS	1,700	26	0	759	734	0	226	1,698	0	5,161
МО	10,136	4,363	397	2,230	80	0	209	393	0	17,808
MT	710 <sup>e</sup>	100 <sup>e</sup>	50 <sup>e</sup>	1,438	0	0	0	55	0	2,353
NE	1,426	1,373	705	1,518	253	0	17	114	0	5,433
NV	4,371	1,662	85	0	51	116	0	47	0	6,332
NH	1,047	470	1,106	388	25	0	0	0	6	3,042
NJ	13,248	97	728	7,986	441	309	0	1,600	12	24,421
NM	985 <sup>e</sup>	DNF	1,844 <sup>e</sup>	1,534 <sup>e</sup>	224 <sup>e</sup>	0	PD	3	PD	5,860 <sup>i</sup>
NY	83,052 <sup>e</sup>	10,894 <sup>e</sup>	1,949	22,794	5,575	DNF <sup>a</sup>	6,723	713	0	131,914 <sup>i</sup>
NC	DNF	DNF	DNF	2,527 <sup>e*</sup>	2,523s*	DNF <sup>a</sup>	0	1,442	0	28,975 <sup>i</sup>
ND	1,031	1,262	24	294	463	0	0	79	0	3,153
ОН	73,518 <sup>d</sup>	15,651	2,312	2,660	5,552	2,555 <sup>ed*</sup>	0	815	0	103,063
ОК	1,969	2,414	350	801 <sup>e</sup>	1,581	0	0	1	0	7,115
OR	12,551	807	3,494*	3,331	0	0	137	0	0	20,320
PA	31,775 <sup>e</sup>	4,521 <sup>e</sup>	1,553	11,385	2,089	4,490 <sup>e</sup>	0	950	0	56,748
RI	1,502	488	267	1,189	25	0	188	7	0	3,666
SC	13,437	664	172	2,906	510	DNF	0	673	0	18,363 <sup>i</sup>
SD	1,988	536	2	1,832	50	0	0	140	0	4,545
TN	7,082	4,077	376	718	780	0	0	240	9	13,282
TX	10,944 <sup>d</sup>	3,648 <sup>d*</sup>		7,901 <sup>d</sup>	5,109 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	3,195 <sup>d</sup>	0 <sup>d</sup>	42,780
UT	2,139	1,244	339	1,598 <sup>e</sup>	587	0	0	202	0	6,161
VT	2,124	359	1,352	137	6	0	0	0	0	3,978
VA	3,252	252	1,491 <sup>e</sup>	4,365	521	0	0	483	0	10,142
WA	12,385	3,951	877	2,223	49	176 <sup>e</sup>	129	765	0	20,507
WV	3,051 <sup>d</sup>	0 <sup>d</sup>	103 <sup>d</sup>	1,154 <sup>d</sup>	509 <sup>d</sup>	0 <sub>d</sub>	0	0 <sup>s</sup>	0	5,030
WI	24,666	6,193*	6,467	2,838	437	34*	0	350	0	40,985
WY	1,002	390*	65*	649*	0	2*	0	70	0	2,178
Reported US Total	654,995	130,452	57,107	184,007	55,054	31,053	9,722	21,486	237	2,170
Estimated US Total	698,566	139,985	61,715	192,738	55,958	31,053	9,775	21,486	259	1,211,535

<sup>&</sup>lt;sup>a</sup> Missing values (DNF) assumed to be zero. <sup>b</sup> Nonstate settings reported, but not state settings. <sup>c</sup>State settings reported, but not nonstate settings. <sup>d</sup>Other date (Usually August 31, 2015 or June 30, 2014). <sup>DNF</sup> Did not furnish (missing data). <sup>e</sup>Estimate. <sup>i</sup> Missing value imputed (RISP estimated at least one value). \*See state notes in Appendix.



People living in nursing homes or psychiatric facilities are excluded from the remaining tables in Section 1 except for **Table 1.11**.

# **Home of a Family Member**

On June 30, 2015, an estimated 58% of the 1,211,535 LTSS recipients with IDD served by or under the authority of state IDD agencies lived in the home of a family member (698,566 people, See **Table 1.4**). The proportion living in the home of a family member ranged from 4% in Maine to 87% in Arizona (See **Figure 1.2**).

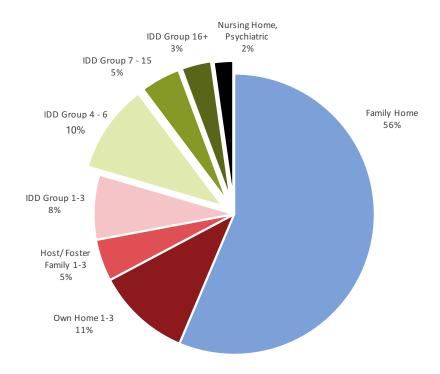
- States reporting the greatest proportion of LTSS recipients with IDD living with family members were Arizona (87%), California (73%), South Carolina (73%), Ohio (71%), Hawaii (71%), and Florida (70%).
- States reporting the smallest proportion of LTSS recipients with IDD living with family members were Connecticut (19%), New Mexico (17%), Alaska (16%), Alabama (12%), Maryland (9%), and Maine (4%).

Some states IDD agencies serve primarily or exclusively adults 22 years or older while other state IDD agencies serve both children and adults. The proportion of recipients living with a family member

is correlated with the proportion of recipients who were 21 years or younger r = .44 (p < .01, df = 43). For example, in Arizona, which reported 87% of LTSS recipients with IDD lived with a family member, 65% of the people on their caseload were 21 years or younger. Similarly in California, which reported 73% of LTSS recipients with IDD lived with a family member, 51% of people on their caseload were 21 years or younger. Conversely, in Maine, which



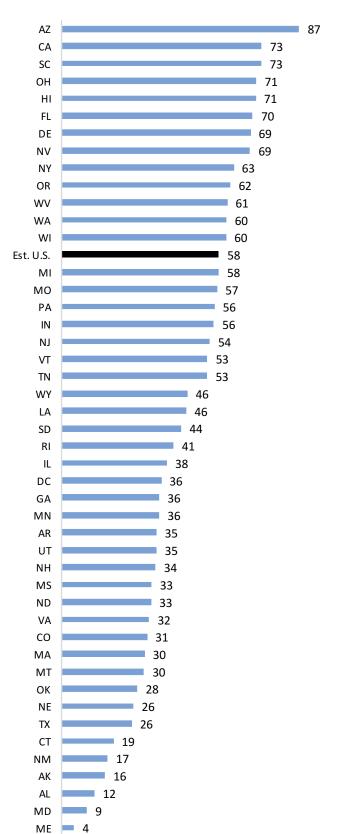
**Figure 1.1** Percent of Long-Term Supports and Services Recipients with IDD by Residential Setting Type and Size on June 30, 2015



**Table 1.4** Number and Percent of LTSS Recipients with IDD Living in the Home of a Family Member by State on June 30, 2015

LTSS Recipients Served by State IDD Agencies State Number Living with % Living with Total Family Member Family Member N States 51 46 3,995 480 12 ΑK 1,781 282 16 ΑZ 35,786 31,151 87 AR 5,682 1,973 35 73 CA 221,335 162,156 CO 14,345 4,483 31 CT 8,012 1,516 19 DE 3,014<sup>e</sup> 69 4,360 36 DC 2,194 799 70 FL 54,814 38,377 GA 8.697 3,105e 36 н 71 3,153 2,241 ID 6.897 DNF DNF IL 29,591 11,390 38 IN 22,869 12,756 56 IA 11,711<sup>i</sup> DNF DNF KS 9,971<sup>i</sup> DNF DNF KY 15,795<sup>i</sup> DNF DNF LA 30,404<sup>i</sup> 13,870 46 ME 3,143 136 4 MD 24,528 2,215 6,948 30 MA 22,899 MI 44,784 25,780<sup>d</sup> 58 MN 31,474 11,232 36 MS 5,161 1,700 33 MO 17,808 10,136 57 MT 2,353 710<sup>e</sup> 30 NE 26 5,433 1,426 N۷ 4,371 69 6,332 NH 3,042 1,047 34 NJ 24,421 13,248 54 17 NM 985e 5,860<sup>i</sup> NY 131,914<sup>i</sup> 83,052<sup>e</sup> 63 NC 28,975<sup>i</sup> DNF DNF ND 3,153 1,031 33 ОН 103,063 73,518<sup>d</sup> 71 ОК 7,115 1,969 28 OR 20,320 12,551 62 PA 56,748 31,775<sup>e</sup> 56 RI 3,666 1,502 41 73 SC 18,363<sup>i</sup> 13,437 SD 4,545 1,988 44 ΤN 7,082 53 13,282 TX 42,780 10,944<sup>d</sup> 26 UT 6,161 2,139 35 VT 3,978 2,124 53 VΑ 10,142 3,252 32 WA 20,507 12,385 60 3,051<sup>d</sup> WV 5.030 61 24,666 WI 40,985 60 WY 2,178 1,002 46 **Estimated** 1,211,535 698,566 **US Total** 

**Figure 1.2** Percent of LTSS Recipients with IDD Living with a Family Member by State on June 30, 2015



d Other date (Usually August 31, 2015 or June 30, 2014). Estimate. DNF Did not furnish. ★ See state notes in Appendix. Missing value imputed (RISP estimated at least one value).



reported 4% of LTSS recipients with IDD lived with family members, 15% of people on their caseload were 21 years or younger. Approximately 19% of the variability in the proportion of LTSS recipients with IDD living with family members could be accounted for by the proportion who were 21 years or younger. Other factors such as eligibility criteria for services and the types of services offered in specific state Waiver plans may also explain some state-to-state differences.

The next several tables examine living arrangements for LTSS recipients with IDD who did not live with a family member.

#### **Own Home**

An estimated 27% of LTSS recipients with IDD (139,985 people) in non-family settings lived in a home they owned or leased (Own Home setting) on June 30, 2015 (See **Table 1.5**). Of those, an estimated 96% shared their home with two or fewer other people with IDD and 4% lived in a home shared by 4 to 6 people with IDD.

In 28 states, all of the people in Own Home settings shared their home with two or fewer other people with IDD. States reporting the largest proportion of own home recipients living in settings of 4 to 6 people were Nevada (38%), Washington (17%) and Nebraska (9%).

Fewer than 2% of people in non-family settings lived in Own Home settings in Delaware (1.3%), the District of Columbia (0.9%), New Jersey (0.9%), Mississippi (0.8%), and West Virginia (0). More than two-thirds of LTSS recipients in non-family settings lived in Own Home settings in Nevada (88%) and Tennessee (66%).

# **Host/Family Foster Home**

An estimated 12% of LTSS recipients with IDD (61,715 people) in non-family settings lived in a host or foster family home (See **Table 1.6**). Of the 48 states reporting the number of people with IDD living in Host/Family Foster Homes, 43 reported the size of those settings and 41 reported the total number of those settings.

**Table 1.5** Number and Percent of LTSS Recipients with IDD in Own Home Settings by State and Setting Size on June 30, 2015

State	People v	vith IDD Pe	er Home		Percent in Own
	1 to 3	4 to 6	Total	Non-Family <sup>1</sup>	Home (%)
N States	39	39	46	51	46
AL	90	6	96	3,515	
AK	687	0	687	1,499	
AZ	265	0	265	4,635	
AR	590	26	616	3,709	
CA	25,097	0	25,097	59,179	
CO	DNF	DNF	4,799	9,862	
CT	1,131	0	1,131	6,496	
DE	18	0	18	1,346	
DC	13	0	13	1,395	
FL	5,743	0	5,743	16,437	
GA	1,113 <sup>e</sup>	43 <sup>e</sup>	1,156 <sup>e</sup>	5,592	
HI	78	0	78	912	
ID	DNF	DNF	1,483*	2,771	54
IL	733	0	733	18,201	4
IN	5,636	300	5,936	10,113	
IA	DNF	DNF	DNF	4,297	
KS	DNF	DNF	DNF	3,955	
KY	DNF	DNF	DNF	6,868	
LA	2,408	0	2,408	16,534	
ME	384	0	384	3,007	
MD	2,529	13	2,542	22,313	
MA	DNF	DNF	2,551	15,951	16
MI	226 <sup>d</sup>	81 <sup>d</sup>	6,980 <sup>id</sup>	19,004	
MN	2,294	0	2,294	20,242	
MS	26	0	26	3,461	
MO	4,363	0	4,363	7,672	
MT	100 <sup>e</sup>	0e	100 <sup>e</sup>	1,643	
NE	1,247	126	1,373	4,007	
NV	1,029	633	1,662	1,961	
NH	470	0	470	1,995	
NJ	97	0	97	11,173	
NM	DNF	DNF	DNF	4,875	
NY	10,894 <sup>e</sup>	0	10,894 <sup>e</sup>	48,862	
NC	DNF	DNF	DNF	11,886	
ND	1,262	0	1,262	2,122	
OH	14,875 <sup>d</sup>	776 <sup>d</sup>	15,651	29,545	
OK	DNF	DNF	2,414	5,146	
OR	807	0	807	7,769	
PA	4,521 <sup>e</sup>	0 <sup>e</sup>	4,521 <sup>e</sup>	24,973	
RI	488	0	488	2,164	
SC	664	0	664	4,926	
SD	536	0	536	2,557	
TN	4,077	0	4,077	6,200	
TX	DNF	DNF	3,648 <sup>d*</sup>	31,836	
UT	1,244	0	1,244	4,022	
VT	359	0	359	1,854	
VA	243	9	252	6,890	
WA	3,274	677	3,951	8,122	
WV	0d	0d	0d	1,979	
WI	DNF	DNF	6,193*	16,319	
WY	DNF	DNF	390*	1,176	33
Reported US Total	99,611	2,690	130,452		
Estimated US Total	134,719	5,266	139,985	512,969	27%

d Other date (Usually August 31, 2015 or June 30, 2014). Estimate. ™ Did not furnish (missing value). See state notes in Appendix. The estimated total excludes people in family homes. People in nursing homes and psychiatric facilities are included only if the state DD agency reported them in state or nonstate other. It includes people in the following settings: state and non-state IDD group, own home, host homes and foster family and people in other non-state settings (estimates are used when states did not furnish complete information).

**Table 1.6** Number of Host or Family Foster Home Settings and People with IDD Living in Them by Setting Size and State on June 30, 2015

Catting Cina		Host/Family F	oster Settings b	y Size			People wit	h IDD by Settin	g Size	
Setting Size	1-3	4-6	1-6	7-15	Total	1-3	4-6	1-6	7-15	Total
N States	40	42	41	43	41	43	43	45	45	48
AL	143	0	143	0	143	175	0	175	0	175
AK	198 <sup>e</sup>	0	198	0	198 <sup>e</sup>	198	0	198	0	198
AZ	921	2	923	0	923	1,389	8	1,397	0	1,397
AR	542	0	542	0	542	542	0	542	0	542
CA	DNF	0	DNF	0	DNF	4,968	0	4,968	0	4,968
СО	1,355 <sup>e</sup>	0	1,355 <sup>e</sup>	0	1,355 <sup>e</sup>	2,710	0	2,710	0	2,710
СТ	295	1	296	1	297	419	12	431	11	442
DE	117	0	117	0	117	135	0	135	0	135
DC	61	0	61	0	61	83	0	83	0	83
FL	50	39	89	7	96	60	151	211	73	284
GA	966 <sup>e</sup>	1 <sup>e</sup>	967 <sup>e</sup>	0	967 <sup>e</sup>	1,231 <sup>e</sup>	4 <sup>e</sup>	1,235 <sup>e</sup>	0	1,235 <sup>e</sup>
HI	291	0	291	0	291	486	0	486	0	486
ID	389	19	408	0	408	529	46	575	0	575
IL	221	0	221	0	221	255	0	255	0	255
IN	155	3	158	0	158	209	12	221	0	221
IA	2	00	2	0	2	2	0	2	0	2
KS	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	735 <sup>e</sup>	0	735 <sup>e</sup>	0	735 <sup>e</sup>	1,249	0	1,249	0	1,249
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	DNF	DNF	496	0	496	DNF	DNF	524	0	524
MD	198	0	198	0	198	212	0	212	0	212
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	2,074	0 <sub>j</sub>	2,074
MI	DNF	DNF	DNF	DNF	DNF	50 <sup>d</sup>	57 <sup>d</sup>	107 <sup>d</sup>	6 <sup>d</sup>	474 <sup>id</sup>
MN	593	5	598	0	598	644	20	664	0	664
MS	0	0	0	0	0	0	0	0	0	0
MO	368	0	368	0	368	397	0	397	0	397
MT	50 <sup>e</sup>	0e	50e	0e	50 <sup>e</sup>	50	0e	50 <sup>e</sup>	0e	50 <sup>e</sup>
NE	636	0	636	0	636	705	0	705	0	705
NV	67	1	68	0	68	81	4	85	0	85
NH	853	1	854	1	855	1,093	6	1,099	7	1,106
NJ	277	0	277	0	277	728	0	728	0	728
NM	1,085 <sup>e</sup>	0e	1,085 <sup>e</sup>	0e	1,085 <sup>e</sup>	1,844 <sup>e</sup>	0	1,844 <sup>e</sup>	0	1,844 <sup>e</sup>
NY	941	157	1,098	0	1,098	1,451	498	1,949	0	1,949
NC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ND	20 2,038 <sup>d</sup>	0 6 <sup>d</sup>	20	0 4 <sup>d</sup>	20	24 2,246 <sup>d</sup>	30 <sup>d</sup>	24	0	24
OH			2,044 350 <sup>e</sup>		2,048			2,276	36 <sup>d</sup>	2,312
OK OR	350 <sup>e</sup> 603	0	1,012	0	350 <sup>e</sup>	350	0	350	0	350 3,494*
PA	1,188	409	1,188	3	1,015 1,188	DNF 1,553	DNF 0	DNF 1,553	DNF 0	1,553
SC RI	267 136	0	267 136	0	267 136	267 172	0	267 172	0	267 172
SD	1	0	1	0	130	2	0	2	0	2
TN	288	0	288	0	288	376	0	376	0	376
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	12,094 <sup>d*</sup>
UT	297 <sup>e</sup>	0	297 <sup>e</sup>	0	297 <sup>e</sup>	339	0	339	0	339
VT	1,197	0	1,197	0	1,197	1,352	0	1,352	0	1,352
VA	DNF	DNF	DNF	DNF	DNF	1,461 <sup>e</sup>	30e	1,491 <sup>e</sup>	0e	1,491 <sup>e</sup>
WA	747	5	752	3	755	829	23	852	25	877
WV	DNF	0 <sub>d</sub>	DNF	0 <sub>q</sub>	DNF	103 <sup>d</sup>	0d	103 <sup>d</sup>	0d	103 <sup>d</sup>
WI	1,743	0	1,743	0	1,743	6,467	0	6,467	0	6,467
WY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	65*
Reported US Total	20,384	649	21,529	19	21,548	37,436	901	40,935	158	57,107
Estimated US Total	36,026	1,050	37,076	31	37,107	59,842	1,619	61,460	255	61,715

d Other date (Usually August 31, 2015 or June 30, 2014). Estimate. Did not furnish. \* See state notes in Appendix.



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

- 97% (59,842 people) lived in homes shared by 3 or fewer people with IDD,
- 2.6% (1,619 people) lived in homes of four to six people with IDD, and
- 0.4% (255 people) lived in homes of seven to fifteen people with IDD.

LTSS recipients with IDD lived in an estimated 37,107 Host/Family Foster Homes on June 30, 2015. Of those settings, 97% served three or fewer people, 3% served 4 to six people, and less than 0.1% served six or more people with IDD. The average Host/Family Foster Home served 1.7 people with IDD. The average number of people per host/foster family home varied by state ranging from 1.0 in Alaska, Arkansas, Iowa, Montana, Oklahoma, and Rhode Island to 2.0 or more in Colorado, Florida, New Jersey, Oregon, South Dakota, and Wisconsin.

- 30% (92,576 people) lived in settings of three or fewer people,
- 38% (119,831 people) lived in settings of 4 to 6 people,
- 18% (56,372 people) lived in settings of 7 to 15 people, and
- 14% (42,490 people) lived in facilities with 16 or more residents.

More than 95% of all people in IDD group settings lived in settings of six or fewer people in New Mexico (100%), Vermont (100%), the District of Columbia (98%), Hawaii (98%), Maryland (97%), and Minnesota (96%). Fewer than 25% of people in IDD group settings lived in settings of six or fewer people in Michigan (23%), Ohio (23%), Iowa (21%), and Arkansas (6%).

# **IDD Group Settings**

IDD group settings include group homes, ICF/IID, and other group settings. They do not include Own Home, Host/Family Foster Home, Nursing Homes or Psychiatric Facilities. An estimated 61% of LTSS recipients with IDD (311,433 people) served by state IDD agencies in non-family settings lived in an IDD group setting (See **Table 1.7**).

#### **Number of Settings**

There were an estimated 93,936 IDD group settings on June 30, 2015. Of those,

- 64% (60,110 settings) served three or fewer people
- 28% (25,855 settings) served four to six people,
- 7% (7,006 settings) served 7 to 15 people, and
- 1% (952 settings) served 16 or more people.

While 92% of IDD group settings served six or fewer people, the proportion varied by state ranging less than 50% in six states to more than 95% in 19 states.

## **Number of People**

An estimated 26% of LTSS recipients with IDD (311,269 people) lived in IDD group settings on June 30, 2015. Of those,



**Table 1.7** Number of IDD Group Settings and People with IDD Living in Them by Setting Size and State on June 30, 2015

-	Nullibe	i oi Group	Homes, ICF	711D OI Otile	droup 3	ettiligs		Number of	People Livin	שווים שטוווון	up settings	
Size	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	37	42	44	43	44	42	41	45	45	46	49
AL	918	111	1,029	88	0	1,117	2,055	447	2,502	742	0	3,244
AK	201	191	392	15	10	417	400 <sup>e</sup>	150 <sup>e</sup>	550 <sup>e</sup>	58 <sup>e</sup>	0e	608
AZ	797	250	1,047	4	2	1,053	1,626	1,090	2,716	33	122	2,871
AR	101	20	121	98	25	244	108	56	164	932	1,450	2,546
CA	PD	PD	5,412	136	63	5,611	PD	PD	25,338	1,129	2,532	28,999
CO	633 <sup>e</sup>	PD	PD	1	PD	PD	1,267	932	2,199	126	29	2,354
СТ	576	545	1,121	34	6	1,161	1,447	2,741	4,188	254	468	4,910
DE	255	122	377	0	2	379 578	684	389	1,073	0	120	1,193
DC	480 124 <sup>a</sup>	92 1,122 <sup>a</sup>	572 1,246 <sup>a</sup>	1 319 <sup>a</sup>	5 61 <sup>a</sup>	1,626 <sup>a</sup>	842 442	433 5,442	1,275 5,884	7	17	1,299 10,346
FL GA	1,107 <sup>e</sup>	240 <sup>e</sup>	1,246°	1e	2	1,826 <sup>a</sup>	1,912 <sup>e</sup>	987 <sup>e</sup>	2,899 <sup>e</sup>	1,811 <sup>e</sup>	2,651 267 <sup>e</sup>	3,177 <sup>e</sup>
HI	0	58	58	1	0	59	0	341	341	7	0	3,177
ID	0	26	26	74	41	141	0	PD	PD	PD	PD	681 <sup>s</sup>
IL	280	935	1,215	857	67	2,139	559	4,651	5,210	7,467	4,535	17,212
IN	0	320	320	333	2	655	0	1,456	1,456	2,454	46	3,956
IA	10 <sup>d</sup>	103 <sup>d</sup>	113	81	24	218	26 <sup>d</sup>	497 <sup>i</sup>	523	782	1,139 <sup>d</sup>	2,444
KS	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PDd
KY	1,001 <sup>ed</sup>	50 <sup>ed</sup>	1,051 <sup>ed</sup>	3 <sup>d</sup>	6 <sup>d</sup>	1,060 <sup>ed</sup>	3,001 <sup>e</sup>	295 <sup>e</sup>	3,296 <sup>e</sup>	23	398 <sup>e</sup>	3,717 <sup>ed</sup>
LA	PD	PD	604	418	20	1,042	PD	PD	PD	PD	PD	PD
ME	PD	PD	727 <sup>a</sup>	13 <sup>a</sup>	2 <sup>a</sup>	857*	PD	PD	1,638 <sup>a</sup>	124 <sup>a</sup>	32 <sup>a</sup>	2,099*
MD	14,600	481	15,081	35	6	15,122	17,007	2,048	19,055	274	228	19,557
MA	DNF	PD	PD	PD	PD	PD	DNF	PD	PD	PD	433 <sup>i</sup>	11,326*
MI *	PD	PD	PD	PD	PD	PD	334 <sup>d</sup>	2,317 <sup>d</sup>	2,651 <sup>d</sup>	387 <sup>d</sup>	209 <sup>d</sup>	11,550*
MN	PD	PD	12,745	43	14	12,802	PD	PD	16,477	422	330	17,229
MS	254	61	315	67	12	394	622 <sup>e</sup>	318 <sup>e</sup>	940 <sup>e</sup>	717 <sup>e</sup>	1,778 <sup>e</sup>	3,435
МО	125	241	366	139	10	515	330	1,033	1,363	1,080	469	2,912
MT	2	87	89	90	1	180	5 <sup>e</sup>	708 <sup>e</sup>	713 <sup>e</sup>	725 <sup>e</sup>	55 <sup>e</sup>	1,493
NE	782	57	839	23	6	868	1,130	250	1,380	191	331	1,902
NV	0	6	6	0	25	62*	0	33	33	0	181	214
NH	174	27	201	2	1	204	288	96	384	10	25	419
NJ	1,104 <sup>ed</sup>	1,226 <sup>ed</sup>	2,330 <sup>d</sup>	99d	8a	2,437 <sup>a</sup>	2,207	4,905	7,112	842	2,394	10,348
NM	PD 1 2523	PD	517 <sup>e</sup>	0	0	517 <sup>ee</sup>	674 <sup>e</sup>	1,144 <sup>e</sup>	1,818 <sup>e</sup>	0	0e	1,818 <sup>e</sup>
NY	1,950 <sup>a</sup>	2,441 <sup>a</sup>	4,398 <sup>a</sup>	2,059 <sup>a</sup>	58 <sup>a</sup>	6,515 <sup>a</sup>	3,481 <sup>a</sup>	12,201 <sup>a</sup>	15,682 <sup>a</sup>	18,462 <sup>a</sup>	1,661 <sup>a</sup>	35,805 <sup>a</sup>
NC	349 <sup>a</sup>	PD 54	PD	PD 54	PD	1,640 <sup>a</sup>	PD	PD	PD	PD 427	PD 100	6,492 <sup>a</sup>
ND OH	1 210 <sup>a</sup>	54 472 <sup>a</sup>	55 682 <sup>a</sup>	54 305 <sup>a</sup>	2 88 <sup>a</sup>	111 1,075 <sup>a</sup>	3 386 <sup>a</sup>	287 2,238 <sup>a</sup>	290 2,624 <sup>a</sup>	437 2,614 <sup>a</sup>	109 3,789 <sup>a</sup>	836 11,582*
OK	0	PD	PD	PD	PD	225 <sup>sd*</sup>	0	818 <sup>e</sup>	818 <sup>e</sup>	598 <sup>e</sup>	967	2,383 <sup>e</sup>
OR	383	452	835	22	14	871	1,053	2,230	3,283	161	24	3,468
PA	8,223 <sup>e</sup>	863 <sup>e</sup>	9,086 <sup>e</sup>	56 <sup>e</sup>	25 <sup>e</sup>	9,167 <sup>e</sup>	12,551	3,679	16,230	483	2,201	18,914 <sup>e</sup>
RI	124	198	322	32	1	355 <sup>s</sup>	258 <sup>s</sup>	873	1,131	253	25	1,409
SC	141 <sup>a</sup>	543 <sup>a</sup>	684 <sup>a</sup>	105 <sup>a</sup>		794 <sup>a</sup>	370 <sup>a</sup>	2,179 <sup>a</sup>	2,549 <sup>a</sup>	867 <sup>a</sup>	673 <sup>a</sup>	4,089 <sup>a</sup>
SD	536	101	637	67	2	706	702	507	1,209	623	190	2,022
TN	96	131	227	90	4	321	239	580	819	732	196	1,747
TX	PD	PD	PD	PD	PD	PD	PD	PD	12,151 <sup>d</sup>	533 <sup>d</sup>	3,521 <sup>d</sup>	16,205 <sup>d</sup>
UT	704 <sup>e</sup>	82 <sup>e</sup>	786 <sup>e</sup>	7 <sup>e</sup>	15	808 <sup>e</sup>	1,135 <sup>e</sup>	415 <sup>e</sup>	1,550 <sup>e</sup>	74 <sup>e</sup>	763 <sup>e</sup>	2,387 <sup>e</sup>
VT	43	17	60	0	0	60	57	86	143	0	0	143
VA	226 <sup>e</sup>	510 <sup>e</sup>	736 <sup>e</sup>	77 <sup>e</sup>	9e	822 <sup>i</sup>	677	3,028	3,705	1,010	654	5,369
WA	559	257 <sup>e</sup>	816 <sup>e</sup>	26 <sup>e</sup>	113 <sup>e</sup>	955 <sup>e</sup>	948	1,224	2,172	229	941 <sup>e</sup>	3,342 <sup>e</sup>
WV	PD	PD	PD	52 <sup>d</sup>	0 <sub>q</sub>	PD	1,016 <sup>d</sup>	222 <sup>d</sup>	1,238 <sup>d</sup>	425 <sup>d</sup>	0 <sub>q</sub>	1,663*
WI	0 <sup>a</sup>	579 <sup>a</sup>	579 <sup>a</sup>	2 <sup>a</sup>	22 <sup>a</sup>	603 <sup>a</sup>	0 <sup>a</sup>	2,838 <sup>a</sup>	2,838 <sup>a</sup>	13 <sup>a</sup>	774 <sup>a</sup>	3,659*
WY	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	PD	721*
Reported US Total	37,069	13,071	69,170	5,929	779	77,836	66,022	79,720	183,524	49,930	39,957	301,634
Estimated	55,661	25,854	81,528	7,006	926	89,460	92,576	119,831	212,407	56,372		311,269

<sup>&</sup>lt;sup>a</sup> Missing values in Nonstate other settings assumed to be zero. <sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014), <sup>e</sup>Estimate. <sup>Def</sup> Did not furnish all component elements. <sup>t</sup> Missing value imputed. <sup>PD</sup> Partial data, calculation incomplete and not included in reported totals. \* See state notes in Appendix. <sup>1</sup> This table includes state and non-state ICF/IID, group homes, and "other" IDD settings. It excludes people living with family members, host family/family foster settings, own home settings, nursing homes or psychiatric facilities.



# **Non-Family IDD Settings**

For FY 2015, 48 states described the size of all state-operated settings, and 29 states described the size of all nonstate settings. All but one state reported complete size information for people in state-operated settings as did 33 states for people in nonstate settings. "Partial data" (PD) is indicated when size information is provided but only for some types of non-family settings. The number of people in "other" nonstate settings was assumed to be 0 unless otherwise specified by the state.

## **Number of Settings**

On June 30, 2015, LTSS recipients with IDD lived in an estimated 230,092 non-family IDD settings (See **Table 1.8**). Of those,

- 1% (2,091 settings) were state-operated,
- 99% (228,001 settings) were nonstate-operated.

Of the estimated 2,091 state-operated non-family IDD settings,

- 18% (386 settings) in 14 states served 1 to 3 people,
- 40% (844 settings) in 20 states served 4 to 6 people,
- 34% (709 settings) in 12 states served 7 to 15 people, and
- 7% (151 settings) in 37 states served 16 or more people.

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

Of the estimated 228,001 nonstate-operated non-family IDD settings,

- 85% (193,263 settings) served 1 to 3 people,
- 12% (27,623 settings) served 4 to 6 people,
- 2.8% (6,327 settings) served 7 to 15 people, and
- 0.3% (775 settings) served 16 or more people.



Table 1.8 Number of Non-Family Settings in Which LTSS Recipients with IDD Live by Size, Type of Operation, and State on June 30, 2015

				,	)			-			,		-			,		
I		Z	Nonstate Settings	ttings		 			State Settings	ngs					Total Settings <sup>1</sup>	ngs ¹		
Size	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	29	30	31	42	44	31	49	48	49	50	50	50	29	30	31	42	43	31
AL	1,141	113	1,254	88	0	1,342	0	0	0	0	0	0	1,141	113	1,254	88	0	1,342
AK	292	191	928	15	10	983	0	0	0	0	0	0	767	191	928	15	10	983
AZ	1,884	249	2,133	0	1	2,134	9	33	6	4	1	14	1,890	252	2,142	4	2	2,148
AR	1,233	26	1,259	86	20	1,377	0	0	0	0	5	5	1,233	26	1,259	98	25	1,382
CA	DNF	PD	PD	136	59	PD	0	0	0	0	4	4	PD	PD	PD	136	63	PD
00	PD	PD	PD	0	0	PD	0	DNF	DNF	_	DNF	PD	PD	PD	PD	_	PD	PD
C	1,963	509	2,472	23	0	2,495	14	37	51	12	9	69	1,977	546	2,523	35	9	2,564
DE	389	122	511	0	-	512	_	0	_	0	-	2	390	122	512	0	2	514
DC	554	92	646	1	5	652	0	0	0	0	0	0	554	92	646	1	2	652
F.	PD	PD	PD	326	58	PD	0	0	0	0	cc	cc	PD	PD	PD	326	61	PD
ВA	3,029	251	3,280	_	0	3,281	0	0	0	0	2	2	3,029	251	3,280	_	2	3,283
Ξ	369	58	427	1	0	428	0	0	0	0	0	0	369	58	427	1	0	428
D	PD	PD	PD	74	40	PD	0	1	1	0	1	2	PD	PD	PD	74	41	PD
_	1,112	935	2,047	857	09	2,964	0	0	0	0	7	7	1,112	935	2,047	857	29	2,971
Z	3,409	398	3,807	333	2	4,142	0	0	0	0	0	0	3,409	398	3,807	333	2	4,142
Ι	PD	PD	PD	81	22	PD	10	7	17	0	2	19	PD	PD	PD	81	24	PD
KS	DNF	PD	PD	PD	PD	PD	0	0	0	0	2	2	PD	PD	PD	PD	PD	PD
ΚY	PD	PD	PD	0	2	PD	0	0	0	Ж	4	7	PD	PD	PD	3	9	PD
LA	DNF	PD	PD	PD	18	PD	0	2	2	2	2	9	PD	PD	PD	PD	20	PD
ME	PD	PD	1,279	13	2	1,409	4	0	4	0	0	4	PD	PD	1,283	13	2	1,413
MD	17,150	484	17,634	35	m	17,672	0	0	0	0	n	m	17,150	484	17,634	35	9	17,675
MA	DNF	PD	PD	PD	PD	PD	DNF	DNF	DNF	DNF	2	262	DNF	PD	PD	PD	PD	PD
MI	DNF	PD	PD	PD	PD	PD	0	0	0	0	0	0	PD	PD	PD	PD	PD	PD
NN	PD	PD	15,483	43	14	15,540	14	102	116	0	0	116	PD	PD	15,599	43	14	15,656
MS	147	32	179	9	9	191	119	29	148	61	9	215	266	61	327	29	12	406
МО	2,172	232	2,404	139	m	2,546	99	6	75	0	7	82	2,238	241	2,479	139	10	2,628
MT	152	87	239	90	0	329	0	0	0	0	_	_	152	87	239	06	_	330
Ш Ш	2,558	82	2,640	21	2	2,663	0	0	0	2	4	9	2,558	82	2,640	23	9	2,669
>2	829	162	991	0	24	1,046	0	0	0	0	_	_	829	162	991	0	25	1,047
IZ	1,497	27	1,524	m	_	1,528	0	-	_	0	0	_	1,497	28	1,525	С	_	1,529
Z	1,478	1,226	2,704	66	3	2,806	0	0	0	0	2	2	1,478	1,226	2,704	66	∞	2,811
ΣZ	PD	PD	PD	0	0	DQ.	DNF	DNF	25	0	0	25	В	PD	PD	0	0	PD
Ν	PD	PD	PD	1,539	33	PD	29	417	491	520	25	1,036	PD	PD	PD	2,059	58	PD
NC	PD	PD	PD	PD	PD	PD	0	7	2	0	4	9	В	PD	PD	PD	PD	PD
ND	1,283	54	1,337	54	_	1,392	0	0	0	0	_	1	1,283	54	1,337	54	2	1,393
ОН	14,835	671	15,506	309	78	15,893	0	0	0	0	10	10	14,835	671	15,506	309	88	15,903
OK	PD	PD	PD	PD	PD	PD	0	0	0	0	1	1	PD	PD	PD	PD	PD	PD
OR	PD	837	PD	25	14	DQ.	0	24	24	0	0	24	В	861	PD	25	14	PD
РА	13,932	863	14,795	26	20	14,871	0	0	0	0	2	2	13,932	863	14,795	99	25	14,876



Table 1.8
Number of Non-Family Settings in Which LTSS Recipients with IDD Live by Size, Type of Operation, and State on June 30, 2015

			Nonstate Settings	ettings					State Settings	ngs					Total Settings <sup>1</sup>	ings 1		
Size	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
<u>R</u>	877	176	1,053	24	-	1,078	2	22	24	∞	0	32	879	198	1,077	32	-	1,110
SC	363	543	906	105	0	1,011	0	0	0	0	2	2	363	543	906	105	2	1,016
SD	1,073	101	1,174	29	_	1,242	0	0	0	0	<u>_</u>	_	1,073	101	1,174	29	2	1,243
Z	2,480	101	2,581	89	2	2,672	2	30	32	_	2	35	2,482	131	2,613	90	4	2,707
¥	DNF	PD	PD	PD	PD	PD	0	2	2	0	13	15	PD	PD	PD	PD	PD	PD
UT	2,135	82	2,217	7	14	2,238	0	0	0	0	1	1	2,135	82	2,217	7	15	2,239
TV	1,579	17	1,596	0	0	1,596	0	0	0	0	0	0	1,579	17	1,596	0	0	1,596
٧A	PD	PD	PD	PD	2	PD	0	0	0	0	4	4	PD	PD	PD	PD	6	PD
WA	3,362	408	3,770	29	109	3,908	20	19	39	0	4	43	3,382	427	3,809	29	113	3,951
\M	PD	PD	PD	52	0	PD	0	0	0	0	0	0	PD	PD	PD	52	0	PD
M	PD	PD	PD	2	19	PD	0	0	0	0	3	c	PD	PD	PD	2	22	PD
WY	DNF	PD	PD	PD	PD	PD	0	0	0	0	1	1	PD	PD	PD	PD	PD	PD
Reported US Total	83,752	9,129	108,806	4,841	653	111,941	325	707	1,064	614	149	2,086	83,982	9,303	109,306	5,453	779	112,607
Estimated US Total	193,263	193,263 27,623	220,898	6,327	775	228,001	386	844	1,231	402	151	2,091	193,649	28,467	222,129	7,036	926	230,092
Did not furnish. Po Partial data, calculation incomplete and not included in reported totals. This table includes group homes or facilities, ICF/IIDs, host homes and family foster homes, own home, and "other" settines are assumed to be zero when not reported.	sh. PD Partia	I data, calc homes. N	culation inco	omplete an	d not inclu hiatric sett	ded in reported totals. <sup>1</sup> This table includes group homes or facilities, ICF/IIDs, host homes and family foster homes, own home, and "citings are only included when reported in state or nonstate other. Nonstate other settings are assumed to be zero when not reported	ed totals. 1T	This table i	ncludes gro ted in state	or nonstate	or facilities	5, ICF/IIDs, I	ost homes a	and family	foster home	es, own hor	ne, and "ot reported.	her"

Overall, of the 230,092 non-family settings, an estimated

- 84% (193,649 settings) served 1 to 3 people,
- 12% (28,467 settings) served 4 to 6 people,
- 3% (7,036 settings) served 7 to 15 people, and
- 0.4% (926 settings) served 16 or more people.

### **People by Setting Size**

An estimated 511,969 people with IDD lived in non-family IDD settings (own home, host/foster family home, group home, ICF/IID or "other") on June 30, 2015 (See **Table 1.9**). Of those,

- 56% (287,136 people) lived in settings of 3 or fewer people with IDD,
- 25% (126,716 people) lived in settings of 4 to 6 people,
- 11% (56,627 people) lived in settings of 7 to 15 people, and
- 8% (42,490 people) lived in settings of 16 or more people.

States reporting no people in non-family settings of 16 or more people included Alabama, Alaska, Hawaii, New Mexico, Vermont and West Virginia. States reporting the highest proportion of people in non-family settings of 16 or more people were Mississippi (51%, 1,778 people), Arkansas (39% of those in non-family settings, 1,450 people), Illinois (25%, 4,535 people), New Jersey (21%, 2,394 people), and Florida (16%, 2,651 people). Other states with more than 3,000 people in settings of 16 or more people included Ohio (13%, 3,789 people) and Texas (11%, 3,521 people). Other states reporting that 15% or more of the people in non-family settings were in settings of 16 or more people included Oklahoma (19%, 967 people) and Utah (19%, 763 people).

## **People by Type of Operation**

Of the 512,969 people in non-family settings, 6% (31,520 people) lived in state-operated settings, and 94% (481,449 people) lived in nonstate settings.

The proportion of people in non-family settings who lived in nonstate settings varied by state. Nine states reported that all people living in non-family IDD settings lived in settings or received services from a nonstate entity (Alabama, Arkansas, the District of Columbia, Hawaii, Indiana, Maine, Michigan, and Vermont). States with the lowest

 Table 1.9
 Number of LTSS Recipients with IDD in Non-Family Settings by Size, Type of Operation, and State on June 30, 2015

		0000		1					201400 04c+0 ai olacod	2001#000					- t-t-0-F			
- Aize	4	4-6 4-6	1-6	7-15	16+	Total	4	4-6	1-6	7-15	16+	       	4,	4-6	1-0.64	7-15	16+	Total
3120	5 2	7 2				100	5				5 2	2	2 2	7		5	5	
N States	34	34	39	43	46	45	46	20	20	50	51	51	34	34	39	43	46	45
AL	2,320	453	2,773	742	0	3,515	0	0	0	0	0	0	2,320	453	2,773	742	0	3,515
AK	1,285	150	1,435	28	0	1,493	0	0	0	0	0	0	1,285	150	1,435	28	0	1,493
AZ	3,265	1,085	4,350	0	29	4,379	15	13	28	33	93	154	3,280	1,098	4,378	33	122	4,533
AR	1,240	82	1,322	932	537	2,791	0	0	0	0	913	913	1,240	82	1,322	932	1,450	3,704
CA	PD	PD	55,403	1,129	1,455	27,987	0	0	0	0	1,077	1,077	PD	PD	55,403	1,129	2,532	59,064
00	PD	PD	9,592	0	0	9,592	0	116	116	126	29	271	PD	PD	802'6	126	59	9,863
CT	2,961	2,553	5,514	175	0	5,689	36	200	236	06	468	794	2,997	2,753	5,750	265	468	6,483
DE	835	389	1,224	0	89	1,292	2	0	2	0	52	54	837	389	1,226	0	120	1,346
DC	938	433	1,371	7	17	1,395	0	0	0	0	0	0	938	433	1,371	7	17	1,395
7	6,245	5,593	11,838	1,884	1,824	15,546	0	0	0	0	827	827	6,245	5,593	11,838	1,884	2,651	16,373
GA	4,256	1,034	5,290	11	0	5,301	0	0	0	0	267	267	4,256	1,034	5,290	11	267	5,568
豆	564	341	905	7	0	912	0	0	0	0	0	0	564	341	902	7	0	912
QI	PD	PD	PD	PD	PD	2,715	0	5	5	0	19	24	PD	PD	PD	PD	PD	2,739
	1,547	4,651	6,198	7,467	2,849	16,514	0	0	0	0	1,686	1,686	1,547	4,651	6,198	7,467	4,535	18,200
Z	5,845	1,768	7,613	2,454	46	10,113	0	0	0	0	0	0	5,845	1,768	7,613	2,454	46	10,113
Ι	PD	PD	PD	782	748	PD	56	32	28	0	391	449	PD	PD	PD	782	1,139	PD
KS	DNF	PD	PD	PD	PD	PD	0	0	0	0	314	314	PD	PD	PD	PD	PD	PD
Κ	PD	PD	PD	0	135	PD	0	0	0	23	263	286	PD	PD	PD	23	398	PD
LA	PD	PD	PD	PD	PD	PD	0	∞	∞	20	469	497	PD	PD	PD	PD	PD	PD
ME	PD	PD	2,546	124	32	3,007*	0	0	0	0	0	0	PD	PD	2,546	124	32	3,007
MD	19,748	2,061	21,809	274	26	22,180	0	0	0	0	131	131	19,748	2,061	21,809	274	228	22,311
MA	DNF	PD	PD	PD	0	14,365	DNF	DNF	DNF	DNF	433	1,586	DNF	PD	PD	PD	433	15,951
Ξ	610	2,455	9,738	393	209	19,004*	0	0	0	0	0	0	610	2,455	9,738	393	209	19,004
MN	PD	PD	19,011	422	330	19,763	28	396	424	0	0	424	PD	PD	19,435	422	330	20,187
MS	498	218	716	107	969	1,519	150	100	250	610	1,082	1,942	648	318	996	717	1,778	3,461
МО	4,917	66	5,914	1,080	26	7,070	173	36	509	0	393	602	2,090	1,033	6,123	1,080	469	7,672
MT	155	708	863	725	0	1,588	0	0	0	0	22	22	155	708	863	725	25	1,643
NE	3,082	376	3,458	174	217	3,849	0	0	0	17	114	131	3,082	376	3,458	191	331	3,980
N/	1,110	029	1,780	0	134	1,914	0	0	0	0	47	47	1,110	029	1,780	0	181	1,961
NH	1,851	96	1,947	17	25	1,989	0	9	9	0	0	9	1,851	102	1,953	17	25	1,995
Ñ	3,032	4,905	7,937	842	782	9,561	0	0	0	0	1,612	1,612	3,032	4,905	7,937	842	2,394	11,173
NM	PD	PD	PD	0	0	PD	09	0	09	0	0	09	PD	PD	PD	0	0	PD
NY	15,661	10,679	26,340	13,859	1,013	41,212	165	2,020	2,185	4,603	648	7,436	15,826	12,699	28,525	18,462	1,661	48,648
NC	DNF	DNF	DNF	DNF	DNF	PD	0	9	9	0	1,436	1,442	PD	PD	PD	PD	PD	PD
ND	1,289	287	1,576	437	30	2,043	0	0	0	0	79	79	1,289	287	1,576	437	109	2,122
ОН	17,507	3,044	20,551	2,650	2,974	28,730*	0	0	0	0	815	815	17,507	3,044	20,551	2,650	3,789	29,545
OK	PD	PD	3,582	298	996	5,146	0	0	0	0	1	1	PD	PD	3,582	298	296	5,147
OR	PD	PD	PD	PD	24	7,632	0	137	137	0	0	137	PD	PD	PD	PD	24	7,769
PA	18,625	3,679	22,304	483	1,251	24,038	0	0	0	0	950	950	18,625	3,679	22,304	483	2,201	24,988
RI	1,006	765	1,771	173	25	1,969	7	108	115	80	0	195	1,013	873	1,886	253	25	2,164

Table 1.9 Number of LTSS Recipients with IDD in Non-Family Settings by Size, Type of Operation, and State on June 30, 2015

		Peop	ole in Nons	People in Nonstate Settings	S			Peo	People in State Settings	e Settings					Total			
Size	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+	lotal
SC	1,206	2,179	3,385	867	0	4,252	0	0	0	0	673	673	1,206	2,179	3,385	867	673	4,925
SD	1,240	207	1,747	623	20	2,420	0	0	0	0	140	140	1,240	202	1,747	623	190	2,560
N.	4,686	460	5,146	718	87	5,951	9	120	126	14	109	249	4,692	580	5,272	732	196	6,200
¥	DNF	PD	PD	PD	335	28,752	0	6	6	0	3,186	3,195	PD	PD	PD	PD	3,521	31,947
TU	2,718	415	3,133	74	561	3,768	0	0	0	0	202	202	2,718	415	3,133	74	763	3,970
ΤΛ	1,768	98	1,854	0	0	1,854	0	0	0	0	0	0	1,768	98	1,854	0	0	1,854
۸۸	2,381	3,067	5,448	1,010	171	6,629	0	0	0	0	483	483	2,381	3,067	5,448	1,010	654	7,112
WA	5,004	1,842	6,846	254	176	7,276	47	82	129	0	765	894	5,051	1,924	6,975	254	941	8,170
AW.	1,119	222	1,341	425	0	1,766		0	0	0	0	0	1,119	222	1,341	425	0	1,766
MI	PD	PD	PD	13	424	15,969	0	0	0	0	350	350	PD	PD	PD	13	774	16,319
ΜΥ	DNF	PD	PD	PD	PD	1,106	0	0	0	0	70	70	PD	PD	PD	PD	PD	1,176
Reported US Total	140,514	58,250	58,250 295,571	41,990	18,393	435,556	715	3,394	4,109	5,616	20,642	31,520	141,115	60,935	299,397	47,586	36,727	464,028
Estimated US Total	286,336	286,336 122,919 409,256	409,256	50,345	21,848	481,449	800	3,796	4,596	6,282	20,642	31,520	287,136	287,136 126,716	413,852	56,627	42,490	512,969
Lobert from the Policy of the last of the	ich PD Darti	10000	00:40	40100	o loci too		* 0 0404  0	0 40 40 0		TT TIPE	1 4 0 1 0	o o por lo	is a considerable of Considerable in Account. (This stell) is all stones or facilities (CHII) a book book one of facilities	1 00:4:1:003.		1	-3 -113 1-	

ow Did not furnish. Po Partial data, calculation incomplete and not included in reported totals. See state notes in Appendix. This table includes group homes or facilities, ICF/IIDs, host homes and family foster homes, own home, and "other" settings. It excludes family homes. Nursing homes and psychiatric settings are only included when reported in state or nonstate other. Nonstate other settings are assumed to be zero when not reported. proportion in nonstate settings were New Jersey (86%), New York (85%), Arkansas (75%), and Mississippi (44%).

Of the 481,449 people in nonstate non-family settings, an estimated

- 59% (286,336 people) lived with three or fewer people,
- 26% (122,919 people) lived with 4 to 6 people,
- 10% (50,345 people) lived with 7 to 15 people, and
- 5% (21,848 people) lived with 16 or more people.

Of the 31,520 people in state-operated non-family settings, an estimated

- 3% (800 people) lived in settings of 3 or fewer people,
- 12% (3,796 people) lived in settings of 4 to 6 people,
- 20% (6,282 people) lived in settings of 7 to 15 people, and
- 65% (20,642 people) lived in settings of 16 or more people with IDD.



**Table 1.10** Percent of LTSS with IDD in Non-Family Settings of 3 or Fewer or 6 or Fewer People; LTSS Recipients in Non-Family Settings Per 100,000 of the Population by State on June 30, 2015

State	Total Facilities	Total Doonlol	People Per		ttings of	State Population	People in Non-
State	Total Facilities	Total People <sup>1</sup>	Setting	3 or Fewer People	6 or Fewer People	in 100,000's	Family Settings Per 100,000
AL	1,342	3,515	2.6	66	79	48.6	72.3
AK	983	1,499 <sup>i</sup>	1.5	86	96	7.4	203.0
AZ	2,148	4,635 <sup>i</sup>	2.2	71	94	68.3	67.9
AR	1,382	3,709 <sup>i</sup>	2.7	33	36	29.8	124.5
CA	27,158 <sup>i</sup>	59,179 <sup>i</sup>	2.2	64	94	391.4	151.2
СО	5,745 <sup>i</sup>	9,862 <sup>i</sup>	1.7	88	98	54.6	180.7
CT	2,564	6,496 <sup>i</sup>	2.5	46	89	35.9	180.9
DE	514	1,346	2.6	62	91	9.5	142.3
DC	652	1,395	2.1	67	98	6.7	207.5
FL	5,969 <sup>i</sup>	16,437 <sup>i</sup>	2.8	38	72	202.7	81.1
GA	3,283	5,592 <sup>i</sup>	1.7	76	95	102.1	54.7
HI	428	912	2.1	62	99	14.3	63.7
ID	1,646 <sup>i</sup>	2,771 <sup>i</sup>	1.7	71	80	16.5	167.4
IL	2,971	18,201 <sup>i</sup>	6.1	8	34	128.6	141.5
IN	4,142	10,113	2.4	58	75	66.2	152.8
IA	1,380 <sup>i</sup>	4,297 <sup>i</sup>	3.1	36	50	31.2	137.6
KS	1,811 <sup>i</sup>	3,955 <sup>i</sup>	2.2	59	83	29.1	135.8
KY	3,192 <sup>i</sup>	6,868 <sup>i</sup>	2.2	89	94	44.3	155.2
LA	4,182 <sup>i</sup>	16,534 <sup>i</sup>	4.0	41	74	46.7	354.0
ME	1,413	3,007	2.1	61	94	13.3	226.2
MD	17,675	22,313 <sup>i</sup>	1.3	89	98	60.1	371.5
MA	6,342 <sup>i</sup>	15,951	2.5	49	82	67.9	234.8
MI	8,573 <sup>i</sup>	19,004	2.2	35	88	99.2	191.5
MN	15,656	20,242 <sup>i</sup>	1.3	64	96	54.9	368.7
MS	406	3,461	8.5	19	28	29.9	115.7
МО	2,628	7,672	2.9	66	80	60.8	126.1
MT	330	1,643	5.0	9	53	10.3	159.1
NE	2,669	4,007 <sup>i</sup>	1.5	77	86	19.0	211.3
NV	1,047	1,961	1.9	57	91	28.9	67.8
NH	1,529	1,995	1.3	93	98	13.3	149.9
NJ	2,824 <sup>i</sup>	11,173	4.0	27	71	89.6	124.7
NM	2,481 <sup>i</sup>	4,875 <sup>i</sup>	2.0	75	100	20.9	233.8
NY	15,670 <sup>i</sup>	48,862 <sup>i</sup>	3.1	32	58	198.0	246.8
NC	5,383 <sup>i</sup>	11,886 <sup>i</sup>	2.2	51	70	100.4	118.4
ND	1,393	2,122	1.5	61	74	7.6	280.3
ОН	15,903	29,545	1.9	67	78	116.1	254.4
ОК	2,360 <sup>i</sup>	5,146 <sup>i</sup>	2.2	52	70	39.1	131.6
OR	2,483 <sup>i</sup>	7,769	3.1	68	97	40.3	192.8
PA	14,876	24,973 <sup>i</sup>	1.7	75	89	128.0	195.1
RI	1,110	2,164	1.9	47	87	10.6	204.9
SC	1,016	4,926 <sup>i</sup>	4.8	24	69	49.0	100.6
SD	1,243	2,557 <sup>i</sup>	2.1	48	68	8.6	297.9
TN	2,707	6,200	2.3	76	85	66.0	93.9
TX	13,197 <sup>i</sup>	31,836 <sup>i</sup>	2.4	58	87	274.7	115.9
UT	2,239	4,022 <sup>i</sup>	1.8	68	78	30.0	134.2
VT	1,596	1,854	1.2	95	100	6.3	296.1
VA	1,905 <sup>i</sup>	6,890 <sup>i</sup>	3.6	35	78	83.8	82.2
WA	3,951	8,122 <sup>i</sup>	2.1	62	86	71.7	113.3
WV	544 <sup>i</sup>	1,979 <sup>i</sup>	3.6	66	79	18.4	107.3
WI	6,926 <sup>i</sup>	16,319	2.4	77	95	57.7	282.8
WY	525 <sup>i</sup>	1,176	2.2	56	84	5.9	200.6
Estimated							159.6
Estimated US Total	230,092	512,969	2.2	56	81	3214.2	1

<sup>&</sup>lt;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. In 2014, this table excluded people in nonstate "other" settings. Missing value imputed (RISP estimated at least one value).

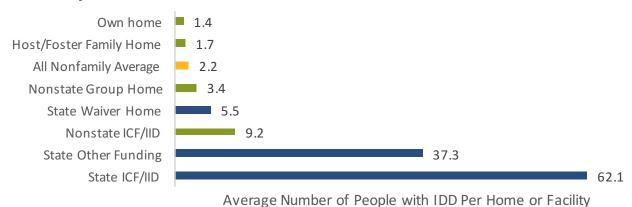


The proportion of people living nonstate settings varied by setting size. Of the 413,852 people in settings of six or fewer people, 99% lived in nonstate settings. Of the 56,627 people in settings of 7 to 15 people, 89% lived in nonstate settings. Of the 42,490 people in IDD settings of 16 or more people, 51% lived in nonstate settings.

## **Average Residence Size**

Overall, 512,969 people with IDD lived in 230,092 non-family settings on June 30, 2015 (an average of 2.2 people per setting; See **Table 1.10**). The average number of people per setting ranged from 1.2 in Vermont to 8.5 in Mississippi. States with averages of less than 1.5 included Maryland (1.3 people per setting), Minnesota (1.3), New Hampshire (1.3) and Vermont (1.2). States with averages of more than 3.5 people per setting

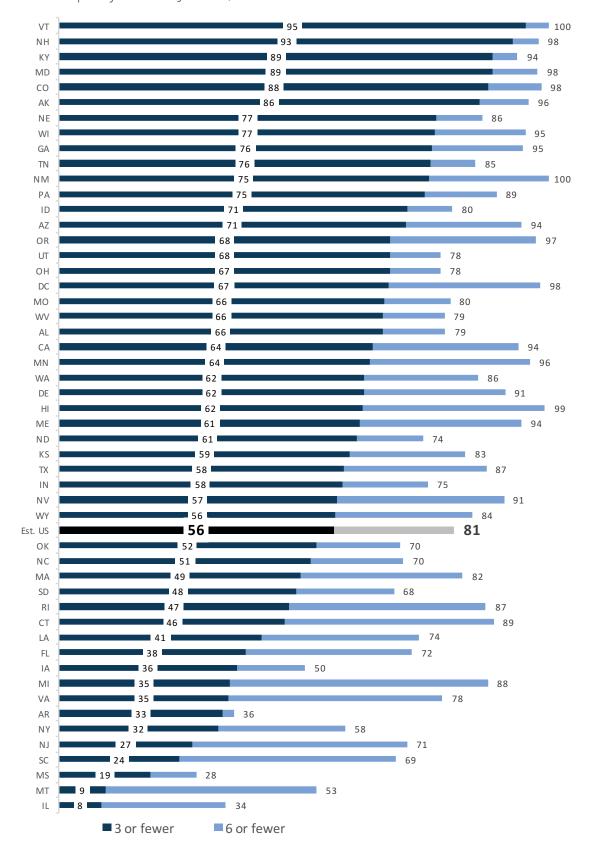
**Figure 1.3** Average Number of People with IDD Per Non-Family Setting by Setting Type in the United States as of June 30, 2015



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



**Figure 1.4** Estimated Percent of People with IDD in Non-Family IDD Settings of 3 or Fewer or 6 or Fewer People by State on June 30, 2015





included Mississippi (8.5), Illinois (6.1), Montana (5.0), South Carolina (4.8), New Jersey (4.0), Louisiana (4.0), Virginia (3.6) and West Virginia (3.6).

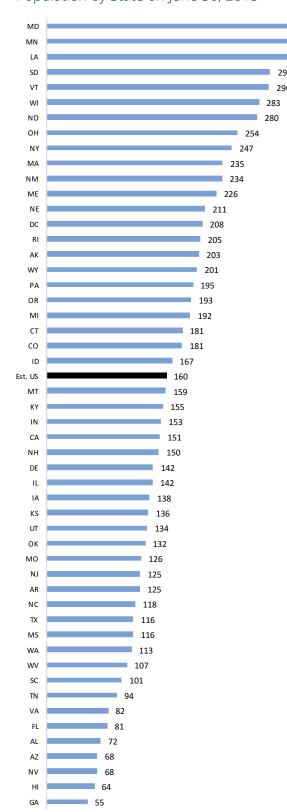
The average number of people per non-family setting varied by setting type. The average number of people with IDD sharing a living arrangement was 1.4 for own home settings, 1.7 for host/foster family homes, 3.4 for nonstate group homes (other than ICF/IID), 5.5 for state-operated Waiverfunded settings, 9.2 for nonstate ICF/IID, 37.3 for state-operated other-funded settings, and 62.1 for state-operated ICF/IID settings (See **Figure 1.3**).

Of the people living in non-family settings, 59% lived in settings shared by three or fewer people with IDD (See **Figure 1.4**). The four states that served 90% or more in settings of 3 or fewer people were Vermont (95%), New Hampshire (93%), Kentucky (93%), and Colorado, 90%). Montana (10%) and Illinois (9%) served 10% or fewer in settings shared by three or fewer people.

Overall, of the people living in non-family settings, 85% lived in settings shared by six or fewer people with IDD. Colorado, Georgia, and New Mexico all reported serving 100% of the people in non-family IDD settings lived in settings of six or fewer people (See **Figure 1.4**). Georgia and Hawaii served 99% of people in non-family settings of six or fewer people. The District of Columbia, Maryland, and New Hampshire served 98% of people in non-family settings of six or fewer people. Iowa (55%), Montana (54%), Mississippi (50%), Arkansas (47%), and Illinois (38%) served the lowest proportion of people in settings of six or fewer people.

While the 2014 HCBS rule does not specify size requirements for Medicaid Waiver-funded residential or vocational settings, it does require person centered planning and practices. Studies examining outcomes of LTSS for people with IDD have reported that size and type of living arrangement are significant predictors of outcomes such as everyday choice, use of preventative health care, and expenditures (e.g., Bershadsky, et. al., 2012; Lakin, et. al., 2008; Ticha, et. al., 2012). People in settings of three or fewer people generally had better outcomes than those living in larger settings. In 37 of 43 studies tracking outcomes for people moving from an institutional

**Figure 1.5** Number of LTSS Recipients with IDD in Non-Family Settings Per 100,000 of the Population by State on June 30, 2015



**Table 1.11** People with IDD Living in State or Nonstate Nursing Homes or Psychiatric Facilities and Per 100,000 of the Population by State on June 30, 2015

_	People in Psychiatric Facilities (Psych)			People in Nursing Homes (NH)			State population	NH per
•	State	Nonstate	Total	State	Nonstate	Total	in 100,000s	100,000
l States	41	29	43	40	38	51	51	51
ıL.	50 <sup>e</sup>	0 <sub>q</sub>	50 <sup>e</sup>	0	935	935	49	19
K	0	0	0	0	0	0	7	0
Z	0	DNF	0 <sup>c</sup>	0	37	37	68	1
.R	0 <sub>q</sub>	0 <sub>q</sub>	0 <sub>q</sub>	53	563	616	30	21
:A	0	38	38	0	1,079	1,079	391	3
:0	0 <sub>q</sub>	0 <sub>q</sub>	0 <sub>q</sub>	0	153	153	55	3
T	3	0	3	0	343	343	36	10
ÞΕ	2	0	2	8	58	66	9	7
C	2	0	2	0	3	3	7	0
L	21	6	27	0	287	287	203	1
iA .	267	DNF	267 <sup>c</sup>	0	DNF	974 <sup>is</sup>	102	10
11	5	0	5	0	68	68	14	5
D	DNF	DNF	DNF	DNF	DNF	126 <sup>is</sup>	17	8
<u> </u>	0	0	0	0	185	185	129	1
N	66	0	66	0	1,579	1,579	66	24
A	4	1,313	1,317	DNF	665	665 <sup>i</sup>	31	21
rs	262	DNF	262 <sup>c</sup>	0	114	114	29	4
Υ	376	DNF	376	DNF	DNF	696 <sup>is</sup>	44	16
A	2 <sup>e</sup>		2 <sup>c</sup>	2e	432 <sup>e</sup>	434 <sup>e</sup>	47	9
лE	0	DNF	0	0	7	7	13	1
		0						
ИD	0	0	0	0	268	268 <sup>s</sup>	60	4
1A	DNF	DNF	DNF	DNF	DNF	455 <sup>is</sup>	68	7
11	0	0	0	0	411	411	99	4
//N	4 <sup>d</sup>	DNF	4 <sup>c</sup>	0	155	155	55	3
ЛS	6 <sup>e</sup>	0	6 <sup>e</sup>	DNF	DNF	426 <sup>is</sup>	30	14
10	260	DNF	260 <sup>c</sup>	0 <sup>d</sup>	DNF	1,051 <sup>is</sup>	61	17
ИT	DNF	DNF	DNF	DNF	DNF	95 <sup>is</sup>	10	9
NE .	0	22	2	0	177	177	19	9
1V	0	0	0	0	114	114	29	4
IH	DNF	DNF	0 <sub>p</sub>	5	103	108	13	8
١J	41	0	41	0	868	868	90	10
IM	DNF	DNF	DNF	11	89	100	21	5
1Y	DNF	DNF	DNF	DNF	DNF	1,552 <sup>i</sup>	198	8
1C	92	DNF	92 <sup>c</sup>	298	DNF	717 <sup>is</sup>	100	7
ID	5	0	5	0	119	119	8	16
OH	DNF	DNF	DNF	0	1,427 <sup>s</sup>	1,427 <sup>s</sup>	116	12
OK	DNF	DNF	DNF	0	1,320	1,320	39	34
)R	0	0	0	0	161	161	40	4
'A	64	51 <sup>e</sup>	115 <sup>e</sup>	0	1,919	1,919	128	15
l .	0	0	0	0	6	6	11	1
C	DNF	DNF	0 <sub>p</sub>	175 <sup>s</sup>	257	432 <sup>s</sup>	49	9
D	0	0	0	0	88	88	9	10
'N	15	DNF	15 <sup>c</sup>	0	567	567	66	9
X	DNF	DNF	DNF	DNF	DNF	2,227 <sup>is</sup>	275	8
<u>^</u> IT	0	0	0	0	34	34	30	1
T	0	0	0	0	30	30		
A	474		474 <sup>c</sup>			836 <sup>is</sup>	6 84	5 10
		DNF		DNF	DNF			
VA	38	0	38	0	0	0	72	0
VV	31 <sup>d</sup>	DNF	31 <sup>c</sup>	DNF	DNF	183 <sup>is</sup>	18	10
VI	0	0	0	0	22	22	58	0
NY	4	DNF	4 <sup>e</sup>	DNF	DNF	22 <sup>is</sup>	6	4
Reported JS Total	2,094	1,410	3,504	552	14,643		3,214	
Estimated JS Total				670	23,587	24,257	3,214	8

<sup>&</sup>lt;sup>b</sup> Excludes state-operated facilities. <sup>c</sup> Excludes nonstate-operated facilities. <sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014) <sup>e</sup> Estimate. <sup>s</sup> Source AHCA (2017c). <sup>i</sup> Missing value imputed (RISP estimated). <sup>\*</sup> See notes in Appendix.



setting of 16 or more people to a community setting of 6 or fewer people, adaptive behavior (daily living skills) of people who moved improved compared to people who remained in institutions (Larson, Lakin & Hill, 2012).

# Utilization of Non-family IDD Settings per 100,000 of the US Population

Overall, state IDD agencies provided services to 159.3 people per 100,000 of the population in nonfamily IDD settings (See Table 1.10 and Figure **1.5**). Utilization rates ranged from 54.7 per 100,000 in Georgia to 371.5 per 100,000 in Maryland. The seven states serving fewer than 100 people per 100,000 were Tennessee (93.9 per 100,000), Florida (81.1), Alabama (72.3), Arizona (67.9), Nevada (67.8), Hawaii (63.7), and Georgia (54.7). The eight states serving more than 250 per 100,000 were Maryland (371.5 per 100,000), Minnesota (368.7), Louisiana (354.0), South Dakota (297.9), Vermont (296.1), Wisconsin (282.8), North Dakota (280.3), and Ohio (254.4). Factors that may contribute to state differences in utilization of non-family settings to serve people with IDD include the proportion of service recipients ages 21 years or younger, utilization of own home and host/foster family home settings, and regional patterns of institutionalization for all population groups.

# PEOPLE WITH IDD IN PSYCHIATRIC FACILITIES OR NURSING HOMES

Most LTSS recipients with IDD live in their own home, with a family member, or in another type of IDD setting. A few live in settings not specific to IDD such as psychiatric facilities or nursing homes. **Table 1.11** shows estimates of the number of people with IDD living in state or nonstate nursing homes or psychiatric facilities on June 30, 2015. Some states were not able to report these numbers because another state agency manages or licenses those services.

## **Psychiatric Facilities**

While Medicaid funds are available for LTSS provided in most settings, they are not available for services provided in "Institutes for Mental Disease." Services in those settings must be funded by state, local or private funds. Forty-

three states reported 3,504 people with IDD were living in psychiatric facilities on June 30, 2015. Of those, 60% (2,094 people) were in state-operated psychiatric facilities, and 40% (1,410 people) were in nonstate psychiatric facilities.

State totals on **Table 1.11** reflect the sum of people in state and nonstate psychiatric facilities when both were provided. For states providing data for one type facility but not the other, the total reflects only the number of people in the reported setting type. The totals would be higher if all states were able to furnish complete information.

## **Nursing Homes**

At least 24,257 people with IDD lived in a nursing home on June 30, 2015. Of those, an estimated 3% (670 people) lived in state operated nursing home and 97% (23,587 people) lived in nonstate facilities (See **Table 1.11**). There was at least one person with IDD in a nursing home in all of the states except Alaska and Washington.

Overall, eight people with IDD per 100,000 of the population lived in a nursing home. The number of people with IDD in nursing homes per 100,000 ranged from a low of zero in Alaska and Washington to 34 per 100,000 in Oklahoma and to more than 20 people per 100,000 in Indiana (24 people per 100,000), Arkansas (21), Iowa (21), and Virginia (21).

The number of people with IDD in nursing homes in states reporting on both state and nonstate nursing homes. The total for states reporting people in one or the other type of nursing home is based on the type reported. The total for states that were unable to furnish any nursing home data is estimated from a review Medicaid CASPER data (AHCA, 2017). The totals would be higher if states were able to furnish complete information on both state and nonstate nursing homes.

# REDUCING THE NUMBER OF PEOPLE WITH IDD CONGREGATE SETTINGS

The Centers for Disease Control Health People establishes a set of objectives updated every 10 years to monitor progress toward improving the health of all Americans. Current objectives are

listed on the Healthy People 2020 website at www. healthypeople.gov. The following objectives from the Disability and Health section specifically address living arrangements for people with IDD:

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

# Children and Youth 21 Years or Younger on Congregate Care Settings

The RISP conducted surveys of state IDD agencies to identify the number of children and youth with IDD 21 years or younger living in congregate LTSS settings in 1997, 2005 and 2009. The number of children and youth ages birth to 21 years living in non-family settings of four or more people declined from 23,870 in 1997 to 20,763 in 2009 (Larson, Lakin, Salmi, Scott, and Webster, 2011).

The FY 2015 RISP survey incorporated a new question to allow us to update this estimate. The survey asked:

How many children and youth with IDD (birth to 21 years) lived in a congregate setting located in your state on June 30, 2015?

Congregate settings are:

- Non-family residential settings (state or nonstate settings of any size, type or funding authority)
- In which two or more individuals with IDD live
- In which rotating (or shift) staff members provide supports and services.

Do not include children and youth who:

- Live with birth or adoptive parents or other family members
- Live in family "foster care" settings in which no shift staff work
- Live only part of the year in a residential PreK-12 school
- Live in correctional facilities

**Table 1.12** Healthy People 2020: People with IDD Ages 21 Years or Younger Living in Nursing Homes or Other Congregate Settings by State on June 30, 2015

	Congr	e			
	Nursing Home Other Total				
N States Reporting	31	44	29		
AL .	DNF	237	PD		
<b>ΑΚ</b>	0	44	44		
ΑZ	0	468	468		
AR	DNF	201 <sup>d</sup>	PD		
CA	DNF	822	PD		
0	0	96	96		
СТ	0	202	202		
DE	25	19	44		
OC .	0	1	1		
·L	19	876	895		
GA	DNF	108 <sup>e</sup>	PD		
	0	3	3		
D	DNF	111	PD		
L	0	37	37		
N	118	394	512		
A	37	276	313		
KS .	0	DNF	PD		
<b>Υ</b>	DNF	DNF	DNF		
-A	19 <sup>e</sup>	484	503		
ME	0	76	76		
MD		20 <sup>d</sup>			
	0		20		
MA	DNF	DNF 255 <sup>d</sup>	DNF		
MI	2		257		
MN	DNF	DNF	DNF		
MS	6 <sup>e</sup>	205	211		
MO	DNF	506 <sup>d</sup>	PD		
MT	DNF	43	PD		
NE	0	140	140		
VV	14	42	56		
NH	DNF	25 <sup>e</sup>	PD		
NJ	0	0	0		
MM	DNF	DNF	DNF		
VY	DNF	1,261	PD		
NC	DNF	325 <sup>ed</sup>	PD		
ND	0	115	115		
OH	DNF	451	PD		
OK	DNF	DNF	DNF		
OR	56	231	287		
PA	0	425	425		
रा	0	0	0		
SC .	0	DNF	PD		
SD	0	98	98		
ΓN	DNF	330 <sup>e</sup>	PD		
ГХ	DNF	1,660	PD		
JT	0	123	123		
/T	0	5	5		
/A	38 <sup>i</sup>	73	111		
WA	0	534	534		
WV	DNF	58	PD		
WI	0	124	124		
NY	DNF	25	PD		
Reported US Total	334	11,529	11,863		
•					
Estimated US Total	822	12,933	13,756		

<sup>&</sup>lt;sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014) <sup>e</sup> Estimate. s Source AHCA (2017c). <sup>†</sup> Missing value imputed (RISP estimated it). \* See notes in Appendix.



- Live in nursing facilities (report those individuals in the nursing home section)
- Receive only respite services from a congregate care facility
- Live in other states (do count children who live in your state whose services are paid by another state)

An estimated 13,753 people with IDD ages 21 years or younger lived in a congregate setting as defined above on June 30, 2015 (See **Table 1.12**). Of those, an estimated 6% (822 people 21 years or younger) lived in nursing homes, and 94% (12,933 people) lived in other congregate settings. State totals are shown only for the 29 states reporting on both nursing homes and other types of congregate settings. The US estimated total includes estimates for states providing partial or no data.

This question on the RISP annual survey in FY 2015 for the first time. As was true for other items added to the survey in recent years, we expect that the number of states able to provide this information will increase over time.







**SECTION TWO** 

# Long-Term Supports and Services Funding Authorities

**FY 2015** 



# Section 2: Medicaid and State LTSS Funding Authorities

# OVERVIEW OF PUBLIC LTSS FUNDING AUTHORITIES

Medicaid offers an array of different mechanisms (or "authorities") through which states can request matching federal funds to provide LTSS. Through this jointly funded state-federal program, states are permitted flexibility in administration and in determining the type, amount, duration, and scope of services, as well as the design and delivery of covered services, consistent with federal regulations. The federal financial portion (called the Federal Medicaid Assistance Percentage - FMAP) varies by state, based on per capita income and the size of the state. For FY 2015, state FMAP ranged from 50% in 16 states to 73% in Mississippi. In states with a 50% FMAP, every dollar the state spends on Medicaid funded supports is matched by a dollar from the federal government.

# State Utilization of LTSS Funding Authorities

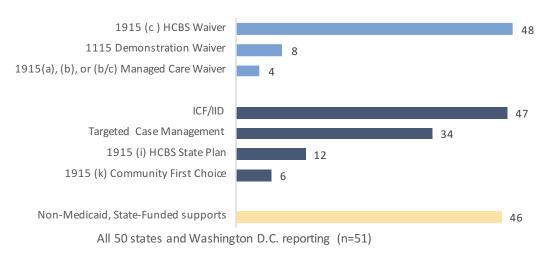
Medicaid Waiver funding authorities used to provide LTSS for people with IDD in 2015 included Medicaid 1915(c) HCBS (48 states), 1115 Demonstration Waiver (8 states), and Medicaid Managed Care Waivers (1915(a), (b), or (b/c)) (four states) (See

**Figure 2.1**). The most commonly used Medicaid State Plan option was the Medicaid ICF/IID (used by 47 states). States also used Medicaid State Plan Targeted Case Management (34 states), Medicaid State Plan 1915(i) (12 states), and Medicaid State Plan 1915(k) Community First Choice (six states) to support people with IDD. Forty-six states reported using a non-Medicaid, state funding authority to provide LTSS to people with IDD.

# LTSS Recipients with IDD by Funding Authority

Of the 1.46 million people with IDD known to, or served under the auspices of, state IDD agencies in FY 2015, an estimated 774,964 people with IDD received Medicaid Waiver-funded LTSS (See Figure 2.2). An estimated 417,722 people received Medicaid State Plan funded LTSS, 77,444 lived in a Medicaid ICF/IID, and 264,822 received non-Medicaid state-funded LTSS. Some people received supports through more than one funding authority (e.g., through Medicaid Waiver and through a state-funded non-Medicaid program). However, 183,164 people (13%) known to state IDD agencies were not receiving LTSS on June 30, 2015, though they may have been waiting for Medicaid Waiver or state-funded services.



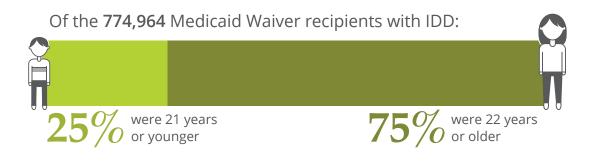


### Medicaid Waiver Recipients and Expenditures 2015

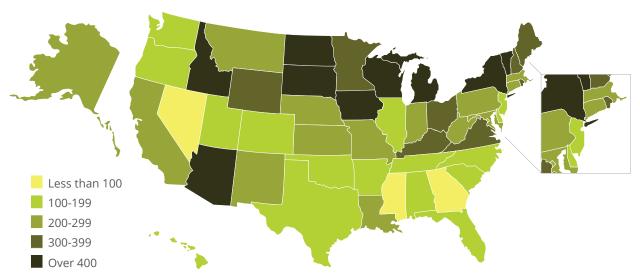
\$34.2 billion expended to provide Medicaid Waiver funded supports to 788,205 people with IDD (\$44,112 per person)

Annual per person Medicaid Waiver expenditures

21 years and younger \$18,009 \$52,722



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



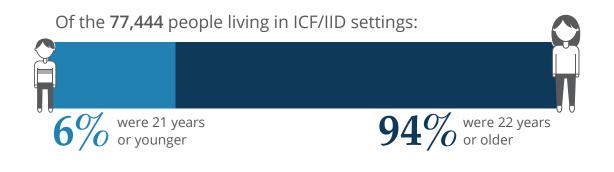


# Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities ICF/IID 2015

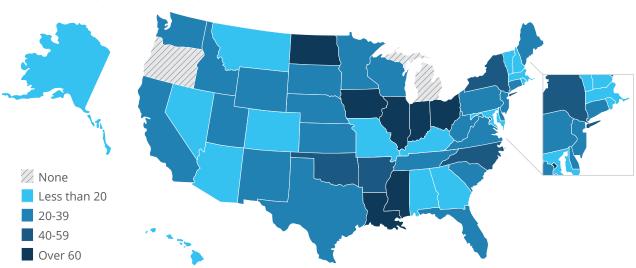
\$10 billion expended to provide Medicaid ICF/IID services to 77,444 people with IDD (\$134,630 per person)

Annual per person ICF/IID expenditures





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



#### **Table C:** Medicaid Funding Authorities

**Medicaid Waiver Authorities** allow states to test new or continue existing ways 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.

**Section 1115 Research and Demonstration Projects.** States may design programs that expand Medicaid eligibility to individuals who are not otherwise eligible, provide services not typically covered by Medicaid, or that use innovative service delivery systems that improve care, increase efficiency, and reduce costs.

**1915(a) Voluntary managed care.** A managed care option in which individuals may (but are not required to) enroll.

**1915(a)/(c) Voluntary managed care program**. A managed care option that incorporates home and community-based services in which individuals may (but are not required to) enroll.

**1915(b) Renewable waiver authority for managed care.** Managed care with options to limit providers as well as to mandate enrollment of certain groups.

**1915(b)/(c) Voluntary, or mandatory, managed care program with home and community-based services.** Allows targeted eligibility and permits states to mandate enrollment. States must apply for both the (b) and the (c) waiver concurrently and comply with the individual requirements of each.

**1915(c) Home and Community-Based Services (HCBS) Waivers**. The most widely used waiver. States may provide community-based LTSS in home and community-based settings to specified populations. States can provide comprehensive supports or can limit the amount or types of services for eligible recipients.





#### **Table C** (continued): Medicaid Funding Authorities

**Medicaid State Plan**. To receive any Federal Financial Participation for Medicaid expenditures states must provide a certain benefits such as inpatient hospital and physician services to all eligible recipients. Early and Periodic Screening, Diagnostic and Treatment services (EPSDT), and nursing facility services must be included. 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.

#### Medicaid State Plan Home and Community Based Services (HCBS):

**1915(i) HCBS State Plan Option.** Provides Home and Community Based LTSS to one or more specific populations and allows any or all of those services to be self-directed. Authorized under the Deficit Reduction Act of 2005, and amended in the 2010 Affordable Care Act.

**1915(j) Self-Directed Personal Assistance Services.** Eligible recipients can set provider qualifications and train self-directed personal assistance services providers. Given a set budget, participants determine how much they will pay for a service, support, or item. Recipients may hire legally liable relatives, such as parents or spouses, to provide supports. States can limit the number of participants and can choose to target only parts of the state. Authorized under the Deficit Reduction Act of 2005.

**1915(k) Community First Choice (CFC).** States may provide statewide HCBS attendant care services and supports to individuals who need the level of supports once offered only in institutions. This program can fund assistance with Activities of Daily Living (ADLs) or Instrumental ADLs (IADLs) and health-related tasks; ensure continuity of services, and provide voluntary training on how to select, manage, and dismiss staff. Recipients may use an agency provider or self-direct services. Authorized by the Affordable Care Act in 2010.

#### **Other Medicaid State Plan Options:**

State plan home health services include skilled nursing services, therapy services, home health aide services, and in 15 states, assistance with instrumental activities of daily living.

1932(a) State plan amendment authority for mandatory and voluntary managed care.

**1905(a) State plan personal care.** Assistance with instrumental activities of daily living, transportation services, and case management.

**1905(a) Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)**. ICFs/ IID offer comprehensive health care and rehabilitation services to individuals with IDD who need and receive daily active treatment services. ICF/IID services have prescriptive Federal regulations. Facilities are institutions regardless of size. Access to ICF/IID services for eligible individuals may not be limited, and cannot be subject to waiting lists, though the program is optional for states.

**1905(a)** - Inpatient psychiatric services for people younger than 21 or older than 65 years in an Institution for Mental Disease.

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

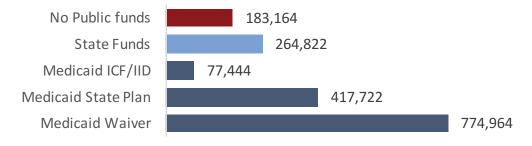
Forty-nine states reported the number of people with IDD living with a family member who had requested Medicaid Waiver-funded services but who were not Medicaid Waiver recipients as of June 30, 2015. The number of people waiting excludes people already receiving Medicaid Waiver-funded supports,

people living in an ICF/IID and people not living with a family member.

### **Number of People Waiting**

An estimated 199,641 people with IDD living with a family member were waiting for Medicaid Waiver-Funded LTSS on June 30, 2015 (see **Table 2.1**). Eleven states reported not having a waiting list or reported no people waiting. Those states were California, Delaware, District of Columbia, Hawaii,

**Figure 2.2** Estimated Number of LTSS Recipients with IDD by Funding Authority (Includes Duplicate Counts) on June 30, 2015



Medicaid Long-Term Supports and Services



People Waiting for Medicaid Waiver



increase in Medicaid needed to serve all waiting Medicaid Waivers



**Table 2.1** Number of People with IDD Living with Family Members Waiting for Medicaid Waiver Funding and Growth in Medicaid Needed to Serve those Waiting by State on June 30, 2015

State					
	Number Waiting	Getting Targeted Case Management	Waiting to Move from Family Home	+ ICF/IID Recipients on June 30, 2015	Increase Needed to Serve All Waiting (%)
N States	49	40	27	51	49
\L	3,432	0	1,660	5,439	63
λK	743	0	546	2,050	36
ΑZ	184	DNF	1	28,549	1
AR	2,838	DNF	DNF	5,566	 51
CA CA	0	0	0	123,354	0
0	3,314	0	3,174	10,106	33
T	638	592	145		6
				10,447	
DE	0	0	0	1,161	0
DC	0	0	0	1,903	0
EL .	21,331	DNF	1,590	35,019	61
GA	8,070	0	DNF	8,797	92
11	0	0	0	2,728	0
D	0	0	0	8,104	0
L	17,566	0	6,073	28,929	61
N	2,579	0	DNF	22,269	12
A	0 <sub>d</sub>	0 <sub>q</sub>	Oq	16,665	0
(S	3,392	1,444 <sup>e</sup>	DNF	9,184	37
Υ	1,964	DNF	DNF	15,302	13
-A	13,085	892 <sup>e</sup>	DNF	17,289	76
ME	1,153	1,153	DNF	5,006	23
MD	5,547	5,165			40
	· · · · · · · · · · · · · · · · · · ·		4,913	14,042	
MA	DNF	DNF	DNF	14,231	DNF
MI	0	0	DNF	45,115	0
MN	3,564	1,412	DNF	19,907	18
MS	1,828	365	35	4,728	39
MO	356	330	179	13,606	3
MT	953	953	DNF	2,853	33
NE	1,838	495	DNF	5,050	36
VV	712	712	620 <sup>e</sup>	2,039	35
NH	79	DNF	DNF	5,260	2
NJ	3,664	DNF	DNF	13,013	28
NM	6,365	DNF	DNF	4,483	142
NY	0	0	6,170	90,241	0
NC	9,569	0	DNF	17,631	54
ND	0	0	0	5,155	0
OH .	30,526 <sup>d</sup>	5,138	DNF	41,612	73
		0			97
OK	6,943		DNF	7,158	
OR	0	0	0	6,932	0
PA	5,493 <sup>e</sup>	4,486 <sup>e</sup>	1,974 <sup>e</sup>	35,652	15
₹I	362	362	DNF	3,686	10
SC	6,150	0	249	10,775	57
SD	0	0	0	3,779	0
ΓN	6,277	0	487 <sup>e</sup>	8,898	71
X	DNF	DNF	DNF	42,816	DNF
JT	1,914	0	1,186	6,082	31
Τ	182	DNF	0	2,923	6
/A	10,339	8,012	4,033	13,204	78
VA	1,033	0	DNF	13,658	8
VV	977 <sup>d</sup>	DNF	DNF	5,585	17
VI	1,890	80		32,247	6
			DNF		
NY Reported US Total	317 187,167	244 31,835	33,035	2,180	15
Estimated US Total	199,641	42,489	76,682	852,408	23%

<sup>&</sup>lt;sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014). <sup>e</sup>Estimate. <sup>DMF</sup> Did not furnish. \*See state notes in Appendix. TCM: Medicaid funded Targeted Case Management Services. HCBS: Home and Community Based Services. ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Idaho, Iowa, Michigan, New York, North Dakota, Oregon, and South Dakota. States reporting more than 10,000 people waiting included Ohio (30,526 people), Florida (21,331 people), Illinois (17,566), Louisiana (13,085) and Virginia (10,339).

In previous years, some states included people living in an ICF/IID, living in a setting other than the home of a family member, or who were already Waiver recipients, but were requesting more funds or to be included in a different set of services in their waiting list report. The number of people waiting in 2015 may differ from previous years for states making this adjustment.

### Number of People Receiving Targeted Case Management Services While Waiting

Of the people waiting for Medicaid Waiver-funded supports, an estimated 21% (42,489 people) received Medicaid State Plan-funded Targeted Case Management Services (TCM) while waiting. Twelve states did not provide TCM to people who were waiting. States providing TCM services to more than 90% of the people waiting included Maine (100%), Montana (100%), Nevada (100%), Rhode Island (100%), Maryland (93%), Connecticut (93%), and Missouri (93%).

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

An estimated 76,682 people (38% of those waiting) were waiting to move to a non-family setting. States reporting the highest proportion of people waiting to move to a non-family setting were Colorado (96%), Maryland (89%), Nevada (87%), Alaska (73%), Utah (62%), Missouri (50%), and Alabama (48%).

# **Growth Required to Serve All People Waiting**

There were an estimated 852,408 people with IDD receiving Medicaid Waiver-funded supports or living in an ICF/IID on June 30, 2015. States would have to increase the number of Medicaid Waiver recipients and/or ICF/IDD residents by 23% to serve all of the people who were waiting as of June 20, 2015. The growth needed to serve people

waiting ranged from none to 142%. States that would need to expand their Medicaid Waiver and/ or ICF/IID programs by more than 50% to meet the needs of the people waiting were New Mexico (142%), Oklahoma (97%), Georgia (92%), Virginia (78%), Louisiana (76%), Ohio (73%), Tennessee (71%), Alabama (63%), Florida (61%), Illinois (61%), South Carolina (57%), North Carolina (52%), Mississippi (54%), and Arkansas (51%).

#### MEDICAID WAIVER RECIPIENTS

The RISP survey asks about Medicaid Waiver recipients by age, by living arrangement, and by whether services are provided by a state or a nonstate entity. It asks separately about the number of people for whom Medicaid Waiver expenditures are reported. In some states, the number of people for whom expenditures data are provided differs from the number of recipients reported by age because recipient characteristics and expenditure data are tracked in different systems. Except in the expenditures section, this chapter refers to the total recipients reported by age.

### **Living Arrangements**

Medicaid Waiver-funded supports may be provided in many different types of settings including the home of a family member, the person's own home, a host/family foster home, or in an IDD group setting.

#### Home of a Family Member

Over half (52%, 401,967 people) of the 774,964 Medicaid Waiver recipients with IDD on June 30, 2015 lived in the home of a family member (see **Table 2.2** and **Figure 2.3**). All states provided Medicaid Waivers to people living in the home of a family member. States serving the greatest number of Waiver recipients in family homes were California (81,404 recipients), New York (46,609 recipients), Arizona (25,140 recipients), Michigan (24,653 recipients), and Ohio (20,057 recipients).

States in which more than half of all Medicaid Waiver recipients live in the home of a family member included:

- Arizona (85%),
- California (71%),

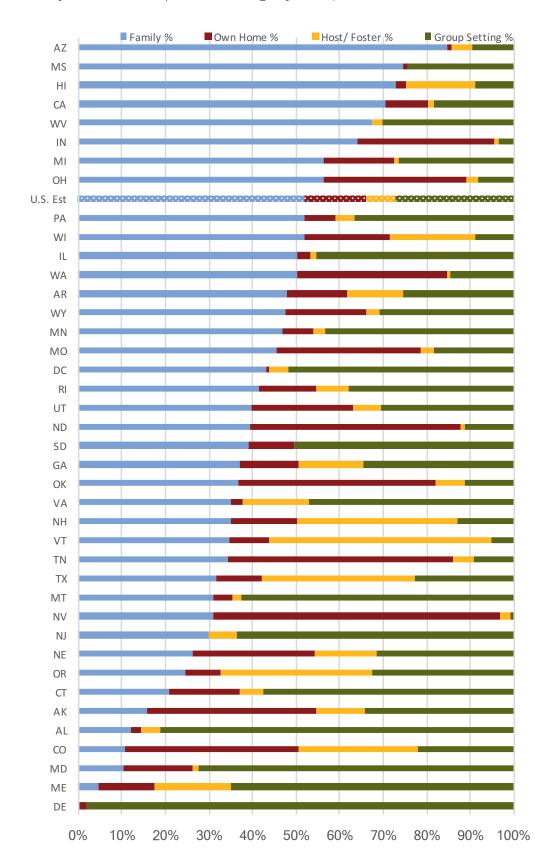


Table 2.2 Number of Medicaid Waiver Recipients with IDD by Residence Type and State on June 30, 2015

					Group	Settings	
	Family Home	Own Home	Host/ Foster	Nonstate IDD Group	Nonstate Other	State IDD Group	Group Tota
N States	46	45	46	44	48	50	41
AL.	480	96	175	3,224	0	0	3,224
λK	282	687	198	608	0	0	608
λZ	25,140	265	1,397	2,677	11	154	2,842
AR	1,925	562	507	1,028	00	0	1,028
CA	81,404	11,360	1,476	21,125	0	0	21,125
0	1,070	3,951	2,710	796	1,267	116	2,179
T	1,416	1,077	371	3,559	0	326	3,885
DE	1	18	0	1,041	0	2	1,043
OC .	799	11	83	953	0	0	953
:L	17,215	5,128	279	DNF	640	0	PD
GA	3,105 <sup>e</sup>	1,156 <sup>e</sup>	1,235 <sup>e</sup>	2,877 <sup>e</sup>	33 <sup>e</sup>	0	2,910
<del>-</del> 11	2,241	78	486	272	0	0	272
D	4,126 <sup>d</sup>	1,386 <sup>d</sup>	575	DNF	0	0	PD
L	11,390	733	255	10,296	0	0	10,296
N	12,156	5,936	221	637	0	0	637
A	DNF	DNF	DNF	DNF	Oi	58	PD
KS	DNF	DNF	DNF	DNF	0 <sup>d</sup>	0	PD
KY	DNF	DNF	1,242	3,153	Oq	0	3,153
-A	11,724	2,353	DNF	DNF	0	0	PD
ME	136	384	524	1,627	305	0	1,932
MD	1,445	2,228	201	5,729	4,360	0	10,089
MA	DNF	2,228 DNF	DNF	5,729 DNF	4,300	1,087	PD
MI	24,653 <sup>d</sup>	6,980 <sup>d</sup>	474 <sup>d</sup>	10,334 <sup>d</sup>	1,216 <sup>d</sup>	0	11,550
						350	
MN	11,232	1,683	664	9,191	775		10,316
MS	1,700	18	0	332	0	226	558
MO	5,992	4,359	388	2,196	0	209	2,405
MT	710 <sup>e</sup>	100 <sup>e</sup>	50	1,438 <sup>e</sup>	0	0	1,438
NE	1,279	1,373	705	1,518	0	17	1,535
VV	599	1,283	42	0	17	0	17
NH	1,047	459	1,106	388	0	0	388
NJ	3,276	0	708	6,988	0	0	6,988
MM	DNF	DNF	DNF	DNF	0 <sub>q</sub>	PD	PD
VY	46,609	6,130 <sup>e</sup>	1,940	22,794	DNF	6,723	PD
NC	11,366 <sup>e</sup>	DNF	1,779 <sup>e</sup>	2,375 <sup>e</sup>	DNF	0	PD
ND	1,031	1,262	24	294	0	0	294
OH	20,057 <sup>d</sup>	11,694 <sup>d</sup>	994 <sup>d</sup>	2,660	267 <sup>d</sup>	0	2,927
OK	1,969	2,414	350	602	0	0	602
OR	2,475	807	3,494	3,130	0	137	3,267
PA	17,536 <sup>e</sup>	2,360 <sup>e</sup>	1,489	11,011	1,357 <sup>e</sup>	0	12,368
રા	1,502	488	267	1,189	0	188	1,377
SC	5,973	601	163	2,854	DNF	0	PD
SD	1,408	368	2	1,813	0	0	1,813
ΓN	2,712	4,073	375	718	0	0	718
TX	10,944 <sup>d</sup>	3,648 <sup>d</sup>	12,094 <sup>d</sup>	7,901 <sup>d</sup>	0 <sub>d</sub>	0 <sub>q</sub>	7,901
JT	2,083	1,225	338	1,597	0	0	1,597
/T	920	239	1,352	137	0	0	137
/A	3,252	252	1,442	4,365	0	0	4,365
WA	5,549	3,804	95	1,414	63 <sup>e</sup>	129	1,606
WV	3,051 <sup>d</sup>	0 <sub>d</sub>	103 <sup>id</sup>	1,370 <sup>d</sup>	0 <sub>q</sub>	0	1,370
WI	16,295	6,181	6,177	2,804	3	0	2,807
NY	1,002	390	65	649	2	0	651
Reported US Total	382,277	99,600	48,615	161,664	10,316	9,722	181,702
Estimated US Total <sup>1</sup>	401,967	110,340	53,956	188,609	10,316	9,775	208,701

<sup>&</sup>lt;sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014). e Estimate. DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals. \* See state notes in Appendix. 1 US estimated totals include Waiver recipients for whom setting type was not known. Some states did not furnish type of residence for all LTSS recipients.

**Figure 2.3** Percent of Medicaid Waiver Recipients with IDD in Family Home, Own Home, Host/Foster Family Home or Group Home Settings by State June 30, 2015





- Hawaii (73%),
- Illinois (50%)
- Indiana (64%),
- Michigan (56%),
- Mississippi (75%),
- Ohio (56%),
- · Pennsylvania (52%),
- · Washington (50%),
- West Virginia (67%),
- Wisconsin (52%).

States serving higher proportions of Waiver recipients in family home settings also served higher proportions of people ages 21 years or younger. In Arizona where 62% of all Medicaid Waiver recipients with IDD were 21 years or younger, 85% lived with a family member. In comparison, fewer than 2% of all Waiver recipients were 21 years or younger in the District of Columbia, Maryland, New Jersey and Rhode Island. The proportion of Waiver recipients living with family members in those states ranged from 10% in Maryland to 43% in the District of Columbia. The correlation between proportion of Waiver recipients 21 years or younger and the proportion living in the home of a family member was a statistically significant -.51 (p < .01) in the 40 states reporting both.

#### **Own Home**

An estimated 14% of Medicaid Waiver recipients (110,340 people with IDD) lived in a home they owned or leased. All states except New Jersey and West Virginia provide Medicaid Waiver-funded services to people living in a home they owned or leased. States serving more than half of all Waiver recipients in own home settings were Nevada (66%) and Tennessee (52%).

#### Host or Family Foster Home

An estimated 7% of Medicaid Waiver recipients (53,956 people with IDD) lived in a host or foster family home. All states except Delaware and Mississippi served Medicaid Waiver recipients living in a host or foster family setting. States serving a large proportion of Medicaid Waiver recipients in a host or foster family setting were Vermont (51%), New Hampshire (37%), Texas (35%), Oregon (35%), Colorado (27%), and Wisconsin (20%).

#### **Group Settings**

An estimated 27% of Medicaid Waiver recipients (208,701 people with IDD) lived in group settings. All states except Nevada served Medicaid Waiver recipients in nonstate-operated group homes. Fourteen states served Medicaid Waiver recipients in nonstate-operated "other" settings and 14 states served Medicaid Waiver recipients living in state-operated group homes. States serving more than half of all Medicaid Waiver recipients in group settings were Delaware (98%), Alabama (81%), Maryland (72%), Maine (65%), New Jersey (64%), and Montana (63%).

# Medicaid Waiver Recipients by Age and Residence Type

The Family Information Systems Project (FISP) focused on the status and trends in supports provided to children and adults with IDD living in their own home or with a family member. The next two tables initially appeared in the FISP reports. The number of states reporting both age and living arrangement of Waiver recipients with IDD increased from 35 in 2013 to 39 in 2015.

## Waiver Recipients Living in the Home of a Family Member by Age

Of the 192,231 Medicaid Waiver recipients 21 years or younger, 87% (162,523 people) lived in the home of a family member (See **Table 2.3**). All Medicaid Waiver recipients 21 years or younger in Massachusetts and Mississippi lived in the home of a family member as did between 95% and 100% of Waiver recipients 21 years or younger in California, Hawaii, Indiana, New York, North Dakota, South Carolina, Wisconsin and Wyoming. Among states with more than 100 Medicaid Waiver recipients ages 21 years or younger, fewer than 20% of those recipients lived in the home of a family member in Alabama, Maine, Nevada, and Oregon.

Of the 582,733 Medicaid Waiver recipients 22 years or older, 41% (239,444 people) lived in the home of a family member. States serving the highest proportion of Waiver recipients with IDD ages 22 years or older living in the home of a family member were Arizona (87%), Mississippi (68%), and Hawaii (64%). States serving less than 5% of Waiver recipients 22 years or older in the

**Table 2.3** Number of Medicaid Waiver Recipients with IDD Living in Family Homes Versus All Other Settings by Age and State on June 30, 2015

	Family	/ Home	Other	Settings <sup>1</sup>	% in Fam	nily Home
Age	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older
N States	39	39	39	39	39	39
L	18	462	237	4,708	7	9
K	279	3	358	1,392	44	0
Z	15,468	9,340	2,251	1,359	87	87
.R	DNF	DNF	DNF	DNF	DNF	DNF
:A	48,934	32,470	1,910	32,051	96	50
:0	1,070	0	664	8,198	62	0
T	473	943	108	4,899	81	16
DE	0	<del>94</del> 3	27	1,013	0	0
OC .	9	573	5	987		37
					64	
L	4,440	12,144	1,024	12,864	81	49
iA 	558	2,647	101	5,200	85	34
11	379	1,290	16	717	96	64
D	DNF	DNF	DNF	DNF	DNF	DNF
L	1,403	10,065	280	10,393	83	49
N	5,687	6,435	300	6,528	95	50
A	DNF	DNF	DNF	DNF	DNF	DNF
S	DNF	DNF	DNF	DNF	DNF	DNF
Υ	DNF	DNF	DNF	DNF	DNF	DNF
A	DNF	DNF	DNF	DNF	DNF	DNF
ЛE	1	136	554	4,148	0	3
ИD	93	1,351	228	12,263	29	10
1A	219 <sup>i</sup>	DNF	0d	DNF	100	DNF
11	11,178 <sup>d</sup>	13,530 <sup>d</sup>	1,283 <sup>ed</sup>	17,666 <sup>d</sup>	90	43
/N	3,138	3,595	646	10,937	83	25
//S	214	1,423	0	659	100	68
			578		76	39
MO	1,834	4,216		6,515		
//T	200 <sup>e</sup>	225 <sup>e</sup>	291 <sup>e</sup>	2,082 <sup>e</sup>	41	10
NE .	124	1,212	107	3,213	54	27
IV .	28	571	118	1,224	19	32
NH .	DNF	1,047	DNF	1,494	DNF	41
IJ	DNF	DNF	DNF	DNF	DNF	DNF
IM	DNF	DNF	DNF	DNF	DNF	DNF
١Y	20,908 <sup>e</sup>	25,200 <sup>e</sup>	830	36,801 <sup>e</sup>	96	41
IC .	DNF	DNF	DNF	DNF	DNF	DNF
ND .	847	184	46	1,540	95	11
OH	5,268	14,112	494	15,371	91	48
OK	440	1,430	293	3,414	60	30
DR	128	2,347	5,766	12,636	2	16
PA	4,239	13,297	588	15,629	88	46
<u> </u>	0	1,502	0	2,514	0	37
C	1,792	4,181	87	3,531	95	54
iD .	892	516	106	2,078	89	20
'N	141	2,571	183	4,983	44	34
X	4,202 <sup>d</sup>	6,732 <sup>d</sup>	2,476 <sup>d</sup>	21,165 <sup>d</sup>	63	24
X IT						
	987	1,096	614	2,546	62	30
T	88	682	170	1,977	34	26
A	DNF	DNF	DNF	DNF	DNF	DNF
VA	1,249	4,272	327	7,031	79	38
VV	DNF	DNF	DNF	DNF	DNF	DNF
VI	4,531	11,764	100	15,065	98	44
VY	620	382	11	1,097	98	26
Reported Total	142,079	193,947	23,177	297,888	86	39
Estimated Total	162,523	239,444	29,708	343,289	85	41

<sup>&</sup>lt;sup>d</sup> Other date (Usually June 30, 2014 or August 31, 2015). e Estimate. DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals. \* See state notes in the Appendix. This table reports the number of people by age and setting for whom Waiver expenditures were reported. 1 Other settings include own home, host or foster family home, and all group settings.



home of a family member were Alaska, Colorado, Delaware and Maine.

#### **Waiver Recipients by Age**

Of the 774,964 Medicaid Waiver recipients with IDD, an estimated 25% (192,231 people) were 21 years old or younger, and 75% (582,733 people) were 22 years or older (see **Table 2.4** and **Figure 2.4**).

The proportion of Medicaid Waiver recipients who were 22 years or older ranged from 38% to 100%. The proportion 22 years or older was 95% or higher of all recipients in New Jersey (100%), Rhode Island (100%), the District of Columbia (99%), Massachusetts (98%), Maryland (98%), Delaware (97%), Oregon (97%), Tennessee (96%), Alabama (95%), and Nebraska (95%). The proportion of Waiver recipients who were 22 years or older less than 60% in Kentucky (56%), California (56%), Idaho (50%), North Dakota (48%), and Arizona (38%).

#### **Waiver Utilization Rates by State**

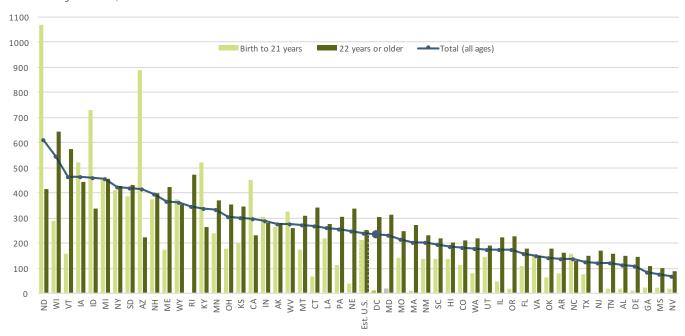
One way to compare Medicaid Waiver utilization across states is to examine the number of recipients per 100,000 of the state population. On June 30, 2015, there were an estimated 241 Medicaid Waiver recipients with IDD per 100,000 of the US population. The utilization rate ranged from 67

per 100,000 in Nevada to 609 per 100,000 in North Dakota. Other states with utilization rates of more than 450 per 100,000 were Wisconsin (545), Oregon (501), Vermont (466), Iowa (465), Idaho (460), and Michigan (455). Other states with Medicaid Waiver utilization rates below 100 per 100,000 were Georgia (83 per 100,000), Mississippi (77), and Nevada (67).

#### **Waiver Utilization Rates by Age and State**

Nationally, there were 211 Medicaid Waiver recipients with IDD ages birth to 21 years per 100,000 of the population, and 253 recipients ages 22 years or older per 100,000 on June 30, 2015. Waiver utilization rates were higher for people with IDD ages 22 years and older than for people 21 years or younger in 40 states. States with lower Waiver utilization rates for people with IDD ages 22 years or older than for people ages 21 years or younger were Arizona, California, Idaho, Indiana, Iowa, Kentucky, North Carolina, North Dakota, Virginia, West Virginia, and Wyoming. Arizona served 4 times more young people (21 and under) per 100,000 than adults. North Dakota served 2.6 more young people per 100,000 than adults. California, Idaho, and Kentucky served twice as many children and youth as adults. The number of Medicaid Waiver recipients per 100,000 of the population ages birth to 21 year and 22 years or older.

**Figure 2.4** Number of Medicaid Waiver Recipients with IDD per 100,000 of the Population by Age and State on June 30, 2015



### 2015

**Table 2.4** Medicaid Waiver Recipients with IDD, People Per 100,000 of the Population by Age and State on June 30, 2015

	Numb	er Waiver Recipie	nts	Percent		oulation in 100's <sup>s</sup>	Recipier	nts per 100,00	0 by Age
Age	Birth to 21 years	22 years or older	All Ages	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	All Ages
N states	51	51	51	51	51	51	51	51	51
AL	255	5,170	5,425	95	13.6	35.0	19	148	112
AK	602	1,442	2,044	71	2.3	5.1	265	282	277
AZ	17,719	10,699	28,418	38	20.0	48.3	888	221	416
AR	678	3,444	4,122	84	8.6	21.1	79	163	138
CA	50,844	64,521	115,365	56	112.6	278.8	451	231	295
СО	1,734	8,198	9,932	83	15.4	39.1	112	209	182
CT	649	8,953	9,602	93	9.8	26.1	66	342	267
DE	27	1,014	1,041	97	2.5	6.9	11	147	110
DC	14	1,560	1,574	99	1.6	5.1	9	306	234
FL	5,459	26,818	32,277	83	50.5	152.2	108	176	159
GA	659	7,847	8,506	92	30.7	71.4	21	110	83
HI	519	2,133	2,652	80	3.8	10.5	136	203	185
ID 	3,805	3,811	7,616	50	5.2	11.3	732	336	460
IL	1,683	20,458	22,141	92	36.5	92.1	46	222	172
IN	5,987	12,963	18,950	68	19.6	46.6	306	278	286
IA	4,759	9,773	14,532	67	9.2	22.1	519	443	465
KS	1,761	6,973	8,734	80	8.9	20.2	198	345	300
KY	6,474	8,393	14,867	56	12.4	31.8	520	264	336
LA	2,945	9,097	12,042	76	13.6	33.1	217	274	258
ME	555 <sup>e</sup>	4,284 <sup>e</sup>	4,839 <sup>e</sup>	89	3.2	10.1	173	425	364
MD	321	13,614	13,935	98	16.6	43.5	19	313	232
MA	219	13,579	13,798	98	18.0	50.0	12	272	203
MI	12,504 <sup>d</sup>	32,611 <sup>d</sup>	45,115 <sup>d</sup>	72	27.6	71.6	453	455	455
MN	3,784	14,532	18,316	79	15.7	39.2	241	371	334
MS	214	2,082	2,296	91	9.0	21.0	24	99	77
MO	2,407	10,726	13,133	82	17.2	43.7	140	246	216
MT	491	2,307	2,798	82	2.8	7.5	175	307	271
NE	231	4,425	4,656	95	5.8	13.2	40	336	246
NV	146	1,795	1,941	92	8.0	20.9	18	86	67
NH	1,275	3,960	5,235	76	3.4	9.9	374	400	393
NJ	0e	10,972	10,972 <sup>e</sup>	100	24.4	65.1	0	168	122
_									
NM	829	3,402	4,231	80	6.1	14.8	136	231	203
NY	21,738	62,001	83,739	74	52.8	145.1	412	427	423
NC	4,511 <sup>e</sup>	9,155 <sup>e</sup>	13,666 <sup>e</sup>	67	28.4	72.0	159	127	136
ND	2,402	2,211	4,613	48	2.2	5.3	1070	415	609
ОН	5,762	29,483	35,245	84	32.4	83.7	178	352	303
ОК	733	4,844	5,577	87	11.7	27.4	62	177	143
OR	206	6,726	6,932	97	10.6	29.7	19	227	172
PA	3,781	28,847	32,628	88	33.9	94.1	112	306	255
RI	0	3,654	3,654	100	2.8	7.8	0	471	346
sc	1,879	7,712	9,591	80	13.6	35.4	138	218	196
SD	998	2,594	3,592	72	2.6	6.0	385	433	418
TN	324	7,554	7,878	96	18.4	47.6	18	159	119
TX	6,681 <sup>d</sup>	27,942 <sup>d</sup>	34,623 <sup>d</sup>	81	87.4	187.3	76	149	126
UT	1,599	3,642	5,241	69	10.9	19.0	146	191	175
VT	258	2,659	2,917	91	1.6	4.6	159	573	466
VA	3,436	8,986	12,422	72	23.3	60.5	147	148	148
			12,422					217	
WA	1,577	11,315		88	19.6	52.1	80		180
WV	1,535 <sup>d</sup>	3,544 <sup>d</sup>	5,079 <sup>d</sup>	70	4.7	13.7	326	258	275
WI	4,631	26,829	31,460	85	16.2	41.6	287	646	545
WY	631	1,479	2,110	70	1.7	4.2	373	355	360
Reported US Total	192,231	582,733	774,964	75	909.5	2,304.7	211	253	241
Estimated US Total	192,231	582,733	774,964	75	909.5	2,304.7	211	253	241

<sup>&</sup>lt;sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014). e Estimate. DNF Did not furnish. s Source U.S. Census Bureau, Population Division (2016). \* See state notes in Appendix.



#### **Medicaid Waiver Compared to LTSS Recipients**

While the most common Medicaid funding authority used to provide LTSS to people with IDD was a Medicaid Waiver, states also funded those services through Medicaid ICF/IID, Medicaid State Plan or State or other local government funded sources. Nationally, of the estimated 1,210,637 people with LTSS on June 30, 2015, an estimated 64% (774,964 people) were Medicaid Waiver recipients. Of the estimated 698,566 LTSS recipients living in the home of a family member, 58% (401,967 people) were Medicaid Waiver recipients (See **Table 2.5**). Of the estimated 139,985 LTSS recipients living in their own home, 79% (110,340 people) were Medicaid Waiver recipients.

Eighteen states reported that all LTSS recipients with IDD living in the home of a family member received Medicaid Waiver-funded supports. In four additional states, more than 95% of LTSS recipients living in the home of a family member received Medicaid Waiver funded supports. Fewer than half of the LTSS recipients living in the home of a family member received Medicaid Waiver-funded supports in Florida (45%), Washington (45%), South Carolina (44%), Vermont (43%), Tennessee (38%), Ohio (27%), New Jersey (25%), Colorado (24%), Oregon (20%), Nevada (14%), and Delaware (less than 1%).

All of the LTSS recipients with IDD living in their own home received Medicaid Waiver funded supports in 19 states. In eight additional states, more 95% of LTSS recipients living in their own home received Medicaid Waiver funded supports. Fewer than half of the LTSS recipients living in their own home received Medicaid Waiver-funded supports in California (45%), New Jersey and West Virginia (none).

#### MEDICAID WAIVER EXPENDITURES

Total Medicaid Waiver expenditures for people with IDD in FY 2015 were \$34.2 billion (see **Table 2.6**). Medicaid Waiver expenditures were reported by 49 states. Expenditures for the other 2 states are estimated from an analysis of Centers for Medicare and Medicaid Services quarterly expense report (CMS 64 data) for Federal Fiscal Year 2015 (Eiken, Sredl, Burwell, and Woodward, 2017). Medicaid Waiver funds may not be used to pay room and

**Table 2.5** Number and Proportion of Medicaid Waiver Recipient with IDD in Own Home or Family Home Settings by State on June 20, 2015

<b>.</b>	All LTSS R	ecipients	Waiver R	ecipients		Waiver ling <sup>1</sup>
State	Own Home	Family Home	Own Home	Family Home	Own Home	Family Home
N States	46	46	45	46	45	44
AL	96	480	96	480	100	100
AK	687	282	687	282	100	100
AZ	265	31,151	265	25,140	100	81
AR	616	1,973	562	1,925	91	98
CA	25,097	162,156	11,360	81,404	45	50
СО	4,799	4,483	3,951	1,070	82 <sup>e</sup>	24
CT	1,131	1,516	1,077	1,416	95	93
DE	18	3,014 <sup>e</sup>	18	1_	100	0e
DC	13	799	11	799	85	100
FL	5,743	38,377	5,128	17,215	89	45
GA	1,156 <sup>e</sup>	3,105 <sup>e</sup>	1,156 <sup>e</sup>	3,105 <sup>e</sup>	100 <sup>e</sup>	100 <sup>e</sup>
HI	78	2,241	78	2,241	100	100
ID	1,483*	DNF	1,386 <sup>d</sup>	4,126 <sup>d</sup>	93	PD
IL	733	11,390	733	11,390	100	100
IN	5,936	12,756	5,936	12,156	100	95
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	DNF	DNF
KY	DNF	DNF	DNF	DNF	DNF	DNF
ME ME	2,408 384	13,870 136	2,353 384	11,724 136	98 100	85 100
				1,445	88	65
MD MA	2,542 2,551	2,215 6,948	2,228 DNF	1,445 DNF	PD	PD
MI	6,980 <sup>id</sup>	25,780 <sup>d</sup>	6,980 <sup>d</sup>	24,653 <sup>d</sup>	100 <sup>id</sup>	96 <sup>d</sup>
MN	2,294	11,232	1,683	11,232	73	100
MS	26	1,700	18	1,700	69	100
MO	4,363	10,136	4,359	5,992	100	59
MT	100 <sup>e</sup>	710 <sup>e</sup>	100 <sup>e</sup>	710 <sup>e</sup>	100 <sup>e</sup>	100 <sup>e</sup>
NE	1,373	1,426	1,373	1,279	100	90
NV	1,662	4,371	1,283	599	77	14
NH	470	1,047	459	1,047	98	100
NJ	97	13,248	0	3,276	0	25
NM	DNF	985 <sup>e</sup>	DNF	DNF	DNF	PD
NY	10,894 <sup>e</sup>	83,052 <sup>e</sup>	6,130 <sup>e</sup>	46,609	56 <sup>e</sup>	56 <sup>e</sup>
NC	DNF	DNF	DNF	11,366 <sup>e</sup>	DNF	PD
ND	1,262	1,031	1,262	1,031	100	100
ОН	15,651	73,518 <sup>d</sup>	11,694 <sup>d</sup>	20,057 <sup>d</sup>	75	27 <sup>d</sup>
OK	2,414	1,969	2,414	1,969	100	100
OR	807	12,551	807	2,475	100	20
PA	4,521 <sup>e</sup>	31,775 <sup>e</sup>	2,360 <sup>e</sup>	17,536 <sup>e</sup>	52 <sup>e</sup>	55 <sup>e</sup>
RI	488	1,502	488	1,502	100	100
SC	664	13,437	601	5,973	91	44
SD	536	1,988	368	1,408	69	71
TN	4,077	7,082	4,073	2,712	100	38
TX	3,648 <sup>d*</sup>	10,944 <sup>d</sup>	3,648 <sup>d</sup>	10,944 <sup>d</sup>	100	100 <sup>d</sup>
UT	1,244	2,139	1,225	2,083	98	97
VT	359	2,124	239	920	67	43
VA	252	3,252	252	3,252	100	100
WA	3,951	12,385	3,804	5,549	96	45
WV	0 <sub>d</sub>	3,051 <sup>d</sup>	0 <sub>d</sub>	3,051 <sup>d</sup>	0 <sub>d</sub>	100 <sup>d</sup>
WI	6,193*	24,666	6,181	16,295	100	66
WY	390*	1,002	390	1,002	100	100
Reported US Total	130,452	654,995	99,600	382,277	78	57
Estimated US Total	139,985	698,566	110,340	401,967	79	58

<sup>&</sup>lt;sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014). <sup>e</sup> Estimate. <sup>DMF</sup> Did not furnish. \* See state notes in Appendix. <sup>1</sup> Proportion of all LTSS recipients with IDD whose services were funded by a Medicaid HCBS Waiver by setting type.

### 2015

**Table 2.6** Total, Per Recipient and Per State Resident Medicaid Waiver Expenditures for Recipients with IDD by Age and State for FY 2015

State	Wa	aiver Expenditures (\$	)	FY 2015 Waiver	Expenditur	es per Recip	ient (\$)	State Population s	Expenditures per State
	Birth to 21	22 Years +	Total	Recipients	Birth to 21	22 years +	Total	(100,000)  51 49 7 68 30 391 55 36 9 7 203 102 14 17 129 66 31 129 66 31 13 60 68 99 55 30 61 10 19 29 13 90 118 119 198 1100 8 1116 39 40	Resident (\$)
N States	48	48	51	51	48	48	51	51	51
AL	15,232,748	308,868,283	324,101,031	5,425	59,736	59,742	59,742	49	67
AK	22,598,513	145,596,777	168,195,290	2,044	37,539	100,969	82,287	7	228
AZ	283,951,150	543,566,190	827,517,340	28,418	16,025	50,805	29,119	68	121
AR	26,230,302	178,531,346	204,761,648	4,122	38,688	51,838	49,675		69
CA	547,023,027	2,249,539,676	2,796,562,703	115,365	10,759	34,865	24,241	391	71
СО	27,149,050	368,318,874	395,467,924	9,932	15,657	44,928	39,818		72
СТ	33,328,134	845,962,843	879,290,977	9,602	51,353	94,489	91,574	36	245
DE	213,287	118,143,785	118,357,072	1,041	7,900	116,513	113,696		125
DC	964,626	183,863,094	184,827,720	1,574	68,902	117,861	117,425	7	275
FL	66,162,000	823,151,799	889,313,799	32,277	12,120	30,694	27,553	203	44
GA	17,247,137	338,758,685	356,005,822	8,506	26,172	43,170	41,853	102	35
н	13,161,310	92,240,010	105,401,320	2,652	25,359	43,244	39,744	14	74
ID	54,841,008	142,061,843	196,902,851	7,616	14,413	37,277	25,854	17	119
IL	45,076,066	784,681,256	829,757,322	22,141	26,783	38,356	37,476	129	65
IN	62,773,085	544,092,497	606,865,582	18,950	10,485	41,973	32,025	66	92
IA	78,502,866	432,395,951	510,898,817	14,532	16,496	44,244	35,157	31	164
KS	79,619,016	334,180,118	413,799,134	8,734	45,212	47,925	47,378	29	142
KY	187,297,156	408,103,316	595,400,472	14,867	28,931	48,624	40,048	44	135
LA	56,647,192	406,371,049	463,018,241	12,042	19,235	44,671	38,450	47	99
ME	13,296,187 <sup>e</sup>	287,231,075 <sup>e</sup>	300,527,262 <sup>e</sup>	4,839	23,957	67,047	62,105	13	226
MD	9,899,027	806,525,291	816,424,318	13,935	30,838	59,242	58,588	60	136
MA	DNF	DNF	1,159,456,123 <sup>s</sup>	13,798	PD	PD	84,031	68	171
MI	242,962,540 <sup>d</sup>	1,194,686,390 <sup>d</sup>	1,437,648,930 <sup>d</sup>	45,115	19,431	36,634	31,866	99	145
MN	177,128,774	1,099,761,663	1,276,890,437	18,316	46,810	75,679	69,714	55	233
MS	6,423,594	64,949,681	71,373,275	2,296	30,017	31,196	31,086	30	24
МО	74,940,426	625,482,664	700,423,090	13,133	31,134	58,315	53,333	61	115
MT	10,869,276	109,752,326	120,621,602	2,798	22,137	47,574	43,110	10	117
NE	11,423,005	153,204,417	164,627,422	4,656	49,450	34,622	35,358	19	87
NV	8,105,904	87,167,553	95,273,457	1,941	55,520	48,561	49,085	29	33
NH	12,362,582	220,569,232	232,931,814	5,235	9,696	55,699	44,495	13	175
NJ	0 <sub>q</sub>	876,940,082	876,940,082	10,972	0	79,925	79,925	90	98
NM	15,261,932 <sup>i</sup>	174,616,820 <sup>i</sup>	189,878,752	4,231	18,410	51,328	44,878	21	91
NY	250,612,719	4,854,062,165	5,104,674,884	83,739	11,529	78,290	60,959	198	258
NC	DNF	DNF	689,198,047 <sup>e</sup>	13,666	PD	PD	50,432	100	69
ND	DNF	DNF	180,687,708	4,613	PD	PD	39,169	8	239
ОН	110,949,570	1,323,212,517	1,434,162,087	35,245	19,255	44,881	40,691	116	123
ОК	19,103,279	293,537,351	312,640,630	5,577	26,062	60,598	56,059	39	80
OR	408,412	51,402,450	51,810,862	6,932	1,983	7,642	7,474	40	13
PA	85,223,981	2,223,387,249	2,308,611,230	32,628	22,540	77,075	70,756	128	180
RI	0	193,372,725	193,372,725	3,654	0	52,921	52,921	11	183
SC	55,103,609	226,162,338	281,265,947	9,591	29,326	29,326	29,326	49	57
SD	8,233,084	104,956,513	113,189,597	3,592	8,250	40,461	31,512	9	132
TN	25,132,300	644,115,700	669,248,000	7,878	77,569	85,268	84,952	66	101
TX	183,789,351 <sup>d</sup>	1,056,421,729 <sup>d</sup>	1,240,211,080 <sup>d</sup>		27,509	37,808	35,820	275	45
UT	31,102,585	161,015,762	192,118,347	5,241	19,451	44,211	36,657	30	64
VT	15,741,138	149,570,808	165,311,946	2,917	61,012	56,251	56,672	6	264
VA	55,235,939	671,917,129	727,153,068	12,422	16,076	74,774	58,538	84	87
WA	88,366,360 <sup>e</sup>	633,759,494 <sup>e</sup>	722,125,854 <sup>e</sup>		56,034	56,011	56,013	72	101
WV	61,085,943 <sup>i</sup>	297,785,582 <sup>i</sup>	358,871,525 <sup>s</sup>	5,079	39,795	84,025	70,658	18	195
WI	55,030,605	986,236,882	1,041,267,487	31,460	11,883	36,760	33,098	58	180
WY	10,547,840	78,925,682	89,473,522	2,110	16,716	53,364	42,405	6	153
Estimated US Total	3,461,867,112	30,722,989,064	34,184,856,176	774,964	18,009	52,722	44,112	3,214	106

<sup>&</sup>lt;sup>d</sup>Other date (Usually June 30, 2014 or August 31, 2015). e Estimate. DNF Did not furnish. i Missing value imputed (RISP estimated). s U.S. Census Bureau, Population Division (2016) for population and Eiken et al., (2017) for expenditures. \* See state notes in Appendix.



board costs (those expenses must be covered through non-Medicaid programs).

# Waiver Expenditures and Recipients by Age

Total FY 2015 Medicaid Waiver expenditures were \$3.5 billion for recipients with IDD ages 21 years or younger, and \$30.7 billion for recipients ages 22 years or older. Overall, 90% of Medicaid Waiver expenditures were for people ages 22 years or older. However, only 75% of waiver recipients were ages 22 years or older. The gap between the proportion of expenditure and the proportion of recipients who were adults (age 22 and over) averaged 15 percent. Waiver recipients 21 years or younger received fewer dollars per person than recipients age 22 years or older. They accounted for 10% of the waiver expenditures and 25% of the recipients. Four states (Nebraska, Nevada, Vermont, and Washington) reported larger per person expenditures for waiver recipients ages 21 and under than for 22 years and older.

# Annual per Recipient Waiver Expenditures

Annual Waiver expenditures averaged \$44,112 per recipient in FY 2015. Per recipient expenditures

ranged from \$7,474 to \$117,425. Seven states reported annual per recipient expenditures of more than \$75,000 including the District of Columbia (\$117,425), Delaware (\$113,696), Connecticut (\$91,574), Tennessee (\$84,952), Massachusetts (\$84,031), Alaska (\$82,287), and New Jersey (\$79,925). States with annual per recipient expenditures of less than \$30,000 were South Carolina (\$29,326), Arizona (\$29,119), Florida (\$27,553), Idaho (\$25,854), California (\$24,241), and Oregon (\$7,474).

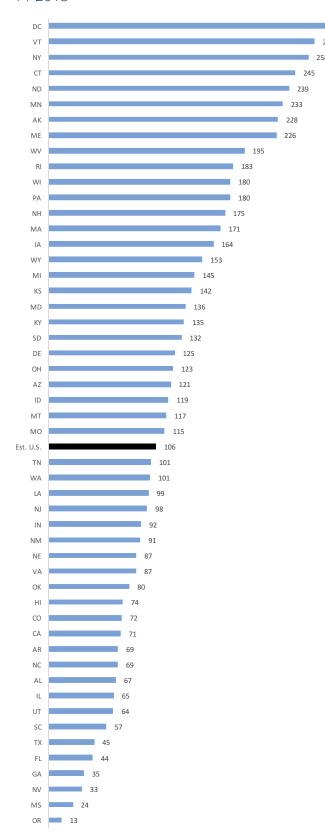
#### Annual per Recipient Waiver Expenditures by Age

Average annual per person Medicaid Waiver expenditures in FY 2015 were \$18,009 for people ages birth to 21 years and \$52,722 for people ages 22 years or older (See **Table 2.6**).

States with the highest average per person expenditures for people ages birth to 21 years were Tennessee (\$77,569), the District of Columbia (\$68,902), and Vermont (\$61,012). States with the lowest average per person Waiver expenditures for people ages birth to 21 years were New Hampshire (\$9,696), South Dakota (\$8,250), Delaware (\$7,900), Oregon (\$1,983), New Jersey (none), and Rhode Island (none).



**Figure 2.5** Annual Medicaid Waiver Expenditures for People with IDD per State Resident by State FY 2015



States with the highest average annual per person Waiver expenditures for people ages 22 years or older were the District of Columbia (\$117,861), Delaware (\$116,513), Alaska (\$100,969), and Connecticut (\$94,489). States with annual Waiver per person expenditures for people ages 22 years and older below \$34,000 were Mississippi (\$31,196), Florida (\$30,694), South Carolina (\$29,326), and Oregon (\$7,642).

#### **Annual per Capita Waiver Expenditures**

Total 2015 waiver expenditures for people with IDD were \$34.2 billion or \$106 per person in the United States (See **Figure 2.5**). The highest per capita waiver expenditures were for the District of Columbia (\$275), Vermont (\$264), New York (\$258), Connecticut (\$245), North Dakota (\$239), Minnesota (\$233), Alaska (\$228), and Maine (\$226). The lowest per capita Waiver expenditures were for South Carolina (\$57), Texas (\$45), Florida (\$44), Georgia (\$35), Nevada (\$33), Mississippi (\$24), and Oregon (\$13).

#### Waiver Expenditures by Age and Residence Type

Thirty-two states reported total Medicaid Waiver expenditures by age and living arrangement for FY 2015 (See **Table 2.7** and **Figure 2.6**).

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

Average annual Medicaid Waiver expenditures for the 162,523 recipients with IDD 21 years or younger who lived with a family member were \$15,786 per person in FY 2015 and ranged from \$268 per person to \$56,070 per person. States reporting average annual Waiver expenditures of less than \$10,000 per person for this group were Missouri (\$9,486), California (\$9,209), Indiana (\$8,678), Florida (\$8,636), Oregon (\$512), and the District of Columbia (\$268). States with average annual Waiver expenditures of more than \$40,000 per person were Washington (\$56,070) and Vermont (\$48,232).

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

The average annual Medicaid Waiver expenditure for the 239,444 recipients with IDD 22 years or older living with a family member was \$27,977 per person in FY 2015 and ranged from \$4,994 per person in Oregon to \$115,893 per person in Alaska. Other states reporting average annual Waiver expenditures



**Table 2.7** Total and Average Per Person Medicaid Waiver Expenditures for People with IDD by Age, Living Arrangement, and State in FY 2015

		Annual Waiver E	xpenditures (\$)				Expenditures (\$)	
State	Family	Home	Other Living A	rrangements	Family H	ome	Other Setti	ngs
	Birth to 21	22 years +	Birth to 21	22 years +	Birth to 21	22 years +	Birth to 21	22 years
N States	34	32	34	33	34	32	34	32
AL	244,488	6,983,987	14,988,260	319,194,280	13,583	15,117	63,242	67,798
AK	10,682,723	347,679	11,915,789	145,249,098	38,289	115,893	33,284	104,346
AZ	247,873,400	474,502,743	36,077,750	69,063,447	16,025	50,803	16,027	50,819
AR	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CA	450,641,895	538,211,126	96,381,132	1,711,328,550	9,209	16,576	50,461	53,394
СО	15,409,810	0	11,739,240	368,318,874	14,402	0	17,680	44,928
СТ	18,324,014	26,325,909	15,004,120	536,995,872	38,740	27,917	138,927	109,613
DE	0	67,045	213,287	118,290,027	0	67,045	7,900	116,772
DC	2,410	22,997,606	127,163	130,763,221	268	40,135	25,433	132,486
FL	38,342,494	234,813,348	53,317,285	562,840,672	8,636	19,336	52,068	43,753
GA	11,935,550	59,328,524	5,311,588	279,430,161	21,390	22,413	52,590	53,737
HI	10,719,440	52,327,060	598,326	36,564,756	28,283	40,564	37,395	50,997
ID	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	19,990,029	221,629,600	25,086,037	563,051,656	14,248	22,020	89,593	54,176
IN	49,353,643	115,827,904	13,419,442	428,264,593	8,678	18,000	44,731	65,604
IA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	156,130,168 <sup>d</sup>	DNF	DNF	DNF	PD
KY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	13,229	6,153,779	13,282,958	281,077,296	13,229	45,248	23,976	67,762
MD	2,101,768	51,659,423	7,797,259	754,885,602	22,600	38,238	34,199	61,558
MA	DNF	DNF	DNF	DNF	PD	DNF	PD	DNF
MI	185,290,949 <sup>d</sup>	273,684,749 <sup>d</sup>	361,078,294 <sup>d</sup>	921,001,643 <sup>d</sup>	16,576 <sup>d</sup>	20,228 <sup>d</sup>	281,433 <sup>de</sup>	52,134 <sup>d</sup>
MN	116,484,187	165,459,990	60,644,587	934,301,673	37,121	46,025	93,877	85,426
MS	6,423,594	44,425,582	0	20,524,098	30,017	31,220	0	31,144
MO	17,398,033	68,037,705	57,542,393	557,444,959	9,486	16,138	99,554	85,563
MT	4,976,472	8,893,125 <sup>e</sup>	5,892,804	82,859,201 <sup>e</sup>	24,882 <sup>e</sup>	39,525 <sup>e</sup>	20,250 <sup>e</sup>	39,798 <sup>e</sup>
NE	3,101,347	24,984,724	11,355,515	142,897,079	25,011	20,614	106,126	44,475
NV	527,295	9,097,147	7,578,609	78,070,406	18,832	15,932	64,226	63,783
NH	DNF	DNF	DNF	DNF	DNF	PD	DNF	PD
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	DNF	DNF	DNF	DNF	PD	PD	PD	PD
NC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ND	DNF	DNF	DNF	DNF	PD	PD	PD	PD
ОН	82,747,374	331,829,856	28,202,197	991,382,661	15,708	23,514	57,089	64,497
ОК	5,050,655	32,520,193	14,052,624	261,017,159	11,479	22,741	47,961	76,455
OR	67,303	11,720,358	147,415,870	603,687,461	526	4,994	25,566	47,775
PA	46,511,061	459,446,749	46,105,462	1,761,389,474	10,972	34,553	78,411	112,700
RI	0	DNF	0	DNF	0	PD	0	PD
SC	52,552,245	122,612,128	2,551,365	103,550,209	29,326	29,326	29,326	29,326
SD	DNF	DNF	DNF	DNF	PD	PD	PD	PD
TN	4,254,100	80,321,400	20,878,200	563,794,300	30,171	31,241	114,089	113,144
TX	96,559,378 <sup>d</sup>	184,800,272 <sup>d</sup>	83,436,839 <sup>d</sup>	852,012,291 <sup>d</sup>	22,979 <sup>d</sup>	27,451 <sup>d</sup>	33,698 <sup>d</sup>	40,256 <sup>d</sup>
UT	12,842,648	18,158,492	18,290,411	142,857,270	13,012	16,568	29,789	56,110
VT	3,804,372	31,356,648	11,936,766	118,214,160	43,232	45,977	70,216	59,795
VA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	70,031,461 <sup>e</sup>	239,531,147 <sup>e</sup>	18,334,898 <sup>e</sup>	394,228,347 <sup>e</sup>	56,070 <sup>e</sup>	56,070 <sup>e</sup>	56,070 <sup>e</sup>	56,070 <sup>e</sup>
WV	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WI	51,336,284	DNF	3,694,320	DNF	11,330	PD	36,943	PD
WY	DNF	DNF	DNF	DNF	PD	PD	PD	PD
Reported Total	1,635,593,651	3,918,055,998	1,204,250,790	14,990,680,663				
Estimated Total	2,565,663,952	6,698,817,084	1,944,270,244	23,670,545,548	15,786	27,977	65,446	68,952

<sup>&</sup>lt;sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014). e Estimate. DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals. i Missing value imputed (RISP estimated based on other available data). \* See state notes in the Appendix.

of more than \$50,000 per person were Arizona, Delaware, and Washington. Other states reporting average annual Waiver expenditures of less than \$20,000 per person were Alabama, California, Florida, Indiana, Missouri, Nevada, and Utah.

## Waiver Recipients 21 Years or Younger Living in Other Settings

Average annual Medicaid Waiver expenditures for the 29,708 recipients with IDD ages 21 and younger living in a non-family setting were \$65,446 per person in FY 2015 and ranged from \$7,900 per person in Delaware to \$281,433 per person in Michigan. Other states reporting average annual Waiver expenditures of more than \$100,000 per person for this group were Connecticut, Nebraska, and Tennessee. Other states reporting average annual Waiver expenditures of less than \$20,000 per person for this group were Arizona and Colorado.

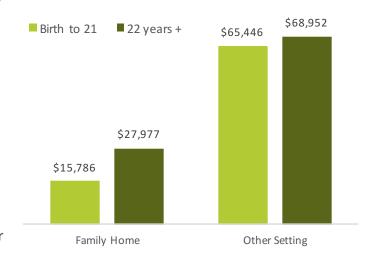
# Waiver Recipients 22 Years or Older Living in Other Settings

The average annual Medicaid Waiver expenditure for the 343,289 recipients with IDD 22 years or older living in a non-family setting was \$68,952 per person in FY 2015 and ranged from \$29,326 per person in South Carolina to \$132,486 per person in Washington DC. Other states with average annual Waiver expenditures of more than \$100,000 were Arkansas, Connecticut, Delaware, Pennsylvania and Tennessee. Other states reporting average annual Waiver expenditures of less than \$40,000 per person were Mississippi and Montana.

Average annual per person expenditures were 4.15 times higher for Medicaid Waiver recipients 21 years or younger living in a non-family setting than for those living with a family member. They were 2.46 times higher for Waiver recipients age 22 years and older living in a non-family setting than for those living with a family member. The higher costs associated with Medicaid Wavier services provided in a setting other than the home of a family member can, in part, be explained by the unreimbursed time family members spend providing supports that would otherwise have to be provided by a paid caregiver.

Among Medicaid Waiver recipients living in the home of a family member, average annual expenditures were 77% higher for people 22 years or older than for people 21 years or younger. Among

**Figure 2.6** Estimated Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement in FY 2015



Waiver recipients living in other settings, average annual expenditures for people 22 years or older were 5% higher than for people 21 years or younger.

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

While most people with IDD who receive LTSS under the auspices of state IDD agencies receive Medicaid Waiver funded supports, a substantial minority resided in an ICF/IID. This section describes ICF/IID settings, recipients and expenditures as of June 30, 2015.

#### **ICF/IID Facilities**

#### **State versus Nonstate Facilities**

There were an estimated 6,396 ICF/IIDs on June 30, 2015 (see **Table 2.8**). Of those, 5% (288) were state-operated, and 95% (6,108) were operated by a nonstate entity. There were no State- or Nonstate-Operated ICF/IID facilities in Alaska, Michigan, and Oregon, though those states may have paid for ICF/IID services provided to a state resident in an out of state facility.

There were no state-operated ICF/IIDs in Alabama, Alaska, Arizona, Arkansas, the District of Columbia, Hawaii, Indiana, Maine, Michigan, New Hampshire, Oregon, and Vermont. There were more than ten state-



operated ICF/IIDs in Mississippi (69 facilities), New York (38), Tennessee (35), Minnesota (15), and Texas (15).

There were no nonstate-operated ICF/IIDs in Alaska, Georgia, Maryland, Massachusetts, Michigan, Montana, Oregon, or Wyoming. There were more than 500 nonstate ICF/IIDs in California (1,205 facilities), Texas (823), New York (536), and Louisiana (518).

#### **Facilities by Size**

Of the ICF/IID settings on June 30, 2015, 59% (3,803 facilities) served six or fewer people, 33% (2,081 facilities) served 7-15 people and 8% (512 facilities) served 16 or more people. In New Mexico, and Vermont all ICF/IID settings served six or fewer people. The only ICF/IID in Alabama served 7 to 15 people. There were more than 20 ICF/IIDs serving 16 or more people in Ohio (87 facilities), New York (57), Florida (51), Illinois (40), Pennsylvania (25), Iowa (23), and Wisconsin (22).

Of the 288 state-operated ICF/IIDs, 24% (69 facilities) had six or fewer residents, 25% (71 facilities) had 7 to 15 residents, and 51% (148 facilities) had 16 or more residents. Of the 39 states with a state-operated ICF/IID, 10 states had at least one facility serving six or fewer people, six states had at least one facility serving 7 to 15 people, and 36 states had at least one facility of 16 or more people. All of the state-operated ICF/IID facilities in Minnesota, New Mexico, and Rhode Island served six or fewer people. In 27 states, all of the state-operated ICF/IID served 16 or more people.

Of the 6,108 nonstate ICF/IIDs, 61% (3,734 facilities) had six or fewer residents, 33% (2,010 facilities) had 7 to 15 residents, and 6% (364 facilities) had 16 or more residents. Of the 43 states with one or more nonstate ICF/IID, 29 states had at least one nonstate ICF/IID of 6 or fewer people, 29 states had at least one nonstate ICF/IID with 7 to 15 people, and 29 had one or more nonstate ICF/IID with 16 or more people. All nonstate ICF/IID in Colorado, New Mexico, and Vermont served six or fewer people. States with 15 or more nonstate ICF/IIDs of 16 or more people were Ohio (77 facilities), Florida (49), Illinois (33), New York (32), Iowa (21), Pennsylvania (20), and Wisconsin (19).

#### People in ICF/IID Settings

#### **State versus Nonstate**

On June 30, 2015, an estimated 77,444 people lived in an ICF/IID (see **Table 2.9**). Of those, 28% (21,486 people) lived in a state-operated ICF/IID and 72% (55,958 people) lived in a nonstate-operated ICF/IID. In five states, all of the people in an ICF/IID lived in a state-operated setting (Georgia, Maryland, Massachusetts, Montana, and Wyoming). In ten states, all of the people living in an ICF/IID lived in a nonstate setting (Alabama, Arizona, the District of Columbia, Hawaii, Indiana, Maine, New Hampshire, Vermont and West Virginia).

Nearly half (46%) of all ICF/IID recipients on June 30, 2015 lived in California, Illinois, New York, Ohio or Texas.

#### Setting Size

On June 30, 2015, of the people living in ICF/IIDs, an estimated 25% (19,690 people) lived settings of six or fewer people, 25% (19,115 people) lived in settings of 7 to 15 people, and 50% (38,638 people) lived in settings of 16 or more people. States with the largest proportions of people living in ICF/IID settings of



### 2015

**Table 2.8** Number of State and Nonstate Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) by Size and State on June 30, 2015

		State Facili	ties			Nonstate Fa	acilities			All Facil	ities	
Size	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	49	49	49	51	49	49	49	51
AL	0	0	0	0	0	1	0	1	0	1	0	1
AK	0	0	0	0	0	0	0	0	0	0	0	0
AZ	0	0	0	0	0	0	1	1	0	0	1	1
AR	0	0	5	5	0	31	5	36	0	31	10	41
CA	0	0	4	4	1,195	0	10	1,205	1,195	0	14	1,209
СО	0	1	1	2	4	0	0	4	4	1	1	6
СТ	0	0	6	6	63	5	0	68	63	5	6	74
DE	0	0	1	11	0	0	11	1	0	0	2	2
DC	0	0	0	0	68	1	0	69	68	1	0	69
FL	0	0	2	2	37 <sup>e</sup>	3	49	89	37	3	51	91
GA	0	0	2	2	0	0	0	0	0	0	2	2
HI	0	0	0	0	16	1	0	17	16	1	0	17
ID	1	0	1	2	25	41	0	66	26	41	1	68
IL	0	0	7	7	33	160	33	226	33	160	40	233
IN	0	0	0	0	166	331	2	499	166	331	2	499
IA	0	0	2	2	71	46	21	138	71	46	23	140
KS	0	0	2	2	17	7	0	24	17	7	2	26
KY	0	3	4	7	0	0	2	2	0	3	6	9
LA	2	2	2	6	301	208	9	518	303	210	11	524
ME	0	0	0	0	2	13	2	17	2	13	2	17
MD	0	0	2	2	0	0	0	0	0	0	2	2
MA	0	0	2	2	0	0	0	0	0	0	2	2
MI	0	0	0	0	0	0	0	0	0	0	0	0
MN	15	0	0	15	136	43	14	193	151	43	14	208
MS	5	58	6	69	2	2	6	10	7	60	12	79
МО	0	0	7	7	0	6	1	7	0	6	8	14
MT	0	0	1	1	0	0	0	0	0	0	1	1
NE	0	0	4	4	6	11	2	9	6	1	6	13
NV	0	0	1	1	6	0	1	7	6	0	2	8
NH	0	0	0	0	0	0	1	1	0	0	1	1
NJ	0	0	5	5	0	0	1 <sup>s</sup>	1	0	0	6	6
NM	11	0s	0	11	56 <sup>e</sup>	0	0	56	57	0	0	57
NY	7	6	25	38	88	416	32	536	95	422	57	574
NC	2	0	4	6	DNF	DNF	DNF	386	DNF	DNF	DNF	392
ND	0	0	1	1	38	29	1	68	38	29	2	69
ОН	0	0	10	10	106	238	77	421	106	238	87	431
OK	0	0	1	1	DNF	DNF	DNF	87	DNF	DNF	DNF	88
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	5	5	127	29	20	176	127	29	25	181
RI	2 <sup>s</sup>	0	0	2	0	0	1	1	2	0	1	3
SC	0	0	5	5	2	61	0	63	2	61	5	68
SD	0	0	1	1	0	0	1	1	0	0	2	2
TN	32	11	2	35	61	50	2	113	93	51	4	148
TX	2 <sup>d</sup>	0 <sub>q</sub>	13 <sup>d</sup>	15	772 <sup>d</sup>	47 <sup>d</sup>	4 <sup>d</sup>	823	774	47	17	838
UT	0	0	1	1	0	2	14	16	0	2	15	17
VT	0	0	0	0	1	0	0	1	1	0	0	1
VA	0	0	4	4	25	25	4	54	25	25	8	58
WA	0	0	4	4	5 <sup>e</sup>	3e	0e	8	5	3	4	12
WV	0	0	0s	0	16 <sup>d</sup>	52 <sup>d</sup>	0 <sub>q</sub>	68	16	52	0	68
WI	0	0	3	3	0	2	19	21	0	2	22	24
WY	0	0	1	11	0	0	0	0	0	0	1	1
Reported Total	69	71	147	287	3,445	1,854	336	6,108	3,512	1,925	478	6,395
Estimated	69	71	148	288	3,734	2,010	364	6,108	3,803	2,081	512	6,396

 $<sup>^{\</sup>rm d}$  Other date (Usually June 30, 2014).  $^{\rm e}$  Estimate.  $^{\rm DNF}$  Did not furnish.  $^{\rm s}$  Other Source (AHCAa, 2017).



**Table 2.9** Number of People with IDD Living in an ICF/IID by Type of Operation, Setting Size and State on June 30, 2015

Operator		St	ate			Nonst	ate			Tota		
Size	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	51	51	51	51	51	51	51	51
AL	0	0	0	0	0	14	0	14	0	14	0	14
AK	0	0	0	0	0	0	0	0	0	0	0	0
AZ	0	0	0	0	0	0	29	29	0	0	29	29
AR	0	0	913	913	0	309	217	526	0	309	1,130	1,439
CA	0	0	1,077	1,077	6,275	0	757	7,032	6,275	0	1,834	8,109
со	0	126	29	155	20	0	0	20	20	126	29	175
СТ	0	0	468	468	322	42	0	364	322	42	468	832
DE	0	0	52	52	0	0	68	68	0	0	120	120
DC	0	0	0	0	322	7	0	329	322	7	0	329
FL	0	0	711	711	210 0 <sup>id</sup>	58 <sup>e</sup>	1,699 0 <sup>id</sup>	1,967 0d	210	58	2,410	2,678
GA HI	0	0	267 0	267 0	69	7	0.0	76	0 69	7	267 0	267 76
ID	5	0	19	24		DNF		432 <sup>s*</sup>	DNF	DNF	DNF	456
IL	0	0	1,686	1,686	DNF 171	2,210	DNF 2,720	5,101	171	2,210	4,406	6,787
IN	0	0	0	0	835	2,438	46	3,319	835	2,438	4,400	3,319
IA	0	0	391	391	333	414	712	1,459	333	414	1,103	1,850
KS	0	0	312	312	73	65	0	138	73	65	312	450
KY	0	23	263	286	0	0	135	135	0	23	398	421
LA	8	20	469	497	1,822	1,598	822	4,242	1,830	1,618	1,291	4,739
ME	0	0	0	0	11	124	32	167	11	124	32	167
MD	0	0	105	105	0	0	0	0	0	0	105	105
MA	0	0	433	433	0	0	0	0	0	0	433	433
MI	0	0	0	0	0	0	0	0	0	0	0	0
MN	74	0	0	74	710	422	330	1,462	784	422	330	1,536
MS	26	590	1,082	1,698	8	30	696	734	34	620	1,778	2,432
МО	0	0	393	393	0	48	32	80	0	48	425	473
MT	0	0	55	55	0	0	0	0	0	0	55	55
NE	0	0	114	114	27	9	217	253	27	9	331	367
NV	0	0	47	47	33	0	18	51	33	0	65	98
NH	0	0	0	0	0	0	25	25	0	0	25	25
NJ	0	0	1,600	1,600	0	0	441	441	0	0	2,041	2,041
NM	3	0	0	3	224 <sup>e</sup>	0	0	224 <sup>e</sup>	227	0	0	227
NY	27	38	648	713	474	4,105	996	5,575	501	4,143	1,644	6,288
NC	6	0	1,436	1,442	DNF	DNF	DNF	2,523 <sup>s*</sup>	DNF	DNF	DNF	3,965
ND OH	0	0	79 815	79 815	207 555	226 2,039	30	463 5,552	207 555	226	109	542
OK	0	0	1	1	158	457	2,958 966	1,581	158	2,039 457	3,773 967	6,367 1,582
OR	0	0	0	0	0	0	0	0	0	0	0	1,562
PA	0	0	950	950	619	219	1,251	2,089	619	219	2,201	3,039
RI	7	0	0	7	0	0	25	25	7	0	25	32
SC	0	0	673	673	10	500	0	510	10	500	673	1,183
SD	0	0	140	140	0	0	50	50	0	0	190	190
TN	126	5	109	240	283	410	87	780	409	415	196	1,020
TX	9d	0d	3,186 <sup>d</sup>	3,195 <sup>d</sup>	4,241 <sup>d</sup>	533 <sup>d</sup>	335 <sup>d</sup>	5,109 <sup>d</sup>	4,250	533	3,521	8,304
UT	0	0	202	202	0	26	561	587	0	26	763	789
VT	0	0	0	0	6	0	0	6	6	0	0	6
VA	0	0	483	483	123	242	156	521	123	242	639	1,004
WA	0	0	765	765	26	23	0e	49	26	23	765	814
WV	0	0	0	0s	84 <sup>d</sup>	425 <sup>d</sup>	0 <sub>d</sub>	509 <sup>d</sup>	84	425	0	509
WI	0	0	350	350	0	13	424	437	0	13	774	787
WY	0	0	70	70	0	0	0	0	0	0	70	70
Reported US Total	291	802	20,393	21,486	18,251	17,013	16,835	55,054	18,531	17,815	35,773	76,540
Estimated US Total	291	802	20,393	21,486	19,399	18,313	18,245	55,958	19,690	19,115	38,638	77,444

<sup>&</sup>lt;sup>d</sup>Other date (Usually June 30, 2014 or August 31, 2015). e Estimate. DNF Did not furnish. i Missing value imputed (RISP estimated). s Other Source (AHCA, 2017). \* See state notes in Appendix.

1 to 6 people were New Mexico (100%), Vermont (100%), the District of Columbia (98%), Hawaii (91%), and California (77%). All ICF/IID recipients in Arizona, Delaware, Georgia, Maryland, Montana, New Hampshire, New Jersey, South Dakota, and Wyoming living in settings of 16 or more people as did 90% or more of those in Wisconsin (98%), Utah (97%), Kentucky (95%), Washington (94%), Nebraska (90%), Florida (90%), and Missouri (90%).

More than half (52%) of all ICF/IID recipients in settings of 16 or more people lived in Florida, Illinois, Mississippi, New Jersey, Ohio, Pennsylvania, or Texas.

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

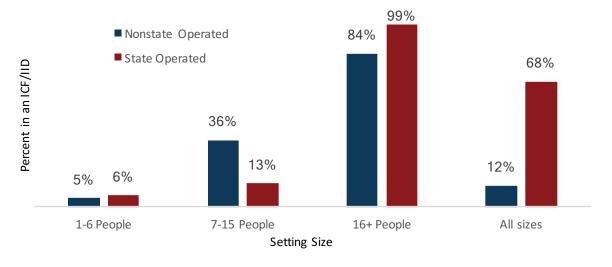
Overall, 12% of people in Nonstate-Operated IDD Group Settings, and 68% of all people in State-Operated IDD Group Settings lived in an ICF/IID (See **Figure 2.7**). Among people living in settings of 16 or more people, 99% of those in state-operated settings and 84% of those in nonstate-operated settings lived in an ICF/IID. Among people living in settings of 7 to 15 people, 13% of those in state-operated settings, and 36% of those in nonstate-operated settings lived in an ICF/IID. Among people living in group homes of one to six people, the proportion living in an ICD/IID was 5% for nonstate settings and 6% for state-operated settings

#### **ICF/IID Recipients by Age**

Of the 77,444 people living in an ICF/IID on June 30, 2015, an estimated 6% (4,942 people) were 21 years old or younger and 94% (72,502 people) were 22 years or older (see **Table 2.10**). States with the highest proportion of ICF/IID residents age 21 and younger were South Dakota (41%), Idaho (23%), North Dakota (21%), Arkansas (19%), Virginia (16%), and Iowa (15%). All ICF/IID recipients were 22 years or older in Alabama, Connecticut, Delaware, Hawaii, Massachusetts, Missouri, Montana, New Jersey, Vermont, Wisconsin, and Wyoming.

An estimated 24.1 people per 100,000 of the US population lived in an ICF/IID on June 30, 2015 (See **Figure 2.8**). ICF/IID utilization rates ranged from zero in Michigan and Oregon to 112.3 per 100,000 in Louisiana. An estimated 5.4 people 21 years or younger per 100,000 of the population lived in an ICF/IID. The rates were highest in North Dakota (43.7 per 100,000), Louisiana (41.6), lowa (35.5), Arkansas (32.2), South Dakota (29.3), and Idaho (21.3). An estimated 31.5 people 22 years or older per 100,000 of the population lived in an ICF/IID. Those rates were highest in Louisiana (141.3), lowa (81.9), Illinois (71.9), Ohio (71.0), North Dakota (68.6), Indiana (66.8), and the District of Columbia (64.3).

**Figure 2.7** Proportion of LTSS Recipients with IDD in Non-Family Settings who Live in ICF/IIDs By Setting Size and Type of Operation on June 30, 2015





**Table 2.10** People with IDD Living in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) and Per 100,000 of the Population by Age and State on June 30, 2015

	Pop	oulation in 100,00	00s s		ICF/IID Residents		ICF/I	ID Residents pe	100k
State	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 <sup>1</sup>
N States	51	51	51	51	51	51	51	51	51
<b>AL</b>	14	35	49	0	14	14	0	0	0
λK	2	5	7	3	3	6	1	1	1
ΑZ	20	48	68	4 <sup>s</sup>	127 <sup>s</sup>	131	0	3	2
٩R	9	21	30	278 <sup>s</sup>	1,166 <sup>s</sup>	1,444	32	55	48
CA	113	279	391	151	7,838	7,989	1	28	20
0.0	15	39	55	14	160	174	1	4	3
CT	10	26	36	0c	468 <sup>c</sup>	845	0	18	24
DE	3	7	9	00	120	120	0	17	13
OC .	2	5	7	1	328	329	1	64	49
FL	51	152	203	108	2,634	2,742	2	17	14
GA	31	71	102	24 <sup>s</sup>	267 <sup>s</sup>	291	1	4	3
HI	4	11	14	00	76	76	0	7	5
ID	5	11	17	111	377	488	21	33	29
IL	36	92	129	164	6,624	6,788	4	72	53
IN	20	47	66	203	3,116	3,319	10	67	50
IA	9	22	31	325	1,808	2,133	35	82	68
KS	9	20	29	6 <sup>b</sup>	132 <sup>b</sup>	450	1	7	15
KY	12	32	44	14 <sup>s</sup>	421 <sup>s</sup>	435	1	13	10
LA	14	33	47	564	4,683	5,247	42	141	112
ME	3	10	13	5	162	167	2	16	13
MD	17	43	60	1 <sup>s</sup>	106 <sup>s</sup>	107	0	2	2
MA	18	50	68	0	433	433	0	9	6
MI	28	72	99	0	0	0	0	0	0
MN	16	39	55	79	1,512	1,591	5	39	29
MS	9	21	30	85 <sup>c</sup>	997 <sup>c</sup>	2,432	9	48	81
MO	17	44	61	0	473	473	0	11	8
MT	3	8	10	0	55	55	0	7	5
NE	6	13	19	31	363	394	5	28	21
NV	8	21	29	12	86	98	11	4	3
NH	3	10	13	25	0	25	7	0	2
NJ	24	65	90	0e	2,041 <sup>i</sup>	2,041	0	31	23
NM	6	15	21	14 <sup>s</sup>	238 <sup>s</sup>	252	2	16	12
NY	53	145	198	663	5,839	6,502	13	40	33
NC	28	72	100	388 <sup>s</sup>	3,577 <sup>s</sup>	3,965	14	50	39
ND	2	5	8	98 <sup>b</sup>	365 <sup>b</sup>	463	44	69	61
OH	32	84	116	423	5,944	6,367	13	71	55
OK OR	12	27	39	0c	0 <sup>c</sup>	1,581	0	0	40
OR	11	30	40	0	0	2.024	0	0	0
PA	34	94	128	114	2,910	3,024	3	31	24
RI	3	8	11	17 <sup>s</sup>	15 <sup>s</sup>	32	6	2	3
SC	14	35	49	22	1,162	1,184	2	33	24
SD	3	6	9	76 25	111	187	29	19	22
TN	18 87	48	66	35 393 <sup>d</sup>	985 7,800 <sup>d</sup>	1,020	2	21	15
TX UT		187	275			8,193	4	42	30
VT	11	19	30	69	772	841	6	41	28
VI VA	2 23	5 61	6	122	6	6 782	0 5	1	1 9
			84 72	122	660 761	782 766		11	
WA WV	<u>20</u> 5	52 14	72 18	5 58 <sup>s</sup>	761 448 <sup>s</sup>	506	0 12	15 33	11 27
WI		42	58						
WY	16 2	42	6	0	787	787 70	0	19 17	14
wy Reported US Total	909	2,305	3,214	4,705	70 69,040	77,365	5	30	24
Estimated US Total	909	2,305	3,214	4,942	72,502	77,444	5	31	24

<sup>&</sup>lt;sup>b</sup> Nonstate settings reported, but not state settings. c State settings reported, but not nonstate settings. d Other date (Usually August 31, 2015 or June 30, 2014). e Estimate. DNF Did not furnish. s Other Source U.S. Census Bureau, Population Division (2016) for population and (AHCA, 2017a) for ICF/IID. \* See state notes in Appendix. 1 The reported number of ICF/IID recipients by age may differ from the overall reported total recipients because information about age was not available for all recipients.

#### **ICF/IID EXPENDITURES**

Total FY 2015 ICF/IID expenditures were \$10.4 billion nationally and ranged from \$945,886 in Alabama to \$1.3 billion in New York (See **Table 2.11**). Michigan and Oregon reported no ICF/IID expenditures for FY 2015. Six states reported less than \$10 million in ICF/IID expenditures (Alabama, Alaska, Hawaii, New Hampshire, Rhode Island, and Vermont). Seven states reported more than \$500 million in ICF/IID expenditures (California, Illinois, New Jersey, New York, Ohio, Pennsylvania, and Texas). Most states report expenditures based on paid claims data, but a few report budgeted rather than actual expenditures. ICF/IID expenditures for states unable to report have a superscript of s and are from Eiken et.al. (2017).

#### **Per Person Expenditures**

Estimated FY 2015 per person ICF/IID expenditures averaged \$134,630 and ranged from \$61,678 in Oklahoma to \$420,989 in Alaska six people from Alaska lived in an ICF/IID in another state. Other states with expenditures averaging less than \$80,000 per person were Nebraska (\$79,978), Minnesota (\$78,218), Louisiana (\$73,201), and Alabama (\$67,563). Other states with average per person ICF/IID expenditures of more than \$250,000 were

New Hampshire (\$355,657), Delaware (\$355,098), Kentucky (\$323,036), Connecticut (\$313,240), District of Columbia (\$290,985), Wyoming (\$275,184), New Jersey (\$249,110) and Rhode Island (\$247,742).

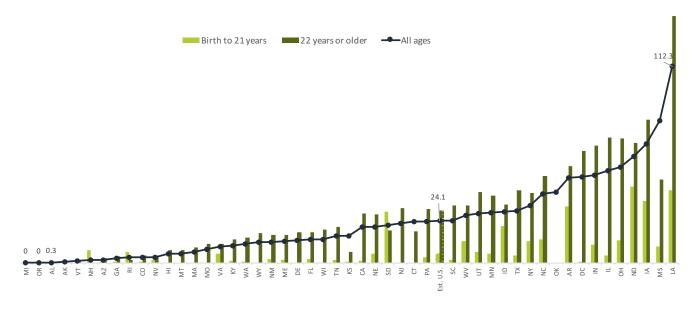
#### **Expenditures per State Resident**

Overall FY 2015 ICF/IID expenditures per state resident averaged \$32.4 and ranged from \$0.2 in Alabama to \$142.4 in the District of Columbia. Expenditures per state resident were also less than \$5.0 in Georgia (\$4.5), Arizona (\$4.0), Alaska (\$3.4), Maryland (\$3.2), and Vermont (\$2.1). Expenditures per state resident were also more than \$90 in North Dakota (92.5), and Iowa (\$91.1).

#### **Expenditures by Age**

Total FY 2015 ICF/IID expenditures were \$538 million for people 21 years or younger and \$9.888 billion for people 22 years or older. Annual per person expenditures averaged \$108,896 for people 21 years or younger and \$136,384 for people 22 years or older (see **Table 2.12**). States with the highest average per person expenditures for people ages birth to 21 years were Alaska (\$370,653), New Hampshire (\$355,657), Washington (\$238,055), and the District of Columbia (\$222,020). States with

**Figure 2.8** Estimated Number of People With IDD Living in an ICF/IID per 100,000 of the Population by State and Age on June 30, 2015





**Table 2.11** ICF/IID Recipients, Expenditures, Expenditure Per Person, and Expenditures Per State Resident by State in Fiscal Year 2015

State	ICF/IID Expenditures	FY 2015 Recipients	Expenditures per FY 2015 Recipient (\$)	State Population (100,000)	Expenditures per State Resident (\$)
N States	50	51	50	51	50
AL	945,886	14	67,563	49	0
AK	2,525,936	6	420,989	7	3
AZ	27,512,500 <sup>s</sup>	131 <sup>s</sup>	210,019 <sup>s</sup>	68	4
AR	178,580,760 <sup>s</sup>	1,444 <sup>s</sup>	123,671 <sup>s</sup>	30	60
CA	695,735,796	7,989	87,087	391	18
СО	40,596,579	174	233,314	55	7
CT	264,688,024	845 <sup>s</sup>	313,240 <sup>s</sup>	36	74
DE	42,611,779	120	355,098	9	45
DC	95,734,207	329	290,985	7	142
FL	334,092,690 <sup>s</sup>	2,742	121,843	203	16
GA	46,292,705 <sup>s</sup>	291 <sup>s</sup>	159,081 <sup>s</sup>	102	5
HI	9,241,744 <sup>s</sup>	76	121,602	14	6
ID	42,634,014	488	87,365	17	26
IL	636,318,364	6,788	93,742	129	49
IN	273,327,092	3,319	82,352	66	41
IA	284,676,738	2,133	133,463	31	91
KS	65,228,609 <sup>s</sup>	450 <sup>s</sup>	144,952 <sup>s</sup>	29	22
KY	140,520,784 <sup>s</sup>	435 <sup>s</sup>	323,036 <sup>s</sup>	44	32
LA	384,087,560	5,247	73,201	47	82
ME	28,972,693	167	173,489	13	22
MD	19,595,815 <sup>s</sup>	107 <sup>s</sup>	183,138 <sup>s</sup>	60	3
MA	DNF	433	DNF	68	DNF
MI	0	0	0	99	0
MN	124,444,235	1,591	78,218	55	23
MS	211,864,398 <sup>s</sup>	2,432	87,115	30	71
MO	85,938,943	473	181,689	61	14
MT	11,852,833	55	215,506	10	11
NE	31,511,391	394	79,978	19	17
NV	17,505,663	98	178,629	29	6
NH	8,891,427 <sup>s</sup>	25	355,657	13	7
NJ	508,433,602 <sup>s</sup>	2,041 <sup>i</sup>	249,110 <sup>i</sup>	90	57
NM	26,285,597 <sup>s</sup>	252 <sup>s</sup>	104,308 <sup>s</sup>	21	13
NY	1,337,718,435	6,502	205,740	198	68
NC	393,260,094 <sup>e</sup>	3,965 <sup>s</sup>	99,183 <sup>s</sup>	100	39
ND	69,985,789 <sup>b</sup>	463 <sup>b</sup>	151,157 <sup>b</sup>	8	92
OH	728,498,096	6,367	114,418	116	63
OK	97,513,437 <sup>s</sup>	1,581	61,678	39	25
OR	97,513,437	0	01,078	40	0
PA	590,834,124	3,024	195,382	128	46
RI	7,927,749 <sup>s</sup>	32 <sup>s</sup>	247,742 <sup>s</sup>	11	8
SC	138,484,390	1,184	116,963	49	28
SD	31,205,012	1,184	166,872	9	36
TN	214,552,400	1,020	210,345	66	33
	1,097,795,812 <sup>d</sup>	8,193 <sup>d</sup>	133,992 <sup>d</sup>		
TX UT				275	40
	72,475,662	841	86,178	30	24
VT	1,347,733	6	224,622	6	2
VA	157,263,686	782	201,104	84	19
WA	183,119,149 <sup>e</sup>	766 506S	239,059	72	26
WV	67,561,689 <sup>s</sup>	506 <sup>s</sup>	133,521 <sup>s</sup>	18	37
WI	141,479,951	787	179,771	58	25
WY	19,262,849	70	275,184	6	33
Reported US Total	9,990,934,421	77,365	129,140	3,214	31
Estimated US Total	10,426,267,298	77,444	134,630	3,214	32

<sup>&</sup>lt;sup>b</sup> Nonstate settings reported, but not state settings. c State settings reported, but not nonstate settings. d Other date (Usually August 31, 2015 or June 30, 2014), e Estimate. i Missing value imputed (RISP estimated). DNF Did not furnish. s U.S. Census Bureau, Population Division (2016) for population; AHCA (2017a) for ICF/IID; Eiken, et al (2017) for Medicaid expenditure data. \*See state notes in Appendix.

**Table 2.12** Total and Average Annual Per Person ICF/IID Expenditures by Age and State in Fiscal Year 2015

	Total Exper	nditures \$	Annual Per	Person \$
Age	Birth to 21 years	22 years +	Birth to 21 years	22 years +
N States	40	40	25	35
AL	0	945,886	N/A	67,563
AK	1,111,959	1,413,977	370,653	471,326
AZ	DNF	DNF	PD	PD
AR	DNF	DNF	PD	PD
CA	6,273,162	689,462,634	41,544	87,964
CO	2,370,144	38,226,435	169,296	238,915
CT	0 <sup>c</sup>	181,364,203 <sup>c</sup>	N/A <sup>c</sup>	387,530 <sup>c</sup>
DE	0	42,611,779	N/A	355,098
DC	222,020	95,712,187	222,020 <sup>d</sup>	291,805 <sup>1</sup>
FL	DNF	DNF	PD	PD
GA	DNF 0	DNF	PD N/A	PD
HI ID	9,043,232	9,241,744 33,590,782	81,471	121,602 <sup>s</sup> 89,100
IL IN	15,373,632 18,612,638	620,944,732 254,714,454	93,742 91,688	93,742 81,744
IA	34,507,087	250,169,651	106,176	138,368
KS	34,307,087 DNF	230,109,031 DNF	PD	PD
KY	DNF	DNF	PD	PD
LA	42,913,215	341,174,345	76,087	72,854
ME	934,976	28,037,717	186,995	173,072
MD	DNF	DNF	PD	PD
MA	DNF	DNF	PD	PD
MI	0	0	N/A	N/A
MN	5,837,347	118,606,888	73,890	78,444
MS	16,596,592	190,860,813	195,254 <sup>c</sup>	191,435 <sup>c</sup>
МО	0	85,938,943	N/A	181,689
MT	0	11,852,833	N/A	215,506
NE	2,479,323	29,032,068	79,978	79,978
NV	1,914,401	15,591,262	159,533	181,294
NH	8,891,427	0	355,657 <sup>s</sup>	N/A
NJ	0	508,433,602	N/A	249,110 <sup>is</sup>
NM	2,112,764	24,172,833	150,912 <sup>is</sup>	101,567 <sup>is</sup>
NY	122,734,572	1,214,983,863	185,120	208,081
NC	DNF	DNF	PD	PD
ND	DNF	DNF	PD	PD
OH	48,242,924	680,255,172	114,049	114,444
OK	0	36,528,359	N/A	N/A
OR	0	0	N/A	N/A
PA	20,809,554	570,024,570	182,540	195,885
RI	DNF	DNF	PD	PD
SC	2,573,190	135,911,200	116,963	116,963
SD	11,940,455	19,264,557	157,111	173,555
TN	5,014,700	209,537,700	143,277 137,611 <sup>d</sup>	212,729 133,810 <sup>d</sup>
TX UT	54,081,104 5,094,415	1,043,714,708 67,381,247	73,832	87,281
VT	5,094,415	1,347,733	73,832 N/A	224,622
VA	17,570,950	139,692,736	144,024	211,656
WA	1,190,274	181,928,875	238,055 <sup>e</sup>	239,066 <sup>e</sup>
WV	7,910,745	59,650,944	136,392 <sup>is</sup>	133,149 <sup>is</sup>
WI	0	141,479,951	N/A	179,771 <sup>e</sup>
WY	0	19,262,849	N/A	275,184
US Estimate	538,185,300	9,888,081,998	108,896	136,384

Note: This table only includes values if the state reported participants and expenditures by age. The US Averages are based only on states that provided complete information for birth to 21 and 22+ years. c State settings reported, but not nonstate settings. d Other date (Usually August 31, 2015 or June 30, 2014). e Estimate. i Missing value imputed (RISP estimated). s Source, AHCA (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.

the highest average annual ICF/IID expenditures per person for people ages 22 years or older were Alaska (\$471,326), Connecticut (\$387,530), Delaware (\$355,098), the District of Colombia (\$291,873), and Wyoming (\$275,184).

#### MEDICAID ICF/IID VERSUS WAIVER

#### **Recipients**

There were 852,408 Medicaid ICF/IID or Waiver recipients with IDD on June 30, 2015. Of those, 91% were Medicaid Waiver recipients while 9% lived in an ICF/IID (See **Table 2.13**). More than 97% of combined Medicaid ICF/IID and Waiver recipients received Medicaid Waiver services in Alabama, Alaska, Arizona, New Hampshire, Oregon, and Vermont (100%); Maryland and Rhode Island (99%); Colorado, Montana, and Wisconsin (98%); and Georgia, Hawaii, Kentucky, Maine, Massachusetts, Missouri, and Wyoming (97%). More than 20% of combined Medicaid ICF/IID and Waiver recipients living in an ICF/IID in Mississippi (51%), Louisiana (30%), Arkansas (26%), Illinois (23%), North Carolina (22%), and Oklahoma (22%).

### **Expenditures**

Combined FY 2015 Medicaid ICF/IID and Medicaid Waiver expenditures totaled \$44.6 billion. Of that total, 77% of expenditures were for Medicaid Waiver recipients and 23% was for ICF/IID recipients. The proportion of Medicaid LTSS expenditures for Waiver recipients ranged from 25% in Mississippi to 100% in Alabama, Michigan, and Oregon. Medicaid Waiver expenditures accounted for 95% or more of combined expenditures in Alabama, Michigan, Oregon (100%); Vermont and Alaska (99%); Maryland (98%); Arizona (97%); and New Hampshire and Rhode Island (96%). Medicaid ICF/IID expenditures accounted for more than 40% of combined expenditures in Mississippi (75%), Texas (47%), Arkansas (47%), Louisiana (45%), and Illinois (43%).

### **Age Differences**

The proportion Medicaid LTSS recipients who were 21 years or younger varied by funding authority and by living arrangement (See **Figure 2.9**). People 21 years or younger were 6% of all ICF/IID recipients



**Table 2.13** Number and Proportion of ICF/IID and Medicaid Waiver Recipients and Expenditures by Funding Authority and State on June 30, 2015

tate -	10tarrer/115	) + Waiver	% of Re	cipients	% of Exp	enditures
tate	Recipients	Expenditures (\$)	Waiver	ICF/IID	Waiver	ICF/IID
l States	51	50	51	51	50	50
\L	5,439	325,046,917	100	0	100	0
K	2,050	170,721,226	100	0	99	1
Z	28,549 <sup>s</sup>	855,029,840 <sup>s</sup>	100	0	97	3
R	5,566 <sup>s</sup>	383,342,408 <sup>s</sup>	74	26	53	47
Α	123,354	3,492,298,499	94	6	80	20
0	10,106	436,064,503	98	2	91	9
T	10,447 <sup>s</sup>	1,143,979,001	92	8	77	23
E	1,161	160,968,851	90	10	74	26
C	1,903	280,561,927	83	17	66	34
L	35,019	1,223,406,489 <sup>s</sup>	92	8	73	27
Α	8,797 <sup>s</sup>	402,298,527 <sup>s</sup>	97	3	88	12
I	2,728	114,643,064 <sup>s</sup>	97	3	92	8
)	8,104	239,536,865	94	6	82	18
	28,929	1,466,075,686	77	23	57	43
J	22,269	880,192,674	85	15	69	31
١	16,665	795,575,555	87	13	64	36
S	9,184 <sup>s</sup>	479,027,743 <sup>s</sup>	95	5	86	14
Υ	15,302 <sup>s</sup>	735,921,256 <sup>s</sup>	97	3	81	19
A	17,289	847,105,801	70	30	55	45
1E	5,006 <sup>e</sup>	329,499,955 <sup>e</sup>	97	3	91	9
ID	14,042 <sup>s</sup>	836,020,133 <sup>s</sup>	99	1	98	2
1A	14,231	PD	97	3	PD	PD
II	45,115 <sup>d</sup>	1,437,648,930 <sup>d</sup>	100	0	100	0
IN	19,907	1,401,334,672	92	8	91	9
1S	4,728	283,237,673 <sup>s</sup>	49	51	25	75
10	13,606	786,362,033	97	3	89	11
IT	2,853	132,474,435	98	2	91	9
E	5,050	196,138,813	92	8	84	16
V	2,039	112,779,120	95	5	84	16
Н	5,260	241,823,241 <sup>s</sup>	100	0	96	4
J	13,013 <sup>ei</sup>	1,385,373,684 <sup>s</sup>	84	16	63	37
М	4,483 <sup>s</sup>	216,164,349 <sup>s</sup>	94	6	88	12
Υ	90,241	6,442,393,319	93	7	79	21
С	17,631 <sup>es</sup>	1,082,458,141 <sup>e</sup>	78	22	64	36
ID	5,076	250,673,497	91	9	72	28
Н	41,612	2,162,660,183	85	15	66	34
K	7,158	410,154,067 <sup>s</sup>	78	22	76	24
R	6,932	51,810,862	100	0	100	0
A	35,652	2,899,445,354	92	8	80	20
<u> </u>	3,686 <sup>s</sup>	201,300,474 <sup>s</sup>	99	1	96	4
C	10,775	419,750,337	89	11	67	33
D	3,779	144,394,609	95	5	78	22
N	8,898	883,800,400	89	11	76	24
X	42,816 <sup>d</sup>	2,338,006,892 <sup>d</sup>	81	19	53	47
<u>T</u>	6,082	264,594,009	86	14	73	27
Т	2,923	166,659,679	100	0	99	1
A	13,204	884,416,754	94	6	82	18
/A	13,658	905,245,003 <sup>e</sup>	94	6	80	20
N	5,585 <sup>ds</sup>	426,433,214 <sup>d</sup>	91	9	84	16
VI	32,247 <sup>d</sup>	1,182,747,438 <sup>d</sup>	98	2	88	12
/Y	2,180	108,736,371	97	3	82	18
		44,611,123,475	91	9	77	23

<sup>&</sup>lt;sup>d</sup> Other date (Usually August 31, 2015 or June 30, 2014). <sup>e</sup> Estimate. DNF Did not furnish. s Source AHCA (2017a) for ICF/IID; Eiken, et al (2017) for Medicaid expenditure data. \* See state notes in Appendix.

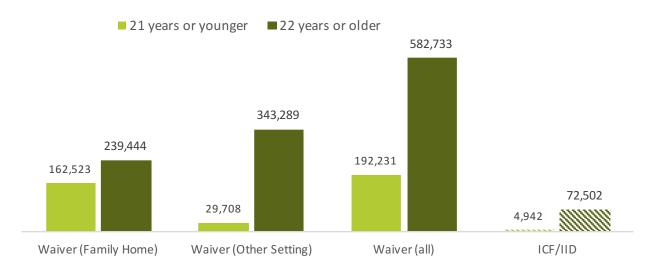
and 25% of all Medicaid Waiver recipients. They were 40% of those living in the home of a family member and 8% of those living in any other setting. More people 21 years or younger received Medicaid Waiver funded services while living in the home of a family member than lived in other Waiver-funded settings or in an ICF/IID. While there were more Medicaid Waiver recipients 22 years or older than there were people 21 years or younger living in the home of a family member, the majority of Medicaid

LTSS 22 years or older lived in non-family settings while receiving Medicaid Wavier funding.

#### **Per Person Expenditure Differences**

Average annual per person Medicaid expenditures varied by age, funding authority and living arrangement (See **Figure 2.10**). FY 2015 expenditures were lower for people 21 years or younger than for people 22 years or older for

**Figure 2.9** Estimated Number of Medicaid LTSS Recipients with IDD by Age, Funding Authority and Living Arrangement on June 30, 2015



**Figure 2.10** Estimated Average Annual Per Person Medicaid Expenditures by Age, Funding Authority and Living Arrangement in FY 2015



Other settings include Foster Family, Own Home, Group Home and Other. Note: Missing data for ICF/IID in AZ, FL, GA, MD, MA, NM, OK.



both Medicaid ICF/IID settings (\$108,896 versus \$136,384) and for Medicaid Waiver-funded services overall (\$18,009 versus \$52,722). Average annual expenditures for Medicaid Waiver recipients 21 years or younger were lower than for recipients 22 years or older regardless of whether they lived in the home of a family member (\$15,221 versus \$41,377) or in another Waiver funded setting (\$69,296 versus \$101,240). Expenditures are lower for people 21 years or younger in part because people 22 and older are no longer eligible for publicly funded educational services under the Individuals with Disabilities Education Act.

Average annual per person costs for Medicaid ICF/IID services were 6.05 times higher than for Medicaid Waiver services for recipients 21 years or younger (\$108,896 versus \$18,009) and 2.59 times higher for recipients 22 years or older (\$136,384 versus \$108,896). Expenditures are lower for Waiver recipients in part because the Medicaid Waiver does not fund room and board costs. However, the

differences are much larger than can be explained by whether room and board expenses are bundled in.

#### **Medicaid Benefit Ratios**

#### **Federal Medicaid Expenditures**

Federal expenditures for Medicaid Waiver and ICF/ IID services for people with IDD were estimated by multiplying total Medicaid expenditures for a state by the state's Federal Medicaid Assistance Percentage (FMAP). The average 2015 FMAP was 55% (ranging from the lowest possible value of 50% in 13 states to 74% in Mississippi). Combined Medicaid ICF/IID and Waiver expenditures for people with IDD in FY 2015 were an estimated \$44.6 billion, of which an estimated \$24.3 billion was federally funded. The federal government paid an estimated \$19.2 billion (56%) of the total \$34.8 billion in Medicaid Waiver expenditures with the rest (\$15.0 billion) paid by states (See **Table 2.14**). Similarly, an estimated \$5.7 billion (55%) of the \$10.4 billion

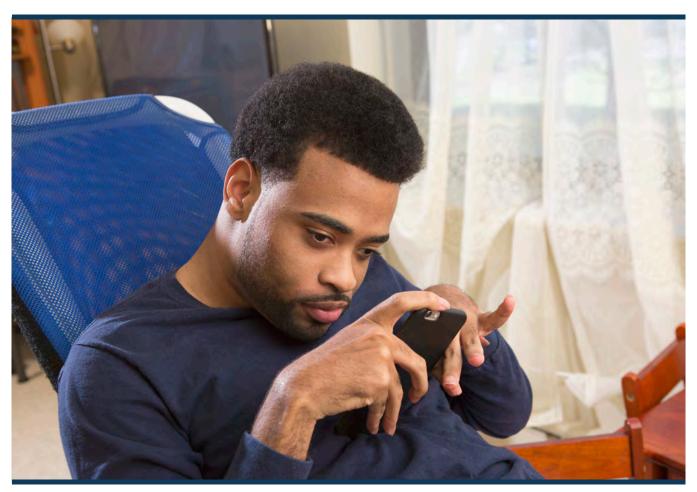


Table 2.14 Total and Federal Medicaid Waiver and ICF/IID Expenditures, Federal Cost Share and Proportion of Expenditures, Federal Income Taxes and Medicaid Benefit Ratios by State for Fiscal Year 2015

, ,	Total	Total FY 2015 Expenditures		Federal Cost	Federal Shar	Federal Share of Total Expenditures (\$)	tures (\$)	Propor	Proportion of Total Federal Expenditures	al Federal res	Federal Inco	Federal Income Tax Paid	State Medicaid
7	Waiver (\$)	ICF/IID (\$)	Combined	Share . (%) ¹	Waiver	ICF/IID	Combined	Waiver	ICF/IID	Combined	Billions (\$)	Percent (%)	Benefit Ratio <sup>2</sup>
AL	324,101,031	945,886	325,046,917	69	223,597,301	652,567	224,249,868	1.16	0.01	0.92	23.2	0.83	1.11
AK	168,195,290	2,525,936	170,721,226	20	84,097,645	1,262,968	85,360,613	0.44	0.02	0.35	5.5	0.20	1.80
AZ	827,517,340	27,512,500 <sup>s</sup>	855,029,840	89	566,518,371	18,835,058	585,353,428	2.95	0.33	2.41	37.0	1.32	1.82
AR	204,761,648	178,580,760 <sup>s</sup>	383,342,408	71	145,135,056	126,578,043	271,713,099	0.76	2.22	1.12	24.0	0.86	1.30
S C	2,796,562,703	962,735,796	3,492,298,499	20	1,398,281,352	347,867,898	1,746,149,250	7.28	6.11	7.18	345.8	12.35	0.58
0	395,467,924	40,596,579	436,064,503	51	201,728,188	20,708,315	222,436,503	1.05	0.36	0.91	48.1	1.72	0.53
b	879,290,977	264,688,024	1,143,979,001	20	439,645,488	132,344,012	571,989,500	2.29	2.32	2.35	49.2	1.76	1.34
DE	118,357,072	42,611,779	160,968,851	54	63,474,898	22,852,697	86,327,595	0.33	0.40	0.35	13.2	0.47	0.75
DC	184,827,720	95,734,207	280,561,927	70	129,379,404	67,013,945	196,393,349	0.67	1.18	0.81	21.2	0.76	1.06
F	889,313,799	334,092,690 <sup>s</sup>	1,223,406,489	09	531,098,201	199,520,154	730,618,355	2.76	3.50	3.00	163.2	5.83	0.52
GA	356,005,822	46,292,705 <sup>s</sup>	402,298,527	29	238,310,297	30,988,337	269,298,634	1.24	0.54	1.11	70.1	2.50	0.44
Ī	105,401,320	9,241,744 <sup>s</sup>	114,643,064	52	55,051,109	4,826,963	59,878,072	0.29	0.08	0.25	7.5	0.27	0.92
Ω	196,902,851	42,634,014	239,536,865	72	141,277,796	30,589,905	171,867,701	0.74	0.54	0.71	9.4	0.34	2.11
-	829,757,322	636,318,364	1,466,075,686	51	421,184,817	322,995,202	744,180,018	2.19	2.67	3.06	132.6	4.74	0.65
Z	606,865,582	273,327,092	880,192,674	29	403,686,985	181,817,182	585,504,167	2.10	3.19	2.41	20.8	1.81	1.33
Δ	510,898,817	284,676,738	795,575,555	26	283,753,203	158,109,460	441,862,663	1.48	2.78	1.82	21.6	0.77	2.36
KS	413,799,134	65,228,609 <sup>s</sup>	479,027,743	57	234,334,450	36,938,961	271,273,411	1.22	0.65	1.11	23.3	0.83	1.34
Κ	595,400,472	140,520,784 <sup>s</sup>	735,921,256	70	416,423,090	98,280,236	514,703,326	2.17	1.73	2.12	28.8	1.03	2.06
LA	463,018,241	384,087,560	847,105,801	62	287,302,819	238,326,331	525,629,150	1.50	4.18	2.16	40.7	1.45	1.49
ME	300,527,262 <sup>e</sup>	28,972,693	329,499,955	62	185,966,270	17,928,302	203,894,572	0.97	0.31	0.84	6.9	0.25	3.38
MD	816,424,318	19,595,815 <sup>s</sup>	836,020,133	20	408,212,159	806'262'6	418,010,067	2.12	0.17	1.72	29.6	2.13	0.81
MA	1,159,456,123 <sup>s</sup>	DNF	PD	20	579,728,062	DNF	PD	3.02	DNF	PD	97.2	3.47	PD
ĪΣ	1,437,648,930 <sup>d</sup>	0	1,437,648,930	99	942,235,109	0	942,235,109	4.90	0.00	3.87	70.3	2.51	1.54
Z	1,276,890,437	124,444,235	1,401,334,672	20	638,445,219	62,222,118	700,667,336	3.32	1.09	2.88	79.3	2.83	1.02
MS	71,373,275	211,864,398 <sup>s</sup>	283,237,673	74	52,516,456	155,889,824	208,406,280	0.27	2.74	0.86	10.5	0.38	2.28
МО	700,423,090	85,938,943	786,362,033	63	444,418,451	54,528,259	498,946,710	2.31	0.96	2.05	54.1	1.93	1.06
MT	120,621,602	11,852,833	132,474,435	99	79,489,636	7,811,017	87,300,653	0.41	0.14	0.36	5.5	0.20	1.81
NE E	164,627,422	31,511,391	196,138,813	53	82,697,028	16,786,118	104,483,146	0.46	0.29	0.43	18.0	0.64	0.67
>2	95,273,457	17,505,663	112,779,120	64	61,317,997	11,266,645	72,584,642	0.32	0.20	0:30	17.3	0.62	0.48
I	232,931,814	8,891,427 <sup>s</sup>	241,823,241	20	116,465,907	4,445,714	120,911,621	0.61	0.08	0.50	10.7	0.38	1.29
Z	876,940,082	508,433,602 <sup>s</sup>	1,385,373,684	20	438,470,041	254,216,801	692,686,842			2.85	114.8	4.10	69.0
ΣZ	189,878,752	26,285,597 <sup>s</sup>	216,164,349	70	132,250,551	18,307,918	150,558,469		0.32	0.62	8.5	0.30	2.03
Σ	5,104,674,884	1,337,718,435	6,442,393,319	20	2,552,337,442	668,859,218	3,221,196,660	13.28	11.74	13.24	233.9	8.35	1.58
NC	689,198,047 <sup>e</sup>	393,260,094 <sup>e</sup>	1,082,458,141	99	454,043,673	259,079,750	713,123,424	2.36	4.55	2.93	67.3	2.40	1.22
ND	180,687,708	69,985,789 <sup>b</sup>	250,673,497	20	90,343,854	34,992,895	125,336,749	0.47	0.61	0.52	7.3	0.26	1.99
ОН	1,434,162,087	728,498,096	2,162,660,183	63	898,359,131	456,331,207	1,354,690,339	4.67	8.01	5.57	121.4	4.33	1.28
OK	312,640,630	97,513,437 <sup>s</sup>	410,154,067	62	194,775,112	60,750,871	255,525,984	1.01	1.07	1.05	25.6	0.91	1.15
OR	51,810,862	0	51,810,862	64	33,190,038	0	33,190,038	0.17	0.00	0.14	28.2	1.01	0.14
PA	2,308,611,230	590,834,124	2,899,445,354	52	1,196,322,339	306,170,243	1,502,492,582		5.37	6.17	115.3	4.12	1.50
RI	193,372,725	7,927,749 <sup>s</sup>	201,300,474	20	96,686,363	3,963,875	100,650,237	0.50	0.07	0.41	10.7	0.38	1.09
SC	281,265,947	138,484,390	419,750,337	71	198,686,265	97,825,373	296,511,638	1.03	1.72	1.22	21.9	0.78	1.56



**Table 2.14** Total and Federal Medicaid Waiver and ICF/IID Expenditures, Federal Cost Share and Proportion of Expenditures, Federal Income Taxes and Medicaid Benefit Ratios by State for Fiscal Year 2015

State	Total	Total FY 2015 Expenditures		Federal Cost	Federal Sha	Federal Share of Total Expenditures (\$)	litures (\$)	Proporti	Proportion of Total Federal Expenditures	1	Federal Income Tax Paid	e Tax Paid	State Medicaid
	Waiver (\$)	ICF/IID (\$)	Combined	Share (%)	Waiver	ICF/IID	Combined	Waiver	ICE/IID (	Waiver ICF/IID Combined	Billions (\$) Percent (%)	ercent (%)	Benefit Ratio <sup>2</sup>
SD	113,189,597	31,205,012	144,394,609	52	58,451,108	16,114,268	74,565,376	0.30	0.28	0.31	7.1	0.25	1.21
Z F	669,248,000	214,552,400	883,800,400	65	434,944,275	139,437,605	574,381,880	2.26	2.45	2.36	54.1	1.93	1.22
X	1,240,211,080 <sup>d</sup>	1,097,795,812 <sup>d</sup>	2,338,006,892	28	719,942,532	637,270,469	1,357,213,001	3.75	11.19	5.58	226.9	8.10	0.69
T	192,118,347	72,475,662	264,594,009	71	135,558,706	51,138,827	186,697,533	0.71	06:0	0.77	18.1	0.65	1.19
ΛŢ	165,311,946	1,347,733	166,659,679	54	89,284,982	727,911	90,012,893	0.46	0.01	0.37	4.1	0.15	2.53
۸A	727,153,068	157,263,686	884,416,754	20	363,576,534	78,631,843	442,208,377	1.89	1.38	1.82	67.8	2.42	0.75
WA	722,125,854 <sup>e</sup>	183,119,149 <sup>e</sup>	905,245,003	20	361,279,565	91,614,510	452,894,075	1.88	1.61	1.86	65.6	2.34	08.0
AW	358,871,525 <sup>s</sup>	67,561,6898	426,433,214	71	256,054,833	48,205,265	304,260,098	1.33	0.85	1.25	6.9	0.25	5.08
M	1,041,267,487	141,479,951	1,182,747,438	28	606,746,565	82,440,367	689,186,932	3.16	1.45	2.83	45.2	1.61	1.75
ΜY	89,473,522	19,262,849	108,736,371	20	44,736,761	9,631,425	54,368,186	0.23	0.17	0.22	4.9	0.17	1.29
Estimated US Total	34,184,856,176	10,426,267,298	44,611,123,475	55	19,216,813,431	5,696,894,778	24,333,980,147 100.00 100.00 100.00	100.00	100.00	100.00	2,800.2	100.00	1.00

Nonstate settings reported, but not state settings. d Other date (Usually August 31, 2015 or June 30, 2014). e Estimate. DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals.
 Source: Internal Revenue Service (2016).\* See state notes in the Appendix. 1 FY 2015 Standard Medicaid Mesicand Percentage, Source: Internal Revenue Service (2016).\* See state notes in the Appendix. 1 FY 2015 Standard Medicaid Mesicand Percentage, Source: Internal Revenue Service (2016).\* See state notes in the proportion of the total federal income tax paid by the state. A value and Waiver expenditures for the state. A value indicates that the state receives a higher proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the state receives a higher proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures than the proportion of Federal Medicaid ICF/IID and Waiver expenditures that the state receives a higher proportion of Federal Medicaid ICF/IID and Waiver expenditures.

in ICF/IID expenditures in FY 2015 were paid by the federal government, with the rest (\$4.7 billion) paid by states.

#### **Proportion of Federal Expenditures by State**

The largest states by population were California (39.1 million people), Texas (27.5 million), Florida (20.1 million), New York (19.8 million) and Illinois (12.8 million). The proportion of FY 2015 Federal Medicaid expenditures for Waiver and ICF/IID recipients with IDD varied by state. States receiving the largest proportion of the \$19.2 billion in Federal Medicaid Waiver expenditures were New York (13.2%), California (7.3%), Pennsylvania (6.2%), Michigan (4.9%), and Ohio (4.7%). States receiving the largest proportion of the \$5.7 billion in Federal Medicaid ICF/IID expenditures were New York (11.7%), Texas (11.2%), Ohio (8.0%), California (6.1%), and Illinois (5.7%). States receiving the largest proportion of the \$24.3 billion in combined Federal Medicaid ICF/IID and Waiver expenditures were New York (13.2%), California (7.2%), Pennsylvania (6.2%), Texas (5.6%) and Ohio (5.6%).

#### **Federal Income Tax Paid**

State contributions to the federal budget were measured by federal income taxes paid. In FY 2015, the Federal Government took in \$2.8 trillion in federal income taxes from the states. States contributing the largest share of those taxes were California (12.4%), New York (8.4%), Texas (8.1%), Florida (5.8%), and Illinois (4.7%).

#### **State Medicaid Benefit Ratios**

"State Medicaid Benefit Ratios" compare the proportion of total Federal Medicaid ICF/IID and Waiver expenditures for the state with the proportion of all federal income taxes paid by the state. A state Medicaid Benefit Ratio of 1.0 indicates that the proportion of Federal Medicaid ICF/IID plus Waiver expenditures for recipients in a state is equal to the proportion of federal income taxes paid by the state. A ratio higher than 1.0 indicates that the state received a higher proportion of Federal Medicaid expenditures for people with IDD than the proportion it paid of total federal income taxes. A ratio of less than 1.0 indicates that the state received a lower proportion of all Federal

#### 2015

Medicaid expenditures for people with IDD than the proportion it paid of total federal income taxes.

For 2015, state Medicaid Benefit Ratios ranged from 0.14 to 5.08. Thirty-five states had ratios of 1.0 or

higher, 15 states had ratios of less than 1.0 and 1 state did not have sufficient data to compute the ratio. States with the lowest ratios were Oregon, (0.14), Georgia (0.44), Nevada (0.48), Florida (0.52), Colorado (0.53), and California (0.58). States with

Medicaid Benefit Ratios of 2.0 or higher were West Virginia (5.08), Maine (3.38), Vermont (2.53), Iowa (2.36), Mississippi (2.28), and Idaho (2.11). ■

#### **State Medicaid Benefit Ratios Example**

With a population of 39.1 million, California was the most populous state in the United States. Total 2015 Medicaid ICF/IID plus Waiver expenditures for 123,354 recipients with IDD in California were \$3.49 billion (\$695 million for ICF/IID recipients and \$2.79 billion for Medicaid Waiver recipients). With a federal Medicaid cost share percentage of 50%, the state of California and the federal Medicaid program each paid half of total Medicaid expenditures (\$1.4 billion for Medicaid Waiver recipients and \$347 million for ICF/IID recipients). Total federal 2015 income taxes paid by California were \$345.8 billion.

#### In 2015 California

- Was home to 12.2% of the population of the United States and served 14.5% of total Medicaid ICF/IID plus Waiver recipients with IDD (14.9% of Medicaid Waiver recipients, 10.5% of ICF/IID residents)
- Paid 7.18% of total Medicaid ICF/IID plus Waiver expenditures for people with IDD (7.28% of Medicaid Waiver expenditures, 6.11% of ICF/IID expenditures)
- Paid 12.35% of all federal income taxes

California's State Medicaid Benefit Ratio was 0.58 (higher than only 5 other states). It paid a higher proportion of federal income taxes than the proportion of all Medicaid ICF/IID and Waiver expenditures for people with IDD the federal government paid for recipients in California.



### A SHORT HISTORY OF LTSS FOR PEOPLE WITH IDD

Most people with IDD in the United States live with family members throughout their lives and get needed supports from family, friends or neighbors. A minority live in non-family settings of different types and sizes. For more than 100 years, most of the people with IDD in the United States who received publicly funded long-term supports and services lived in state-operated facilities shared by 16 or more people with IDD. The world of LTSS for people with IDD (both those living with family members and those receiving supports in other settings) has been radically transformed over the last 140 years. This section summarizes some of the key milestones marking that transformation.

The 1880 US Census enumerated 76,895 people with IDD of whom 9,725 (13%) lived in institutions, almshouses, or prisons. By 1903, 96.8% of the 15,511 people with IDD living in institutions lived in a state-operated facility. The number of people living in state-operated IDD facilities increased 10 fold between 1903 and 1946 to 115,928. The number doubled again between during the baby boom between 1946 and 1964 to all time high of 228,500 in 1967.

Despite their widespread use, by the 1950s families, parent associations, professionals, and policy makers protested that large state-operated IDD institutions

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

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

Against this backdrop, professionals argued that segregating and institutionalizing people based on disability enhanced negative stereotypes and was dehumanizing. Wolf Wolfensberger, Bengt Nirje, and others articulated a Normalization Principle, which argued that people with IDD should not be segregated in institutions (e.g., Kugle



& Wolfensberger, 1969). Instead, they should be supported to live, play, work, and learn in culturally normative physically and socially inclusive settings regardless of the type or severity of a person's disability. This meant:

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

Lawsuits and subsequent settlement agreements challenging the quality of care in institutions, seeking improved conditions as well as access to community alternatives, were filed in the 1970s in several states including Pennsylvania (PARC v. Commonwealth of Pennsylvania, 1972); New York (ARC v. Rockefeller, 1972); Alabama (Wyatt v. Stickney, 1971) and Minnesota (Welsch v. Likins, 1972).

Legislative action during the 1960's and 1970's propelled a movement to deinstitutionalize services for people with IDD.

#### THE MEDICAID PROGRAM

Before 1965, there was no federal funding for LTSS for persons with IDD. In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. Medicaid is a state-federal partnership in which the federal government covers at least half of the

eligible service costs for eligible recipients. Initially, Medicaid funded long-term medical supports for qualified people living in Skilled Nursing Facilities (SNF). Many state-operated facilities were converted to Medicaid SNFs and the number of people in Medicaid certified facilities increased rapidly. However, federal officials grew concerned that some people in SNFs were receiving more and more costly medical care than they needed. There were particular concerns that the services offered in SNFs were not a good match for children and adults with IDD (e.g., The Arc of the United States 1975).

# INTERMEDIATE CARE FACILITIES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

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

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



invested in facility improvements to meet ICF/IID standards (Gettings & Mitchell, 1980).

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

Many states began to reduce the number of children living in state IDD facilities to reduce overcrowding as required by the ICF/IID standards, and to respond to the new educational requirements of PL 94-142. The proportion of state IDD facility residents ages 21 years or younger peaked in 1965 at 49% (91,592 of 187,305 residents; NIMH, 1966). RISP data show that by 1977, the proportion of state IDD facility residents who were children had dropped to 36% (54,098 of 151,532), and by 1987 the proportion was 13% (12,310 of 94,695). The proportion declined to 5% in 1998 and was 3.5% in 2015.

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

These criticisms and the growing desire to increase access to federal matching funds for

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

#### **Community ICF/IID Group Homes**

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

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

In 1981, the Health Care Financing Administration (HCFA), now the Centers for Medicare and Medicaid Services (CMS), issued "Interpretive Guidelines" for certifying ICF/IIDs of four to fifteen people. Following the publication of the guidelines, substantially more states began to develop ICF/IIDs of that size. 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 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 would remain in, or be at a risk of placement in a Medicaid funded institution (i.e., a Skilled Nursing Facility, an Institution for Mental Disease for people 21 or younger and 65 or older, or an ICF/IID).

Regulations for the 1915(c) HCBSs 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 the Medicaid eligible populations to be served and specific services that would be included such as homemaker, home health aide, personal care, adult day services, day and residential habilitation, and respite care (www.Medicaid. gov, 2016). Although not allowed to use HCBS reimbursements to pay for room and board, all states provide residential support services under categories such as personal care, residential habilitation, and in-home supports. HCBS recipients with IDD use their own resources, usually cash assistance from other Social Security Act programs and state supplements to cover room and board costs.

Today, while some Medicaid Waiver recipients live in group homes or in host/foster family homes, most live in a home they own or lease or with family members. Given their flexibility and potential for promoting individualized services, the Medicaid Waiver authorities have become the primary source of funding community based LTSS.

# BALANCING MEDICAID HOME AND COMMUNITY-BASED SERVICES AND INSTITUTIONAL SERVICES

Medicaid LTSS expenditures for people with IDD living in home and community based settings first exceeded expenditures for institutional services in 2001. However, it was not until 2013 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). Several recent Medicaid reforms and initiatives have supported the shift from institutional to community based LTSS.

#### 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).

#### AMERICANS WITH DISABILITIES ACT AND THE 1999 US SUPREME COURT'S OLMSTEAD DECISION

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 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.



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

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

The US Department of Justice (DOJ) has monitored states to ensure compliance with the provisions of the Olmstead Decision. Its website chronicles nearly two decades of Olmstead enforcement briefs, complaints, letters of findings and settlement agreements.

## EXPANSION OF MEDICAID WAIVER FUNDING AUTHORITIES

Since 1999, CMS has added several additional Medicaid Waiver authorities, regulations, and interpretive guidelines allowing states to expand the use of Medicaid-funded community services to reduce the need for institutional services. Many states now operate two or more HCBS programs. In October 2017, the Medicaid website www.medicaid. gov/medicaid/hcbs/authorities/index.html listed 294 approved Section 1915(c) Home and Community Based Waivers.

#### SUPPORTS FOR FAMILIES

While the Medicaid program initially funded LTSS in only institutional settings, funding options for people with IDD living in the homes of family members have expanded in recent years. 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. 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 added several funding authorities, such as Medicaid State Plan or Waiver options, to better accommodate services provided to people living with family members or in their own homes.

#### Money Follows the Person

The Money Follows the Person (MFP) initiative authorized in the Deficit Reduction Act of 2005, and expanded through the Affordable Care Act, is a federal demonstration program designed to help states reduce their use of institutional care while expanding options for people to receive care in the community. The legislation provided a system of flexible and augmented financing to assist states in moving people to smaller, more integrated, appropriate, and preferred settings.

MFP is the largest demonstration program in the history of Medicaid designed to transform LTSS. MFP grants enabled states to develop systems and services to help long-term residents of nursing facilities, ICF/IIDs, and Institutions for Mental Disease (i.e., psychiatric hospitals) to move to home or community-based settings. The program began in 2007, and by December 2015, it had supported more than 63,300 people with disabilities to move from institutions to community residences. The program was expanded through provisions of the Affordable Care Act, and as of August 2017, 43 states and the

District of Columbia were participating (Medicaid.gov, August 21, 2017).

#### **BALANCING INCENTIVE PAYMENT**

The Balancing Incentive Payments program offers federal funding for a higher proportion of LTSS expenditures when services are provided in community-based settings. The BIP program also provides extensive technical assistance to states to support transition from institutional to community based service models.

## Managed Long-Term Services and Supports

Since 2000, an increasing number of states have opted to use a capitated managed care model as an alternative to fee-for-service financing to manage Medicaid LTSS. Section 1115 Research and Demonstration Projects allow states the flexibility to test new or existing approaches for financing and delivering Medicaid services, including the option to provide home and community-based services through a managed care entity. Similarly, states can amend their Medicaid State Plan under the 1932(a) federal authority to implement a managed care delivery system. Section 1915(a) and (b) Managed Care authorities also allow states to use managed care delivery systems. A hybrid program (concurrent 1915(c) and 1915(b) waivers – also referred to as 1915(b)/(c) waivers) allows states to implement two types of waivers at the same time as long as all federal requirements were met for both programs.

Developed in the private healthcare sector, managed care models and operational strategies are designed to reduce the costs of care while simultaneously improving accessibility, quality, and outcomes at both the individual and systems-levels by shifting risk away from state agencies to private managed care companies. While states must administer publicly financed services in the most cost effective manner possible, some people are concerned. Managed care contracting and operational strategies for LTSS furnished to people with IDD and other disabilities could decrease access to care, narrow the scope of services, and divert funds that could

be used to address waiting lists and unmet service needs to cover expanded administrative activities.

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

Many states see managed care as a way to gain additional control over the costs of LTSS delivery. According to NASUAD, in 2011, the vast majority of Medicaid recipients (74.2%) across all states and all eligible population groups received at least some of their Medicaid funded services through managed care arrangements. Managed care models for LTSS for people with IDD exist in Arizona, California, Kansas, Michigan, New York, North Carolina, Texas, Vermont, and Wisconsin. Florida, Georgia, Hawaii, Illinois, Kentucky, Louisiana, Minnesota, New Jersey, and Rhode Island plan to move to managed LTSS for people with IDD in the near future (NASUAD, 2015).

#### SELF-DIRECTED SERVICES

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



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

# Key Milestones in the Development of Long-Term Supports and Services for People with IDD in the United States

- 1965 Medicaid Program. While not focusing specifically on the needs of people with IDD as it was a general anti-poverty program, is fundamental to later policy changes as a payment source for new funding programs.
- 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 Individuals with Disabilities Education Act. In 1976 PL 94-142 was enacted requiring 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 Medicaidreimbursed 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 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.

2014 Medicaid Home and Community Based Services (HCBS) Rule. In 2014, the Centers for Medicare and Medicaid Services promulgated new rules that strengthen the requirements for integration, autonomy, choice and control, and person-centered services for Waiver recipients. States have until 2022 to implement transition plans to bring all HCBS funded service settings into compliance with the rule. ■





#### **SECTION THREE**

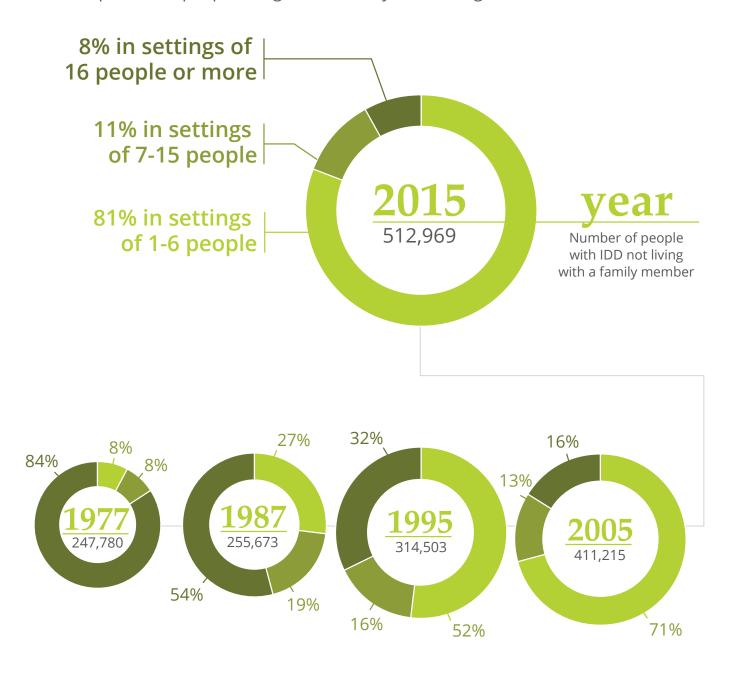
# Historical Perspectives and Trends through 2015 in Long-Term Supports and Services

**FY 2015** 



# Change in the Total Number of People in Non-Family IDD Settings and Proportion in Settings of Different Sizes Between 1977 and 2015

Proportion of people living in non-family IDD settings



#### Section 3: Historical Perspectives and Trends through 2015

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

# Trends in Living Arrangements 1998 through 2015

The RISP longitudinal study has collected detailed information about people living in the home of a family member, in their own home or in a host/foster family home since 1998. Between 1998 and 2015, there were dramatic changes in the number of service recipients with IDD living in those settings. For example, the number living in their own home more than doubled from 62,669 in 1998 to 134,719 in 2015.

Of the LTSS recipients with IDD who lived in the home of a family member in 1998, 24.9% received Medicaid Waiver-funded supports. By 2015, the proportion was 60%. The number receiving Medicaid Waiver-funded supports increased four-fold from

80,799 in 1998 to 409,778 in 2015 and was larger than the number receiving supports from other sources by 2012. The number of people with IDD living with a family member receiving supports funded by a non-Medicaid program increased from 244,851 in 1998 to a peak of 344,756 in 2006 but has since declined to 288,788.

Between 1998 and 2015, the number of LTSS recipients with IDD living in settings other than their own home or the home of a family member increased 33% from 305,372 to 405,134 people. The number of people with IDD living in non-family settings other than their own home varied by setting size. Between 1998 and 2015, the number of people in settings of:

- 3 or fewer people increased 141% from 63,279 to 152,417 people,
- 4 to 6 people increased 72% from 73,658 to 126,603 people,
- 7 to 15 people increased 4% from 53,940 to 56,292) people, and
- 16 or more people declined -39% from 114,495 to 69,822.

The proportion living in non-family settings other than their own home who lived in settings of six or fewer people increased from 45% in 1998 to 69% in 2015.

Studies examining service outcomes for LTSS recipients with IDD have found that size and type of living arrangement are significant predictors of outcomes such as everyday choice, use of preventative health care, and expenditures (e.g., Bershadsky, et. al., 2012; Lakin, et. al., 2008; Ticha, et. al., 2012). People in settings of three or fewer people generally had better outcomes than those living in larger settings. In 37 of 43 studies tracking outcomes for people moving from an institutional setting of 16 or more people to a community setting of 6 or fewer people, adaptive behavior (daily living skills) of people who moved improved compared to people who remained in institutions (Larson, Lakin & Hill, 2012).

The size of the places in which LTSS recipients with IDD live continues to decline. People with IDD are increasingly living with family, in their own homes or in very small group settings. As the



2014 Medicaid HCBS rule is implemented, we can expect this trend to continue.

## Non-family IDD Settings Between 1977 and 2015

**Table 3.1** and **Figure 3.2** show changes in the sizes and type of non-family settings in which LTSS recipients with IDD live since 1977. Non-family IDD settings include own home, host/foster family home, group homes (including ICF/IID), and "other" group settings. They do not include nursing homes or psychiatric facilities except in the few states that counted people in those settings as living in "other" group settings. They do include state-operated IDD units located in state nursing homes or psychiatric facilities.

Between 1977 and 2015, the total number of nonfamily settings in which people with IDD lived with

 1 to 6 people increased nearly 32 fold from 6,898 to 222,129 settings,

- 7 to 15 people increased 6.5 times from 2,405 to 7,036 settings, and
- 16 or more people decreased 54% from 1,705 to 926 settings.

In 1977, 65% of 10,543 nonstate-operated settings, and 9% of 465 state-operated settings served six or fewer people. By 2015, 97% of 228,001 nonstate-operated settings, and 59% of 2,091 state-operated settings served 6 or fewer people.

There were 3.5 times more state-operated IDD settings in 2015 (2,091 settings) than in 1977 (465 settings). Between 1977 and 2015, the number of state IDD settings of

- 1 to 6 people increased 27.6 times from 43 to 1,231 settings,
- 7 to 15 people increased 6.5 times from 95 to 709 settings, and
- 16 or more people decreased 54% from 327 to 151 settings.

There were 21.6 times more nonstate IDD settings in 2015 (228,001) than in 1977 (10,543). Between 1977 and 2015, the number of nonstate IDD settings of

**Table 3.1** Estimated Number of Non-Family IDD Residences by Type of Operation and Setting Size on June 30 of Selected Years 1977 to 2015

						Nur	mber of I	Residentia	al Setting	gs					
		Nonsta	ate				Stat	te					Total		_
Size	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6
1977	6,855	2,310	1,378	10,543	65%	43	95	327	465	9%	6,898	2,405	1,705	11,008	63%
1982	10,073	3,181	1,370	14,624	69%	182	426	349	957	19%	10,255	3,607	1,719	15,581	66%
1987	26,475	4,713	1,370	32,558	81%	189	443	287	919	21%	26,664	5,156	1,657	33,477	80%
1992	41,444	5,158	1,320	47,922	86%	382	852	323	1,557	25%	41,826	6,010	1,643	49,479	85%
1997	87,917	5,578	1,040	94,535	93%	1,047	702	246	1,995	52%	88,964	6,280	1,286	96,530	92%
2002	116,189	5,880	1,026	123,095	94%	1,634	713	233	2,580	63%	117,823	6,593	1,259	125,675	94%
2003	135,700	6,320	849	142,869	95%	1,707	771	234	2,712	63%	137,407	7,091	1,083	145,581	94%
2004	139,963	5,173	831	145,967	96%	1,621	703	229	2,553	63%	141,584	5,876	1,060	148,520	95%
2005	144,084	4,987	782	149,853	96%	1,542	718	209	2,469	62%	145,626	5,705	991	152,322	96%
2006	149,114	6,436	849	156,399	95%	1,506	737	201	2,444	62%	150,620	7,173	1,050	158,843	95%
2007	158,365	6,092	784	165,241	96%	1,683	733	217	2,633	64%	160,048	6,825	1,001	167,874	95%
2008	161,830	6,214	791	168,835	96%	1,628	734	215	2,577	63%	163,458	6,948	1,006	171,412	95%
2009	164,379	5,659	764	170,802	96%	1,637	732	205	2,574	64%	165,682	6,391	969	173,042	96%
2010	176,596	7,086	833	184,516	96%	1,501	692	203	2,396	63%	178,097	7,778	1,036	186,912	95%
2011	191,457	5,259	885	197,601	97%	1,485	701	200	2,386	62%	192,942	5,960	1,085	199,987	96%
2012	193,008	5,518	879	199,213	97%	1,315	685	187	2,165	61%	194,323	6,203	1,066	201,378	96%
2013	197,384	5,595	815	203,794	97%	1,258	710	167	2,135	59%	198,642	6,305	982	205,929	96%
2014	196,320	6,071	829	203,220	97%	1,330	723	150	2,203	60%	197,650	6,794	979	205,423	96%
2015	220,898	6,327	775	228,001	97%	1,231	709	151	2,091	59%	222,129	7,036	926	230,092	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. The increase between 2014 and 2015 in the number of nonstate facilities of 1 to 6 people is due in part to states reporting living arrangements for people recieving only non-residential LTSS.

- 1 to 6 people increased 31.9 times from 6,855 to 220,898,
- 7 to 15 people increased 1.7 times from 2,310 to 6,327, and
- 16 or more people decreased 42% from 1,378 to 775.

The proportion of non-family IDD settings that were nonstate-operated increased from 96% in 1998 to 99% in 2015. The proportion of non-family IDD settings that were nonstate-operated with

- 1 to 6 people remained at 99% between 1977 and 2015,
- 7 to 15 people, declined from 96% in 1977 to 86% in 1986 and was 91% in 2015, and
- 16 or more people increased from 81% in 1977 to 84% in 2015.

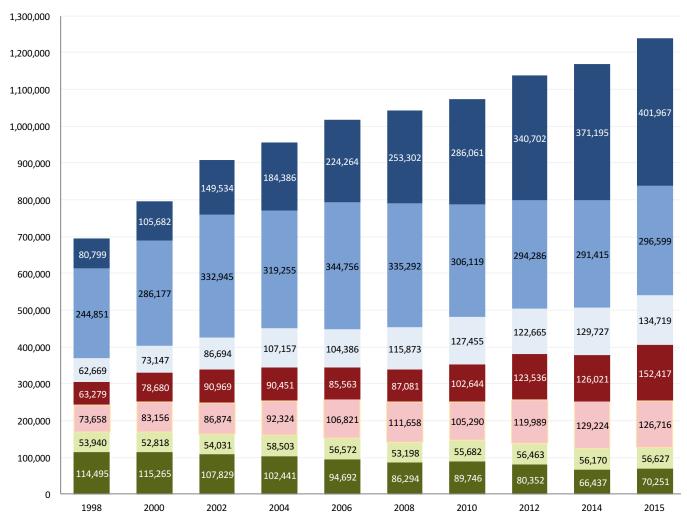
# People in State and Nonstate IDD Settings by Size and Type of Operation 1977 to 2015

The number LTSS recipients living in non-family IDD settings doubled from 247,780 people in 1977 to 512,969 people in 2015 (See **Table 3.2**).

Between 1977 and 2015, the number of people living in settings of

- 6 or fewer people increased 19 times from 20,400 to 413,852,
- 7 to 15 people increased 1.8 times from 20,024 to 56,627,

**Figure 3.1** Estimated Number of LTSS Recipients with IDD by Living Arrangement Type and Size, Select Years 1998 to 2015





 16 or more people decreased 80% from 207,356 to 42,490.

Of the people living in non-family IDD settings, the proportion in nonstate-operated settings increased from 37% (91,976 or 247,780 people) to 94% (481,449 of 512,969 people) between 1977 and 2015 (See **Figure 3.3**).

#### **State Operated Settings**

Between 1977 and 2015, the number of people with IDD living in state-operated IDD serving

- 1 to 6 people increased 20.3 times from 216 to 4,596 people,
- 7 to 15 people increased 5.6 times from 950 to 6,282 people, and
- 16 or more people decreased 87% from 154,638 to 20,642 people.

#### **Nonstate Operated Settings**

Between 1977 and 2015, the number of people with IDD living in nonstate IDD settings serving

- 1 to 6 people increased 19.3 times from 20,184 to 409,143 people,
- 7 to 15 people increased 1.6 times from 19,074 to 50,010 people, and
- 16 or more people decreased 59% from 52,718 to 21,293 people.

Of the people living in non-family IDD settings, the proportion living in settings of 6 or fewer people

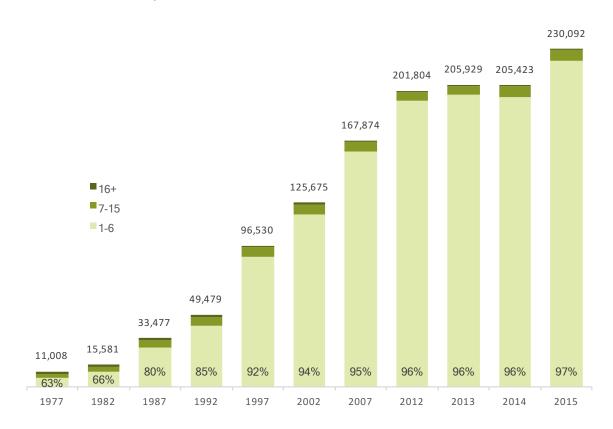
- Overall increased from 8% in 1977 to 81% in 2015,
- In nonstate-operated settings increased from 22% in 1977 to 85% in 2015, and
- In state-operated settings increased from less than 1% in 1977 to 15% in 2015.

### More People Live in Nonstate-Operated Than in State-Operated IDD Settings of 16 or more People

Of the people living in non-family IDD settings, the proportion living in settings of 16 or more people

 Overall decreased from 84% (207,356 people) in 1977 to 8% (42,490 people) in 2015,

**Figure 3.2** Estimated Number of Non-Family Residences for LTSS Recipients with IDD by Setting Size June 30 of Selected Years, 1977 to 2015

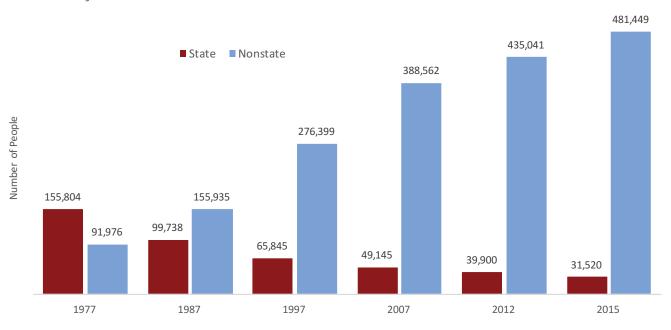


**Table 3.2** Estimated Number of People with IDD in Non-Family IDD Settings by Type of Operation and Setting Size on June 30 Selected Years 1977 to 2015

							Numb	er of Peop	le with ID	D <sup>1</sup>					
		No	onstate					State					Total		
Size	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6	1-6	7-15	16+	Total	%1-6
1977	20,184	19,074	52,718	91,976	22%	216	950	154,638	155,804	0%	20,400	20,024	207,356	247,780	8%
1982	32,335	28,810	57,396	118,541	27%	853	1,705	122,750	125,308	1%	33,188	30,515	180,146	243,849	14%
1987	68,631	45,223	42,081	155,935	44%	1,302	3,414	95,022	99,738	1%	69,933	48,637	137,103	255,673	27%
1992	118,304	46,023	45,805	210,132	56%	1,371	7,985	74,538	83,894	2%	119,675	54,008	120,343	294,026	41%
1997	190,715	46,988	38,696	276,399	69%	4,253	6,926	54,666	65,845	6%	194,968	53,914	93,362	342,244	57%
2002	258,709	46,728	30,676	336,113	77%	5,532	7,029	44,066	56,627	10%	264,241	53,757	74,742	392,740	67%
2003	269,907	46,961	29,639	346,507	78%	5,554	7,385	42,835	55,774	10%	275,461	54,346	72,474	402,281	68%
2004	289,456	49,248	27,495	366,199	79%	5,540	6,810	41,653	54,003	10%	294,996	56,058	69,148	420,202	70%
2005	285,671	46,027	27,005	358,703	80%	5,471	6,980	40,061	52,512	10%	291,142	53,007	67,066	411,215	71%
2006	293,755	53,458	26,559	373,772	79%	5,429	7,089	38,305	50,823	11%	299,184	60,547	64,864	424,595	70%
2007	310,874	51,842	25,846	388,562	80%	5,417	7,078	36,650	49,145	11%	316,291	58,920	62,496	437,707	72%
2008	320,065	45,039	23,818	388,922	82%	5,360	6,994	35,035	47,389	11%	325,425	53,424	57,462	436,866	74%
2009	316,036	51,400	26,695	394,131	80%	5,427	7,048	32,909	45,384	12%	321,463	58,448	59,604	439,515	73%
2010	348,039	49,711	25,712	423,677	82%	5,156	6,875	31,101	43,132	12%	353,195	56,586	56,813	466,809	76%
2011	342,339	51,273	22,796	419,783	82%	5,059	6,786	28,969	40,814	12%	347,398	58,059	51,765	460,597	75%
2012	360,804	50,069	24,168	435,041	83%	5,386	6,394	28,120	39,900	13%	366,190	56,463	52,288	474,941	77%
2013	367,069	51,804	26,175	445,048	82%	5,317	6,431	23,865	35,613	15%	372,386	58,235	50,040	480,661	77%
2014	378,477	51,141	24,372	453,989	83%	5,267	6,402	21,698	33,367	16%	383,744	57,543	46,070	487,356	79%
2015	409,256	50,345	21,848	481,449	85%	4,596	6,282	20,642	31,520	15%	413,852	56,627	42,490	512,969	81%

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

**Figure 3.3** Estimated Number of People with IDD Living in Non-Family Settings by Type of Operation and Year on June 30 of Selected Years 1977 to 2015





- In nonstate-operated settings decreased from 57% (52,718 people) in 1977 to 5% (21,848 people) in 2015), and
- In state-operated settings decreased from 99% (154,638 people) in 1977 to 65% (20,642 people) in 2015.

There have been more people with IDD living nonstate-operated than in state-operated IDD facilities of 16 or more people since 2013. Since 2003, number of people in nonstate-operated IDD settings has been declining more slowly than in state-operated IDD settings of 16 or more people. Between 2003 and 2015, the number of people with IDD living in nonstate-operated IDD facilities of 16 or more people declined by only 8,247 people (an average of 687 people per year) while the number living in state-operated IDD facilities of 16 or more people declined by 22,193 (an average 1,849 people per year).

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

- Will states continue the deinstitutionalization process for people with IDD in nonstate IDD facilities of 16 or more people, nursing homes, and psychiatric facilities who would like to move to a home in their community?
- How might deinstitutionalization strategies need to change for nonstate settings?
- What are the similarities and differences between state and nonstate IDD facilities

- of 16 or more people? Why are the deinstitutionalization rates different?
- How important is it to continue to monitor and report the status of the 42,034 people with IDD living in IDD facilities of 16 or more people, and the 27,761 people with IDD in psychiatric facilities or nursing homes?

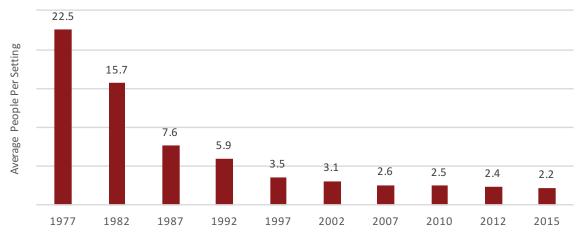
#### **Average People per Setting**

The average number of people per non-family IDD setting declined from 22.5 in 1977 to 2.2 in 2015 (See **Figure 3.4**). The average in nonstate settings was 8.7 people in 1977, 4.8 in 1997, 2.4 in 2007, and 2.1 in 2015. The average number of people in state-operated settings was 335.1 people in 1977, 33.0 in 1997, 18.7 in 2007, and 15.1 in 2015.

# MEDICAID EXPENDITURES FOR PEOPLE WITH IDD AS A PROPORTION OF ALL MEDICAID EXPENDITURES

Total Medicaid expenditures for all populations grew from \$14.55 billion in 1980 to \$524.29 billion in 2015 (Eiken, et al., 2017). Medicaid ICF/IID and Waiver funding for people with IDD increased from \$1.74 billion in 1980 to \$44.37 billion in 2015 (See **Table 3.3**). The proportion of Medicaid expenditures allocated to LTSS for people with IDD declined from 11.9% in 1980 to 8.5% in 2015.





# TRENDS IN MEDICAID WAIVER AND ICF/IID RECIPIENTS AND EXPENDITURES

This section describes changes in Medicaid ICF/IID and Waiver recipients and expenditures for people with IDD between 1977 (ICF/IID) or 1982 (Medicaid Waiver) and 2015.

#### **Recipients**

The number of people in ICF/IID settings grew from 106,166 in 1977 to a peak of 147,729 in 1993, then declined to 77,444 in 2015 (See **Figure 3.5a**). In 1982, 1,381 people (1%) received Medicaid Waiver-funded LTSS and 140,752 (99%) lived in an ICF/IID. The number of Medicaid Waiver recipients with IDD first exceeded the number of ICF/IID residents in 1995. By June 30, 2015, there were 774,964 Medicaid Waiver recipients with IDD (91% of the combined total) and only 77,444 in ICF/IID settings (9% of the total).

#### **Expenditures**

In 1982, Medicaid ICF/IID expenditures for people with IDD were \$3.35 billion while Medicaid Waiver expenditures were \$2.24 million (99% of expenditures were for ICF/IID compared to less than 1% for waivers, See **Figure 3.5b**). By 2001, annual Waiver expenditures exceeded annual ICF/IID expenditures (\$11.0 billion compared with \$10.35 billion). In 2015, annual waiver expenditures for people with IDD were three times higher than annual ICF/IID expenditures (\$34.2 billion versus \$10.4 billion, 22% of expenditures are 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 (\$3,996 in 2015 inflation adjusted dollars) and \$23,806 for people in ICF/IID settings (\$58,562 in 2015 inflation adjusted dollars). In 2015, average annual per recipient expenditures were \$44,112 for waiver recipients and \$134,630 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 and year. Between 2012 until 2015, the number of

- People receiving Medicaid Waiver-funded supports increased by 13%
- Expenditures for Medicaid Waiver-funded supports increased by 11%
- People living in an ICF/IID decreased by 9%
- Expenditures for ICF/IID services decreased by 23%

Interactive visualizations showing these data for all available years are on the RISP project website at https://risp.umn.edu/viz. The website shows per recipient ICF/IID and Medicaid Waiver expenditures for all available years. The state profiles at the end of this report summarize the historical trends for individual states.

**Table 3.3** Medicaid Expenditures for ICF/IID and Waiver Recipients with IDD as a Proportion of All Medicaid Expenditures Select Years 1980 to 2015

Fiscal Year	Total Medicaid Expenditures (Billions)	Medicaid ICF/IID and HCBS 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 <sup>1</sup>	\$391.72	\$41.85	10.7%
2011 <sup>1</sup>	\$414.50	\$40.68	9.8%
<b>2012</b> <sup>2</sup>	\$419.83	\$42.62	10.2%
<b>2013</b> <sup>2</sup>	\$437.86	\$42.21	9.6%
<b>2014</b> <sup>2</sup>	\$476.82	\$41.71	8.7%
<b>2015</b> <sup>2</sup>	\$524.29	\$44.37	8.5%

<sup>1</sup>Updated from Eiken et al (2016). 2 Updated from Eiken et al. (2017).



Figure 3.5a Number of Medicaid ICF/IID and HCBS Waiver Recipients with IDD From 1982 to 2015

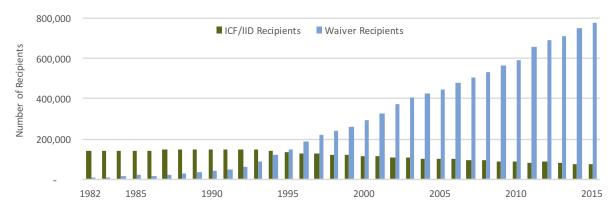
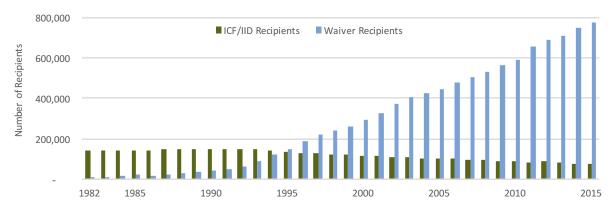


Figure 3.5b Total Medicaid ICF/IID and HCBS Waiver Expenditures for People with IDD From 1982 to 2015



**Figure 3.5c** Average Annual Per Person ICF/IID and Waiver Expenditures For People with IDD From 1982 to 2015

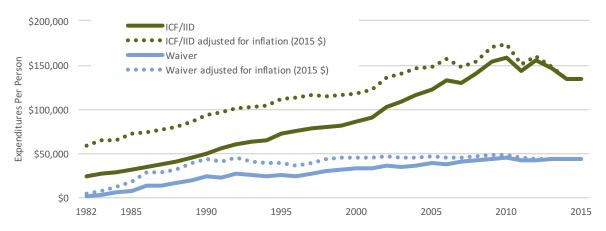


Table 3.4 Estimated Medicaid Waiver Recipients with IDD by State on June 30th Selected Years, 1982-2015

				) 					)		
State	1982	1987	1992	1997	2002	2007	2012	2013	2014	2015	% change 2012-2015
AL	0	1,570	2,184	3,713	4,764	5,230	5,604	6,247	5,807	5,425	-3
AK	0	0	0	353	884	1,011	1,703	1,865	1,942	2,044	20
AZ	0	0	4,832	8,508	13,471	19,066	24,617	25,896	27,071	28,418	15
AR	0	0	415	496	2,494	3,342	4,037	4,147	4,160	4,122	2
5	0	3,027	3,360	37,478	44,205	73,024	97,868	103,008	109,048	115,365	18
00	0	1,389	2,204	4,276	6,516	7,148	8,147	7,903	8,569	9,932	22
Ь	0	0	1,693	3,371	5,972	7,692	8,638	9,346	9,534	9,602	11
DE	0	81	290	379	547	788	855	686	686	1,041	22
DC	0	0	0	0	225	1,090	1,479	1,577	1,595	1,574	9
FL	0	2,631	2,637	11,399	25,921	31,425	29,353	28,849	30,281	32,277	10
GA	0	0	359	2,332	8,190	9,194	11,621	8,068	8,295	8,506	-27
豆	0	56	452	260	1,560	2,481	2,544	2,544	2,661	2,652	4
Π	0	55	225	434	1,139	2,015	2,660	5,100	6,598	7,616	186
IL	0	664	2,006	5,400	6,787	12,800	18,355	20,300	21,226	22,141	21
<u>Z</u>	0	0	0	1,067	3,802	9,976	12,786	13,917	17,407	18,950	48
Ы	0	4	137	3,932	6,228	12,751	11,359	14,638	14,725	14,532	28
KS	0	135	555	3,872	6,239	7,195	8,274	7,795	8,695	8,734	9
KY	0	609	819	1,040	1,807	3,033	11,046	12,015	15,000	14,867	35
LA	0	0	939	2,048	4,232	6,915	6,957	11,663	11,539	12,042	21
ME	0	400	509	1,078	2,440	2,781	4,101	4,208	4,308	4,839	18
MD	0	685	1,972	3,392	6,768	10,294	12,489	11,730	10,970	13,935	12
MA	0	593	3,288	8,027	11,315	11,962	11,987	12,368	13,361	13,798	15
IΜ	0	3	2,741	6,199	8,550	8,089	39,838	36,600	36,600	45,115	13
ZΣ	0	1,423	2,890	6,097	14,735	14,593	18,963	18,066	18,185	18,316	e-
MS	0	0	0	231	1,673	1,978	1,831	2,008	2,209	2,296	25
МО	0	0	2,241	6,282	8,143	8,396	11,041	12,147	12,242	13,133	19
MT	21	210	444	891	1,452	2,242	2,668	2,686	2,699	2,798	5
NE	0	0	710	2,010	2,419	3,304	4,531	4,687	4,836	4,656	СС
N	0	129	136	374	1,083	1,372	1,652	1,719	1,877	1,941	17
H	0	541	1,059	2,063	2,779	3,339	4,519	4,179	4,834	5,235	16
Z	0	2,596	3,971	5,705	7,486	9,923	11,297	10,740	10,977	10,972	<del>د</del> ٠
MN	0	220	334	1,603	2,794	3,711	4,115	4,662	4,943	4,231	3
N	0	0	379	29,019	48,165	56,401	77,047	79,491	80,574	83,739	6
UN	0	328	686	3,726	6,013	6)309	12,800	12,906	12,881	13,666	7
ND	0	724	1,334	1,792	2,011	3,535	4,059	4,000	4,277	4,613	14
НО	0	100	397	2,646	7,858	16,362	30,872	32,853	34,274	35,245	14



 Table 3.4
 Estimated Medicaid Waiver Recipients with IDD by State on June 30th Selected Years, 1982-2015

State	1982	1987	1992	1997	2002	2007	2012	2013	2014	2015	% change 2012-2015
OK V	0	70	949	2,497	4,100	5,308	5,223	5,236	5,463	5,577	7
OR	1,360	832	1,458	2,586	8,017	10,287	14,865	17,735	16,922	6,932	-53
PA	0	1,203	2,705	8,931	24,969	26,558	29,963	29,013	31,695	32,628	6
R	0	136	993	2,178	2,674	3,126	3,316	3,937		3,654	10
SC	0	0	471	3,412	4,410	5,186	8,394	8,527	8,646	9,591	14
SD	0	596	852	1,457	2,295	2,609	3,215	3,362	3,433	3,592	12
Z	0	213	704	3,293	4,340	7,244	7,680	7,695	7,799	7,878	ĸ
¥	0	70	896	4,753	7,873	16,301	29,193	29,939	31,535	34,623	19
L)	0	0	1,367	2,315	3,589	4,003	4,319	4,350	4,941	5,241	21
М	0	196	413	1,372	1,844	2,200	2,649	2,770	2,833	2,917	10
۸۸	0	0	537	1,764	5,491	7,523	9,754	10,282	11,096	12,422	27
WA	0	886	1,918	6,643	006'6	9,317	11,898	12,197	12,483	12,892	∞
\M	0	124	513	1,441	2,796	3,852	4,447	4,492	5,079	5,079	14
MI	0	190	1,812	6,558	9,474	12,504	23,396	27,317	27,838	31,460	34
WY	0	0	318	916	1,507	2,079	2,150	2,035	1,813	2,110	-2
US Total	1,381	22,689	62,429	221,909	373,946	501,864	688,410	709,804	740,120	774,964	13
N States	2	35	48	20	51	51	90	51	51	51	

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

Table 3.5 Estimated Medicaid Waiver Expenditures for People with IDD by State Selected Years 1982 to 2015

0										
	8,325,700	12,400,000	72,327,370	120,395,453	253,259,493	288,701,202	315,062,765	318,480,978	324,101,031	2
0	0	0	17,668,470	51,865,764	70,954,834	134,516,256	151,464,381	143,610,221	168,195,290	25
0	0	98,716,400	203,897,500	386,529,149	556,449,700	640,785,297	707,083,624	788,832,352	827,517,340	22
0	0	11,250,000	12,063,322	53,076,898	91,379,808	173,134,527	180,663,580	190,226,399	204,761,648	19
0	30,400,000	54,048,900	355,246,000	853,788,100	1,532,880,000	2,107,489,165	2,372,250,800	2,551,065,192	2,796,562,703	∞
0	25,454,800	60,191,500	133,282,479	205,028,144	268,080,321	331,009,675	328,631,387	355,864,334	395,467,924	-2
0	7,000	83,575,000	222,364,121	386,546,536	454,124,513	720,877,844	743,373,207	693,438,314*	879,290,977	11
0	845,500	5,105,100	16,279,225	34,181,392	75,089,815	94,328,870	91,636,647	103,491,162 <sup>e</sup>	118,357,072	22
0	0	0	0	1,647,800	19,678,020	147,196,144	146,829,961	160,466,106	184,827,720	22
0	12,849,800	20,246,000	131,804,756	496,921,252	908,572,039	879,855,035	840,403,403	857,528,282	889,313,799	9-
0	0	10,250,000	63,129,643	286,389,800	263,542,265	407,211,908	307,651,561	350,999,007*	356,005,822	13
0	564,600	4,385,200	11,720,944	34,727,501	97,000,000	102,909,919	102,909,593	104,338,769*	105,401,320	m
0	568,200	1,188,000	9,996,472	27,804,290	60,937,200	64,424,617	75,777,942	103,036,140*	196,902,851	-54
0	12,839,600	79,600,000	116,000,000	140,200,000	416,200,000	591,460,042	636,100,000	723,467,619	829,757,322	11
0	0	0	33,300,620	198,630,045	402,596,549	489,970,561	534,025,571	578,990,198*	606,865,582	4-
0	0	773,500	48,271,477	127,081,323	275,727,517	387,579,845	431,259,100	473,300,661	510,898,817	11
0	637,700	13,737,300	93,518,741	189,358,115	247,333,699	330,269,359	342,562,454	400,136,206	413,799,134	15
0	10,974,100	19,821,000	29,429,581	91,755,864	163,060,166	406,429,143	459,959,093	551,471,229	595,400,472	34
0	0	1,785,000	44,291,400	129,015,073	258,219,940	407,247,885	452,163,129	446,673,888*	463,018,241	2
0	5,673,800	13,250,000	60,066,647	136,460,573	230,661,475	291,071,088	329,737,271	270,678,407 <sup>e*</sup>	300,527,262 <sup>e</sup>	9-
0	21,708,000	72,326,500	140,673,425	251,357,000	495,385,519	686,893,892	764,038,854	557,424,779	816,424,318	14
0	13,278,000	000'000'06	280,000,000	483,391,204	587,453,199	876,813,984	715,841,922	883,274,710 <sup>s</sup>	1,159,456,123 <sup>s</sup>	24
0	79,800	81,039,000	162,808,522	538,108,524	316,274,000	445,712,073	1,184,470,148	1,184,470,148	1,437,648,930 <sup>d</sup>	9
0	13,170,000	95,380,700	260,223,164	896'989'669	889,902,016	1,215,080,921	1,160,776,082	1,191,169,273	1,276,890,437	18
0	0	0	631,007	20,699,255	39,460,620	43,976,251	49,311,709	69,586,843	71,373,275	19
0	0	65,792,000	154,767,652	235,896,984	379,435,294	533,966,837	610,064,502	668,192,078	700,423,090	13
374,900	3,595,900	10,826,700	22,500,000	42,005,397	68,411,681	90,871,419	91,967,982	120,729,711	120,621,602	6-
0	0	25,521,600	58,901,127	108,402,150	140,171,512	239,920,704	175,539,547	174,122,370	164,627,422	14
0	1,489,400	2,400,000	4,877,293	24,367,276	61,584,554	78,766,702	75,610,199	93,448,000	95,273,457	80
0	13,518,400	44,400,000	89,427,245	117,921,627	143,208,714	192,024,701	198,451,066	208,839,906	232,931,814	6
0	35,888,000	108,600,700	180,006,000	402,988,000	496,612,000	737,870,549	708,497,828	824,873,688 <sup>s</sup>	876,940,082	24
0	1,409,600	8,829,000	46,295,349	157,256,000	247,597,401	285,948,508	300,718,774	277,066,357 <sup>i</sup>	189,878,752	-3
0	711,800	34,496,200	1,114,422,787	2,125,806,338	3,449,069,061	5,468,224,696	5,328,884,532	4,899,992,876	5,104,674,884	13



Table 3.5 Estimated Medicaid Waiver Expenditures for People with IDD by State Selected Years 1982 to 2015

State	1982	1987	1992	1997	2002	2007	2012	2013	2014	2015	% change 2012-2015
	0	3,058,900	13,833,400	106,199,243	254,336,689	377,746,642	619,805,304	442,241,550	755,613,932 <sup>e</sup>	689,198,047 <sup>e</sup>	2
	0	5,438,200	18,974,900	30,176,000	47,531,203	71,823,487	129,617,461	142,124,660	168,827,063 <sup>s</sup>	180,687,708	25
	0	1,130,500	12,824,000	90,058,170	245,009,370	660,978,417	1,240,862,952	1,320,136,278	1,375,523,420	1,434,162,087	12
	0	392,000	39,375,300	93,592,963	222,356,146	253,400,544	273,951,817	277,760,615	301,540,486 <sup>e</sup>	312,640,630	-2
	1,868,500	8,305,800	58,604,300	105,178,092	361,704,793	385,761,698	597,868,202	561,250,632	683,931,909	51,810,862	14
	0	35,974,800	133,681,000	415,398,542	977,487,155	1,199,738,817	1,816,306,161	2,022,669,290	2,175,066,007*	2,308,611,230	10
	0	5,648,000	14,366,800	107,961,796	160,859,473	245,521,023	203,663,206	209,000,000	218,000,000 <sup>S</sup>	193,372,725	-19
	0	0	4,961,000	51,300,000	142,500,000	185,700,000	291,243,055	253,154,908	258,611,956	281,265,947	22
	0	6,153,300	16,256,600	38,738,683	58,935,238	81,944,579	101,739,037	105,085,510	107,606,699	113,189,597	2
	0	1,853,100	14,431,120	72,738,465	205,313,600	525,963,523	604,098,205	624,787,616	642,522,366	669,248,000	2
	0	1,828,100	39,754,600	159,896,149	321,670,578	566,475,093	1,058,827,386	1,102,141,224	1,148,582,363 <sup>ed*</sup>	1,240,211,080 <sup>d</sup>	14
	0	0	23,000,000	50,793,746	88,990,989	113,867,000	155,514,728	162,828,701	178,260,955	192,118,347	5
	0	4,839,900	14,154,200	47,980,267	74,856,153	109,071,348	141,617,128	150,655,198	158,833,549	165,311,946	9
	0	0	15,974,600	67,429,885	198,911,231	394,326,044	602,412,138	573,768,026	737,955,990	727,153,068	10
	0	12,068,200	39,973,500	105,005,621	214,490,497	315,623,788	550,895,554	573,992,065	603,214,931 <sup>e</sup>	722,125,854 <sup>e</sup>	24
	0	777,200	13,200,000	43,659,534	120,217,738	203,371,121	303,861,581	335,535,555	422,183,821	358,871,525 <sup>s</sup>	19
	0	3,503,400	39,078,200	155,238,000	312,784,855	439,299,106	855,374,008	915,230,020	978,759,826	1,041,267,487	19
	0	0	12,508,000	33,428,015	56,956,535	87,040,867	98,496,506	97,571,704	95,006,103	89,473,522	∞
Reported Total	2,243,400	304,961,100	1,654,886,820	5,964,965,510	13,224,202,038	20,177,966,022	29,538,694,048	30,783,652,165	32,329,327,579	34,184,856,176	1
N States	2	36	47	50	51	51	51	51	51	51	

dother date (Usually August 31, 2015 or June 30, 2014). e Estimate. i Missing value imputed (RISP estimated based on available data and other sources). DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals. s Other Source (Eiken et al., 2017). Data for all states and all years since 1982 can be viewed in the Chart Gallery of the RISP umn.edu website.

 Table 3.6
 Estimated Number of ICF/IID Recipients by State Selected Years 1982 to 2015

State	1977	1982	1988	1992	1997	2002	2007	2012	2013	2014	2015	% cnange 2012-2015
AL	0	1,470	1,364	1,304	745	472	244	41	14	14	14	99-
AK	135	118	107	98	10	0	0	0	14	9	9	
AZ	0	0	0	214	214	207	185	148	145	137	131	-11
AR	1,385	1,420	1,453	1,737	1,558	1,684	1,616	1,467	1,468	1,455	1,444	-2
CA	0	10,374	10,871	10,923	10,681	10,839	865'6	8,726	8,468	8,230	7,989	89
00	4,537	2,017	1,149	754	229	111	125	343	352	175	174	-49
b	289	1,598	1,414	1,378	1,377	1,192	1,148	993	917	871	845	-15
DE	477	513	439	325	292	241	141	135	127	125	120	-11
DC	0	436	999	761	754	734	640	363	352	341	329	6-
చ	370	2,128	3,180	3,118	3,476	3,338	3,205	2,806	2,857	2,788	2,742	-2
GA	2,369	2,491	1,913	1,935	1,770	1,475	1,034	300	248	249	291	ů.
ᇁ	524	387	296	154	122	94	78	79	79	70	92	4-
QI	583	482	461	519	579	576	543	487	487	469	488	0
II.	5,353	8,144	10,346	12,311	10,500	9,923	9,213	8,344	7,560	7,360	6,788	-19
Z	1,026	2,798	4,690	6,234	5,938	4,981	4,012	3,839	3,760	3,595	3,319	-14
ΙA	1,432	1,673	1,840	2,088	2,268	2,157	2,123	2,002	2,005	2,176	2,133	7
KS	1,810	2,078	2,081	1,921	1,395	889	299	509	209	462	450	-12
KY	666	1,250	1,187	1,200	1,180	876	637	523	394	448	435	-17
4	3,682	4,849	6,016	5,645	6,014	5,539	5,320	4,604	4,941	4,825	5,247	14
ME	310	630	677	630	548	246	222	202	205	171	167	-17
MD	1,367	1,851	1,429	954	624	205	336	54	153	143	107	86
MA	4,242	4,041	3,698	3,304	1,598	1,125	952	594	516	499	433	-27
M	2,760	4,002	3,683	3,180	2,899	173	151	0	0	0	0	
N	5,303	668'9	6,339	5,202	3,604	2,756	2,513	1,719	1,726	1,685	1,591	-7
MS	491	1,614	1,678	1,825	2,256	2,534	2,601	2,765	2,514	2,433	2,432	-12
МО	2,051	1,878	1,868	1,751	1,466	1,398	1,020	290	269	909	473	-20
MT	0	290	253	170	148	119	54	55	29	51	55	0
NE	1,356	086	808	739	643	642	582	433	391	392	394	6-
NV	0	175	188	146	275	242	118	104	100	100	86	9
HN	288	339	204	81	23	25	25	25	25	25	25	0
Ñ	525	4,366	3,815	3,942	3,948	3,370	2,963	3,153	3,035	2,365	2,041	-35
ΣN	426	553	709	730	348	284	182	234	229	265	252	∞
NY	18,601	15,577	17,567	18,497	11,472	9,815	7,995	7,288	7,127	6,782	6,502	-11
NC	2,073	2,762	3,445	4,502	4,777	4,645	4,124	3,930	3,273	3,359	3,965	_



Table 3.6 Estimated Number of ICF/IID Recipients by State Selected Years 1982 to 2015

State	1982	1987	1992	1997	2002	2007	2012	12	2013	2014	2015	% change 2012-2015
ND	0	219	888	476	609	629	593	559	544	545	463	-17
НО	2,488	6,040	7,535	8,384	7,615	7,240	6,667	6,926	6,678	6,555	6,367	φ
OK	1,978	1,803	3,242	2,776	2,292	2,243	1,630	1,549	1,549	1,265	1,581	2
OR	1,989	1,918	1,284	899	373	51	41	0	0	0	0	
PA	7,355	8,598	7,364	7,282	6,192	4,280	3,833	3,419	3,247	3,153	3,024	-12
RI	763	881	1,093	602	21	40	41	42	42	42	32	-24
SC	1,017	2,665	3,300	3,261	2,555	1,992	1,615	1,313	1,261	1,206	1,184	-10
SD	540	721	650	552	328	189	158	199	191	190	187	9-
Z <sub>F</sub>	2,149	2,377	2,198	2,399	1,900	1,460	1,223	1,108	1,007	666	1,020	φ
¥	10,486	13,959	12,211	11,187	12,985	12,684	11,447	9,467	9,025	9,626	8,193	-13
TU	1,193	1,199	945	930	833	783	794	801	824	838	841	5
ΤΛ	352	385	238	146	12	12	9	9	9	9	9	0
٧A	3,558	3,616	3,018	2,743	2,225	1,885	1,684	1,326	1,116	992	782	-41
WA	440	2,464	2,539	1,695	1,126	880	767	629	862	841	992	22
\w	0	176	417	669	574	515	477	295	292	553	506	-10
WI	3,696	3,548	3,378	4,110	3,187	2,580	1,059	895	877	791	787	-12
WY	0	0	0	06	139	106	93	79	06	75	70	-11
US Total	106,166	140,752	146,134	146,260	126,697	110,572	96,427	85,384	82,511	80,249	77,444	6-
N States	51	51	49	51	51	20	20	48	47	49	49	51

PD Partial Data. State data for all available years can be viewed in the Chart Gallery Section of the RISP.umn.edu website.

Table 3.7 Estimated Medicaid ICF/IID Expenditures by State Selected Years 1982 to 2015

State	1982	1988	1992	1997	2002	2007	2012	2013	2014	2015	% change 2012-2015
AL	31,075,591	54,013,748	80,701,331	58,305,599	60,516,473	31,522,229	10,586,376	1,784,376	1,092,487	945,886	-91
AK	6,830,128	9,037,943	10,383,643	2,032,452	0	161,277	3,050,708	3,191,791	3,055,280 <sup>s</sup>	2,525,936	-17
AZ	0	0	0	0	0	0	32,592,983	26,949,532 <sup>s</sup>	29,758,592	27,512,500 <sup>s</sup>	-16
AR	34,603,287	51,086,511	88,047,375	105,949,531	28,958,296	146,959,897	168,540,154	163,191,817 <sup>s</sup>	177,477,436 <sup>s</sup>	178,580,760 <sup>s</sup>	9
CA.	87,543,910	269,637,723	316,071,576	380,655,498	663,954,138	824,989,564	821,839,879	674,213,696	687,937,930	695,735,796	-15
00	(1,194,225)	43,403,360	55,494,909	23,574,819	19,202,441	22,646,984	39,533,350	43,509,184	44,401,927	40,596,579	С
<del>ل</del>	41,722,212	109,463,764	192,888,207	188,190,274	213,455,475	240,164,975	284,641,964	294,694,866 <sup>s</sup>	257,577,351	264,688,024	-7
DE	8,280,692	15,246,191	26,543,416	31,232,628	31,219,292	26,647,205	17,461,859	31,266,202 <sup>s</sup>	29,913,432 <sup>s</sup>	42,611,779	144
DC	7,350,298	40,108,105	51,773,630	74,257,976	79,480,032	85,050,758	69,494,028	83,608,160	91,521,955	95,734,207	38
균	48,047,516	130,435,326	181,801,704	248,207,991	310,393,230	319,288,105	328,459,559	321,883,150 <sup>s</sup>	326,678,953 <sup>s</sup>	334,092,690 <sup>s</sup>	2
GA	48,271,338	84,730,397	115,391,129	127,303,085	110,659,329	105,885,144	67,117,294	50,453,220 <sup>s</sup>	30,132,753 <sup>s</sup>	46,292,705 <sup>s</sup>	-31
豆	10,961,878	14,290,183	6,570,589	11,627,954	8,572,313	8,682,856	7,714,574	8,331,867 <sup>s</sup>	8,801,232 <sup>s</sup>	9,241,744 <sup>s</sup>	20
<u>Q</u>	12,490,191	23,129,878	35,545,134	43,453,845	57,714,097	59,701,562	23,064,006	48,640,003 <sup>s</sup>	47,805,696 <sup>s</sup>	42,634,014	85
IL	120,855,066	243,824,403	499,573,261	580,152,170	720,931,511	696,182,835	688,114,511	572,400,000	627,855,900	636,318,364	ø <sub>-</sub>
Z	37,325,581	86,776,690	272,735,397	304,187,079	338,947,070	318,530,548	294,063,947	291,497,636	280,518,255	273,327,092	-7
ΙA	52,266,560	88,710,333	150,455,720	178,213,310	192,996,276	276,650,630	301,738,929	284,048,012	281,400,871	284,676,738	9-
KS	40,646,701	806'262'69	102,522,826	94,467,990	65,862,911	65,288,398	64,412,398	63,473,900 <sup>5</sup>	61,238,528 <sup>5</sup>	65,228,609 <sup>s</sup>	1
KY	39,052,684	47,597,483	59,843,010	75,690,587	97,888,453	151,886,094	130,480,686	175,466,890 <sup>s</sup>	142,907,257 <sup>s</sup>	140,520,784 <sup>s</sup>	∞
ΓA	97,075,753	165,291,176	260,924,945	422,009,351	362,343,106	442,023,340	467,516,687	390,662,003	390,497,610	384,087,560	-18
ME	15,699,455	30,613,278	62,854,319	45,548,200	50,370,111	71,663,625	74,914,882	35,076,254	32,372,318	28,972,693	-61
MD	53,169,976	83,621,494	65,023,118	63,699,255	61,628,216	68,465,522	123,036	57,596 <sup>s</sup>	10,653,445 <sup>s</sup>	19,595,815 <sup>s</sup>	15,827
MA	125,500,190	198,722,295	385,149,336	254,061,832	198,022,895	206,611,974	165,995,204	122,672,000	122,672,000 <sup>d</sup>	DNF	DNF
Ī	152,838,152	213,104,699	180,560,636	519,144,242	27,647,769	28,824,017	0	215,843 <sup>s</sup>	0	0	N/A
Z	155,020,197	238,699,655	283,108,496	238,628,363	207,841,249	175,376,449	164,144,639	122,605,083	124,466,610	124,444,235	-24
MS	20,579,205	32,523,716	62,156,453	119,385,969	178,042,983	255,287,075	270,287,227	283,435,119	288,525,981	211,864,398 <sup>s</sup>	-22
МО	35,207,045	71,080,489	106,866,327	155,767,782	230,168,835	105,836,412	108,468,442	97,757,183	89,549,993	85,938,943	-21
MT	0	10,178,621	13,123,538	15,809,400	14,061,080	10,631,730	11,320,106	10,297,076 <sup>s</sup>	11,119,444 <sup>s</sup>	11,852,833	5
NE	21,336,101	25,477,085	32,910,189	36,895,824	47,671,206	66,940,338	57,653,500	32,607,856	32,043,236	31,511,391	-45
N N	5,661,466	9,522,660	16,670,311	22,844,573	30,309,013	21,390,455	17,955,488	17,737,664 <sup>s</sup>	18,575,749 <sup>s</sup>	17,505,663	ę.
HN	6,338,717	14,141,600	6,127,254	1,299,177	1,952,826	2,521,518	3,154,211	1,841,199 <sup>s</sup>	641,458 <sup>s</sup>	8,891,427 <sup>s</sup>	182
Z	122,552,250	237,997,341	276,342,092	373,077,452	462,968,767	628,420,857	650,873,269	697,128,262 <sup>s</sup>	664,348,972 <sup>s</sup>	508,433,602 <sup>s</sup>	-22
ΣN	12,077,857	23,586,513	39,164,075	21,728,673	18,993,063	21,263,002	24,809,317	24,977,074 <sup>s</sup>	25,888,375 <sup>s</sup>	26,285,597 <sup>s</sup>	9
λ	797,385,360	1,158,161,443	1,715,103,364	2,010,005,630	2,472,622,451	3,057,176,529	3,382,394,941	2,710,068,708	1,453,111,247	1,337,718,435	09-
NC	79,191,812	158,440,075	278,484,521	363,152,959	416,623,359	466,788,997	444,382,868	213,838,383 <sup>e</sup>	472,629,789 <sup>e</sup>	393,260,094 <sup>e</sup>	-12



Table 3.7 Estimated Medicaid ICF/IID Expenditures by State Selected Years 1982 to 2015

51	48	47	49	49	20	50	51	50	49	48	N States
-23	9,990,934,421	10,518,234,667	11,770,523,488	12,936,860,293	12,449,871,648	11,383,282,475 12,449,871,648	9,996,223,859	8,706,396,499	5,887,947,479	3,350,725,663	Reported Total
-7	19,262,849	17,451,654 <sup>s</sup>	19,640,307 <sup>s</sup>	20,744,605	20,006,774	15,542,906	17,777,773	2,555,987	0	0	W
-28	141,479,951	156,347,153	162,450,803	197,495,917	131,157,781	226,014,485	201,998,484	193,185,110	89,337,023	63,845,110	M
3	67,561,689 <sup>s</sup>	67,189,026	67,189,436	65,414,249	57,353,867	47,513,217	52,705,244	15,030,627	8,661,642	1,982,377	\ \
73	183,119,149 <sup>e</sup>	187,484,396	166,514,999 <sup>e</sup>	106,119,745	114,853,985	127,817,207	128,968,222	182,044,573	119,319,852	72,202,304	WA
-45	157,263,686	203,014,704	302,425,620 <sup>s</sup>	288,115,881	231,029,591	216,052,352	159,666,989	153,992,077	106,785,389	78,609,105	٧A
11	1,347,733	1,275,024	1,150,464	1,211,654	0	1,630,657	1,478,677	17,840,748	11,335,014	13,420,528	VT
15	72,475,662	67,957,140	65,086,544	63,278,359	58,133,589	54,883,090	45,047,084	39,659,369	27,666,341	23,710,593	UT
5	1,097,795,812 <sup>d</sup>	1,083,265,241	1,076,531,378	1,047,598,095	906,152,352	811,721,857	640,849,004	468,605,077	357,822,572	233,538,852	X
<u>-</u>	214,552,400	211,207,200 <sup>s</sup>	221,987,200	216,276,177	243,129,310	252,512,375	212,774,040	111,714,785	77,504,336	56,831,429	N
5	31,205,012	30,628,198	29,351,861	29,593,899	20,148,861	18,447,709	20,194,106	29,221,372	22,004,514	14,889,821	SD
φ	138,484,390	101,871,631	214,796,614 <sup>e</sup>	150,913,668	157,179,948	174,843,154	174,750,114	165,299,433	94,198,457	36,019,948	SC
-13	7,927,7498	9,004,728	9,870,914 <sup>s</sup>	9,159,578	7,810,448	7,244,449	10,401,463	90,367,789	60,547,566	28,759,032	<b>≅</b>
2	590,834,124	570,818,786	568,539,061	580,875,842	584,411,017	506,212,065	527,594,322	502,754,669	384,251,708	326,339,634	PA
N/A	0	0	0	0	22,407,372	11,346,249	75,273,311	83,138,263	73,726,772	5,286,751	OR
-14	97,513,437 <sup>s</sup>	92,179,420 <sup>s</sup>	111,630,604 <sup>s</sup>	113,227,985	127,291,449	112,292,158	100,899,598	111,772,704	83,724,996	32,395,470	OK
4	728,498,096	754,497,151	758,249,245	757,787,874	697,689,305	962,507,011	391,631,028	468,321,849	278,623,574	36,633,650	НО
-24	de87,789,0	96,871,153 <sup>s</sup>	95,526,833 <sup>s</sup>	92,145,743	61,655,098	54,683,268	43,652,930	39,980,236	40,215,637	498,116	ND
% change 2012-2015	2015	2014	2013	2012	2007	2002	1997	1992	1987	1982	State

b Nonstate settings reported, but not state settings. d Other date (Usually August 31, 2015 or June 30, 2014), e Estimate. DNF Did not furnish. PD Partial data, calculation incomplete and not included in reported totals. s Other Source (Eiken et al., 2016) Data for all states and all years since 1980 (except 1987) can be viewed in the Chart Galleny at the RISP.umn.edu website.







**SECTION FOUR** 

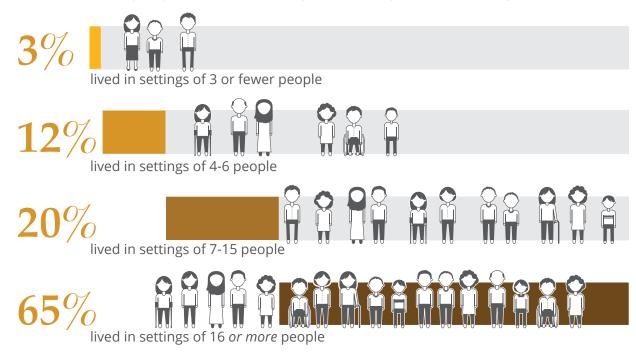
# STATUS AND TRENDS IN STATEOPERATED IDD FACILITIES SERVING 16 OR MORE PEOPLE

**FY 2015** 

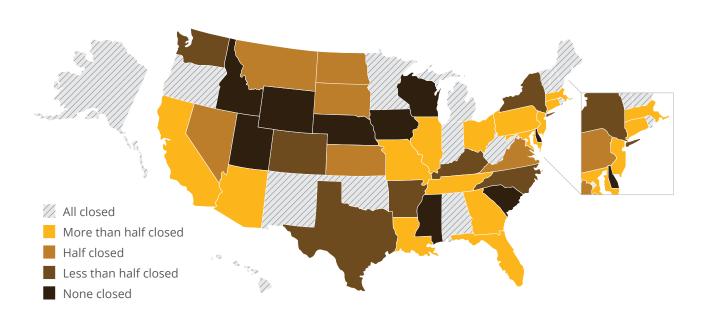


# State-Operated Facilities Serving People with Intellectual or Developmental Disabilities 2015

Of the 31,520 people with IDD living in state-operated settings,



Status of state-operated IDD facilities serving 16 or more people In 1977 there were 327 state-operated IDD facilities serving 16 or more people, by 2015 the total had dropped to 145.



## Section 4: Status and Trends in State-Operated IDD Facilities Serving 16 or more People

Section 4 describes state-operated IDD facilities serving 16 or more people (Public Residential Facilities, or PRFs for short). It includes information about average daily per person cost in FY 2015, longterm and short-term admissions, discharges, deaths, facility closures, and selected resident characteristics. Tables 4.1, 4.2, 4.3, and 4.7 summarize findings from the FY 2015 survey of state IDD Directors. **Tables 4.5**, **4.6**, **4.11** and **4.12** and **Figure 4.9** summarize findings from the FY 2015 survey of administrators of stateoperated IDD facilities serving 16 or more people fielded in conjunction with the Association of Public and Private Developmental Disabilities Administrators (APDDA). The remaining tables and figures show trends over time in the utilization of state-operated IDD facilities serving 16 or more people.

## Average Population and Movement Patterns in FY 2015

The average daily PRF population was 20,933 people in FY 2015 (See **Table 4.1**). Total populations declined 7% from 22,543 on June 30, 2014 to 20,933 on June 30, 2015. Oklahoma closed its last PRF in July 2015. One person remained in the facility on June 30, 2015. States with populations declining of 10% or more between June 30, 2014 and June 30, 2015 were:

- · Oklahoma (47 to 1 person, 98% fewer),
- Maryland (185 to 131 people, 29% fewer),
- · Idaho (26 to 19 people, 27% fewer),
- Tennessee (143 to 109 people, 24% fewer),
- Virginia (613 to 483 people, 21% fewer),
- Kentucky (304 to 263 people, 13% fewer),
- · Massachusetts (497 to 433 people, 13% fewer),
- New Jersey (1,835 to 1,612 people, 12% fewer),
- Ohio (921 to 815 people, 12% fewer), and
- Connecticut (521 to 468 people, 10% fewer).

States reporting increases the number of people living in PRFs on June 30, 2015 than on June 30, 2014 were North Carolina (the number increased from 1,220 in 2014 to 1,436 in 2015, which was 18% more people), Montana (51 to 55 people, 8% more), Georgia (249 to 267 people, 7% more), Louisiana (454 to 469 people, 3% more), and Arkansas (906 to 913 people, 1% more).

#### Admissions

An estimated 1,269 people were admitted to PRFs during FY 2015 (6% of the year's average daily population). The number of people admitted to large state-operated IDD facilities equaled or exceeded 20% of the 2015 average daily population in seven states (North Dakota, Montana, Kentucky, Nevada, South Dakota, Maryland, and Idaho). Admissions do not include people who transferred from one large state-operated IDD facility to another during 2015.

#### **Discharges**

An estimated 2,126 people were discharged from a PRF in 2015 (10% of the average daily population). More than 20% of the average daily population was discharged in FY 2015 in ten states: Oklahoma (288%), Montana (44%), Idaho (38%), Maryland (29%), Kentucky (28%), Virginia (24%), Nevada (23%), South Dakota (22%), and Ohio (20%).

#### **Deaths**

An estimated 702 people with IDD (3% of the average daily population) died while residing in a PRF in 2015. Five states with PRFs reported no deaths in FY 2015 (Montana, Nebraska, Nevada, Oklahoma, and South Dakota). States with double the national average or more deaths were Tennessee (11%), Maryland (8%), Delaware (7%), Massachusetts (7%), Wyoming (7%), North Dakota (6%), and Connecticut (6%).

#### **Short-Term Admissions**

An estimated 957 people with IDD were admitted to a PRF for a short-term stay (less than 90 days) in FY 2015 (See **Table 4.2**). There were no short-term admissions to PRFs serving people with Waiver funding. One state (Maryland) reported five short-term admissions to a non-Medicaid facility, and thirteen states reported short-term admissions to an ICF/IID. States reporting the most short-term ICF/IID admissions were Washington (403), Wisconsin (179), and Ohio (122).



**Table 4.1** Average Daily, Beginning, and Year End PRF Population - Admissions, Discharges, Deaths (Number and Percent of Average Daily Population) for FY 2015

	Average Daily	Admis	ssions	Disch	narges	De	eaths	,	Year End Residents	
State <sup>1</sup>	Population	N	% Ave Daily	N	% Ave Daily	N	% Ave Daily	July 1, 2014	June 30, 2015	1-Year % Change
N States	35	35		36		36		35	37	35
AZ	95	0	0%	0	0%	4	4%	97	93	-4%
AR	913	82	9%	68	7%	15	2%	906	913	1%
CA	1,077	67	6%	209	19%	32	3%	1,120 <sup>e</sup>	1,077	-4%
со	28	0	0%	2	7%	1	4%	DNF <sup>*</sup>	29	DNF
СТ	493	4	1%	26	5%	28	6%	521	468	-10%
DE	54	2	4%	1	2%	4	7%	56	52	-7%
FL	848	117	14%	39	5%	19	2%	873	827	-5%
GA	259	0	0%	24	9%	12	5%	249	267	7%
ID	24	5	21%	9	38%	1	4%	26	19	-27%
IL	1,723	69	4%	117	7%	27	2%	1,761	1,686	-4%
IA	400	13	3%	20	5%	7	2%	404	391	-3%
KS	311	13	4%	9	3%	11	4%	319	314	-2%
KY	263	63	24%	74	28%	6	2%	304	263	-13%
LA	453	53	12%	34	8%	11	2%	454	469	3%
MD	135	29	21%	39	29%	11	8%	185*	131	-29%
MA	478	21	4%	84	18%	34	7%	497*	433	-13%
MS	1,100	132	12%	153	14%	26	2%	1,139	1,082	-5%
МО	410	2	0%	29	7%	19	5%	432	393	-9%
MT	52	16 <sup>e</sup>	31%	23	44%	0	0%	51	55	8%
NE	114	0	0%	0	0%	0	0%	114	114	0%
NV	47	11	23%	11	23%	0	0%	47	47	0%
NJ	1,701	DNF	DNF	153	9%	66	4%	1,835	1,612	-12%
NY	DNF	0	DNF	DNF	DNF	DNF	DNF	PD	648	DNF
NC	DNF	61	DNF	42	DNF	20	DNF	1,220	1,436	18%
ND	82	28	34%	15	18%	5	6%	86	79	-8%
ОН	923	39	4%	189	20%	34	4%	921	815	-12%
ОК	16	0	0%	46	288%*	0	0%	47	1*	-98%
PA	973	6	1%	9	1%	42	4%	995	950	-5%
SC	681	56	8%	53	8%	31	5%	701	673	-4%
SD	139	31	22%	31	22%	0	0%	140	140	0%
TN	127	0	0%	20	16%	14	11%	143	109	-24%
TX	3,241 <sup>d</sup>	186 <sup>d</sup>	6%	265 <sup>d</sup>	8%	97 <sup>d</sup>	3%	3,362 <sup>d</sup>	3,186 <sup>d</sup>	-5%
UT	208	23	11%	15	7%	8	4%	202	202	0%
VA	534	22	4%	126	24%	15	3%	613	483	-21%
WA	777	6	1%	4	1%	21	3%	789*	765	-3%
WI	357	0	0%	1	0%	15	4%	366	350	-4%
WY	72	1	1%	<u>·</u> 1	1%	5	7%	75	70	-7%
Reported US Total	19,108	1,158	6%	1,941	10%	641	3%	21,050	20,642	-2%
Estimated US Total	20,933	1,269	6%	2,126	10%	702	3%	22,271	20,642	-7%

<sup>&</sup>lt;sup>d</sup>Other date (Usually August 31, 2015 or June 30, 3014). e Estimate. DNF Did not furnish. \* See state notes in the Appendix. N/A Not applicable. 1 States reporting no state-operated IDD facilities with 16 or more people are not shown (AL, AK, DC, HI, IN, ME, MI, MN, NH, NM, OR, RI, VT, WV).

#### **Daily per Person Expenditures**

Average per-person PRF expenditures in FY 2015 were \$729 per day (\$266,111 per person per year; See **Table 4.3**). The average was \$461 (\$168,265 per person per year using Medicaid Waiver HCBS funds) in Arizona, \$747 per day (\$272,807 per person per year) for ICF/IID settings in 33 reporting states, and \$654 per day (\$238,814 per person per year) for other funded PRFs in three states. Average per person daily costs in ICF/IID facilities ranged from \$334 in South Carolina (\$121,910/year) to \$1,319 in Tennessee (\$481,300/year). The average per person per day costs in ICF/IID settings exceeded \$1,000 in four states (Delaware, Kentucky, Nebraska, and Tennessee). Very high daily per person costs are most common for facilities that are downsizing or closing.

#### Facilities Open on June 30, 2015

Of the 374 PRFs in operation between 1960 and 2015, 219 (59%) had closed by June 30, 2014, 10 (3%) closed during FY 2015, and 145 remained open on June 30, 2015 (See **Table 4.4**). As of June 30, 2015, 12 additional facilities (3%) were projected to close by June 2019. Two additional facilities were projected to close by the end of 2021.

Of the 124 facilities in the RISP PRF longitudinal study, 115 returned FY 2015 surveys (See **Table 4.5**). Responding facilities served 93% of all people reported by state IDD agencies to be living in PRFs. The number of people with IDD per facility on June 30, 2015 ranged from 19 in the Southwest Idaho Treatment Center in Nampa Idaho to 500 in Hunterdon Development Center in Clinton, New Jersey. The average daily population for FY 2015 in the reporting facilities was 189 people. Eighteen facilities reported population declines of 10% or more and two facilities reported a population increase of more than 10% during FY 2015.

In most facilities, the number of people living on the campus was equal to the number of people with IDD served. One or more facility in Arkansas, Georgia, Illinois, Maryland, Missouri, Mississippi, North Carolina, Ohio, South Carolina, Virginia, Washington, Wisconsin, and Wyoming reported one or more person living in the facility who did not have IDD.

**Table 4.2** Number of Short-Term Admissions to PRFs by Funding Authority and State in FY 2015

Chahal	F	unding Authori		Total
State <sup>1</sup>	ICF/IID	Waiver	Non- Medicaid	TOLAI
N States	36	41	40	36
AZ	0	0	0	0
AR	33	0	0	33
CA	0	0	0	0
СО		0	0	
СТ	0	0	0	0
DE	1	0	0	1
FL	0	0	0	0
GA	0	0	0	0
ID	3	0	0	3
IL	0	0	0	0
IA	0	0	0	0
KS	0	0	0	0
KY		0	0	
LA	0	0	0	0
MD	2	0	5	7
MA	2	0	0	2
MS	21	0	0	21
МО	17	0	0	17
MT	0	0	0	0
NE	0	0	0	0
NV	0	0	0	0
NH	0	0	0	0
NJ		0		
NY		0	0	
NC	85	0	0	85
ND	0	0	0	0
ОН	122	0	0	122
ОК	0	0	0	0
PA	0	0	0	0
SC	79	0	0	79
SD	0	0	0	0
TN	0	0	0	0
TX	0	0	0	0
UT	5	0	0	5
VT	0	0	0	0
VA		0	0	
WA	403	0	0	403
WI	179	0	0	179
WY	0	0	0	0
Reported US total	952	0	5	957

<sup>&</sup>lt;sup>d</sup> Other date. e Estimate. DNF Did not furnish. \* See state notes in the Appendix. States with no state-operated IDD facilities in FY 2015 are not shown on this table (AL, AK, DC, HI, IN, ME, MI, MN, NM, OR, RI, and WV).



**Table 4.3** Average Daily Per Person PRF Costs by State and Funding Authority in FY 2015

State<sup>1</sup> HCBS (\$) ICF/IID (\$) Other (\$) N States ΑZ 461 N/A N/A AR N/A 401 N/A CA N/A 946 N/A N/A 792 N/A СТ N/A 985 N/A DE N/A 1,115 N/A FL N/A 364 332 GΑ N/A N/A 552 ID N/A 861 N/A IL N/A 407 407 N/A 842 N/A KS N/A 929 929 KY N/A 1,163 N/A LA N/A 722 N/A 791 d MD N/A 816 MA N/A N/A DNF MS N/A 340 N/A МО N/A 677 N/A MT N/A 716 N/A NE N/A 1,038 N/A N/A 629 N/A NJ N/A 812 DNF NY N/A N/A DNF NC N/A 623 N/A ND N/A 811 N/A ОН N/A 542 N/A ОК N/A N/A N/A PA N/A 933 N/A N/A 334 d N/A SD N/A 481 N/A ΤN N/A 1,319 N/A TX N/A 754 d N/A UT N/A 521 N/A VT N/A N/A N/A ۷A N/A 827 N/A WA N/A 575 N/A WI N/A 870 N/A WY N/A 786 N/A **Estimated US** 461 747 654 Average Average all 729 Types

**Table 4.4** Operational Status of PRFs by State on June 30, 2015 with Projected Closures to June 2019

	Operating Between		onverted nsized¹	Open	Projected to Close July
State	1960 and 2015	1960 to 2014	FY 2015	June 30, 2015	2015 - June 2019
AL	5	5	0	0	0
AK	1	1	0	0	0
AZ	4	3	0	1	0
AR	6	1	0	5	0
CA	13	8	1	4	1
со	3	1	0	2	0
CT	15	10	0	5	1
DE	1	0	0	1	0
DC	3	3	0	0	0
FL	10	5	2	3	0
GA*	12	9	1	2	0
HI	2	2	0	0	0
ID	1	0	0	1	0
IL	17	10	0	7	0
IN	11	11	0	0	0
IA	2	0	0	2	0
KS	4	2	0	2	0
KY	5	2	0	3	0
LA	10	8	0	2	0
ME	3	3	0	0	0
MD*	9	7	0	2	0
MA	11	8	1	2	0
MI	13	13	0	0	0
MN	9	9	0	0	0
MS	6	0	0	6	0
MO	18	11	0	7	1
MT	2	1	0	1	1
NE*	1	0	0	1	0
NV	2	1	0	1	0
NH	2	2	0	0	0
NJ	11	4	2	5	0
NM	3	3	0	0	0
NY*	45	19	1	25	3
NC	6	1	0	5	0
ND	2	1	0	1	0
OH*	22	12	0	10	2
OK*	4	2	2	0	0
OR	3	3	0	0	0
PA	23	18	0	5	0
RI	3	3	0	0	0
SC	5	0	0	5	0
SD	2	1	0	1	0
TN	5	3	0	2	2
TX	15	2	0	13	0
UT	1	0	0	1	0
VT	1	1	0	0	0
VA	8	4	0	4	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
US Total	374	219	10	145	13
% of Total		59%	3%	39%	3%

<sup>\*</sup>See additional state notes in the Appendix. ¹ Downsized facilities serve 15 or fewer people with IDD.

<sup>&</sup>lt;sup>d</sup> Other date (UsuallyAugust 31, 2015 or June 30, 2014). e Estimate. DNF Did not furnish. N/A Not appliable, no facilities of this type \* See state notes in the Appendix. 1 Reported no state-operated facilities with 16 or more people in FY2015: AL, AK, DC, HI, IN, ME, MI, MN, NM, OR, RI, WV.

Average per person per day expenditures in the 100 PRFs reporting expenditures ranged from \$180 in Maryland's Holly Center to \$1,535 in Kentucky's Bingham Gardens in Louisville. Fourteen facilities (14%) reported per diem expenditures of less than \$400, 21 reported per diem expenditures between \$400 and \$599, 36 reported per diem expenditures between \$600 and \$799, and 29 reported expenditures of more than \$800 including 10 that reported per diem expenditures exceeding \$1,000.

The number of admissions or readmissions per facility ranged from zero for 16 facilities to 93 at Florida's Developmental Disabilities Defendant Program in Chattahoochee. The number of discharges per facility ranged from zero in 11 facilities to 149 at Brooklyn Developmentally Disabled Service Offices in New York. Other facilities with more than 50 discharges were at Texas's Mexia State School (80), California's Porterville Development Center (68), and New Jersey's Woodbine Developmental Center (63). Total deaths per facility ranged from zero in nine facilities to 26 in Connecticut's Southbury Training School.

#### PRFs closed by June 30, 2015

State-operated IDD facilities that closed, converted to another use, converted from state-operation to private operation or served fewer than 16 people with IDD on or before June 30, 2015 are listed on **Table 4.6**. The table lists the name of the facility at disposition, the year the facility opened, the calendar year the facility status changed, and the type of final disposition if known. Some of the facilities merged, split off or changed names one or more times while they were open.

#### Closures in FY 2015 included:

- Lanterman Developmental Center (Pomona, CA)
- Templeton Developmental Center (Baldwinville, MA)
- North Jersey Developmental Center (Totowa, NJ)
- Woodbridge Developmental Center (Woodbridge, NJ)
- Capital District DDSO (Schenectady, NY)
- Northern Oklahoma Resource Center (Enid, OK)

#### Other Changes in FY 2015

 Southern Oklahoma Resource Center (Pauls Valley, OK) downsized in FY2015 and closed in FY2016.

- Florida State Hospital Unit 27 merged with the Developmental Disabilities Defendant Program (DDDP) (Chattahoochee, FL),
- · Seguin Unit merged with DDDP (Gainesville, FL),
- Gracewood State School and Hospital, merged with East Central Regional Hospital (Gracewood, GA),

#### **Projected Closures**

Thirteen PRFs serving 16 or more people anticipate closing between July 1, 2015 and June 30, 2017. Two additional PRFs anticipate closing in FY 2018, one in FY 2020, and one in FY 2021. Projected closures by year include:

#### FY 2016 (July 1, 2015 - June 30, 2016)

- Ella T. Grasso Regional Center (Stratford, CT)
- Marshall Habilitation Center (Marshall, MO)
- Brooklyn DDSO (Brooklyn, NY)
- Broome DDSO (Binghamton, NY)
- Clover Bottom Developmental Center (Nashville, TN)
- Northern Virginia Training Center (Fairfax, VA)

#### FY 2017 (July 1, 2016 - June 30, 2017)

- Montana Developmental Center (Boulder, MT)
- Bernard M. Fineson Developmental Center (Hillside: Howard Park, NY)
- Montgomery Developmental Center (Huber Heights, OH)
- Youngstown Center (Mineral Ridge, OH)
- Greene Valley Developmental Center (Greeneville, TN)

#### FY 2018 (July 1, 2017 - June 30, 2018)

- Sonoma Developmental Center (Eldridge, CA)
- Southwestern Virginia Training Center (Hillsville, VA)

#### **FY 2020**

Central Virginia Training Center (Lynchburg, VA)

#### FY 2021

- Fairview Development Center (Costa Mesa, CA)
- Porterville Development Center (Porterville, CA)

#### **Trends in PRF Closures**

Deinstitutionalization trends can be seen by the rate that PRFs were closed, downsized to fewer than 16 people, privatized, or converted for use by a different population (See **Figure 4.1**). Only 12 PRFs closed or converted before 1980. During the 1980's, 45 PRFs closed. PRF closures peaked in the 1990s



Table 4.5 Open PRFS on June 30, 2015: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By Facility Name for Fiscal Year 2015

ARRA Machelipha Inturan Dev. Ctr. (Andeadephale)         1983         478	State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2015	All Residents June 2015	Average Daily with IDD FY 2015	Residents With IDD June 2014	% Change 2014 - 2015	Average Daily Per Person Cost (\$)	Admissions/ Readmissions	Discharges	Deaths
Comment Hold (Notice mellich)         1973         142         142         143         418         4	AR	Arkadelphia Human Dev. Ctr. (Arkadelphia)	1968		117	117	118	118	<u>-</u> -	385	4	2	2
Convolvey)         1959         478 <th< td=""><td>AR</td><td>Booneville HDC (Booneville)</td><td>1972</td><td></td><td>122</td><td>122</td><td>138</td><td>132</td><td>ø,</td><td>382</td><td>4</td><td>13</td><td>_</td></th<>	AR	Booneville HDC (Booneville)	1972		122	122	138	132	ø,	382	4	13	_
Southeast Mediculation (Coloridate)         1970         DNF         DNF         POF	AR	Conway HDC (Conway)	1959		478	478	478	478	0	404	12	4	∞
Automatic programment of Cybarnesis HOC (Warrens) 1973 — 187	AR	Jonesboro HDC (Jonesboro)	1970		102	104	94	86	4	332	16	12	2
Conyonal String Frogram (Coolidge)         1952         87         87         95         96         97	AR	Southeast Arkansas HDC (Warren)	1978		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
Exercise (Cathedral Cloy)         2001         21         51         51         51         51         52         31         43         52         44           Ferriver Dev Ctr. (Catherwile)         1959         Dec. 2021         271         272         273         311         -13         DNF         149         43           Sonoma Dev. Ctr. (Editedique)         1953         Dec. 2021         320         324         439         -10         DNF         48         48           Sonoma Dev. Ctr. (Editedique)         1919         2         22         22         22         29         129         149         949         949         96 </td <td>AZ</td> <td>Arizona Trng. Program (Coolidge)</td> <td>1952</td> <td></td> <td>87</td> <td>87</td> <td>95</td> <td>92</td> <td>8-</td> <td>DNF</td> <td>0</td> <td>0</td> <td>80</td>	AZ	Arizona Trng. Program (Coolidge)	1952		87	87	95	92	8-	DNF	0	0	80
Equation Dev. Ctr. (Costa Mesa)         1999         Dec.         2021         371         271         289         371         -139         one         144           Sonoma Dev. Ctr. (Edicidega)         1933         Dec.         2021         351         353         419         439         -10         10         powe         48           Sonoma Dev. Ctr. (Edicidega)         1891         21         22         22         22         22         22         22         34         1135         powe         38           Grand Junction Regional Ctr. (Wheatridge)         1912         22         22         22         22         22         24         1,135         powe         38           Morthwest Ctr. (Tendricut)         1962         22         22         22         23         38         3	S S	Canyon Springs (Cathedral City)	2001		51	51	51	52	-2	DNF	2	14	DNF
Sonoma Dev. Ctr. (Floridege)         1953         Dec. 2021         361         381         489         410         410         bow         48           Sonoma Dev. Ctr. (Floridege)         1891         201         393         419         439         -10         Dwr         3           Grand Junction Regional Ctr. (Meartidge)         1919         201         22         27         29         -24         1,135         Dwr           Wheat Ridge Regional Ctr. (Meartidge)         1912         129         129         129         129         9         -24         1,135         Dwr           Begantment of Developmental Services North         1965         3         36         40         -10         Dwr         9         36           Lower Fairfield Curry Ctr. (Norwalk)         1956         3         5         5         9         9         9         9         9           Lower Fairfield Curry Ctr. (Norwalk)         1976         3         5         5         9         9         9         9         9           Scotchey Ctr. (George Courry Ctr. (Norwalk)         197         3         16         16         16         175         170         177         177         177           St	S	Fairview Dev. Ctr. (Costa Mesa)	1959		271	271	295	311	-13	DNF	14	43	11
Sonoma Dev. Ctr. (Eldridge)         1891         208         393         393         419         439         -10         DNF         3           Grand Junction Regional Ctr. (Grand Junction)         1919         22         22         27         29         24         1,135         DNF           Wheat Ridge Regional Ctr. (Wheatridgen)         1912         123         123         123         3         645         36         36           Department Developmental Services North         1965         31         31         31         32         35         0	S S	Porterville Dev. Ctr. (Porterville)	1953		361	361	382	401	-10	DNF	48	89	10
Wheat Rigge Regional Ctr. (Grand Junction)         1919         22         22         27         29         24         1,135         DNF           Wheat Rigge Regional Ctr. (Mheatridge)         1912         129 <td< td=""><td>CA</td><td>Sonoma Dev. Ctr. (Eldridge)</td><td>1891</td><td>2018</td><td>393</td><td>393</td><td>419</td><td>439</td><td>-10</td><td>DNF</td><td>3</td><td>37</td><td>12</td></td<>	CA	Sonoma Dev. Ctr. (Eldridge)	1891	2018	393	393	419	439	-10	DNF	3	37	12
Wheat Ridge Regional Ctr. Wheatridge)         1912         129	8	Grand Junction Regional Ctr. (Grand Junction)			22	22	27	29	-24	1,135	DNF	9	1
Morthwest Ctr. (Torrington)         1984         38         38         DNF         DNF         DNF         OP           Ella Grasso Ctr. (Stratford)         1981         June         2016         31         31         32         -3         350         0           Department of Developmental Services North         1965         36         36         36         40         -10         999         0           Lower Fairfield County Ctr. (Norwalk)         1975         291         291         37         40         10         999         0           Southbury Trng. School (southbury)         1940         291         291         37         50         7         1,079         DNF           Stockley Ctr. (Georgetown)         1921         291         31         36         40         -15         1,079         DNF           ObDb. Charland Sollies Defendant Program         1951         16         116         116         126         32         -1         32         33         33           Lacarbale Ctr. (Asarianna)         1951         1921         31         32         4         4         33         33         33           Lacarbale Ctr. (Asarial Regional Hospital (Gracewood & 1927         1951	8	Wheat Ridge Regional Ctr. (Wheatridge)	1912		129	129	123	125	С	645	36	25	4
lead of casso Ctr. (Stratford)         1981         June         2016         31         31         32         350         99         99           Department of Developmental Services North         1965         36         36         40         -10         999         0           Lower Fairfield County Ctr. (Norwalky)         1976         291         291         371         335         -13         1,232         0           Stockley Ctr. (Georgetown)         1921         291         291         371         335         -13         1,232         0           Stockley Ctr. (Georgetown)         1921         291         291         375         52         52         57         57         1,079         poly           Stockley Ctr. (Georgetown)         1971         116         116         126         32         12         32         12	D	Northwest Ctr. (Torrington)	1984		38	38	38	DNF	DNF	DNF	0	0	0
Department of Developmental Services North         1965         36         36         36         36         40         -10         999         0           Lower Fairfield County Ctr. (Norwalk)         1976         59         59         59         59         59         69         99         0           Lower Fairfield County Ctr. (Norwalk)         1970         291         291         311         335         -13         1,323         0         0           Stockley Ctr. (Georgetown)         1921         291         316         116         116         126         -7         1,079         DNF           Developmental Disabilities Defendant Program         1977         116         116         126         126         -7         1,079         DNF           CDDP, Chattahoocheel         1951         1961         316         316         32         -3         33         33         16           Tacachale Ctr. (Marianna)         1921         326         326         401         409         -3         309         8           Tacachale Ctr. (Marianta (Decatur)         1968         18         24         26         4         806         7         309         8           Georgia Regional	Ь	Ella Grasso Ctr. (Stratford)	1981	201	31	31	31	32	۴-	350	0	0	_
Lower Fairfield County Ctr. (Norwalk)         1976         59         59         59         59         59         69         350         0           Southbury Trng. School (Southbury)         1940         291         291         311         335         -13         1,079         DNF           Stockley Ctr. (Georgetown)         1921         25         52         DNF         56         -7         1,079         DNF           Developmental Disabilities Defendant Program         1977         116         116         126         136         -15         332         93           Sunland Ctr. (Abdrainna)         1961         316         316         321         325         -3         321         16           Tacachale Ctr. (Abdrainna)         1921         35         321         401         409         -3         333         16           East Central Regional Hospital (Gracewood & 1921         1921         224         373         216         4         775         23           Augusta)         1876         187         28         24         4         76         775         20           Georgia Regional Hospital of Atlanta (Decatur)         1918         153         124         124         13	b	Department of Developmental Services North Region (Newington)	1965		36	36	36	40	-10	666	0	2	2
Stockley Ctr. (Georgetown)         1940         291         311         335         -13         1,323         0           Stockley Ctr. (Georgetown)         1921         52         52         DNF         56         -7         1,079         DNF           Developmental Disabilities Defendant Program         1977         116         116         126         -15         325         -15         1,079         DNF           Sunland Ctr. (Marianna)         1961         316         316         326         -15         332         93         93           Lacachale Ctr. / Sequin Unit (Gainesville)         1921         395         401         409         -3         331         16           Lacachale Ctr. / Sequin Unit (Gainesville)         1921         224         375         216         4         775         33           Augusta)         1968         43         28         24         4         775         23           Georgia Regional Hospital of Atlanta (Decatur)         1968         43         24         42         46         47         806         7           Glenwood Resource Ctr. (Glenwood)         1917         153         154         157         15         24         805         6 <td>D</td> <td>Lower Fairfield County Ctr. (Norwalk)</td> <td>1976</td> <td></td> <td>59</td> <td>59</td> <td>59</td> <td>59</td> <td>0</td> <td>350</td> <td>0</td> <td>0</td> <td>0</td>	D	Lower Fairfield County Ctr. (Norwalk)	1976		59	59	59	59	0	350	0	0	0
Stockley Ctr. (Georgetown)         1921         52         5DNF         56         -7         1,079         DNF           Developmental Disabilities Defendant Program         1977         116         116         126         136         -15         332         93           Sunland Ctr. (Marianna)         1961         316         316         321         325         -3         331         16           Tacachale Ctr. / Sequin Unit (Gainesville)         1921         395         401         409         -3         331         16           Lacachale Ctr. / Sequin Unit (Gainesville)         1921         224         373         216         4         775         8         8           Augusta)         1968         43         24         42         4         775         23         7           Georgia Regional Hospital of Atlanta (Decatur)         1876         188         42         42         42         7         7         3         7           Glenwood Resource Ctr. (Jenwood)         1917         153         154         154         154         13         1         1         1         1         1         1         1         1         1         1         1         1         <	D	Southbury Trng. School (Southbury)	1940		291	291	311	335	-13	1,323	0	18	26
Developmental Disabilities Defendant Program (DDDP, Chattahoochee)         1961         116         116         126         136         136         136         329         331         16           Sunland Ctr. (Marianna)         1961         316         316         321         325         -3         331         16           Tacachale Ctr. (Marianna)         1921         395         401         409         -3         309         8           East Central Regional Hospital (Graewood & 1921         1921         224         373         216         4         775         23           Augusta)         Georgia Regional Hospital of Atlanta (Decatur)         1876         43         42         42         42         42         775         23           Georgia Regional Hospital of Atlanta (Decatur)         1876         238         246         44         46         47         806         7           Glenwood Resource Ctr. (Glenwood)         1917         153         153         154         157         4         806         7           Woodward Resource Ctr. (Wnna)         1918         191         167         167         167         167         167         167         167         167         167         167	DE	Stockley Ctr. (Georgetown)	1921		52	52	DNF	26	-7	1,079	DNF	0	4
Sunland Ctr. (Marianna)       1961       316       316       325       325       -3       -3       16       16         Tacachale Ctr. / Sequin Unit (Gainesville)       1921       395       395       401       409       -3       309       8         East Central Regional Hospital Gracewood & Augusta)       1921       224       373       216       4       775       23         Georgia Regional Hospital of Atlanta (Decatur)       1876       43       284       42       36       19       1,337       20         Glenwood Resource Ctr. (Glenwood)       1876       153       154       154       157       -4       806       7         Woodward Resource Ctr. (Moodward)       1918       191	H	Developmental Disabilities Defendant Program (DDDP, Chattahoochee)	1977		116	116	126	136	-15	332	93	111	0
Tacachale Ctr. / Sequin Unit (Gainesville)       1921       395       365       401       409       -3       309       8         East Central Regional Hospital (Gracewood & 1921)       1921       224       373       216       215       4       775       23         Georgia Regional Hospital of Atlanta (Decatur)       1968       43       284       42       36       19       1,337       20         Glenwood Resource Ctr. (Glenwood)       1876       238       238       246       248       4       806       7         Woodward Resource Ctr. (Woodward)       1918       19       19       19       24       25       24       861       5         Choate Dev. Ctr. (Anna)       1873       167       167       167       167       167       167       24       861       5         Fox Dev. Ctr. (Dwight)       1965       110       110       111       112       27       27       782       2	႕	Sunland Ctr. (Marianna)	1961		316	316	321	325	-3	331	16	17	8
East Central Regional Hospital (Gracewood & June Adgusts)       1921       224       373       216       42       61       775       23         Georgia Regional Hospital of Atlanta (Decatur)       1968       43       284       42       36       19       1,337       20         Glenwood Resource Ctr. (Glenwood)       1876       238       246       248       -4       806       7         Woodward Resource Ctr. (Woodward)       1917       153       154       157       -3       905       6         Southwest Idaho Treatment Center (Nampa)       1918       167       167       167       167       167       169       -7       504       44         Choate Dev. Ctr. (Anna)       1965       110       110       111       112       -2       782       2	급	Tacachale Ctr. / Sequin Unit (Gainesville)	1921		395	395	401	409	-3	309	8	11	11
Georgia Regional Hospital of Atlanta (Decatur)       1968       43       284       42       36       19       1,337       20         Glenwood Resource Ctr. (Glenwood)       1876       238       238       246       248       -4       806       7         Woodward Resource Ctr. (Woodward)       1917       153       153       154       157       -3       905       6         Southwest Idaho Treatment Center (Nampa)       1873       167       167       167       169       -1       504       44         Fox Dev. Ctr. (Dwight)       1965       110       110       111       112       -2       782       2	GA	ral Regional Hospital (Gracewood	1921		224	373	216	215	4	775	23	9	∞
Glenwood Resource Ctr. (Glenwood)         1876         238         246         248         -4         806         7           Woodward Resource Ctr. (Woodward)         1917         153         153         154         157         -3         905         6           Southwest Idaho Treatment Center (Nampa)         1918         19         24         25         -24         861         5           Choate Dev. Ctr. (Anna)         1873         167         167         167         17         17         782         24	d G	Georgia Regional Hospital of Atlanta (Decatur)	1968		43	284	42	36	19	1,337	20	9	9
Woodward Resource Ctr. (Woodward)         1917         153         154         157         -3         905         6           Southwest Idaho Treatment Center (Nampa)         1918         19         24         25         -24         861         5           Choate Dev. Ctr. (Anna)         1873         167         167         167         169         -1         504         44           Fox Dev. Ctr. (Dwight)         1965         110         111         112         -2         782         2	≤	Glenwood Resource Ctr. (Glenwood)	1876		238	238	246	248	4-	908	7		4
Southwest Idaho Treatment Center (Nampa)         1918         19         24         25         -24         861         5           Choate Dev. Ctr. (Anna)         1873         167         167         167         169         -1         504         44           Fox Dev. Ctr. (Dwight)         1965         110         111         111         112         -2         782         2	⊴	Woodward Resource Ctr. (Woodward)	1917		153	153	154	157	-3	905	9	7	3
Choate Dev. Ctr. (Anna)       1873       167       167       167       169       -1       504       44         Fox Dev. Ctr. (Dwight)       1965       110       110       111       112       -2       782       2		Southwest Idaho Treatment Center (Nampa)	1918		19	19	24	25	-24	861	5	6	1
Fox Dev. Ctr. (Dwight)         1965         110         110         111         112         -2         782         2	⊒	Choate Dev. Ctr. (Anna)	1873		167	167	167	169	-1	504	44	46	0
	=	Fox Dev. Ctr. (Dwight)	1965		110	110	111	112	-2	782	2	4	0

Table 4.5 Open PRFS on June 30, 2015: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By Facility Name for Fiscal Year 2015

State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2015	All Residents June 2015	Average Daily with IDD FY 2015	Residents With IDD June 2014	% Change 2014 - 2015	Average Daily Per Person Cost (\$)	Admissions/ Readmissions	Discharges	Deaths
⊒	Kiley Dev. Ctr. (Waukegan)	1975		187	190	190	198	9-	782	7	17	1
=	Ludeman Dev. Ctr. (Park Forest)	1972		401	401	409	417	4-	782	8	17	7
_	Mabley Dev. Ctr. (Dixon)	1987		101	101	102	101	0	715	4	2	2
=	Murray Dev. Ctr. (Centralia)	1964		221	221	221	232	-5	881	æ	6	5
_	Shapiro Dev. Ctr. (Kankakee)	1879		496	496	512	530	9-	638	12	36	10
KS	Kansas Neurological Institute (Topeka)	1960		144	144	145	145	<u>-</u>	510	4	0	2
KS	Parsons State Hospital (Parsons)	1952		168	168	170	173	-3	419	6	6	9
Ϋ́	Bingham Gardens (Louisville)	1873		24	24	21	21	14	1,535	4	_	0
₹	Bluegrass Oakwood ICF/IID (Somerset)	1972		109	109	114	114	4-	1,180	7	16	С
₹	Hazelwood Ctr. (Louisville)	1971		89	68	06	92	ကု	1,045	2	5	2
≤	Louisiana Special Education Center (Alexandria)	1952		59	59	59	09	-2	929	5	9	DNF
4	Pinecrest Supports and Services Center (Pineville)	1918		410	410	406	400	т	722	48	28	10
Μ	Hogan Regional Ctr. (Hawthorne)	1967		123	123	127	130	-5	797	0	0	7
MA	Wrentham Dev. Ctr. (Wrentham)	1907		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	Holly Ctr. (Salisbury)	1975		64	64	71	71	-10	180	0	1	9
MD	Potomac Ctr. (Hagerstown)	1978		40	41	44	41	-2	984	6	10	2
MO	Bellefontaine Habilitation Ctr. (St. Louis)	1924		126	135	126	133	-5	653	DNF	1	7
ΘW	Higginsville Habilitation Ctr. (Higginsville)	1956		41	41	41	41	0	733	-	0	_
MO	Marshall Habilitation Ctr. (Marshall)	1901	Dec 2015	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	Southeast Missouri Residential Services (Poplar Bluff and Sikeston)	1992		89	89	71	70	£-	509	DNF	DNF	2
MO	St. Louis Dev. Disabilities Treatment Ctrs. (South County Hab. Ctr. St. Louis / St. Charles Hab. Ctr.)*	2002		118	118	DNF	127	-7	641	0	5	4
MS	Boswell Regional Ctr. (Sanatorium)	1976		107	107	105	101	9	369	25	19	1
MS	Ellisville State School (Ellisville)	1920		305	311	341	333	φ	367	2	25	5
MS	Hudspeth Regional Ctr. (Whitfield)	1974		254	254	261	268	-5	300	5	13	9
MS	Mississippi Adolescent Center (Brookhaven)	2011										
MS	North Mississippi Regional Ctr. (Oxford)	1973		249	249	250	258	-3	288	7	11	5
MS	South Mississippi Regional Ctr. (Long Beach)	1978		138	138	143	146	-5	335	9	11	3
M	Montana Developmental Ctr. (Boulder)	1905	June 2017	52	52	DNF	50	4	850	17	16	0



Table 4.5 Open PRFS on June 30, 2015: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By Facility Name for Fiscal Year 2015

State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2015	All Residents June 2015	Average Daily with IDD FY 2015	Residents With IDD June 2014	% Change 2014 - 2015	Average Daily Per Person Cost (\$)	Admissions/ Readmissions	Discharges	Deaths
NC	Black Mountain Ctr. (Black Mountain)	1982		80	151	81	79	-	485	∞	2	2
NO	Caswell Ctr. (Kinston)	1914		338	340	334	342	1-	694	19	7	16
UN	J. Iverson Riddle Dev.Ctr. (Morganton)	1963		286	286	289	296	£-	574	9	6	7
N	Murdoch Ctr. (Butner)	1957		433	440	433	433	0	642	27	19	14
UN	O'Berry Ctr. (Goldsboro)	1957		219	219	223	231	-5	722	1	5	∞
ΩN	Life Skills and Transition Center (Grafton)	1904		79	79	82	98	φ	811	28	30	5
Ä	Sheridan Cottages ICF (Beatrice)	1875		116	116	123	124	9-	1,072	7	6	9
Z	Green Brook Regional Ctr. (Green Brook)	1981		108	108	106	106	2	768	23	13	∞
Z	Hunterdon Dev. Ctr. (Clinton)	1969		200	200	501	501	0-	767	20	т	15
Z	Vineland Dev. Ctr. (Vineland)	1888		268	268	290	285	9-	836	23	26	14
Z	New Lisbon Dev. Ctr. (New Lisbon)	1914		388	388	405	416	-7	958	15	32	11
Z	Woodbine Dev. Ctr. (Woodbine)	1921		342	342	372	371	φ.	958	47	63	13
2	Desert Regional Ctr. (Las Vegas)	1975		47	47	47	47	0	629	11	11	DNF
ž	Bernard M. Fineson Dev. Ctr. (Hillside; Howard Park)	1970	Mar 2017	116	116	DNF	133	-13	DNF	DNF	36	DNF
×	Brooklyn DDSO (Brooklyn)	1972	Dec 2015	29	29	DNF	193	-85	DNF	DNF	149	DNF
×	Broome DDSO (Binghamton)	1970	Mar 2016	114	114	DNF	144	-21	DNF	3	34	DNF
ž	Staten Island DDSO (Staten Island)	1987		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
×	Sunmount DDSO (Tupper Lake)	1965		173	173	DNF	163	9	DNF	28	40	DNF
λ	Valley Ridge (Norwich)	2000		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ЮН	Cambridge Dev. Ctr. (Cambridge)	1965		72	72	88	92	-22	497	17	35	2
НО	Columbus Dev. Ctr. (Columbus)	1857		96	96	95	105	6-	607	20	29	0
НО	Gallipolis Dev. Ctr. (Gallipolis)	1893		73	73	85	88	-18	554	14	21	6
НО	Montgomery Dev. Ctr. (Huber Heights)	1981	June 2017	84	84	87	92	6-	509	9	14	2
НО	Mount Vernon Dev. Ctr. (Mount Vernon)	1948		96	96	66	100	-4	554	12	6	7
НО	Northwest Ohio Dev. Ctr. (Toledo)	1977		95	95	92	92	33	554	18	13	2
ЮН	Southwest Ohio Dev. Ctr. (Batavia)	1981		86	86	93	96	2	515	37	33	3
НО	Tiffin Dev. Ctr. (Tiffin)	1975		96	100	66	66	ç.	514	_	DNF	4
ЮН	Warrensville Dev. Ctr. (Warrensville)	1975		96	96	95	93	3	617	30	22	2
НО	Youngstown Ctr. (Mineral Ridge)	1980	June 2017	71	71	83	85	-16	501	5	17	2

Table 4.5 Open PRFS on June 30, 2015: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By Facility Name for Fiscal Year 2015

State	Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2015	All Residents June 2015	Average Daily with IDD FY 2015	Residents With IDD June 2014	% Change 2014 - 2015	Average Daily Per Person Cost (\$)	Admissions/ Readmissions	Discharges	Deaths
PA	Ebensburg Ctr. (Ebensburg)	1957		238	238	238	246	ကု	871	<b>-</b>	4	5
PA	Hamburg Ctr. (Hamburg)	1960		92	92	96	100	ø <sub></sub>	1,048	0	_	7
PA	Polk Ctr. (Polk)	1897		244	244	232	244	0	1,465	2	_	13
PA	Selinsgrove Ctr. (Selinsgrove)	1929		246	246	248	257	4-	918	_	_	6
PA	White Haven Ctr. (White Haven)	1956		127	127	129	135	9-	914	-	2	7
SC	Coastal Ctr. (Ladson)	1968		152	153	153	160	-5-	DNF	12	1	6
SC	Midlands Ctr. (Columbia)	1956		143	148	144	147	ς-	DNF	14	12	9
SC	Pee Dee Regional Ctr. (Florence) and Thad E. Saleeby Ctr. (Hartsville)	1971		186	189	186	187	<u>-</u>	DNF	26	18	6
SC	Whitten Ctr. (Clinton)	1920		192	196	198	207	-7	DNF	4	12	7
SD	South Dakota Dev. Ctr. (Redfield	1902		140	140	139	140	0	481	45	31	0
Z	Clover Bottom Dev. Ctr. (Nashville)	1923	Nov 2015	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
Z	Greene Valley Dev. Ctr. (Greeneville)	1960	May 2017	88	88	101	115	-23	1,178	0	17	10
X	Abilene State School (Abilene)	1957		321	321	336	356	-10	770	5	24	16
×	Austin State School (Austin)	1917		192	192	223	266	-28	770	0	33	5
X	Brenham State School (Brenham)	1974		279	279	283	283	<u>-</u> -	770	8	13	7
×	Corpus Christi State School (Corpus Christi)	1970		221	221	223	224	1-	770	12	9	7
X	Denton State School (Denton)	1960		458	458	456	460	0-	770	13	13	16
¥	El Paso State Ctr. (El Paso)	1973		106	106	106	110	-4	770	4	7	1
¥	Lubbock State School (Lubbock)	1969		201	201	202	203	<u>-</u>	770	10	6	4
¥	Lufkin State School (Lufkin)	1962		308	308	318	322	-4	770	18	23	10
¥	Mexia State School (Mexia)	1946		256	256	255	288	-11	770	28	80	9
¥	Richmond State School (Richmond)	1968		330	330	330	335	-1	770	11	14	6
X	Rio Grande State Ctr. (Harlingen)	1973		71	71	69	29	9	770	10	80	1
X	San Angelo State School (Carlsbad)	1969		214	214	209	208	3	770	30	22	1
X	San Antonio State School (San Antonio)	1978		229	229	231	240	-5	770	7	13	14
TU	Utah State Dev. Ctr. (American Fork)	1931		203	203	202	203	0	521	23	15	∞
۸۸	Central Virginia Trng. Ctr. (Lynchburg)	1911	2020	234	234	260	286	-18	702	2	38	16
۸ ۸	Northern Virginia Trng. Ctr. (Fairfax)	1973	Mar 2016	57	57	83	106	-46	1,205	0	46	С



**Table 4.5** Open PRFS on June 30, 2015: People Served, Movement Patterns, Average Daily Per Person Cost, Admissions, Discharges and Deaths By Facility Vame for Fiscal Year 2015

VA         Southeastern Virginia Trng. Ctr. (Chesapeake)         1975         June         2018         69         69         69         69         75           VA         Southeastern Virginia Trng. Ctr. (Hillsville)         1976         June         2018         124         133         144           WA         Fircrest (Seattle)         1959         196         196         197         199           WA         Lakeland Village School (Medical Lake)         1939         317         326         211           WA         DSHS Rainier School (Buckley)         1958         67         67         66         70           WA         Yakima Valley School (Selah)         1959         215         229         220         226           WI         Central Wisconsin Ctr. (Madison)         1919         138         142         140         142           WY         Wyoming Life Resource Ctr. (Lander)         1912         70         79         75         76	State	State Facility Name (City) *	Year Opened	(Projected) Closure Date	Residents With IDD June 2015	All Residents June 2015	Average Daily with IDD FY 2015	Residents With IDD June 2014	% Change 2014 - 2015	Average Daily Per Person Cost (\$)	Admissions/ Readmissions	Discharges	Deaths
Southwestern Virginia Trng. Ctr. (Hillsville)       1976       June       2018       124       133         Fircrest (Seattle)       1959       196       196       197         Lakeland Village School (Medical Lake)       1915       200       200       206         DSHS Rainier School (Buckley)       1939       317       326       311         Yakima Valley School (Selah)       1958       67       67       66         Central Wisconsin Ctr. (Madison)       1959       215       229       220         Southern Wisconsin Ctr. (Union Grove)       1919       138       142       140         Wyoming Life Resource Ctr. (Lander)       1912       70       79       72	× ×	Southeastern Virginia Trng. Ctr. (Chesapeake)			69	69	99	75	φ	893	m	∞	-
Fircrest (Seattle)       1959       196       196       197         Lakeland Village School (Medical Lake)       1915       200       200       206         DSHS Rainier School (Buckley)       1939       317       326       311         Yakima Valley School (Selah)       1958       67       67       66         Central Wisconsin Ctr. (Madison)       1959       215       229       220         Southern Wisconsin Ctr. (Union Grove)       1919       138       142       140         Wyoming Life Resource Ctr. (Lander)       1912       70       79       72	۸	Southwestern Virginia Trng. Ctr. (Hillsville)	1976		123	124	133	144	-15	269	2	17	9
Lakeland Village School (Medical Lake)       1915       200       206       206         DSHS Rainier School (Buckley)       1939       317       326       311         Yakima Valley School (Selah)       1958       67       67       66         Central Wisconsin Ctr. (Madison)       1959       215       229       220         Southern Wisconsin Ctr. (Union Grove)       1919       138       142       140         Wyoming Life Resource Ctr. (Lander)       1912       70       79       72	WA	Fircrest (Seattle)	1959		196	196	197	199	-2	296	_	_	7
DSHS Rainier School (Buckley)       1939       317       326       311         Yakima Valley School (Selah)       1958       67       66         Central Wisconsin Ctr. (Madison)       1959       215       229       220         Southern Wisconsin Ctr. (Union Grove)       1919       138       142       140         Wyoming Life Resource Ctr. (Lander)       1912       70       79       72	WA	Lakeland Village School (Medical Lake)			200	200	206	211	-5-	582	0	0	1
Yakima Valley School (Selah)       1958       67       66         Central Wisconsin Ctr. (Madison)       1959       215       229       220         Southern Wisconsin Ctr. (Union Grove)       1919       138       142       140         Wyoming Life Resource Ctr. (Lander)       1912       70       79       72	WA	DSHS Rainier School (Buckley)	1939		317	326	311	305	4	548	2	3	11
Central Wisconsin Ctr. (Madison)       1959       215       229       220         Southern Wisconsin Ctr. (Union Grove)       1919       138       142       140         Wyoming Life Resource Ctr. (Lander)       1912       70       79       72	WA	Yakima Valley School (Selah)	1958		29	29	99	70	4-	DNF	0	0	cc
Southern Wisconsin Ctr. (Union Grove)         1919         138         142         140         70         79         72	M		1959		215	229	220	226	-5	821	DNF	DNF	11
Wyoming Life Resource Ctr. (Lander) 1912 70 79 72	M	Southern Wisconsin Ctr. (Union Grove)			138	142	140	142	£-	946	0	0	4
	₩	Wyoming Life Resource Ctr. (Lander)	1912		70	62	72	9/	8-	718	DNF	_	2

when 93 facilities closed. Thirty-eight PRFs closed in the 2000s. Between 2010 and 2014, 35 PRFs closed (including some closed between July 1, 2014 and December 31, 2014). Survey respondents reported at least 23 additional closures between 2015 and 2024. Based on known closures as of the writing of this report, the decade of the 2010's will be second only to the 1990s in the total number of closures.

#### **Methodology Note**

Data regarding closures and the status of particular state facilities comes from the public residential facility (PRF) survey administered to the facilities and state DD office staff. In several states, the number of facilities reported by state IDD agencies differed from the number of PRFs listed. In a few states, a small number of PRFs are not included in the RISP longitudinal PRF survey sample frame.

States differ in how they report multiple units colocated on a single campus. For example,

- Colorado operates 23 ICF/IID units on two campuses: Grand Junction Regional Center (Grand Junction, CO) and Wheat Ridge Regional Center (Wheat Ridge, CO).
- Beatrice State Developmental Center (Beatrice, NE) is one campus with four ICF/IID units.
- Other facilities are reported separately for the state-level RISP survey but jointly on the PRF. For example,
  - The Sequin Unit at the Alachua Retarded Development Center was reported with the Tacachale Community of Excellence (Gainesville, FL) on the PRF survey
  - East Central Regional Hospital has two campuses (Gracewood & Augusta, GA)
  - Thad E. Saleeby Ctr. (Hartsville, SC) was reported under Pee Dee Regional Ctr. (Florence, SC)

#### TRENDS IN AVERAGE DAILY PRF POPULATION

Nationally, the average daily population of large state-operated IDD facilities decreased 85% from 131,345 people in 1980 to 19,380 people in 2015, an average decrease of 2.4% (3,199 people) per year (See **Table 4.7** and **Figure 4.2**).

ONF Did not furnish \* See state notes in the Appendix

**Table 4.6** 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, 2015

			Fina	al Status
State	Facility Name at Closure, Downsizing or Conversion	Year Opened —	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	
ΑZ	Arizona State Hospital (Phoenix)	1978	1994	
AZ	Arizona Trng. Program (Phoenix)	1973	1988	
ΑZ	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	
СО	Pueblo State Regional Ctr. (Pueblo)	1935	1988	
СТ	Bridgeport Ctr. (Bridgeport)	1965	1981	
СТ	Clifford Street Group Home (Hartford)	1982	1995	
СТ	John Dempsey Ctr. (Putnam)	1964	1997	
СТ	Mansfield Trng. School (Mansfield)	1917	1993	
СТ	Martin House Group Home (Norwalk)	1971	2000	
СТ	Meridan Ctr. (Wallingford)	1979	2014	Downsized
СТ	Mystic Ctr. (Groton)	1979	2010	
СТ	New Haven Ctr. (New Haven)	1962	1994	
СТ	Seaside Ctr. (Waterford)	1961	1996	
СТ	Waterbury Ctr. (Cheshire)	1971	1989	
DC	Bureau of Forest Haven (Laurel, MD)	1925	1990	
DC	D.C. Village (Washington, DC)	1975	1994	
DC	St. Elizabeth's Hopital (Washington, DC)	1987	1994	
FL	Community of Landmark (Miami)	1966	2005	
FL	Florida State Hospital Unit 27 now with DDDP (Chattahoochee)	1976	2015	Merged
FL	Gulf Coast Ctr. (Fort Meyers)	1960	2010	
FL	N.E. Florida State Hospital (MacClenny)	1981	2000	
FL	Seguin Unit now with DDDP (Gainesville)	1989	2015	Merged
FL	Sunland Trng. Ctr. (Orlando)	1960	1984	
FL	Sunland Trng. Ctr. (Tallahassee)	1968	1983	
GA	Brook Run (Atlanta)	1969	1997	
GA	Central State Hospital (Milledgeville)	1842	2012	Converted
GA	Georgia Regional Hospital (Savannah)	2000	2005	
GA	Gracewood State School and Hospital, now East Central (Gracewood)	1921	2015	Merged
GA	Northwest Regional Hospital (Rome)	1971	2011	
GA	River's Crossing (Athens)		1996	
GA	Rose Haven (Thomasville)	1968	2000	



**Table 4.6** 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, 2015

State	Facility Name at Closure, Downsizing or Conversion	Year Opened -	Fina	al Status
			Year	Disposition
iΑ	Southwestern Development Center (Bainbridge)	1967	2000	
iΑ	Southwestern State Hospital (Thomasville)	1967	2013	
Α	West Central Georgia Regional Hospital (Columbus)	2000	2004	
I	Kula Hospital (Kula)	1984	1994	
I	Waimano Trng. School and Hospital (Pearl City)	1921	1999	
	Alton Mental Health & Dev. Ctr. (Alton)	1914	1994	
-	Bowen Ctr. (Harrisburg)	1966	1982	
	Dixon Ctr. (Dixon)	1918	1987	
-	Elgin Mental Health & Dev. Ctr. (Elgin)	1872	1994	
-	Galesburg Ctr. (Galesburg)	1959	1985	
-	Howe Dev. Ctr. (Tinley Park)	1973	2010	
-	Jacksonville Dev. Ctr. (Jacksonville)	1851	2012	
-	Lincoln Dev. Ctr. (Lincoln)	1866	2002	
•	Meyer Mental Health Ctr. (Decatur)	1967	1993	
•	Singer Mental Health & Dev. Ctr. (Rockford)	1966	2002	
N	Central State Hospital (Indianapolis)	1848	1995	
N	Evansville State Hospital (Evansville)	1890	2011	
<b>J</b>	Fort Wayne Dev. Ctr. (Fort Wayne)	1890	2007	
J	Logansport State Hospital (Logansport)	1888	2012	Converted
J	Madison State Hospital (Madison)	1910	2012	Converted
J	Muscatatuck Dev. Ctr. (Butlerville)	1920	2005	
1	New Castle Ctr. (New Castle)	1907	1998	
J	Norman Beatty Memorial Hospital (Westville)	1951	1979	
J	Northern Indiana Ctr. (South Bend)	1961	1998	
J	Richmond State Hospital (Richmond)	1890	2010	
J	Silvercrest State Hospital (New Albany)	1974	1995	
S	Norton State Hospital (Norton)	1963	1988	
S	Winfield State Hospital (Winfield)	1884	1998	
Y	Frankfort State Hospital and School (Frankfort)	1860	1973	
Y	Outwood ICF/IID (Dawson Springs)1	1962	1994	Privatized
A	Acadiana Region Supports and Services Center (lota)	1972	2011	Privatized
A	Bayou Region Supports and Services Center (Thibodaux)	1982	2010	Closed
A	Columbia Dev. Ctr. (Columbia)1	1970	2009	Downsized
Α	Leesville Dev. Ctr. (Leesville)	1964	2012	Downsized
Α	Metropolitan Development Center	1967	2007	
Α	North Lake Supports and Services Center (Hammond)		2012	Privatized
Α	Northeast Supports and Services Center (Ruston)	1959	2010	
A	Northwest Louisiana Dev. Ctr. (Bossier City)	1973	2012	
1E	Aroostook Residential Ctr. (Presque Isle)	1972	1995	
1E	Elizabeth Levinson Ctr. (Bangor)	1971	1998	
1E	Pineland Ctr. (Pownal)	1908	1995	
1D	Great Oaks Ctr. (Silver Springs)	1970	1996	
1D	Henryton Ctr. (Henryton)	1962	1985	
1D	Highland Health Facility (Baltimore)	1972	1989	
1D	Joseph Brandenburg Ctr. (Cumberland)	1978	2011	
	Rosewood Ctr. (Owings Mills)	1887	2009	

**Table 4.6** 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, 2015

State	Facility Name at Closure, Downsizing or Conversion	Year Opened -	Fina	l Status
	. acms, name at closary points. By a contession		Year	Disposition <sup>1</sup>
MD	Victor Cullen Ctr. (Sabillasville)	1974	1992	
MD	Walter P. Carter Ctr. (Baltimore)	1978	1990	
MA	Belchertown State School (Belchertown)	1922	1992	
MA	Berry Regional Ctr. (Hawthorne)	1967	1994	
MA	Glavin Regional Ctr. (Shrewsbury)	1974	2013	
MA	Medfield State Hospital (Medfield)	1898	1994	
MA	Monson Dev. Ctr. (Palmer)	1898	2012	
MA	Paul A. Dever Dev. Ctr. (Taunton)	1946	2001	
MA	Templeton Dev Ctr (Baldwinsville)	1967	2015	
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	
VII	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	
VII	Muskegon Regional Ctr. for DD (Muskegon)	1969	1992	
ΛI	Newberry Regional Mental Health Ctr. (Newberry)	1895	1992	
VII	Northville Residential Trng. Ctr. (Northville)	1972	1983	
MI	Oakdale Regional Ctr. for DD (Lapeer)	1895	1992	
MI	Plymouth Ctr. for Human Development (Northville)	1960	1984	
MI	Southgate Regional Ctr. (Southgate)	1977	2002	
MN	Brainerd Regional Human Services Ctr. (Brainerd)	1958	1999	
MN	Faribault Regional Ctr. (Faribault)	1879	1998	
MN	Fergus Falls Regional Treatment Ctr. (Fergus Falls)	1969	2000	
MN	MN Ext. Treatment Options Program (Cambridge)	1997	2011	Converted
MN	Moose Lake Regional Treatment Ctr. (Moose Lake)	1970	1994	
MN	Owatonna State Hospital (Owatonna)	1945	1972	
ΜN	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	Midtown Habilitation Ctr. (St. Louis)		2004	
ИO	Northwest Habilitation Ctr. (St. Louis)	2002	2012	
MO	Poplar Bluff Regional Ctr. (Poplar Bluff)	1968	1992	
MO	Rolla Regional Ctr. (Rolla)	1968	1984	
MO	Sikeston Regional Ctr. (Sikeston)	1969	1992	
MO	Springfield Regional Ctr. (Springfield)	1967	1990	
ИT	Eastmont Human Services Ctr. (Glendive)	1969	2003	
٧V	Sierra Regional Ctr. (Sparks)	1977	2008	



**Table 4.6** 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, 2015

State	Facility Name at Closure, Downsizing or Conversion	Year Opened 👤	Fina	l Status
	Tuelity Nume at closure, Downsizing or conversion	real Opened	Year	Disposition
IH I	Laconia State School and Trng. Ctr. (Laconia)	1903	1991	
IH I	New Hampshire Hospital, Brown Building (Concord)	1842	1990	
J	Ctr. at Ancora (Hammonton)		1992	
IJ	E.R. Johnstone Trng. & Research Ctr. (Bordentown)	1955	1992	
IJ	Edison Habilitation Ctr. (Princeton)	1975	1988	
J	North Jersey Dev Ctr (Totowa)	1928	2014	
J	North Princeton Ctr. (Princeton)	1975	1998	
J '	Woodbridge Dev Ctr (Woodbridge)	1965	2015	
М	Fort Stanton Hospital and Trng. Ctr. (Fort Stanton)	1964	1995	
M	Los Lunas Hospital and Trng. Ctr. (Los Lunas)	1929	1997	
M	Villa Solano-Hagerman Residential School (Roswell)	1964	1982	
Υ	Bronx DDSO (Bronx)	1971	1992	
Υ	Capital District DDSO (Schenectady)	1973	2015	
Υ	Central New York DDSO (Syracuse)	1851	1998	
Υ	Craig DDSO (Sonyea)	1935	1988	
Υ	Finger Lakes DDSO (Rochester)	1969	2013	
Υ	Gouverneur (New York)	1962	1978	
Υ	Hudson Valley DDSO (Thiells)	1911	2000	
Υ	J.N. Adams (Perrysburg)	1960	1993	
Υ	Long Island DDSO (Commack)	1965	1993	
Υ	Long Island Suffolk DDSO (Melville)	1965	1992	
	Manhattan Ctr. (New York)	1972	1992	
	Newark Ctr. (Newark)	1878	1991	
	Rome Ctr. (Rome)	1894	1989	
	Sampson State School (Willard)	1961	1971	
	Taconic DDSO (Wassaic)	1930	2013	
	Valatie (Valatie)	1971	1974	
	Westchester NY DDSO (Tarrytown)	1979	1988	
	Western NY DDSO (West Seneca)	1962	2011	
	Willowbrook State School (Staten Island)	1947	1988	
	Wilton DDSO (Wilton)	1960	1995	
	Broughton Ctr. (Morganton)	1883	1994	
			1987	
	San Haven State Hospital (Dunseith)	1973		
	Apple Creek Dev. Ctr. (Apple Creek)	1931	2006	
	Athens Mental Health & Dev. Ctr. (Athens)	1975	1994	
	Broadview Ctr. (Broadview Hghts.)	1967	1992	
	Cambridge Mental Health Ctr. (Cambridge)	1978	1990	
	Central Ohio Psychiatric Hospital (Cleveland)	1978	1994	
	Cleveland Ctr. (Cleveland)	1976	1988	
	Dayton Ctr. (Dayton)	1979	1983	
	Dayton Mental Health Ctr. (Dayton)	1978	1994	
	Massillon State Hospital (Massillon)	1978	1994	
Н	Orient Ctr. (Orient)	1898	1984	
H :	Springview Developmental Ctr. (Springfield)	1975	2005	
H '	Western Reserve Psychiatric Hab. Ctr. (Northfield)	1978	1990	
K	Hisson Memorial Ctr. (Sand Springs)	1964	1994	

**Table 4.6** 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, 2015

State	Facility Name at Closure, Downsizing or Conversion	Year Opened —	Fina	l Status
		. car opened	Year	Disposition <sup>1</sup>
ЭК	Robert M. Greer Memorial Ctr. (Enid)	1992	2000	Privatized
ΣK	Southern Oklahoma Resource Center (Pauls valley)	1952	2015	
OR	Columbia Park Hospital & Trng. Ctr. (The Dalles)	1963	1977	
OR	Eastern Oregon Trng. Ctr. (Pendleton)	1964	2009	
OR	Fairview Trng. Ctr. (Salem)	1908	2000	
PA	Allentown Mental Retardation Unit (Allentown)	1974	1988	
PA	Altoona Ctr. (Altoona)	1982	2006	
PA	Clarks Summit Mental Retardation Unit (Clarks Summit)	1974	1992	
PA	Cresson Ctr. (Cresson)	1964	1982	
PA	Embreeville Ctr. (Coatesville)	1972	1997	
PA	Harrisburg Mental Retardation Unit (Harrisburg)	1972	1982	
PA	Hollidaysburg Mental Retardation Ctr. (Hollidaysburg)	1974	1976	
PA	Laurelton Ctr. (Laurelton)	1920	1998	
PA	Marcy Ctr. (Pittsburgh)	1975	1982	
PA	Mayview Mental Retardation Unit (Mayview)	1974	2001	
PA	Pennhurst Ctr. (Pennhurst)	1908	1988	
PA	Philadelphia Mental Retardation Unit (Philadelphia)	1983	1989	
PΑ	Somerset Mental Retardation Unit (Somerset)	1974	1996	
Α	Torrance Mental Retardation Unit (Torrance)	1974	1998	
PA	Warren Mental Retardation Unit (Warren)	1975	1976	
PΑ	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	
el .	Dr. Joseph H. Ladd Ctr. (N. Kingstown)	1908	1994	
	Zamborano Memorial Hospital (Wallum Lake)	1967	1989	
	Custer State Ctr. (Custer)	1964	1996	
	Arlington Dev. Ctr. (Arlington)	1969	2010	
	Harold Jordan Habilitation Ctr. (Nashville)	1979	2003	
	Winston Ctr. (Bolivar)	1979	1998	
	Ft. Worth State School (Ft. Worth)	1976	1996	
	Travis State School (Austin)	1961	1996	
	Brandon Trng. School (Brandon)	1915	1993	
	Eastern State Hospital (Williamsburg)		1990	
	Southside Virginia Trng. Ctr. (Petersburg)	1939	2014	
	Southwestern State Hospital (Marion)	1887	1988	
	Western State Hospital (Stanton)	1828	1990	
	Frances Haddon Morgan Ctr. (Bremerton)	1972	2011	
	Interlake School (Medical Lake)	1967	1994	
	Colin Anderson Ctr. (St. Mary's)	1932	1994	
	·	1932		
	Greenbrier Ctr. (Lewisburg)		1994	
	Spencer State Hospital (Spencer)	1893	1989	
	Weston State Hospital (Weston) Northern Wisconsin Ctr. (Chippewa Falls)	1985 1897	1988	Converted

<sup>&</sup>lt;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 facility.



The fourteen states that closed all of their IDD facilities between 1980 and 2015 included: Alabama, Alaska, the District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia. The number of states with more than 1,000 people living in large facilities declined from 32 in 1980 to 5 in 2015. All of the states with one or more facility open on June 30, 2015 had reductions in average daily population between 1980 and 2015. States with open PRFs in 2015 with the largest reductions since 1980 were Oklahoma (-99%), Colorado (-98%), Maryland (-95%), Tennessee (-94%), Idaho (-94%), North Dakota (-92), Georgia (-90%), and Delaware (-90%).

Nationally, the average daily population of large state IDD facilities decreased 39% from 31,654 in 2010 to 20,933 in 2015. States that closed their last PRF between 2010 and 2015 were Alabama, Indiana, Minnesota, and Oregon. Of the states with open PRFs in 2015, the largest population reductions since 2010 were in Oklahoma (-94%), Tennessee (-69%), Georgia (-68%), Idaho (-65%), Louisiana (-60%), Virginia (-55%), and California (-50%). Kentucky reported an increase of 55% in their PRF population between 2010 and 2015.

## Average Daily Population PRFs 1880 to 2015

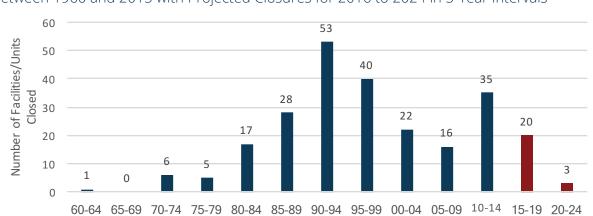
While data on the number of people with IDD in stateoperated psychiatric facilities is only available since 1950, periodic reports chronicled the population of state-operated IDD facilities back to 1880 when the average daily population was 2,429 people (Lakin, 1979). Estimates of the average daily populations of state IDD facilities have been available since 1926 when the population was 55,466.

Remarkably, the average daily population of state IDD facilities in 2015 (20,003 people) was smaller than in any recorded year in more than a century. The average daily population of state-operated IDD facilities exceeded 25,000 between 1910 when the average daily population was 19,499 and 2013 when it was 23,724.

# Average Daily Population of PRFs plus State-Operated Psychiatric Facilities from 1890 to 2015

Of the estimated 148,209 people living in state-operated institutions serving 16 or more people with IDD in 1950, 124,304 lived in PRFs, and 16% (23,905 people) lived in psychiatric facilities (See **Table 4.8** and **Figure 4.3**). The total combined population peaked in 1967 at 228,500. The population dropped by 43% from 1967 to 1980 (140,750 people), 63% from 1967 to 1990 (85,726 people), 79% from 1967 to 2000 (48,360 people), and 91% from 1967 to in 2015 (20,933 people).

The number of people with IDD living in stateoperated psychiatric facilities declined 99% from



**Figure 4.1** Number of PRFs Closed, Downsized, or Converted to Non-IDD Use or Nonstate Operation Between 1960 and 2015 with Projected Closures for 2016 to 2024 in 5-Year Intervals

Count for 2010-2014 adjusted for facility scheduled to close in 2015 that did not close until 2015.

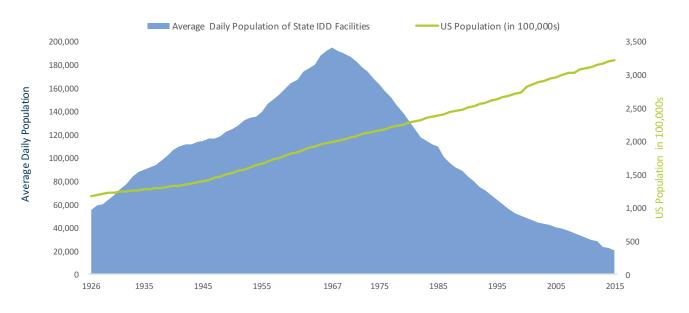
37,641 people in 1960 to 300 people in 2008. However, while the number of people reported to be in those settings remained below 1,000 from 2000 to 2011, the number has increased each year since then and was 2,094 in 2015.

#### Discussion

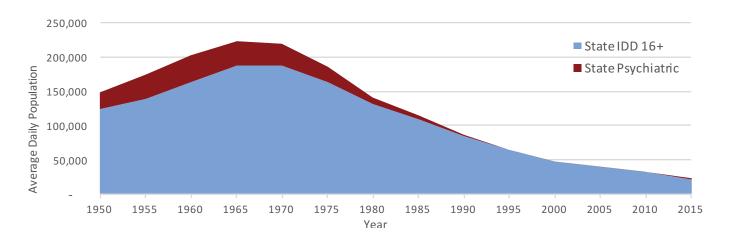
Utilization of state-operated psychiatric facilities to serve people with IDD may have changed over time for several different reasons. For example,

legislation in the late 1960s and early 1970s allowed states to obtain federal Medicaid cost sharing for institutional services provided in ICF/IIDs and in nursing homes, but prohibited use of Medicaid funding people for ages 18 to 64 years in facilities for "mental disease." This provided a significant incentive for states to move people with IDD from psychiatric facilities to IDD units or separate IDD facilities and was largely responsible for the decline in the proportion of people with IDD in psychiatric facilities between 1950 and 2000.

**Figure 4.2** Average Daily Population of State-Operated IDD Facilities Serving 16 or More People and Total US Population 1926 through 2015



**Figure 4.3** Average Daily Population of State-Operated IDD Facilities Serving 16 or More People and Total US Population 1926 through 2015





**Table 4.7** Average Daily PRF Population by State Selected Years 1980 to 2015

State -				Average Daily	Population				% ch	ange
State	1980	1985	1990	1995	2000	2005	2010	2015	1980- 2015	2010-2015
N States	51	51	51	51	51	51	50	49	49	34
AL	1,651	1,422	1,305	985	642	212	178	0	-100	N/A
AK	86	76	58	33	0	0	0	0	-100	N/A
AZ	672	538	360	183	166	138	119	95	-86	-20
AR	1,550	1,254	1,260	1,262	1,229	1,079	1,067	913	-41	-14
CA	8,812	7,524	6,768	5,494	3,879	3,307	2,149	1,077	-88	-50
CO	1,353	1,125	466	241	129	110	DNF	28	-98	DNF
CT	2,944	2,905	1,799	1,316	992	847	705	493	-83	-30
DE	518 775	433 351	345 309	308	256 0	123	71	54	-90 -100	-24 N/A
FL	3,750	2,268	1,992	1,502	1,508	1,341	963	848	-77	-12
GA	2,535	2,200	2,069	1,979	1,510	1,202	802	259	-90	-68
HI	432	354	162	83	0	0	0	0	-100	-06 N/A
ID	379	317	210	139	110	94	68	24	-94	-65
IL	6,067	4,763	4,493	3,775	3,237	2,833	2,183	1,723	-72	-03
IN	2,592	2,248	1,940	1,389	854	456	205	0	-100	N/A
IA	1,225	1,227	986	719	674	646	525	400	-67	-24
KS	1,327	1,309	1,017	756	379	360	340	311	-77	-9
KY	907	671	709	679	628	489	170	263	-71	55
LA	3,171	3,375	2,622	2,167	1,749	1,571	1,144	453	-86	-60
ME	460	340	283	150	0	0	0	0	-100	N/A
MD	2,527	1,925	1,289	817	548	380	138	135	-95	-2
MA	4,531	3,580	3,000	2,110	1,306	1,089	759	478	-89	-37
MI	4,888	2,191	1,137	392	271	173	0	0	-100	N/A
MN	2,692	2,065	1,392	610	42	29	25	0	-100	N/A
MS	1,660	1,828	1,498	1,439	1,383	1,359	1,324	1,100	-34	-17
МО	2,257	1,856	1,860	1,492	1,286	1,152	671	410	-82	-39
MT	316	258	235	163	131	84	52	52	-84	0
NE	707	488	466	414	401	372	182	114	-84	-37
NV	148	172	170	160	157	93	47	47	-68	0
NH	578	267	87	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	-77	-37
NM	500	471	350	221	0	0	0	0	-100	N/A
NY	15,140	13,932	7,694	4,552	2,466	2,233	2,019	DNF	DNF	DNF
NC	3,102	2,947	2,654	2,288	1,939	1,736	1,515	DNF	DNF	DNF
ND	1,056	763	232	156	144	140	120	82	-92	-32
ОН	5,045	3,198	2,665	2,150	1,996	1,728	1,376	923	-82	-33
OK	1,818	1,505	935	618	391	368	270	16	-99	-94
OR	1,724	1,488	838	462	62	43	22	0	-100	N/A
PA	7,290	5,980	3,986	3,460	2,127	1,452	1,189	973	-87	-18
RI	681	415	201	0	0	0	0	0	-100	N/A
SC	3,043	2,893	2,286	1,788	1,129	953	786	681	-78	-13
SD	678	557	391	345	196	172	149	139	-79	-7
TN	2,074	2,107	1,932	1,669	948	680	416	127	-94	-69
TX	10,320	9,638	7,320	5,459	5,431	4,977	4,337	3,241	-69	-25
UT	778	706	462	357	240	230	215	208	-73	-3
VT VA	331 3,575	200	180	2 240	1 625	1 524	0 1,197	0	-100 oc	N/A -55
		3,069	2,650	2,249	1,625	1,524	•	534	-85 -65	
WA	2,231 563	1,844 498	1,758 304	1,320 94	1,143	973	914	777		-15 N/A
WI	2,151	2,058	1,678	1,341	900	590	448	357	-100 -83	-20
WY	473	413	367	1,341	113	98	83	72	-83 -85	-20 -14
	4/3	413	307	131	113	30	0.5	12	-03	-14
Reported Total	131,345	109,614	84,239	63,762	47,872	40,532	31,654	19,108	-85	-40
Estimated total	131,345	109,614	84,239	63,762	47,872	40,532	31,654	20,933	-84	-34

d 2014 data. e Estimate. DNF Did not furnish. N/A No people in large state facilities in 2010, 2015, or both. \* See state notes in the Appendix.

The number of states that reported the number of people in psychiatric facilities declined from 50 in 2000 to 34 in 2015. For state IDD facilities, **Table 4.8** shows reported totals for people in state IDD facilities. However, the numbers shown for psychiatric facilities is not adjusted for missing states because there has not been sufficient information on which to base an estimate.

While variations in response rates for utilization of state-operated psychiatric facilities contributes to instability in the year-to-year totals, decreases

in the number of reporting states is unlikely to be responsible for the increased totals reported since 2010. Further analyses are needed to identify the reason for the increase. Increased utilization of state-operated psychiatric facilities may be due to increased diagnosing of mental health disorders in people with IDD, increasing awareness of fetal alcohol spectrum disorder and autism spectrum disorder, shortages of community based mental health services, and/or a shift to using mental health facilities for certain people as PRFs are downsized or closed.

**Table 4.8** 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 1890-2015

	Av	erage Daily Populatio	n	- % in	US Population -	Per 10	0,000 of the Popul	ation
Year	State IDD	State Psychiatric	Total	Psychiatric	(100,000) <sup>s</sup>	State IDD	State Psychiatric	Total
1890	5,103				629.8	8.1		
1910	19,499				922.3	21.1		
1923	47,963				1,119.5	42.8		
1930	68,035				1,232.2	55.2		
1935	89,760				1,272.5	70.5		
1940	106,944				1,321.6	80.9		
1945	114,018				1,399.3	81.5		
1950	124,304	23,905	148,209	16%	1,513.3	82.1	15.8	97.9
1955	138,831	34,999	173,830	20%	1,650.7	84.1	21.2	105.3
1960	163,730	37,641	201,371	19%	1,806.7	90.6	20.8	111.5
1965	187,305	36,285	223,590	16%	1,650.7	113.5	22.0	135.5
1970	186,743	31,884	218,627	15%	2,050.5	91.1	15.5	106.6
1975	162,654	22,881	185,535	12%	2,159.7	75.3	10.6	85.9
1980	131,345	9,405	140,750	7%	2,277.3	57.7	4.1	61.8
1985	109,614	4,536	114,150	4%	2,384.7	46.0	1.9	47.9
1990	84,239	1,487	85,726	2%	2,499.7	33.7	0.6	34.3
1995	63,762	1,381	65,143	2%	2,630.8	24.2	0.5	24.8
2000	47,872	488	48,360	1%	2,823.9	17.0	0.2	17.1
2005	40,532	396	40,928	1%	2,961.9	13.7	0.1	13.8
2006	38,810	361	39,171	1%	2,990.0	13.0	0.1	13.1
2007	37,172	782	37,954	2%	3,020.0	12.3	0.3	12.6
2008	35,651	300	35,951	1%	3,018.0	11.8	0.1	11.9
2009	33,682	417	34,099	1%	3,074.4	11.0	0.1	11.1
2010	31,654	873	32,527	3%	3,087.5	10.3	0.3	10.5
2011	29,809	864	30,673	3%	3,115.9	9.6	0.3	9.8
2012	28,146	1,075	29,221	4%	3,139.1	9.0	0.3	9.3
2013	23,724	1,151	24,875	5%	3,161.3	7.5	0.4	7.9
2014	22,262	1,295	23,557	5%	3,188.6	7.0	0.4	7.4
2015	20,933	2,094	23,027	9%	3,214.2	6.5	0.7	7.2

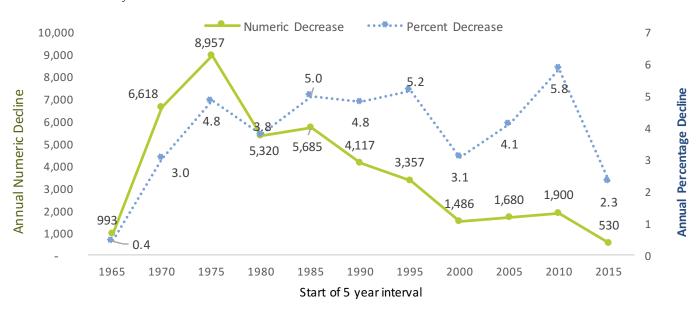
<sup>1</sup> States that did not report number of people with IDD in psychiatric settings by year are as follows: 2000 (NY); 2001 (NJ,NY,VA); 2002 (NJ,NY,VA); 2003 (CO,NY,VT); 2004 (IN,NJ); 2005 (CO,NJ,VT); 2006 and 2007 (CO,CT,NJ,VT); 2008 (CT, IN, NJ, VT); 2009 (CT, NJ, VT); 2010 (CA, CO, CT, ID, NC);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



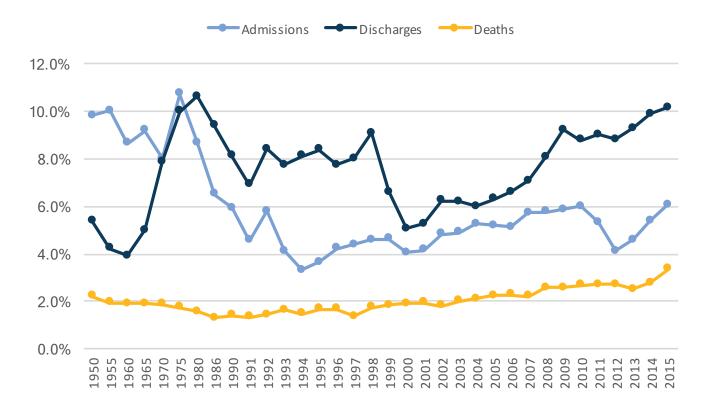
# Rate of Decrease in the Population of State-Operated IDD or Psychiatric Facilities of 16 or More People

Between 1965 and 1969, the number of people with IDD in large state IDD or psychiatric facilities declined at a rate of 993 people per year (See **Figure 4.4**). The peak rate of reduction in absolute numbers was

**Figure 4.4** Average Annual Numeric and Percentage Decrease in the Number of People with IDD in PRFs or State Psychiatric Facilities in Five Year Intervals 1965 to 2015



**Figure 4.5** Annual PRF Admissions, Discharges and Deaths as a Proportion of the Average Daily Population, Selected Years 1950 to 2015



**Table 4.9** Change in Average Daily Population and Annual Admissions, Discharges and Deaths in PRFs Selected Years 1950-2015

Year	Average Daily	Annı	ual Number of		One Year
	Population	Admissions	Discharges	Deaths	Net Change
1950	124,304	12,197	6,672	2,761	2,764
1955	138,831	13,906	5,845	2,698	5,363
1960	163,730	14,182	6,451	3,133	4,598
1965	187,305	17,225	9,358	3,585	4,282
1970	186,743	14,979	14,702	3,496	(3,219)
1975	168,214	18,075	16,807	2,913	(1,645)
1980	128,058	11,141	13,622	2,019	(4,500)
1986	100,190	6,535	9,399	1,322	(4,186)
1990	84,732	5,034	6,877	1,207	(3,050)
1991	80,269	3,654	5,541	1,077	(2,964)
1992	75,151	4,349	6,316	1,075	(3,042)
1993	71,477	2,947	5,536	1,167	(3,756)
1994	67,673	2,243	5,490	995	(4,242)
1995	63,697	2,338	5,337	1,068	(4,067)
1996	59,936	2,537	4,652	996	(3,111)
1997	56,161	2,467	4,495	777	(2,805)
1998	52,469	2,414	4,761	908	(3,255)
1999	50,094	2,317	3,305	927	(1,915)
2000	47,872	1,936	2,425	915	(1,404)
2001	46,236	1,927	2,433	897	(1,403)
2002	44,598	2,149	2,785	803	(1,439)
2003	43,289	2,117	2,679	873	(1,435)
2004	42,120	2,215	2,534	887	(1,206)
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	24,490	1,124	2,275	617	(1,768)
2014	22,156	1,199	2,191	616	(1,608)
2015	20,933	1,269	2,126	702	(1,560)

between 1975 and 1980 with an average decline of 8,957 people per year. The average annual decline was 5,320 people between 1980 and 1985, and 5,685 people between 1985 and 1990. The average annual decline slowed to 1,486 people per year moving out of large facilities between 2000 and 2005 but increased to an average of 2,086 people per year moving out of large facilities between 2010 and 2015.

A different pattern emerges when looking at reductions in percent rather than in raw numbers. The percent reduction in the average daily population in large state IDD or psychiatric facilities exceeded 3% in each five-year interval since 1970. The average decline on average every year was -4.8% of people in facilities from 1975-1980, -3.8% from 1980-1985, -5% from 1985-1990, -4.8% from 1990-1995, -5.2% from 1995-2000, -3.1% from 2000-2005, -4.1% from 2005-2010, and the largest ever percentage decrease was from 2010-2014 with a reduction of -5.8% of people with IDD living in large facilities.

#### Admissions, Discharges and Deaths

**Table 4.9** show annual admissions, discharges, and deaths for PRFs between 1950 and 2015. Transfers between PRFs are not included. In 1950, PRFs reported an average daily population of 124,304 with 12,197 (10%) admissions, 6,672 (5%) discharges, and 2,761 (2.2%) deaths. In 2015, the average daily population was 20,933 with 1,269 admissions (6%), 2,126 discharges (10%), and 702 deaths (3.4%).

Annual admissions as a proportion of the average daily population declined from 10% to 7% between 1950 and 1986, from 6% to a low of 3% between 1990 and 1994, were between 4% and 5% from 1995 to 2006, and increased slightly to between 5% and 6% between 2006 and 2015 (See **Figure 4.5**).

Annual discharges as a proportion of the average daily population increased from lows of 4% in 1955 and 1960 to a high of 11% in 1980. Discharges ranged from 7% to 8% from 1990 to 1997, increased to 9% in 1998, declined to between 5% and 7% from 1999 through 2007, and increased from 8% to 10% between 2008 and 2015.

Annual deaths of people residing in PRFs as a proportion of the average daily population declined from 2.2% in 1950 to 1.3% in 1986, rose to 2.2% in 2007, and continued to rise reaching 3.4% by 2015. People who died while living in a PRF were 33% of all leavers in 1960, declined to 12% by 1986, increased to 16% by 1998, increased to between 22% and 27% between 1999 and 2014, and were 25% in 2015. The rate of deaths increased as the proportion of people in PRFs in the oldest age groups increased (See **Figure 4.7**).

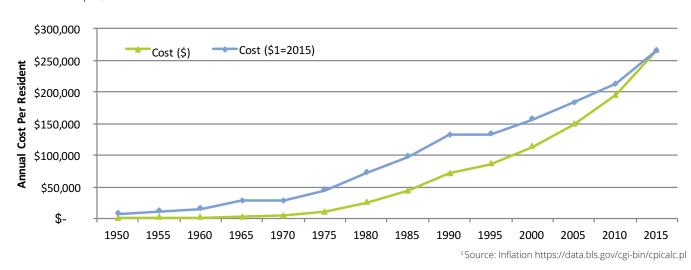


#### **Annual per Person Cost for PRFs**

The annual per person cost for PRFs increased from \$746 in 1950 to \$266,111 in 2015. Adjusted for inflation to 2015, the costs increased from \$7,478 in 1950 to \$98,281 in 1985, \$202,659 in 2007, and \$270,464 in 2013. They declined slightly to \$266,111 in 2015 (See **Table 4.10** and **Figure 4.6**).

Several factors influenced changes in per person expenditures. In 1970, one year before enactment of the ICF/IID program, average annual per person expenditures were \$28,504 (in 2015 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

**Figure 4.6** Average Annual Per Person Expenditures for State-Operated IDD Facilities Serving 16 or More People, Selected Years 1950-2015





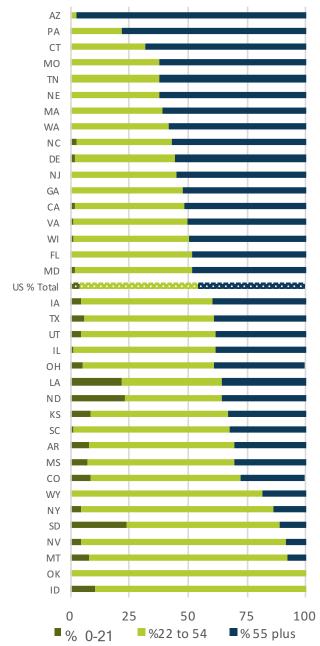
**Table 4.10** Annual Per Person Expenditures for People with IDD Living in PRFs Selected Years 1950-2015

Year	Cost (\$)	Cost (\$1=2015) s
1950	746	7,478
1955	1,286	11,492
1960	1,868	15,054
1965	2,361	17,826
1970	4,635	28,504
1975	10,155	45,188
1980	24,944	72,088
1985	44,271	98,281
1990	71,660	131,855
1995	85,760	133,786
2000	113,863	157,131
2005	148,811	183,037
2006	167,247	197,351
2007	176,226	202,659
2008	188,318	205,267
2009	196,710	218,348
2010	195,197	212,765
2011	226,106	239,672
2012	237,149	246,635
2013	265,161	270,464
2014	258,796	258,796
2015	266,111	266,111

States provided the average daily cost per person, this is the average daily cost per person ICF/IID facilities with 16 or more people in the United States. s Source: Inflation https://data.bls.gov/cgi-bin/cpicalc.pl

daily activities and improve physical environments. By 1977, more than 70% of all PRFs were ICF/IID certified and by 1980, annual per person expenditures had more than doubled to \$72,088. By 2000, expenditures doubled again to 157,131. Since 2000, continuing population declines in smaller settings have contributed to increasing per person expenditures, since fixed costs (e.g., grounds, utilities, food service, laundry, physical plant and so forth) were shared

**Figure 4.7** Percent of PRF Residents by Age Group and State on June 30, 2015



by fewer people. Declines in inflation adjusted expenditures occurred during the great recession between 2009 (\$218,348) and 2010 (\$212,765) and again as several high cost large facilities closed between 2013 (\$270,464) and 2015 (\$266,111).



## STATUS AND TRENDS IN THE CHARACTERISTICS OF People LIVING IN PRFS

#### Age in 2015

Based on the PRF survey, in 2015, 4% of all PRF residents were age 21 years or younger (736 people), 19% were 22 to 39 years (3,985 people), 56% were 40 to 62 years (11,594 people), 21% were 63 years old or older (4,303 people), and age was unknown for 0.1% (See **Table 4.11**). States serving the highest proportion of people 21 years or younger in 2015 were South Dakota (24%), North Dakota (23%) and Louisiana (22%). States in which 80% or more of the 2015 population were between 22 and 54 years

were Oklahoma (100%), Idaho (89%), Nevada (87%), Montana (85%), New York (82%) and Wyoming (81%). Fourteen states reported more than 50% of all PRF residents were 55 years or older. States with the highest proportions in the ages 55 years or older group in 2015 were Arizona (98%), Pennsylvania (78%) and Connecticut (68%).

#### **Age Trends**

The age composition of people living in PRFs has been steadily shifting from young to old (See **Figure 4.8**). The proportion (and estimated number) of residents who were 21 years or younger on June 30 was

• 36% (54,400 people) in 1977

**Table 4.11** Proportion of People with IDD Living in PRFs by Age Group and State on June 30, 2015

	<u> </u>	<u> </u>				0 1		,	
				Age Gro	up (Years)				Reported
State	0-14	15-18	19-21	22-39	40-54	55-62	63+	Unknown	Residents
AZ	0	0	0	0	2	41	56	0	87
AR	1	3	4	25	37	22	9	0	819
CA	0	0	2	26	20	30	21	0	1,076
СО	0	1	7	36	26	17	10	2	151
СТ	0	0	0	4	28	25	43	0	455
DE	0	0	2	12	31	27	29	0	52
FL	0	0	0	22	29	25	23	0	827
GA	0	0	0	9	38	19	33	0	267
ID	0	11	0	68	21	0	0	0	19
IL	0	0	1	20	41	24	14	0	1,683
IA	0	2	3	28	28	24	16	0	391
KS	1	4	4	24	35	23	10	0	312
KY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	4	10	7	23	20	16	20	0	469
MD	0	1	1	24	26	30	18	0	104
MA	0	0	0	2	37	28	33	0	123
MS	2	2	4	32	31	16	15	0	1,053
МО	0	0	0	8	29	39	24	0	353
MT	0	0	8	67	17	4	4	0	52
NE	0	0	0	10	28	38	24	0	116
NV	0	0	4	72	15	6	2	0	47
NJ	0	0	0	7	38	30	25	0	1,606
NY	0	0	4	54	28	9	4	0	432
NC	0	1	1	11	30	27	30	0	1,356
ND	8	10	5	16	25	18	18	0	79
ОН	0	1	3	25	29	21	17	2	877
ОК	0	0	0	0	100	0	0	0	1
PA	0	0	0	3	19	40	38	0	947
SC	0	0	1	19	48	18	14	0	673
SD	6	8	10	52	14	6	4	0	140
TN	0	0	0	5	33	35	27	0	88
TX	1	2	2	21	34	22	17	0	3,186
UT	0	1	3	24	33	25	14	0	203
VA	0	0	1	16	32	26	25	0	484
WA	0	0	1	13	28	27	31	0	780
WI	0	1	0	13	37	29	21	0	353
WY	0	0	0	30	51	0	19	0	70
US % Total	0	1	2	19	32	24	21	0	19,731
U.S. Est. Total	103	264	369	3,985	6,540	5,054	4,303	25	20,642
		,		-,	-,5.0	-,	.,505		

<sup>&</sup>lt;sup>1</sup> Stateswith no state-operated IDD facilities of 16 or more people are not shown. DNF Data not furnished or insufficient reporting (60% or less of the total population in state IDD facilities represented). N = 113 facilities reported

- 4% (1,306 people) in 2010
- 4% (736 people) in 2015

The proportion (and estimated number) of residents who were 63 years or older on June 30 was

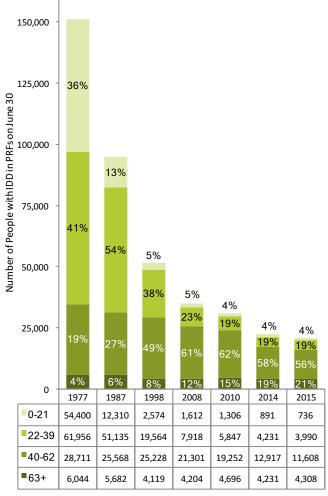
- 4% (6,044 people) in 1977
- 15% (4,696 people in 2010
- 21% (4,308 people) in 2015

Change in the number and proportion of PRF residents 21 years or younger has mirrored the overall rise and fall of the average daily population of those facilities (See **Figure 4.9**). Between 1950 and 1965 the proportion of PRF residents 21 years or younger increased from 39% to a high of 49%. Between 1965 and 1977 (two years after PL 94-142 "The Education for All Handicapped Children Act" was enacted), the number of people 21 years or younger in large state IDD facilities decreased from 91,592 to 54,098 (41%). The proportion 21 years or younger continued to decrease and has been less than 5% since 1995.

#### **Level of Intellectual Disability in 2015**

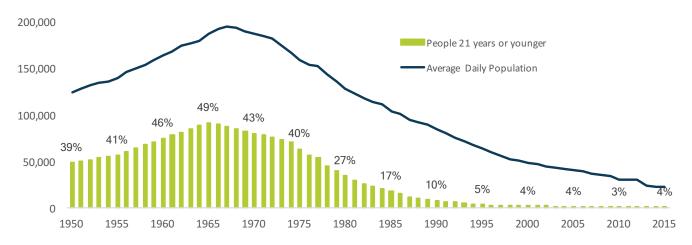
Respondents reported level of ID for 19,718 of the estimated 20,642 PRF residents on June 30, 2015 (See **Table 4.12** and **Figure 4.10**). On June 20, 2015, an estimated 55% of the people living in large state IDD facilities had profound ID, 16% had severe ID, 14% had moderate ID and 13% had mild or no intellectual disability, (level of ID was unknown for 2%).

**Figure 4.8** Estimated Number and Proportion of People in PRFs by Age Group on June 30 of Selected Years 1977 to 2015



This figure excludes people whose age was unknown.

Figure 4.9 Average Daily Population of PRFs and Percent 21 Years or Younger, 1950 to 2015





**Table 4.12** Proportion of People with IDD Living in PRFs by Level of Intellectual Disability and State on June 30, 2015

			vel of Intellectual Disa				Reported Resident
State	None	Mild ID	Moderate ID	Severe ID	Profound ID	Unknown	
AZ	0	7	17	30	46	0	87
AR	0	7	11	18	64	0	819
CA	0	25	11	14	49	1	1,076
СО	0	31	17	13	32	7	151
СТ	0	6	12	23	59	0	455
DE	0	0	6	13	81	0	52
L.	2	26	17	10	44	1	827
GA	0	3	5	15	72	6	267
D	0	32	37	26	5	0	19
L	0	12	18	18	46	6	1,683
A	0	22	17	17	45	0	391
KS	0	16	16	16	53	0	312
KY	DNF	DNF	DNF	DNF	DNF	DNF	DNF
_A	0	21	22	9	48	0	469
MD	0	14	14	14	56	1	104
MA	0	14	7	28	51	0	123
MS	0	5	10	15	70	0	1,053
MO	0	14	18	30	37	0	353
MT	2	73	21	4	0	0	52
NE	0	13	16	17	54	0	116
٧V	9	23	26	26	17	0	47
NJ	0	11	8	12	69	0	1,606
NY	2	56	16	6	11	9	432
NC	0	4	10	17	68	1	1,356
ND	3	38	11	10	33	5	79
OH	0	12	32	19	35	2	877
OK	0	0	0	0	100	0	1
PA	0	5	7	15	73	0	947
SC	0	5	14	16	64	0	673
SD	0	56	31	6	7	0	127
ΓN	0	2	2	11	84	0	88
ГХ	0	16	15	15	53	1	3,186
JT	0	8	5	11	65	11	203
/A	0	2	9	19	70	0	484
NA	0	7	13	18	61	1	780
WI	0	1	3	25	71	0	353
WY	0	9	6	16	70	0	70
Total Percent	0	13	14	16	55	2	19,718
Estimated Total	41	2,749	2,815	3,281	11,444	312	20,642

States with no state-operated facilities are not shown on this table. DNF Data not furnished or insufficient reporting (60% or less) from among the large state facilities. N = 113 facilities reported; N = 19,718

There were dramatic differences between states in the distribution of level of intellectual disability among PRF residents on June 30, 2015. The proportion of residents with no, mild or moderate ID ranged from 0% in Oklahoma to 96% in Montana. In addition to Montana, states reporting that more than half of all PRF residents had no, mild or moderate ID included South Dakota (87%), New York (74%), Idaho (68%), Nevada (57%) and North Dakota (52%).

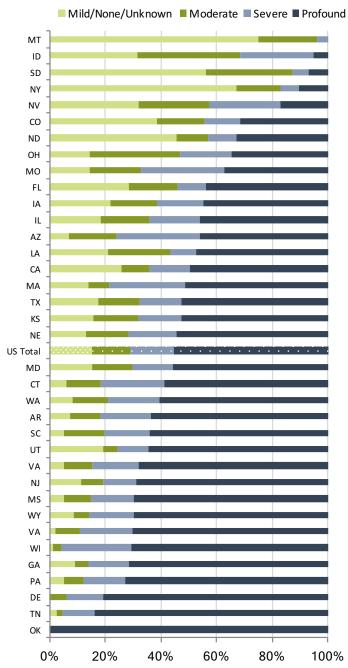
At the other end of the spectrum, more than half of all PRF residents on June 30, 2015 had profound ID. The proportion of residents with profound ID ranged from none in Montana to

100% in Oklahoma. In addition to Oklahoma, states reporting that 70% or more of all PRF residents had profound ID included Tennessee (81%), Delaware (81%), Pennsylvania (73%), Georgia (72%), Wisconsin (71%), and Virginia (70%).

#### **Level of Intellectual Disability Trends**

As the census of large state IDD facilities declined from its peak of 194,650 in 1967, the characteristics of the people served also changed (See **Figure 4.11**). Between 1964 and 1977, the total census declined from 179,629 to 151,112 but number of people with profound ID increased from 48,492 (27% of the

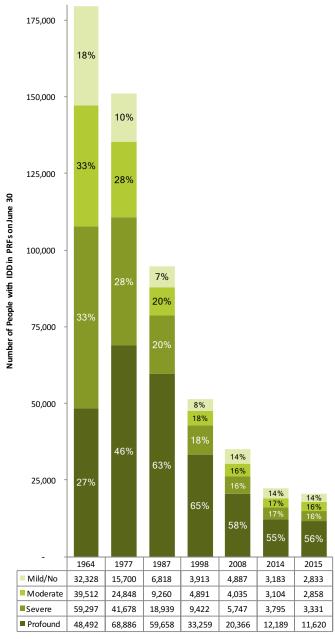
**Figure 4.10** Percent of People Living in PRFs by Level of Intellectual Disability by State on June 30, 2015



Note: Kentucky did not furnish sufficient data for percentage by ID level. Oklahoma was in the process of closing their last facility of this kind.

1977 total) to 68,886 (46% of the 1977 total). The proportion with profound ID continued to increase until it reached 65% in 1998. Since 1998 both the number and proportion of residents with profound ID has decreased reaching 58% in 2015. While the number of people with mild, moderate or no IDD

**Figure 4.11** Estimated Number and Proportion of People with IDD Living in PRFs by Level of Intellectual Disability on June 30 of Selected Years 1964 to 2015



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

decreased from 8,804 in 1998 to 5,354 in 2015, the proportion increased from 8% to 14%.

 The proportion (and estimated number) of PRF residents who had profound ID was



- 46% (68,886 people) in 1977
- 59% (18,489 people) in 2010
- 56% (11,620 people) in 2015
- The proportion (and estimated number) of PRF residents with mild or no ID was
  - 10% (15,700 people)in 1977
  - 12% (3,701 people) in 2010
  - 14% (2,833 people) in 2015

• 14% (2,633 people

**Discussion** 

Dramatic state to state differences in the age and level of intellectual disabilities of people living in PRFs in FY 2015 suggests there is not a single profile of the "typical" person living in PRFs. In fact, there are likely at least two subpopulations - one group is young and has mild or moderate intellectual disabilities the second is older and has profound intellectual disabilities. Additional information about the variety of support needs in the PRF population is in the FY 2014 RISP report. In that report we noted that more than half of all people remaining in PRFs have a behavior or psychiatric disorder requiring ongoing supervison or intervention. We also noted that 39% of PRF residents needed assistance or supervision walking, 55% needed assistance dressing, and 53% used a nonverbal form of communication.

Since 15 states no longer operate any PRF's we can conclude that it is possible to serve people across the age range and across the spectrum of level of intellectual disability in community settings. The challenges to overcome to move the remaining people in PRFs to community settings will likely vary from state to state. There are now models throughout the country of how to build community infrastructures to address the full array of support needs of people similar to those who are still in PRFs. States that continue to operate PRFs may find it useful to consult with states that have closed all of those facilities for ideas about the critical elements that must be built into community infrastructures to serve people like those still in PRFs. The 2014 HCBS rules offer guidance about processes to develop individualized personcentered plans, and to develop services in inclusive environments that support full participation in community for the people who will be leaving institutions in the coming years.

Since 2000, more than 41,000 people with IDD have moved from PRFs to homes in community settings, including 14,000 who moved since 2010. Only 20,933 people remain. With the support and advice of states who have already closed their last PRF, the goal of closing the last of the PRFs by 2030 seems in reach.







**SECTION FIVE** 

### **STATE NOTES AND PROFILES**

**FY 2015** 



#### **SECTION 5: STATE NOTES AND PROFILES**

#### STATE NOTES

#### **Alabama**

Beginning in FY 2015, people waiting for but not receiving LTSS were excluded from the count of people living in the home of a family member.

Medicaid Waiver expenditures by age were reported only for 290 of the 495 recipients living in family homes.

#### Alaska

The people in ICF/IID live out of state.

#### **Arizona**

Arizona manages ICF/IID settings within their 1115 Managed Care Demonstration Waiver. ICF/IID data for 2013 and 2014 were updated in this report.

#### California

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

#### Colorado

More people enrolled in Supported Living services in FY2015 than had in previous years, resulting in greater total caseload.

Colorado reported one state-operated facility for 7-15 people and one for 16 or more people in FY 2015. It operates multiple facilities on two different campuses. Grand Junction Regional Center was not reported as an institutional setting in FY 2014 because the center operates units both on the campus and in the community. In FY 2015, Grand Junction was reported as a facility with 16 or more people on campus. Grand Junction's community ICF/ IIDs serve 15 or fewer people and are reported in the smaller setting sizes. The 129 people reported on Table 4.5 in Wheat Ridge Regional Center are likely reported in setting sizes with fewer than 16 people.

People reported in nonstate other type facilities are living in Personal Care Alternative settings, which are residential settings for 1-2 residents.

#### Connecticut

The waiting list is not limited to people requesting Medicaid Waiver but most people on the 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 included only state-operated ICF/IID settings by age from FY2013 through FY2015. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the total number of people, expenditures and cost per person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

The count of large state-operated ICF/IID facilities reflects one large institution and five regional centers. Admissions and readmissions all reflect individuals entering regional centers. There have been no admissions since 1986.

#### **Delaware**

Beginning in FY 2013, Family Support Specialist services were categorized as LTSS and recipients were added to the count of those living in the home of a family member.

ICF/IID recipients and expenditures included only state-operated ICF/IID settings by age from FY2013 through FY2014. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the total number of people, expenditures and cost per person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

#### **Florida**

In FY 2015, the Florida State Hospital Unit 27 merged with the Developmental Disabilities Defendant program in Chattahoochee. The Seguin Unit-Alachua Defendant Ctr. (Gainesville) merged with the Tacachale Community of Excellence.

#### Georgia

For the FY 2015 survey of large state-operated IDD facilities the Gracewood and Augusta Campuses of the East Central Regional Hospital were reported together.

#### Idaho

FY2014 report of IDD caseload ages 22 years or older may have been underestimated due to a different data filtering system.

Idaho redesigned its children's IDD Waiver program in FY 2015 resulting in a large increase in the number of people ages birth to 21 years receiving Waiver-funded supports.

Some nonstate group homes serve multiple populations. Only people with IDD in those homes are reported.

The Idaho State School and Hospital was renamed Southwest Idaho Treatment Center.

#### Illinois

People who are 21 years old are reported with the 22 years or older group in Section 4.

#### Indiana

The number service recipients in the home of a family member increased in FY 2014 when access to the Family Supports Waiver was expanded.

#### **Kansas**

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

Some Survey, Certification, Licensing providers are listed in group homes.

ICF/IID recipients and expenditures included only nonstate-operated ICF/IID settings by age from FY2013 through FY2015. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the total number of people, expenditures and cost per person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

#### Kentucky

Total IDD caseload is an estimate and does not include people served by state general funds (some of whom are also Medicaid Waiver recipients). Age breakdowns were not available for people served by state general funds.

The number of people on the IDD caseload receiving one or more Medicaid or state-funded

long-term support or service only includes Medicaid Waiver recipients.

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

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

Residence type was unknown for 651 of the 4,312 people using Supports for Community Living (SCL) Waiver services.

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

The state-operated Bingham Gardens facility was renamed Central State/Bingham Gardens. Outwood (Dawson Springs) was converted from a state-operated to a nonstate facility in 2014.

#### Maine

Maine has four short-term stay state-operated facilities. No residents are reported because none of the residents stayed for more than 90 days.

There were 305 people in "nonstate other" settings which were private, non-medical facilities. Those people were included in the totals only on Tables 1.7 and 1.9 because size information was not available.

Medicaid expenditures for FY 2013 were based on the authorized budget, but for FY 2014 were based on paid claims.

#### Maryland

People listed in the "nonstate other" category received Community Coordination Services, Behavior Support Services (BSS), and Residential, Individual Family Care (IFC), or self-directed supports.

#### Massachusetts

The number of service recipients reported by setting type includes only people ages 22 years or older. In previous years, children living with a family member who received LTSS were reported.



#### Michigan

The number of people in nonstate settings is 19,004. Setting size information is unknown for 8,664 people. People reported in nonstate setting size categories include those eligible for the State's Medicaid programs (1915(b), 1915 (c), 1915(i), managed care with LTSS, and State Plan Targeted Case Management.

The "nonstate other" category includes people eligible for Medicaid/State and 26 people who are homeless, in prison, or who live in other institutional settings.

Michigan began reporting the number of 1915(b/c) waiver recipients in FY 2011 accounting for the jump in waiver recipients for that year.

#### Minnesota

Nonstate other settings include Customized Living (Assisted Living) and Board and Care. Most Customized Living arrangements are funded through Medicaid Waiver-funded supports.

In FY 2015, 416 family foster care homes were converted into corporate foster care settings with shift staff while still serving the same individuals at the same address. The number of people reported to be living in host home foster family settings versus group home settings changed as a result.

Nonstate group homes are corporate foster care settings where people with IDD or other health conditions reside. Minnesota tracks the number of people who receive long term supports and services for settings of 1-4 people typically, and under certain circumstances up to 5 people with IDD or other mental and physical health conditions. Setting size information based on claims is not available for 1-3 and 4-6, but is reported for 1-6. The most reliable number for people with IDD in nonstate group homes is for setting size 1-6.

#### Mississippi

Alternate data sources were used for the number of people with IDD in nursing homes (AHCA, 2017).

ICF/IID recipients and expenditures included only state-operated ICF/IID settings by age from FY2013 through FY2015. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the total number of people, expenditures and cost per

person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

#### Missouri

State general revenue funds are appropriated for in-home supports through regional autism projects and for general in-home services to families.

Host homes were a relatively new service in FY13 and 14. More individuals are now taking advantage of it, which explains the sharp increase in number of facilities and people.

MO received a large appropriation in FY15 to eliminate its in-home waiting list. MO also received supplemental funding late in FY14 to deal with increased demand for crisis placements. The second half of that funding was received in FY15.

Recipients of Targeted Case Management are included in Medicaid State Plan recipient count. These individuals were formerly reported as receiving no LTSS funding. Beginning in FY 2015, only individuals on the wait list are reported as receiving No Long-term Supports and Services funding. Of those, 356 individuals got active case management, and roughly, 10 were waiting for service coordinator assignment.

#### Montana

Children ages 1-3 receiving Part C and/or SSBG Title XX funding are reported on the caseload this year, but were not previously.

Prior to 2015, people waiting for services who received case management services were not included in the caseload. All people with DD 16 years or older are entitled to Medicaid State Plan-funded Case Management services.

The number of Type II (Group Home) settings was reported incorrect in 2012 and earlier. The number of group homes for one to three people were significantly over counted. The numbers reported from 2013 onward are felt to be correct.

#### Nebraska

The number of large state-operated facilities varies across tables because the Beatrice State Development Center is a single campus, but four buildings are licensed separately.

#### Nevada

Nevada does not recognize or offer group home services.

The "nonstate other" category includes hospitals, correctional/ incarceration facilities, and rehabilitation centers serving 16 or more people. Those settings served multiple populations not just people with IDD.

ICF/IID recipients and expenditures included only state-operated ICF/IID settings by age from FY2013 through FY2015. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the total number of people, expenditures and cost per person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

#### **New Hampshire**

An alternate data source was used for total ICF/IID expenditures (Eiken et al., 2017). The same number of people were reported in ICF/IID facilities from FY2013 to FY2015, but total expenditures and expenditures per person varied.

#### **New Jersey**

The total caseload decreased significantly between FY2014 to FY 2015 because 2,000 people who were not receiving or requesting services were moved off the caseload because they declined to seek eligibility.

All state-operated facilities for 1-15 people were converted to nonstate-operated facilities in FY15.

Twelve people with developmental disabilities are housed in a separate building at an ICF/IDD as they have been convicted of crimes and have been court ordered to be in a disability rehabilitation setting. These people are reported as living in an "Other Funded" ICF/IID facility, although no such facilities are reported, as a means of noting the difference in their living setting.

Changes to the statewide data led to the significant decrease in the number of people with IDD living in the home of a family member reported in FY15.

An alternative data source was used for Medicaid Waiver and ICF/IID expenditures (Eiken et al., 2017).

ICF/IID recipients and expenditures included only state-operated ICF/IID settings by age from FY2013 through FY2015. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the

total number of people, expenditures and cost per person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

#### **New Mexico**

Due to the transition to a new Third Party Assessor, there have been extended delays in processing DD Waiver claims. This has affected the numbers reported on the FY 2015 survey (Spring 2015 to current).

New Mexico has 25 state-operated group homes with 1 to 4 residents.

Type I (Nonstate ICF/IID), Type II (Group Home), and Type III (Host Family/Family Foster Care) settings and residents are estimated based on a count of five providers operating residences with 1 to 6 occupants, assuming those settings operate at or near capacity.

Total Waiver and ICF expenditures by age were imputed based on the number of recipients in each age group.

Alternative data sources were used for ICF/ IID residents (AHCA, 2017), ICF/IID and Waiver expenditures (Eiken et al., 2017).

#### **New York**

The number of people waiting to live in a non-family setting includes only those who indicated they wanted to move within two years from when they were last interviewed by Office for People with Developmental Disabilities (OPWDD) staff.

New York operated 6 large IDD residential campus facilities and 18 community ICF/IID facilities serving 16 people or more people as of June 30, 2015. The 18 state-operated community ICF/IID facilities were not included in the survey of large state IDD facilities.

#### **North Carolina**

The Local Management Entities/Managed Care Organizations (LME-MCO) system continues to transition. NC increased the use of (b)(3) services under its 1915 b/c waiver. These changes, in addition to NC's continued work to improve its LME-MCO's data collection and reporting procedures and processes, may explain the reported increase in caseload. Most but not all of the LME-MCOs reported data for the FY 2015 report.



NC 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). In the past, the Black Mountain Center, a Skilled Nursing Facility, was included in NC's list of large state-operated facilities with 16 or more individuals.

OBNMTC is a specialized Nursing Facility (NF) for individuals with intellectual disabilities and complex medical and/or behavior concerns that co-exist with neuro-cognitive disorders. OBNMTC also serves individuals who receive ICF/IID level of care. As of 2003, OBNMTC no longer accepts admissions to either NF or ICF/IID units, as it is transitioning all of its beds to specialized nursing level of care.

#### **North Dakota**

Medicaid Waiver recipients receiving day and employment services but not in-home or residential services are include in the overall count of Waiver recipients but their living arrangements are not reported.

The North Dakota Development Center was renamed Life Skills & Transition Center.

#### Ohio

Medicaid Waiver recipients in the "nonstate other" category include recipients in other, unknown, or temporary living arrangements. The total number of Waiver recipients reported is larger than the total by setting type because it includes Waiver recipients living in other, unknown, and temporary living arrangements.

The number of state-operated facilities with 16 or more people open between 1960 and 2015 was reduced from 23 to 22 in FY 2015 because one facility had previously been counted twice due to a name change.

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 closed its publicly operated ICF/IID (The Northern Oklahoma Resource Center, November 2014 and The Southern Oklahoma Resource Center, July 2015). Many of the individuals who moved could not be served in private ICF/IID and now receive Medicaid Waiver-funded supports.

ICF/IID recipients and expenditures included only state-operated ICF/IID settings by age from FY2013 through FY2015. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the total number of people, expenditures and cost per person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

Oklahoma has four Medicaid Waivers. Two are capped and comparable to the private institutions: CAP \$21k for adults and private institutions \$54k. The other two waivers are comprehensive serving only people with high needs. Their costs are over \$65k and over \$120K.

#### Oregon

Oregon began offering home and community based services through the Medicaid State Plan 1915(k) funding authority in FY 2015. Medicaid Waiver recipients and expenditures declined as recipients moved from the Waiver to the State Plan 1915(k) funding authority.

#### Pennsylvania

All Medicaid Waiver recipients with housing in FY 2015 were included in the setting type and total recipient sections. The expenditures section only included people with Waiver funding on June 30, 2015.

#### **Rhode Island**

ICF/IID recipients and expenditures included only state-operated ICF/IID settings by age from FY2013 through FY2015. Both state and nonstate ICF/IID settings were included from FY2013 to FY2015 in the total number of people, expenditures and cost per person. An alternate data source was used for the total ICF/IID expenditures (Eiken et al., 2017).

The list of large-state operated IDD facilities open on June 30, 2015 does not include the BHDDH/RICLAS Special Care Facility or the Tavares Pediatric Center.

#### **South Carolina**

Pee Dee Regional & Thad E. Saleeby Centers submitted one joint PRF survey for FY 2015.

#### **Tennessee**

Tennessee does not collect data on the number of people waiting to live in a setting other than the home of a family member. Tennessee's estimate is

based on number of people on waiting list in crisis and urgent category.

There are children living in ICF/IID settings but the number of people was not available by age.

The increase in ICF/IID recipients between 2013 and 2014 reflects better data about public and private facilities.

#### **Texas**

The fiscal year ends on August 31 of each year (rather than June 30) in Texas.

Texas uses an interest list, instead of a waiting list. This means that anyone can sign up for the interest list. They are not evaluated for eligibility until their name is reached.

Small ICFs in Texas have a capacity of six people. There are also medium sized and large ICFs in Texas with greater capacity.

Twenty-two children in congregate settings were in an "Out of State" Residential Treatment Center; 29 lived in In-State congregate settings.

Alternative data sources were used for the number of people in nursing facilities (AHCA, 2017).

#### Virginia

The number of children with IDD in nursing homes was not reported prior to FY2014.

#### Washington

The number of people in Own Home settings was lower in FY 2014 and FY2015 than in previous years because data were not available for those individuals for all funding authorities.

"Nonstate other" settings included assisted living, generic nursing and correctional facilities as well as people who were homeless.

The State-operated ICF/IID and nursing facility are on the same campus and are reported together.

#### Wisconsin

Total caseload reported increased in FY15 due to inclusion of children not receiving services.

The number of adults in Type IV vs Type V home settings is estimated based on a ratio, derived

from functional screening data collected from each individual annually, but it is not specific to the requested June 30th point in time.

Wisconsin's financial data are usually not available until after the survey deadline. Wisconsin elected to post the previous FY's financial data, beginning with the 2015 RISP survey, in order to ensure complete data, as well as consistency across internal and external reports, which also follow this reporting methodology.

Beginning in FY 2014, the number of people living family home and some other settings includes LTSS recipients whose services are not funded by a Waiver. Prior to FY 2015, only waiver recipients in those settings were counted.

There are three large state-operated IDD facilities in WI. One of them (The Northern Wisconsin Center) was converted into a short-term stay facility in 2005.

#### **West Virginia**

IDD units in two state psychiatric facilities were erroneously listed as open in the FY 2013 report. They are not included in the FY 2015 report.

ICF/IID data for June 30, 2016 was used for this report.

#### **Wyoming**

Only people receiving Medicaid Waiver-funded supports are counted in the nonstate group home, host/foster family home, and own home setting types. LTSS recipients with IDD in those settings whose supports were funded by another funding authority are not included.

In FY14 Wyoming completed their waiver redesign project, which included several cost cutting measures. Since most of the participants that completed the process to become actively enrolled during FY15 did not have complete plans, providers did not bill for services. This caused the large decline in expenditures and the influx of participants.

Alternative data sources were used to estimate the number of ICF/IID recipients (ACHA, 2017).



#### STATE PROFILES

Profiles for each state and for the United States describe LTSS recipients and expenditures for people with IDD in FY 2015 and summarize historical trends in the provision of LTSS by state IDD agencies.

#### **Reading the State Profiles**

Blank spaces or breaks in a trend line indicate years in which the data were not collected or that a state provided incomplete or no data. Large year-to-year changes may reflect changes in data source or methodology, the addition or termination of a funding authority, or inclusion of a narrower or broader set of recipients. The State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation.

Figure 1 shows the number people with IDD living in Medicaid Intermediate Care Facilities for People with Intellectual Disabilities (ICF/IID) between 1977 and 2015 and the number of Medicaid Waiver recipients with IDD between 1982 and 2015. Complete data on ICF/IID and Waiver recipients by year and state can be viewed in the Chart Gallery of the RISP.umn.edu website.

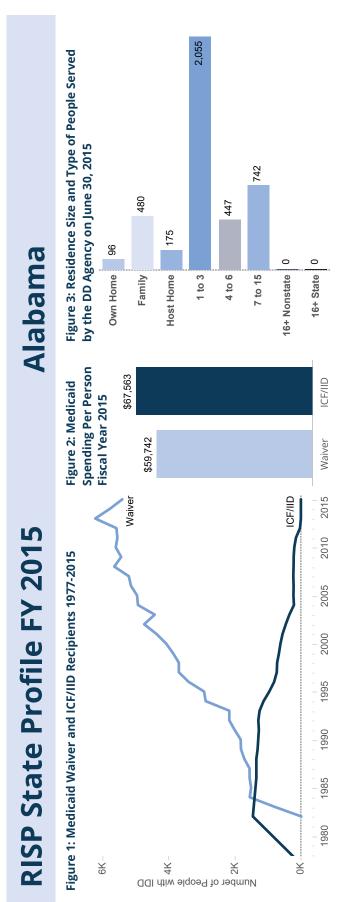
Figure 2 shows average annual per person ICF/ IID and Medicaid Waiver expenditures for the year ending June 30, 2015. Average per person Medicaid expenditures for other years can be viewed in the Chart Gallery of the RISP.umn.edu website.

Figure 3 shows the number of LTSS recipients with IDD living in various types of residential settings on June 30, 2015. Setting types include the home of a family member, a person's own home, host/family foster homes, IDD group settings serving 1 to 3, 4 to 6, 7 to 15 or 16 or more people at a single location. IDD settings of 16 or more people are divided into state- and nonstate-operated facilities.

Table 1 shows data for selected years on the types and size of places in which people with IDD lived. It also shows the number of people living with a family member who were waiting for Medicaid Waiverfunded LTSS, the total number of people served by state IDD agencies, Medicaid Waiver and ICF/IID per

person expenditures, and the number of Medicaid Waiver and ICF/IID recipients per 100,000 of the state's population.

Operational definitions for the waiting list questions were clarified in 2015 (see text for details). A few states changed their reporting based on the clarifications. Differences between 2013, 2014 and 2015 waiting list numbers may be due to this change.



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Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				27	222	213	127	110	132	96
Individualized	Family				99	3,441	3,659	1,895	2,324	2,512	480
Settings	Host Home				101	247	220	166	205	210	175
	1 to 3				975	1,202	1,715	2,110	2,047	1,931	2,055
People in	4 to 6				253	399	488	527	467	403	447
Congregate	1 to 6	49	121	295	1,228	1,601	2,203	2,637	2,514	2,334	2,502
Settings	7 to 15	61	183	585	795	897	206	816	200	644	742
	16+	1,995	1,639	1,258	665	214	173	0	0	0	0
People Served by	People Served by Caseload (known to the DD agency)								9,246	9,018	8,893
the DD Agency	LTSS Recipients *(1)	2,105	1,943	2,138	2,882	6,622	7,375	6,495	5,862	5,832	3,995
	Waiting for Medicaid Waiver *				214	807	2,372	2,901	2,975	3,186	3,432
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,321	26	971	777	854	901	926	935
Settings	Psychiatric Facility *(2)			0	0	0	0	0	0	0	20
Medicaid	Waiver Expenditures per Person			\$6,136	\$23,518	\$44,111	\$48,505	\$51,517	\$50,434	\$54,844	\$59,742
Recipients and	ICF/IID Expenditures per Person			\$56,475	\$101,021	\$113,534	\$162,893	\$19,232	\$127,455	\$78,035	\$67,563
Expenditures :	Waiver Recipients per 100,000			49.4	92.2	109.2	117.7	116.2	129.2	119.7	111.6
	ICF/IID per 100,000			31.5	14.2	5.3	4.5	6.0	0.3	0.3	0.3

Settings by size include ICF/IID, group homes, and nonstate other, but if nonstate other data is DNF it is assumed to be zero. DNF = Did Not Furnish. PD = Partial data (a DNF present in a calculation). (s) Data may be from an outside source. \* See state notes and the RISP FY2015 report for further explanation. (1) Long Term Supports and Service (LTSS) recipients may include imputed values to replace DNF; up until 2012 people in psychiatric and nursing homes not served directly by the DD agency may be part of LTSS recipients. (2) Psychiatric Facility data prior to 2013 was only for state facilities, after 2013 it includes people in state and nonstate operated facilities when available, see report for details. Updated 9/20/2017





# Alaska

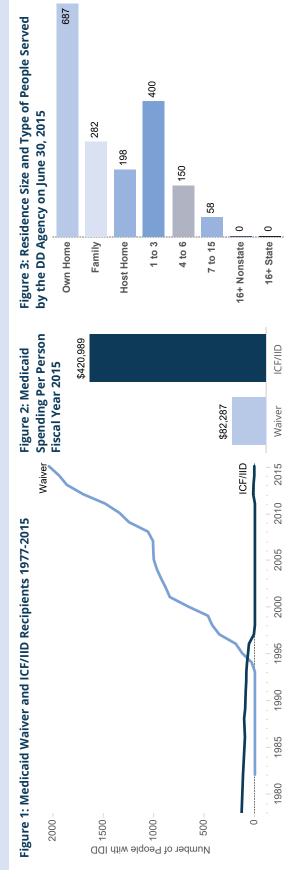


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				365	224	399	473	205	411	687
Individualized	Family				3,737	3,700	231	292	332	332	282
Settings	Host Home				425	172	209	218	165	203	198
	1 to 3				285	239	234	300	200	400	400
People in	4 to 6				145	201	106	128	150	128	150
Congregate	1 to 6	53	122	291	430	440	340	428	350	528	550
Settings	7 to 15	17	38	37	25	0	2	0	20	0	58
	16+	173	88	51	0	0	11	0	15	0	0
eople Served by	People Served by Caseload (known to the DD agency)								2,477	2,714	2,793
the DD Agency	LTSS Recipients *(1)	243	248	379	4,982	4,536	1,195	1,421	1,131	1,480	1,781
	Waiting for Medicaid Waiver *				958	1,400	662	461	613	629	743
eople in Non-DD	People in Non-DD Nursing Facility *(s)			48	0	80	20	10	0	0	0
Settings	Psychiatric Facility *(2)			_	0	0	0	0	0	0	0
Medicaid	Waiver Expenditures per Person			0	\$46,043	\$62,822	\$75,164	\$78,988	\$81,214	\$73,950	\$82,287
Recipients and	ICF/IID Expenditures per Person			\$109,041				\$179,453	\$227,985	\$509,213	\$420,989
Expenditures	Waiver Recipients per 100,000			0.0	106.1	151.1	189.1	232.8	253.7	263.6	276.8
	ICF/IID per 100,000			16.0				2.3	1.9	0.8	0.8

Settings by size include ICF/IID, group homes, and nonstate other, but if nonstate other data is DNF it is assumed to be zero. DNF = Did Not Furnish. PD = Partial data (a DNF present in a calculation). (s) Data may be from an outside source. \* See state notes and the RISP FY2015 report for further explanation. (1) Long Term Supports and Service (LTSS) recipients may include imputed values to replace DNF; up until 2012 people in psychiatric and nursing homes not served directly by the DD agency may be part of LTSS recipients. (2) Psychiatric Facility data prior to 2013 was only for state facilities, after 2013 it includes people in state and nonstate operated facilities when available, see report for details. Updated 9/20/2017



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

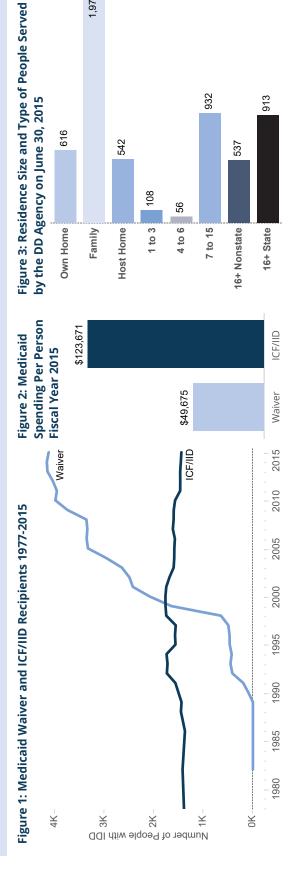
Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				207	434	454	439	456	282	265
Individualized	Family				15,412	20,914	26,185	27,983	28,198	29,369	31,151
Settings	Host Home				623	749	1,166	1,281	1,543	1,462	1,397
	1 to 3				721	1,342	1,422	1,463	1,494	1,575	1,626
People in	4 to 6				1,848	1,058	1,117	1,166	1,182	1,242	1,090
Congregate	1 to 6	120	689	2,263	2,569	2,400	2,539	2,629	2,676	2,817	2,716
shiings	7 to 15	116	137	91	70	40	32	25	25	25	33
	16+	1,216	206	238	225	181	153	143	141	134	122
People Served by	People Served by Caseload (known to the DD agency)								33,079	33,933	35,685
the DD Agency	LTSS Recipients *(1)	1,452	1,733	2,592	19,106	24,718	30,529	32,573	33,149	34,189	35,786
	Waiting for Medicaid Waiver *				DNF	173	29	62	414	238	184
People in Non-DD	People in Non-DD Nursing Facility *(s)			88	96	53	49	73	40	39	37
Settings	Psychiatric Facility *(2)			0	0	0	2	0	0	0	DNF
Medicaid	Waiver Expenditures per Person			\$21,112	\$25,541	\$23,866	\$26,632	\$26,030	\$27,305	\$29,139	\$29,119
Recipients and	ICF/IID Expenditures per Person			\$33,590	\$98,237	\$99,082	DNF	\$220,223	\$185,859	\$217,216	\$210,019
Expellulues	Waiver Recipients per 100,000			101.2	219.4	281.6	356.0	375.6	390.8	402.2	416.2
	ICF/IID per 100,000			3.9	3.4	3.2	2.9	2.3	2.2	2.0	1.9

Settings by size include ICF/IID, group homes, and nonstate other, but if nonstate other data is DNF it is assumed to be zero. DNF = Did Not Furnish. PD = Partial data (a DNF present in a calculation). (s) Data may be from an outside source. \* See state notes and the RISP FY2015 report for further explanation. (1) Long Term Supports and Service (LTSS) recipients may include imputed values to replace DNF; up until 2012 people in psychiatric and nursing homes not served directly by the DD agency may be part of LTSS recipients. (2) Psychiatric Facility data prior to 2013 was only for state facilities, after 2013 it includes people in state and nonstate operated facilities when available, see report for details. Updated 9/20/2017





# **Arkansas**



1,973

Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				1,126	534	641	642	633	639	616
Individualized	Family				0	1,567	2,023	1,994	2,044	2,054	1,973
settings	Host Home				0	436	574	260	268	220	542
	1 to 3				16	184	113	111	112	115	108
People in	4 to 6				06	61	53	53	26	99	99
Congregate	1 to 6	12	42	228	106	245	166	164	168	171	164
Settings	7 to 15	134	148	773	873	835	865	867	936	940	932
	16+	1,767	1,505	1,403	1,751	1,580	1,604	1,504	1,461	1,427	1,450
eople Served by	People Served by Caseload (known to the DD agency)								DNF	DNF	DNF
the DD Agency	LTSS Recipients *(1)	1,913	1,695	2,404	3,856	5,197	5,873	6,328	5,824	5,832	5,682
	Waiting for Medicaid Waiver *				009	DNF	1,522	2,180	2,580	2,959	2,838
eople in Non-DD	People in Non-DD Nursing Facility *(s)			1,100	867	006	0	265	614	622	616
Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	DNF	0
Medicaid	Waiver Expenditures per Person			\$2,168	\$16,338	\$22,709	\$35,050	\$42,887	\$43,565	\$45,727	\$49,675
Recipients and	ICF/IID Expenditures per Person			\$52,234	\$68,652	\$88,845	\$101,207	\$106,855	\$111,166	\$121,978	\$123,671
Experiores	Waiver Recipients per 100,000			8.3	78.0	119.8	136.7	136.9	140.1	140.2	138.4
	ICE/IID per 100.000			99	66.1	57.1	53.0	49.7	49.6	49.0	48.5

Settings by size include ICF/IID, group homes, and nonstate other, but if nonstate other data is DNF it is assumed to be zero. DNF = Did Not Furnish. PD = Partial data (a DNF present in a calculation). (s) Data may be from an outside source. \* See state notes and the RISP FY2015 report for further explanation. (1) Long Term Supports and Service (LTSS) recipients may include imputed values to replace DNF; up until 2012 people in psychiatric and nursing homes not served directly by the DD agency may be part of LTSS recipients. (2) Psychiatric Facility data prior to 2013 was only for state acilities, after 2013 it includes people in state and nonstate operated facilities when available, see report for details. Updated 9/20/2017

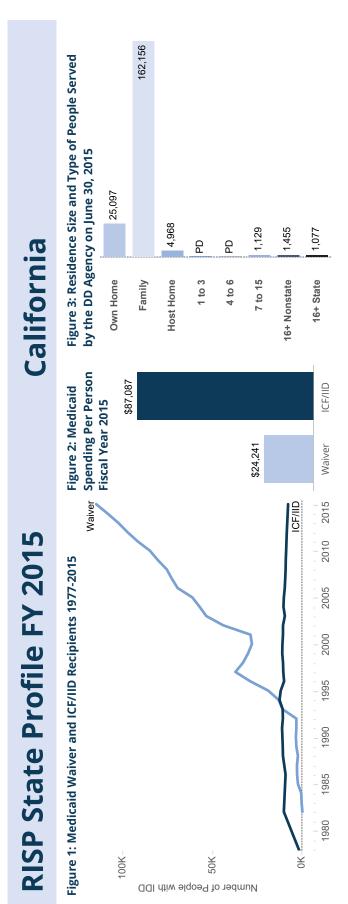


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				14,318	17,671	21,627	23,097	23,763	24,510	25,097
Individualized	Family				111,311	149,386	133,809	140,887	145,176	152,592	162,156
Semings	Host Home				3,900	3,901	3,559	3,892	4,160	4,472	4,968
	1 to 3				DNF	DNF	DNF	DNF	PD	PD	PD
People in	4 to 6				DNF	DNF	6,235	DNF	PD	PD	PD
Congregate	1 to 6	6,942	8,759	17,046	39,757	23,994	25,329	25,593	25,618	25,487	25,338
Seunds	7 to 15	1,947	2,592	3,074	2,433	1,487	1,229	1,152	1,181	1,176	1,129
	16+	17,291	15,715	12,331	7,087	5,820	3,993	3,390	3,192	2,660	2,532
People Served by	People Served by Caseload (known to the DD agency)								231,836	240,037	249,643
the DD Agency	LTSS Recipients *(1)	26,180	27,066	32,451	178,806	202,261	189,546	199,168	202,953	210,951	221,335
	Waiting for Medicaid Waiver *				0	0	0	0	0	0	0
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,075	1,409	6,902	1,217	1,157	1,060	1,077	1,079
Settings	Psychiatric Facility *(2)			0	0	0	DNF	0	64	44	38
Medicaid	Waiver Expenditures per Person			\$16,086	\$16,940	\$19,252	\$22,740	\$21,534	\$23,030	\$23,394	\$24,241
Recipients and	ICF/IID Expenditures per Person			\$25,966	\$34,703	\$62,671	\$78,119	\$82,731	\$79,619	\$83,589	\$87,087
Expellullules	Waiver Recipients per 100,000			11.1	83.4	170.4	229.0	257.3	268.7	281.0	294.7
	ICF/IID per 100,000			37.5	32.9	28.7	24.4	22.9	22.1	21.2	20.4

Settings by size include ICF/IID, group homes, and nonstate other, but if nonstate other data is DNF it is assumed to be zero. DNF = Did Not Furnish. PD = Partial data (a DNF present in a calculation). (s) Data may be from an outside source. \* See state notes and the RISP FY2015 report for further explanation. (1) Long Term Supports and Service (LTSS) recipients may include imputed values to replace DNF; up until 2012 people in psychiatric and nursing homes not served directly by the DD agency may be part of LTSS recipients. (2) Psychiatric Facility data prior to 2013 was only for state facilities, after 2013 it includes people in state and nonstate operated facilities when available, see report for details. Updated 9/20/2017



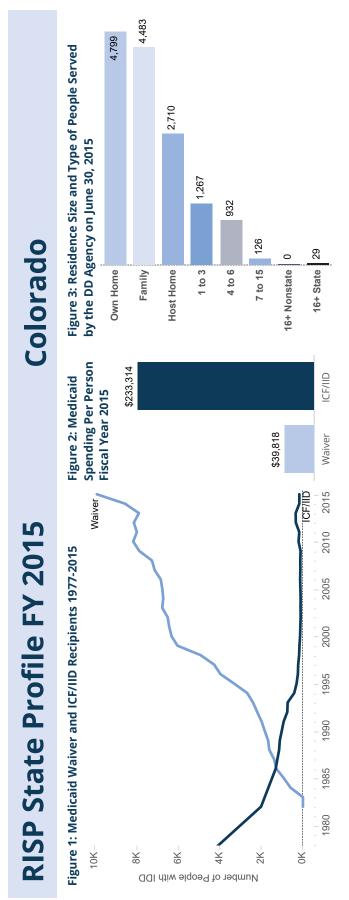


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				712	865	729	1,020	3,884	3,884	4,799
Individualized	Family				6,540	5,628	7,017	5,807	2,580	3,210	4,483
Settings	Host Home				0	0	2,492	2,204	2,460	2,605	2,710
	1 to 3				2,288	33	DNF	2,118	937	1,192	1,267
People in	4 to 6				616	646	1,370	110	1,018	866	932
Congregate	1 to 6	119	029	1,819	2,904	629	1,370	2,228	1,955	2,190	2,199
Settings	7 to 15	421	029	910	456	499	203	207	166	154	126
	16+	2,111	1,960	999	122	105	29	296	168	PD	29
People Served by	People Served by Caseload (known to the DD agency)								21,833	22,085	24,883
the DD Agency	LTSS Recipients *(1)	2,651	3,300	3,395	10,734	7,776	11,878	11,857	11,233	12,043	14,345
	Waiting for Medicaid Waiver *				2,692	940	1,562	1,794	3,712	3,712	3,314
People in Non-DD	People in Non-DD Nursing Facility *(s)			428	270	161	26	92	240	160	153
Settings	Psychiatric Facility *(2)			0	0	DNF	DNF	0	DNF	0	0
Medicaid	Waiver Expenditures per Person			\$26,450	\$30,214	\$36,110	\$41,127	\$40,630	\$41,583	\$41,529	\$39,818
Recipients and	ICF/IID Expenditures per Person			\$60,300	\$130,331	\$481,362	\$134,414	\$115,258	\$123,606	\$253,725	\$233,314
Expenditures	Waiver Recipients per 100,000			29.0	147.2	145.2	162.6	157.0	150.0	160.0	182.0
	ICF/IID per 100,000			27.5	3.2	2.6	4.2	9.9	6.7	3.3	3.2

Settings by size include ICF/IID, group homes, and nonstate other, but if nonstate other data is DNF it is assumed to be zero. DNF = Did Not Furnish. PD = Partial data (a DNF present in a calculation). (s) Data may be from an outside source. \* See state notes and the RISP FY2015 report for further explanation. (1) Long Term Supports and Service (LTSS) recipients may include imputed values to replace DNF; up until 2012 people in psychiatric and nursing homes not served directly by the DD agency may be part of LTSS recipients. (2) Psychiatric Facility data prior to 2013 was only for state acilities, after 2013 it includes people in state and nonstate operated facilities when available, see report for details. Updated 9/20/2017

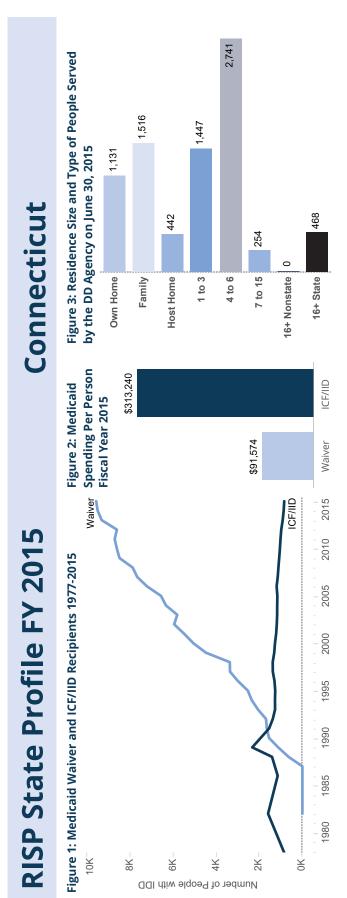


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

	•										
Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,363	859	1,388	1,349	1,292	1,138	1,131
Individualized	Family				6,612	7,546	7,896	1,381	1,416	1,459	1,516
Settings	Host Home				503	542	497	458	469	459	442
	1 to 3				622	742	1,293	1,431	1,330	1,393	1,447
People in	4 to 6				2,197	2,685	2,696	2,654	2,678	2,673	2,741
Congregate	1 to 6	251	353	3,113	2,819	3,427	4,000	4,085	4,008	4,066	4,188
Settings	7 to 15	364	540	220	452	472	354	338	288	278	254
	16+	3,881	3,660	1,652	988	839	989	612	552	521	468
People Served by	People Served by Caseload (known to the DD agency)								15,918	16,280	16,328
the DD Agency	LTSS Recipients *(1)	4,496	4,553	5,335	12,737	13,685	14,821	8,599	8,025	7,921	8,012
	Waiting for Medicaid Waiver *				1,405	089	531	612	618	682	638
People in Non-DD	People in Non-DD Nursing Facility *(s)			482	358	411	382	376	388	375	343
Settings	Psychiatric Facility *(2)			3	8	0	DNF	0	9	4	က
Medicaid	Waiver Expenditures per Person			\$37,205	\$67,965	\$64,000	\$74,492	\$83,454	\$79,539	\$72,733	\$91,574
Recipients and	ICF/IID Expenditures per Person			\$135,601	\$180,740	\$188,575	\$279,101	\$257,596	\$321,368	\$295,726	\$313,240
Expelialiais	Waiver Recipients per 100,000			50.3	149.1	187.5	241.7	240.6	259.9	265.1	267.4
	ICF/IID per 100,000			47.1	37.5	33.2	29.3	27.4	25.5	24.2	23.5



#### Delaware

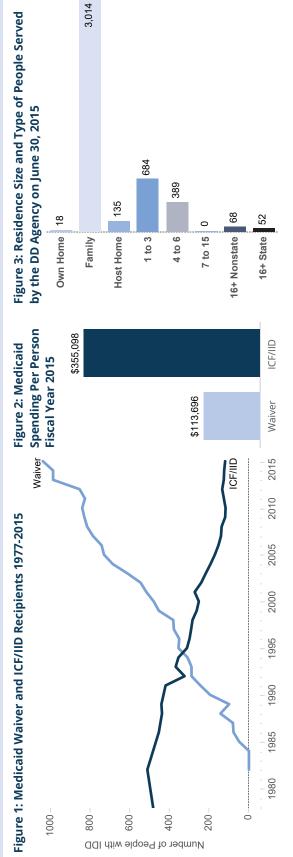
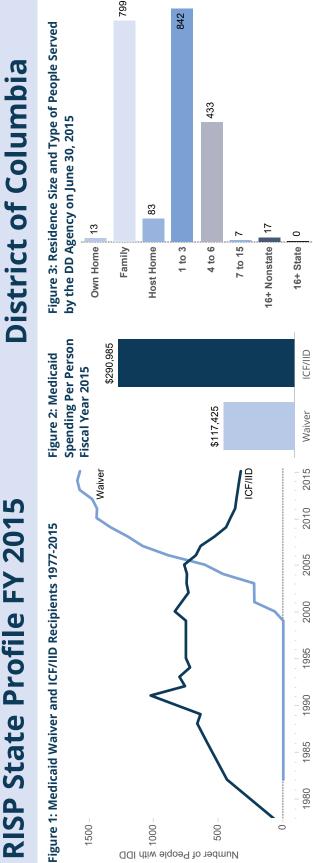


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				19	25	27	20	18	18	18
Individualized	Family				1,209	1,691	2,149	2,428	2,610	2,798	3,014
Settings	Host Home				154	206	145	132	135	126	135
	1 to 3				160	207	259	283	443	439	684
People in	4 to 6				217	340	467	474	525	564	389
Congregate	1 to 6	179	148	278	377	547	726	757	896	1,003	1,073
Settings	7 to 15	6	10	88	0	0	0	23	0	0	0
	16+	622	909	332	253	172	118	135	127	125	120
eople Served by	People Served by Caseload (known to the DD agency)								3,679	3,936	4,204
the DD Agency	LTSS Recipients *(1)	810	764	669	2,012	2,641	3,165	3,458	3,858	4,070	4,360
	Waiting for Medicaid Waiver *				145	7	174	17	0	0	0
eople in Non-DD	People in Non-DD Nursing Facility *(s)			09	78	09	43	29	7	46	99
Settings	Psychiatric Facility *(2)			0	0	11	7	က	2	က	2
Medicaid	Waiver Expenditures per Person			\$19,204	\$57,032	\$73,563	\$105,893	\$110,326	\$92,656	\$104,642	\$113,696
Recipients and	ICF/IID Expenditures per Person			\$56,016	\$128,636	\$150,125	\$260,454	\$264,574	\$246,191	\$239,307	\$355,098
Expenditures	Waiver Recipients per 100,000			36.0	61.4	8.98	93.8	93.2	106.8	105.7	110.0
	ICF/IID per 100.000			619	32.3	20.4	13.1	14.7	13.7	13.4	12.7





Number of People with IDD

Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				0	22	28	19	18	15	13
Individualized	Family				0	540	510	715	727	798	799
Settings	Host Home				70	82	72	81	104	88	83
	1 to 3				4	DNF	687	789	785	811	842
People in	4 to 6				601	DNF	487	489	471	465	433
Congregate	1 to 6	28	139	646	969	933	1,193	1,278	1,256	1,276	1,275
Settings	7 to 15	0	9/	304	340	118	52	0	0	6	7
	16+	096	671	137	0	0	0	0	15	0	17
People Served by	People Served by Caseload (known to the DD agency)								2,120	2,197	2,225
the DD Agency	LTSS Recipients *(1)	988	886	1,087	1,105	1,695	1,855	2,099	2,120	2,186	2,194
	Waiting for Medicaid Waiver *				DNF	0	0	0	0	0	0
People in Non-DD	People in Non-DD Nursing Facility *(s)			34	0	_	15	9	2	4	3
Settings	Psychiatric Facility *(2)			_	0	0	0	0	9	5	2
Medicaid	Waiver Expenditures per Person			0	\$4,140	\$14,914	\$96,271	\$99,524	\$93,107	\$100,606	\$117,425
Recipients and	ICF/IID Expenditures per Person			\$36,860	\$83,667	\$103,254	\$169,585	\$173,206	\$237,523	\$268,393	\$290,985
Expenditures	Waiver Recipients per 100,000			0.0	11.7	110.6	240.3	233.9	243.9	242.1	234.1
	ICF/IID per 100,000			171.7	146.8	139.3	0.89	57.4	54.5	51.8	48.9



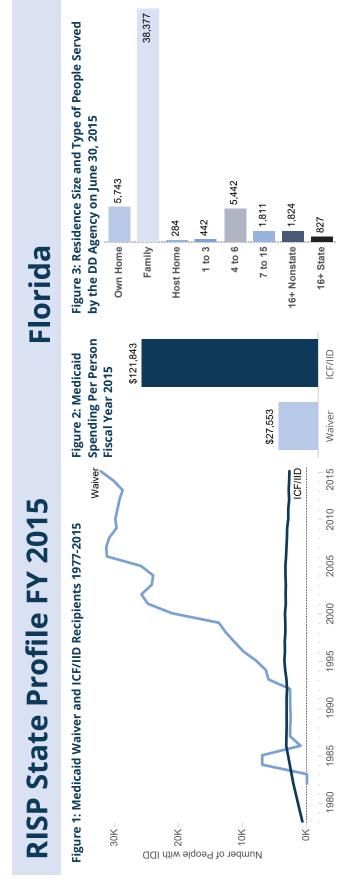


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				3,127	4,012	5,326	5,883	5,872	5,742	5,743
Individualized	Family				19,417	31,173	36,218	37,082	37,424	37,323	38,377
settings	Host Home				0	0	DNF	7,254	323	308	284
	1 to 3				179	236	359	969	534	516	442
People in	4 to 6				3,309	4,515	5,704	6,343	6,198	6,375	5,442
Congregate	1 to 6	791	937	1,987	3,482	4,751	6,063	7,039	6,732	6,891	5,884
settings	7 to 15	1,008	1,474	2,244	1,359	1,286	1,233	1,642	1,606	1,647	1,811
	16+	6,304	5,649	4,628	4,662	3,347	2,925	2,764	2,876	2,919	2,651
People Served by	People Served by Caseload (known to the DD agency)								55,442	55,366	57,112
the DD Agency	LTSS Recipients *(1)	8,103	8,060	8,859	32,047	44,569	DNF	62,118	55,000	54,906	54,814
	Waiting for Medicaid Waiver *				618	3,100	3,835	4,311	22,432	21,165	21,331
People in Non-DD	People in Non-DD Nursing Facility *(s)			212	191	284	309	308	336	306	287
Settings	Psychiatric Facility *(2)			4	0	0	0	28	41	33	27
Medicaid	Waiver Expenditures per Person			\$6,842	\$11,921	\$25,536	\$31,124	\$29,975	\$29,131	\$28,319	\$27,553
Recipients and	ICF/IID Expenditures per Person			\$53,117	\$81,728	\$89,374	\$114,326	\$117,219	\$112,665	\$117,173	\$121,843
Experiorunes	Waiver Recipients per 100,000			19.8	132.2	146.2	159.6	151.9	147.5	152.2	159.2
	ICE/IID per 100.000			0.10	21 5	18.0	12.5	14.4	14.6	14.0	12.5



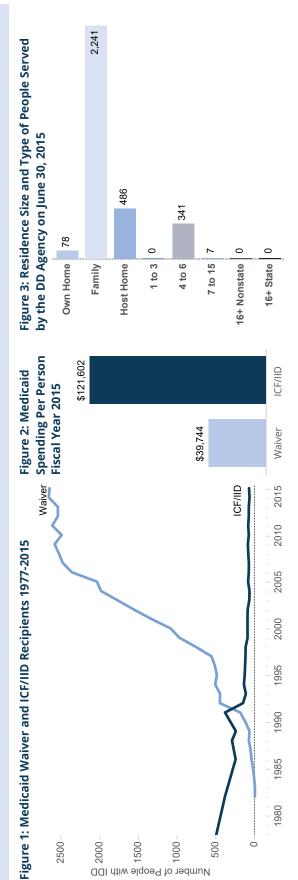
Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,640	2,228	3,316	1,366	1,151	1,148	1,156
Individualized	Family				6,186	4,123	5,344	5,495	2,925	3,080	3,105
Settings	Host Home				462	542	1,240	1,044	1,186	1,215	1,235
	1 to 3				630	1,004	1,155	DNF	1,805	1,845	1,912
People in	4 to 6				419	298	1,225	DNF	066	966	987
Congregate	1 to 6	96	200	1,608	1,049	1,602	2,380	DNF	2,795	2,841	2,899
Semings	7 to 15	236	138	11	0	0	0	DNF	11	1	11
	16+	2,994	2,710	2,292	1,645	1,300	751	DNF	293	249	267
People Served by	People Served by Caseload (known to the DD agency)								8,308	15,632	16,576
the DD Agency	LTSS Recipients *(1)	3,326	3,557	3,911	10,982	9,795	13,031	11,414	8,309	8,544	8,697
	Waiting for Medicaid Waiver *				2,004	1,441	1,640	2,735	7,074	7,337	8,070
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,941	1,800	1,576	754	1,095	1,095	1,174	974
Settings	Psychiatric Facility *(2)			9	0	0	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$14,348	\$37,301	\$25,986	\$30,311	\$35,041	\$38,132	\$42,315	\$41,853
Recipients and	ICF/IID Expenditures per Person			\$56,424	\$67,003	\$88,878	\$137,249	\$19,525	\$203,440	\$121,015	\$159,081
Expellulles	Waiver Recipients per 100,000			5.3	30.1	93.4	120.1	117.1	80.7	82.2	83.3
	ICF/IID per 100,000			29.3	20.1	12.4	6.9	3.0	2.5	2.5	2.8





#### Hawaii



Number of People with IDD

Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				103	150	48	123	123	180	78
Individualized	Family				1,465	2,108	1,584	2,202	2,202	2,078	2,241
Settings	Host Home				767	740	554	699	699	448	486
	1 to 3				569	က	3	0	0	0	0
People in	4 to 6				909	164	163	227	227	239	341
Congregate	1 to 6	366	445	948	1,175	167	166	227	227	239	341
Settings	7 to 15	18	12	7	0	00	8	7	7	0	7
	16+	543	400	146	13	0	0	0	0	0	0
eople Served by	People Served by Caseload (known to the DD agency)								3,281	2,756	3,349
the DD Agency	LTSS Recipients *(1)	927	857	1,101	3,523	3,173	2,360	3,281	3,228	3,113	3,153
	Waiting for Medicaid Waiver *				0	0	0	0	0	0	0
eople in Non-DD	People in Non-DD Nursing Facility *(s)			138	55	103	87	53	61	61	68
Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	DNF	5
Medicaid	Waiver Expenditures per Person			\$16,148	\$21,120	\$35,279	\$40,088	\$40,452	\$40,452	\$39,210	\$39,744
Recipients and	ICF/IID Expenditures per Person			\$19,406	\$83,079	\$97,790	\$114,104	\$97,653	\$105,467	\$125,732	\$121,602
Expenditures	Waiver Recipients per 100,000			16.7	89.9	160.0	183.4	182.7	181.2	187.5	185.2
	ICF/IID per 100,000			34.0	7.9	6.9	5.8	5.7	5.6	4.9	5.3

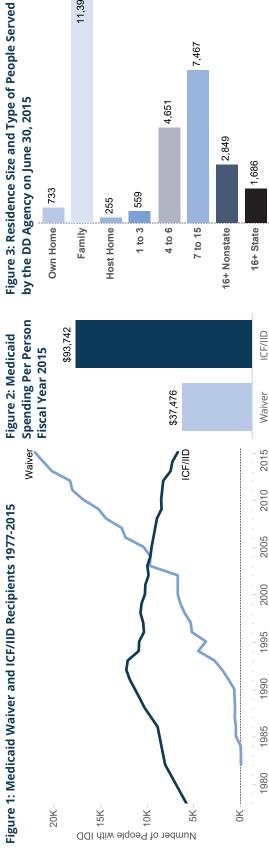


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				931	1,228	1,437	942	1,286	DNF	1,483
Individualized	Family				6,713	8,992	12,791	1,182	1,182	DNF	DNF
Settings	Host Home				1,009	1,215	1,729	1,694	627	614	575
	1 to 3				41	38	23	0	4	0	0
People in	4 to 6				211	205	196	DNF	PD	PD	PD
Congregate	1 to 6	42	41	342	252	243	219	DNF	PD	PD	PD
Settings	7 to 15	92	180	475	481	202	515	DNF	PD	PD	PD
	16+	869	639	649	436	280	461	141	PD	PD	PD
People Served by	People Served by Caseload (known to the DD agency)								5,100	6,599	7,393
the DD Agency	LTSS Recipients *(1)	816	860	1,466	9,822	12,465	17,152	4,595	3,820	6,828	6,897
	Waiting for Medicaid Waiver *				0	0	0	0	0	0	0
People in Non-DD	People in Non-DD Nursing Facility *(s)				28	125	233	49	86	112	126
Settings	Psychiatric Facility *(2)			0	0	0	DNF	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$13,018	\$20,324	\$29,689	\$33,827	DNF	\$14,858	\$15,616	\$25,854
Recipients and	ICF/IID Expenditures per Person			\$63,995	\$89,883	\$97,655	\$126,447	\$37,585	\$99,877	\$101,931	\$87,365
Experimines	Waiver Recipients per 100,000			15.9	61.9	119.1	187.1		316.4	403.7	460.2
	ICF/IID per 100,000			51.5	45.8	39.1	33.4	30.4	30.2	28.7	29.5



#### **Ilinois**



11,390 ICF/IID

Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,579	3,775	3,999	DNF	167	200	733
Individualized	Family				11,864	11,324	11,996	DNF	10,416	11,258	11,390
Settings	Host Home				93	245	254	244	260	216	255
	1 to 3				629	92	155	403	470	516	559
People in	4 to 6				3,108	3,640	3,844	4,366	3,931	4,355	4,651
Congregate	1 to 6	69	331	897	3,677	3,716	3,999	4,769	4,401	4,871	5,210
Settings	7 to 15	101	387	3,824	5,395	6,463	7,703	8,202	7,193	7,242	7,467
	16+	13,228	12,170	11,824	7,676	099'9	5,545	5,223	5,116	4,773	4,535
People Served by	People Served by Caseload (known to the DD agency)								50,859	53,645	54,771
the DD Agency	LTSS Recipients *(1)	13,398	12,888	16,545	30,284	31,183	33,496	30,173	28,153	29,310	29,591
	Waiting for Medicaid Waiver *				DNF	DNF	15,042	12,076	22,999	22,000	17,566
People in Non-DD	People in Non-DD Nursing Facility *(s)				1,267	635	DNF	1,094	1,094	212	185
Settings	Psychiatric Facility *(2)			7	0	0	0	0	_	0	0
Medicaid	Waiver Expenditures per Person			\$12,631	\$20,657	\$34,341	\$31,002	\$32,223	\$31,335	\$34,084	\$37,476
Recipients and	ICF/IID Expenditures per Person			\$30,741	\$62,968	\$71,743	\$74,255	\$82,468	\$75,714	\$85,307	\$93,742
Experiores	Waiver Recipients per 100,000			11.6	54.6	81.9	132.1	142.6	157.6	164.8	172.2
	ICF/IID per 100,000			103.5	83.0	75.2	8.99	64.8	58.7	57.1	52.8



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,447	6,553	4,404	5,136	3,778	5,492	5,936
Individualized	Family				1,358	5,048	5,881	6,888	7,850	10,682	12,756
Semulas	Host Home				490	316	248	207	204	206	221
	1 to 3				0	0	479	0	0	0	0
People in	4 to 6				1,037	3,254	1,682	1,657	1,527	1,605	1,456
Congregate	1 to 6	466	487	2,015	1,037	3,254	2,151	1,657	1,527	1,605	1,456
Settings	7 to 15	172	243	2,424	2,754	0	2,525	2,447	2,554	2,339	2,454
	16+	4,218	3,231	2,648	1,632	736	510	290	272	163	46
People Served by	People Served by Caseload (known to the DD agency)								19,294	22,323	27,414
the DD Agency	LTSS Recipients *(1)	4,856	3,961	7,087	8,718	15,907	15,719	18,284	16,185	20,589	22,869
	Waiting for Medicaid Waiver *				DNF	DNF	17,142	DNF	5,109	3,533	2,579
People in Non-DD	People in Non-DD Nursing Facility *(s)			2,587	1,933	1,697	1,533	1,553	1,527	1,624	1,579
Settings	Psychiatric Facility *(2)			0	33	0	12	106	74	74	99
Medicaid	Waiver Expenditures per Person			0	\$42,563	\$40,755	\$45,301	\$38,321	\$38,372	\$33,262	\$32,025
Recipients and	ICF/IID Expenditures per Person			\$32,930	\$47,659	\$80,963	\$77,683	\$77,926	\$77,526	\$78,030	\$82,352
Expenditures	Waiver Recipients per 100,000			0.0	34.2	148.0	173.4	195.6	211.8	263.9	286.3
	ICF/IID per 100,000			107.8	89.2	62.7	62.3	58.7	57.2	54.5	50.1



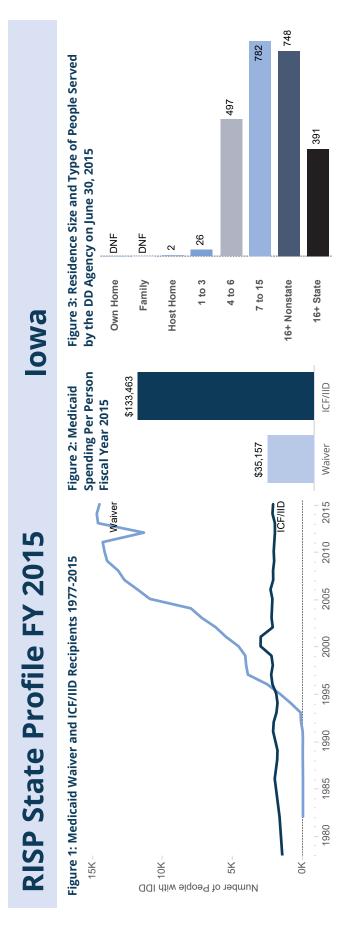


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				2,487	4,866	5,863	DNF	DNF	DNF	DNF
Individualized	Family				2,166	4,145	5,411	DNF	DNF	DNF	DNF
Settings	Host Home				9	9	8	4	2	2	2
	1 to 3					DNF	0	18	18	24	26
People in	4 to 6				1,126	DNF	380	467	493	208	497
Congregate	1 to 6	94	211	1,860	1,132	694	380	485	511	532	523
Settings	7 to 15	296	588	1,571	725	1,060	798	920	806	872	782
	16+	3,109	3,742	2,997	4,495	1,724	2,405	1,431	1,380	1,304	1,139
eople Served by	People Served by Caseload (known to the DD agency)								14,588	14,991	14,950
the DD Agency	LTSS Recipients *(1)	3,499	4,541	6,428	11,011	12,495	14,860	14,838	12,045	12,707	11,711
	Waiting for Medicaid Waiver *				DNF	62	94	0	0	0	0
eople in Non-DD	People in Non-DD Nursing Facility *(s)			1,379	150	808	619	634	664	642	999
Settings	Psychiatric Facility *(2)			9	65	0	0	0	1,394	1,406	1,317
Medicaid	Waiver Expenditures per Person			\$2,842	\$19,242	\$20,258	\$24,238	\$34,121	\$29,462	\$32,143	\$35,157
Recipients and	ICF/IID Expenditures per Person			\$64,095	\$63,161	\$114,002	\$137,290	\$150,719	\$141,670	\$129,320	\$133,463
Expenditures	Waiver Recipients per 100,000			0.7	157.3	368.6	465.3	369.5	473.7	473.9	465.2
	ICF/IID per 100.000			76.3	103 5	73.6	88	65.1	64.0	70.07	88

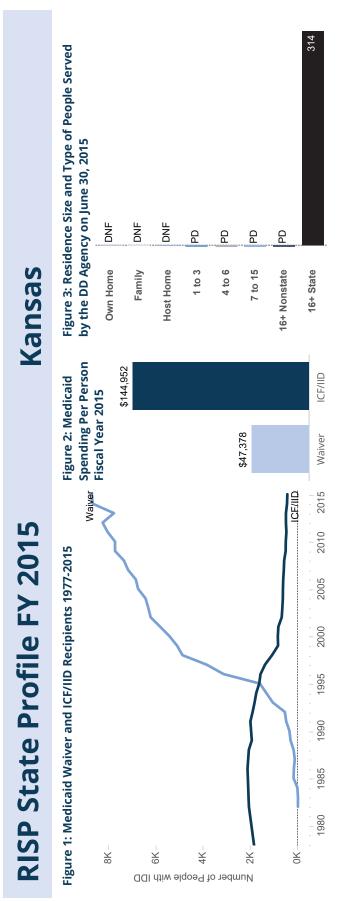


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

	:										
Category	Type	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				1,005	1,774	2,561	DNF	82	DNF	DNF
Individualized	Family				2,901	1,590	2,591	2,811	2,811	DNF	DNF
Settings	Host Home				129	141	227	82	82	DNF	DNF
	1 to 3				1,359	1,873	650	1,910	PD	PD	PD
People in	4 to 6				1,305	1,275	1,493	DNF	PD	PD	PD
Congregate	1 to 6	220	184	764	2,664	3,148	2,143	DNF	PD	PD	PD
Settings	7 to 15	406	482	533	229	327	477	DNF	PD	PD	PD
	16+	2,080	2,209	1,698	290	427	347	334	PD	PD	PD
People Served by	People Served by Caseload (known to the DD agency)								9,045	11,689	12,131
the DD Agency	LTSS Recipients *(1)	2,706	2,875	2,995	7,518	7,407	8,346	9,045	8,488	10,291	9,971
	Waiting for Medicaid Waiver *				206	1,194	1,287	DNF	DNF	2,995	3,392
People in Non-DD	People in Non-DD Nursing Facility *(s)			31	38	0	432	262	262	245	114
Settings	Psychiatric Facility *(2)			4	0	0	0	0	DNF	80	DNF
Medicaid	Waiver Expenditures per Person			\$23,481	\$31,119	\$32,107	\$36,224	\$39,917	\$43,946	\$46,019	\$47,378
Recipients and	ICF/IID Expenditures per Person			\$48,846	\$78,458	\$105,345	\$119,983	DNF	\$124,703	\$132,551	\$144,952
Expellulues	Waiver Recipients per 100,000			19.9	202.4	246.7	271.6	286.7	269.4	299.4	300.0
	ICF/IID per 100,000			80.8	31.7	23.2	18.1	17.6	17.6	15.9	15.5





### Kentucky

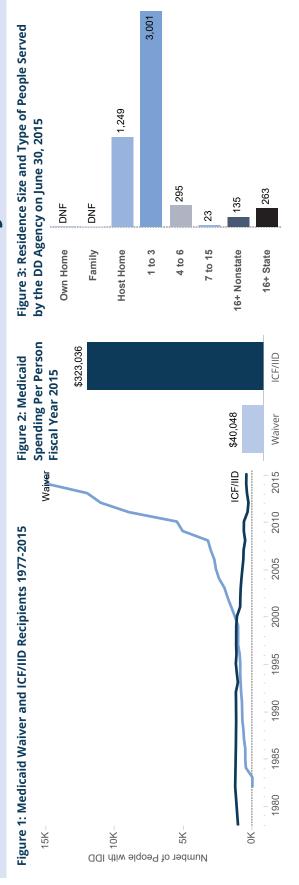


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				167	770	297	261	327	327	DNF
Individualized	Family				4,236	1,073	1,506	1,135	1,599	DNF	DNF
settings	Host Home				368	512	644	761	767	1,069	1,249
	1 to 3				691	1,850	2,275	2,372	2,547	2,721	3,001
People in	4 to 6				41	44	0	103	131	159	295
Congregate	1 to 6	44	112	747	732	1,894	2,275	2,475	2,678	2,880	3,296
Settings	7 to 15	29	63	150	274	114	24	9	0	24	23
	16+	1,585	1,685	1,244	1,133	703	591	279	352	456	398
People Served by	People Served by Caseload (known to the DD agency)								DNF	DNF	18,000
the DD Agency	LTSS Recipients *(1)	1,658	1,860	2,141	6,910	5,066	5,337	5,190	5,765	7,704	15,795
	Waiting for Medicaid Waiver *				1,279	288	295	802	DNF	1,974	1,964
People in Non-DD	People in Non-DD Nursing Facility *(s)	217			1,640	450	850	273	191	647	969
Settings	Psychiatric Facility *(2)			5	0	0	0	0	242	DNF	376
Medicaid	Waiver Expenditures per Person			\$21,335	\$47,249	\$59,076	\$48,463	\$36,794	\$38,282	\$36,765	\$40,048
Recipients and	ICF/IID Expenditures per Person			\$55,764	\$74,575	\$148,208	\$236,622	\$457,827	\$445,347	\$318,989	\$323,036
Experiores	Waiver Recipients per 100,000			20.5	31.6	63.6	126.6	252.2	273.4	339.9	336.0
	ICF/IID per 100.000			32.1	27.7	17.4	14.2	6.5	0.0	10.2	9.6

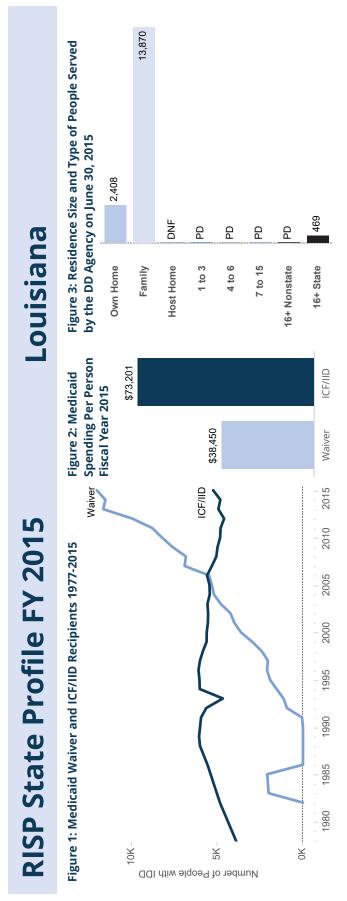


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

				-							
Category	Type	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,391	1,891	2,340	2,468	2,420	2,408	2,408
Individualized	Family				1,894	6,512	13,894	15,946	14,938	13,462	13,870
Settings	Host Home				108	53	54	0	0	DNF	DNF
	1 to 3				0	37	0	0	0	PD	PD
People in	4 to 6				2,096	2,026	2,861	3,035	1,728	PD	PD
Congregate	1 to 6	39	85	2,224	2,096	2,063	2,861	3,035	1,728	PD	PD
Settings	7 to 15	112	185	222	779	1,030	346	181	1,675	PD	PD
	16+	4,298	4,785	5,418	2,745	2,470	1,631	1,388	1,401	PD	PD
People Served by	People Served by Caseload (known to the DD agency)								11,399	44,902	48,305
the DD Agency	LTSS Recipients *(1)	4,449	5,055	7,864	9,013	14,019	21,126	23,545	22,299	28,997	30,404
	Waiting for Medicaid Waiver *				530	DNF	DNF	DNF	10,756	12,906	13,085
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,252	1,109	229	382	511	549	439	434
Settings	Psychiatric Facility *(2)			0	0	0	16	16	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$3,643	\$26,281	\$45,489	\$48,370	\$40,901	\$38,769	\$38,710	\$38,450
Recipients and	ICF/IID Expenditures per Person			\$39,948	\$61,822	\$77,963	\$97,633	\$100,133	\$79,065	\$80,932	\$73,201
Expenditures	Waiver Recipients per 100,000			1.3	81.2	117.7	181.6	216.4	252.1	248.2	257.8
	ICF/IID per 100,000			140.0	125.8	120.7	106.7	100.0	106.8	103.8	112.3





#### Maine

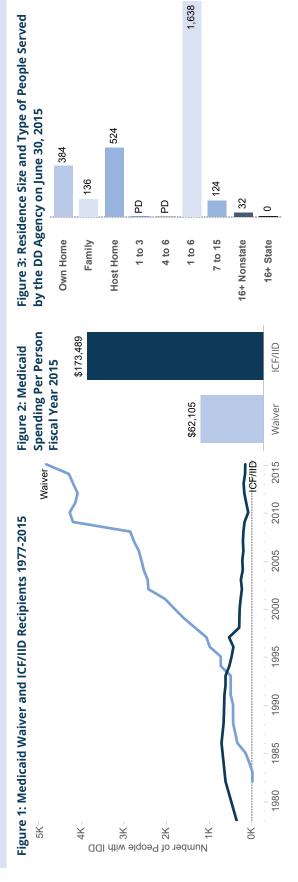
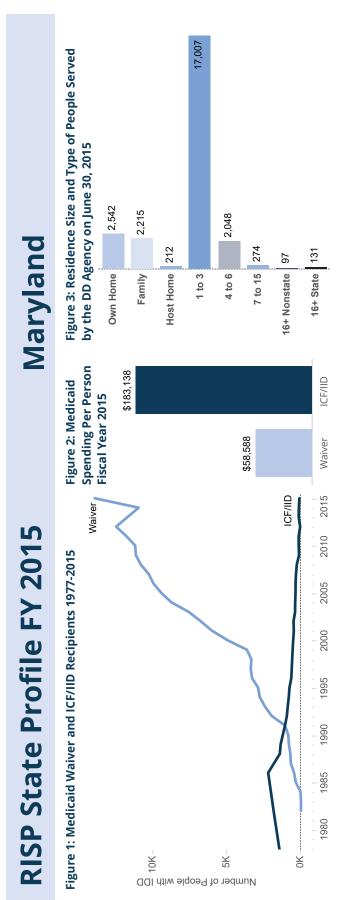


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				1,000	568	303	541	400	310	384
Individualized	Family				2,000	299	387	1,563	1,575	1,342	136
settings	Host Home				1,850	728	418	793	753	714	524
	1 to 3				096	939	1,201	1,304	PD	1,261	PD
People in	4 to 6				309	966	657	775	PD	498	PD
Congregate	1 to 6	429	524	1,259	1,269	1,935	1,858	2,079	2,116	1,759	1,638
settings	7 to 15	75	179	187	330	202	65	116	113	114	124
	16+	989	761	572	78	49	32	117	28	58	32
eople Served by	People Served by Caseload (known to the DD agency)								5,648	5,925	6,499
the DD Agency	LTSS Recipients *(1)	1,493	1,464	2,018	6,527	4,081	3,063	5,261	5,113	4,394	3,143
	Waiting for Medicaid Waiver *				494	105	337	85	725	957	1,153
eople in Non-DD	People in Non-DD Nursing Facility *(s)			190	0	112	72	49	DNF	DNF	7
Settings	Psychiatric Facility *(2)			2	0	0	0	3	DNF	DNF	0
Medicaid	Waiver Expenditures per Person			\$24,558	\$59,074	\$74,951	\$71,657	\$70,976	\$78,360	\$62,832	\$62,105
Recipients and	ICF/IID Expenditures per Person			\$83,983	\$118,477	\$236,310	\$623,838	\$225,031	\$171,104	\$189,312	\$173,489
Expenditures	Waiver Recipients per 100,000			41.2	143.9	197.0	322.8	308.5	316.8	323.9	364.0
	ICF/IID per 100.000			53.1	23.4	17.9	7.3	14.2	15.4	12.9	12.6



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Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				290	1,509	1,747	2,014	2,195	2,368	2,542
Individualized	Family				4,329	2,139	2,228	2,215	2,215	2,198	2,215
Settings	Host Home				176	251	216	208	213	210	212
	1 to 3				2,285	2,819	3,544	3,660	5,936	5,891	17,007
People in	4 to 6				1,393	1,663	1,629	1,757	1,853	1,950	2,048
Congregate	1 to 6	62	352	3,325	3,678	4,482	5,173	5,417	7,789	7,841	19,055
Settings	7 to 15	71	163	0	385	313	256	236	219	240	274
	16+	3,238	2,731	1,159	599	392	144	54	277	185	228
eople Served by	People Served by Caseload (known to the DD agency)								24,480	24,905	24,911
the DD Agency	LTSS Recipients *(1)	3,371	3,246	4,484	9,457	9,086	9,764	10,385	12,908	13,042	24,528
1	Waiting for Medicaid Waiver *				3,349	7,710	2,770	4,065	5,276	5,660	5,547
eople in Non-DD	People in Non-DD Nursing Facility *(s)			537	121	843	DNF	241	0	0	268
Settings	Psychiatric Facility *(2)			6	0	0	0	0	0	0	0
Medicaid	Waiver Expenditures per Person			\$39,722	\$59,787	\$39,383	\$52,511	\$55,000	\$65,135	\$50,814	\$58,588
Recipients and	ICF/IID Expenditures per Person			\$58,134	\$112,038	\$171,896	\$163,291	DNF		\$74,500	\$183,138
Expenditures	Waiver Recipients per 100,000			22.3	93.6	168.5	194.0	212.2	197.8	183.6	232.0
	ICF/IID per 100,000			22.2	6.6	9.9	2.7		2.6	2.4	1.8



### **Massachusetts**

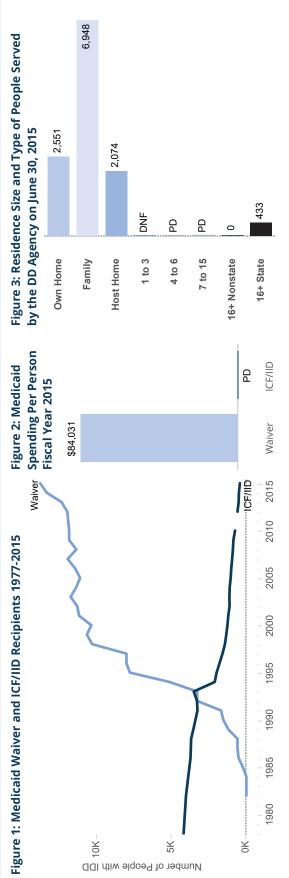


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				1,912	1,308	2,114	638	2,696	2,696	2,551
Individualized	Family				16,700	19,665	19,916	21,000	19,000	19,000	6,948
Settings	Host Home				1,133	934	1,569	2,807	3,296	3,296	2,074
	1 to 3				1,463	1,725	1,447	DNF	2,430	2,428	DNF
People in	4 to 6				4,126	5,334	5,024	DNF	6,435	6,435	PD
Congregate	1 to 6	282	911	3,440	5,589	7,059	6,471	7,809	8,865	8,863	PD
settings	7 to 15	1,012	1,129	1,661	740	885	1,188	799	652	652	PD
	16+	6,429	4,682	2,694	1,293	1,092	786	580	516	497	433
People Served by	People Served by Caseload (known to the DD agency)								34,447	34,447	35,438
the DD Agency	LTSS Recipients *(1)	7,723	6,722	7,795	27,367	30,943	32,044	34,000	35,025	35,004	22,899
	Waiting for Medicaid Waiver *				2,227	372	0	DNF	0	0	DNF
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,600	1,499	1,056	712	367	253	253	455
Settings	Psychiatric Facility *(2)			00	0	0	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$33,546	\$40,860	\$55,719	\$56,241	DNF	\$57,879	\$66,108	\$84,031
Recipients and	ICF/IID Expenditures per Person			\$101,183	\$165,906	\$203,152	\$49,492	\$21,483	\$237,736	\$245,836	PD
Expenditures	Waiver Recipients per 100,000			28.4	163.4	173.9	181.1	180.4	184.8	198.1	203.1
	ICF/IID per 100.000			54.6	19.9	16.4	11.6	8.9	7.7	7.4	6.4



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				1,760	2,612	6,319	7,571	6,412	6,194	6,980
Individualized	Family				DNF	9,421	19,431	25,772	20,431	19,879	25,780
Settings	Host Home				1,196	992	564	009	177	33	474
	1 to 3				0	DNF	1,110	DNF	492	128	334
People in	4 to 6				6,469	DNF	7,439	DNF	3,634	1,937	2,317
Congregate	1 to 6	1,306	3,529	7,513	6,469	10,729	8,549	DNF	4,126	2,065	2,651
settings	7 to 15			0	0	0	1,904	DNF	640	290	387
	16+	9,002	5,705	1,013	269	190	754	DNF	341	194	209
eople Served by	People Served by Caseload (known to the DD agency)								DNF	DNF	45,115
the DD Agency	LTSS Recipients *(1)	10,308	3,529	8,526	DNF	23,718	37,521	47,546	38,575	36,179	44,784
	Waiting for Medicaid Waiver *				DNF	0	DNF	DNF	DNF	DNF	0
eople in Non-DD	People in Non-DD Nursing Facility *(s)				902	357	209	609	609	209	411
Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	0	0
Medicaid	Waiver Expenditures per Person			\$27,632	\$38,728	\$38,448	\$48,974	DNF	\$32,363	\$32,363	\$31,866
Recipients and	ICF/IID Expenditures per Person			\$116,394	\$103,657	\$109,363	0	0	0	0	0
Experiores	Waiver Recipients per 100,000			22.7	80.7	85.0	86.9	403.1	369.9	369.3	454.7
	ICF/IID per 100.000			30.4	2.7	19	0 0	0 0	0 0	00	0





### Minnesota

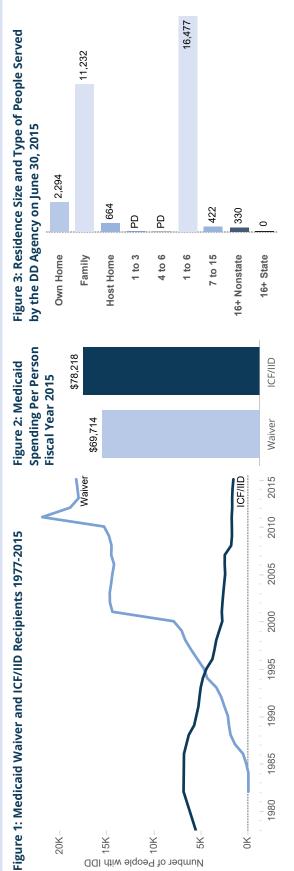


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				2,310	2,092	2,418	1,384	2,716	2,638	2,294
Individualized	Family				8,088	15,231	14,678	10,332	11,003	11,009	11,232
Settings	Host Home			525	1,175	1,507	922	1,438	1,168	953	664
	1 to 3				651	833	1,067	DNF	PD	PD	PD
People in	4 to 6				5,848	6,909	8,800	DNF	PD	PD	PD
Congregate	1 to 6	286	652	4,504	6,499	7,742	9,867	DNF	9,461	15,780	16,477
Settings	7 to 15	911	1,805	1,853	1,225	1,027	589	DNF	452	436	422
	16+	4,985	4,612	3,027	770	838	401	DNF	387	379	330
People Served by	People Served by Caseload (known to the DD agency)								31,104	31,282	31,486
the DD Agency	LTSS Recipients *(1)	6,182	7,069	606'6	20,067	28,437	28,875	25,586	31,059	31,251	31,474
	Waiting for Medicaid Waiver *				1,277	3,855	3,243	2,718	3,630	3,575	3,564
People in Non-DD	People in Non-DD Nursing Facility *(s)			827	491	246	218	218	154	155	155
Settings	Psychiatric Facility *(2)			0	0	0	0	0	18	4	DNF
Medicaid	Waiver Expenditures per Person			\$31,103	\$51,362	\$58,640	\$65,005	\$64,076	\$64,252	\$65,503	\$69,714
Recipients and	ICF/IID Expenditures per Person			\$50,162	\$75,212	\$69,387	\$96,195	\$87,415	\$71,034	\$73,867	\$78,218
Expendimes	Waiver Recipients per 100,000			97.2	161.6	281.9	289.5	352.5	333.3	333.2	333.6
	ICF/IID per 100,000			120.0	56.4	48.1	33.1	32.0	31.8	30.9	29.0

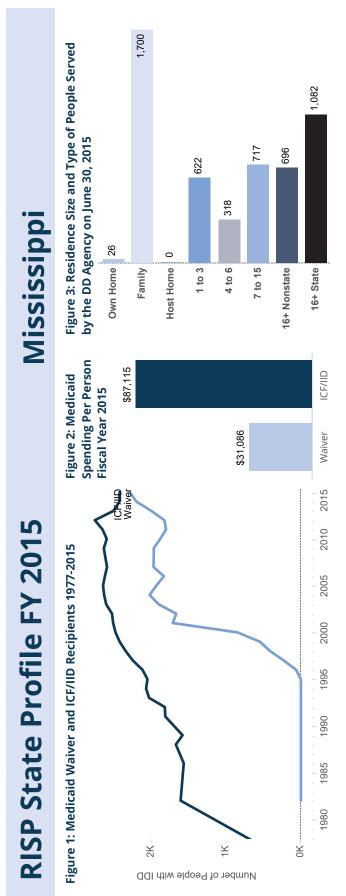


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				93	127	09	15	26	26	26
Individualized	Family				157	1,378	1,693	1,087	1,680	DNF	1,700
Settings	Host Home				0	0	0	0	0	DNF	0
	1 to 3				166	437	309	184	254	285	622
People in	4 to 6				141	123	80	128	158	PD	318
Congregate	1 to 6	17	29	310	307	260	388	312	412	PD	940
Settings	7 to 15	102	210	115	617	718	682	652	909	PD	717
	16+	2,055	2,201	2,081	2,039	2,036	2,036	2,173	1,944	PD	1,778
People Served by	People Served by Caseload (known to the DD agency)								DNF	DNF	7,140
the DD Agency	LTSS Recipients *(1)	2,174	2,478	2,506	3,213	4,819	4,859	4,396	4,667	4,929	5,161
	Waiting for Medicaid Waiver *				DNF	DNF	DNF	DNF	DNF	DNF	1,828
People in Non-DD	People in Non-DD Nursing Facility *(s)			300	321	172	140	140	371	346	426
Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	DNF	9
Medicaid	Waiver Expenditures per Person			0	\$5,202	\$18,814	\$18,869	DNF	\$24,558	\$31,502	\$31,086
Recipients and	ICF/IID Expenditures per Person			\$23,736	\$63,611	\$78,761	\$103,469	\$97,753	\$112,743	\$118,589	\$87,115
Expelialities	Waiver Recipients per 100,000			0.0	47.1	66.4	83.6		67.1	73.8	76.7
	ICF/IID per 100,000			70.2	87.4	6.06	63.6	92.6	84.0	81.3	81.3



#### Missouri

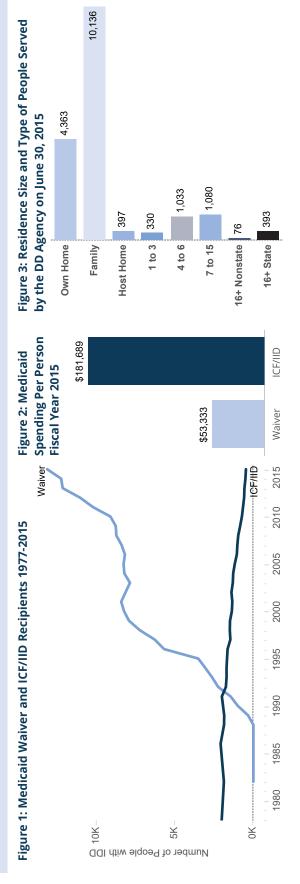


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				2,270	2,391	3,230	3,984	4,131	4,170	4,363
Individualized	Family				8,582	7,644	6,199	8,089	8,955	9,599	10,136
Settings	Host Home				85	41	19	20	208	375	397
	1 to 3				263	492	422	468	355	351	330
People in	4 to 6				778	330	1,276	1,156	1,197	1,112	1,033
Congregate	1 to 6	599	470	1,368	1,041	1,313	1,698	1,624	1,552	1,463	1,363
Settings	7 to 15	1,059	1,180	1,700	1,231	1,224	926	1,108	1,126	1,072	1,080
	16+	4,847	4,331	2,804	1,749	1,351	992	623	575	546	469
People Served by	People Served by Caseload (known to the DD agency)								31,369	32,219	33,289
the DD Agency	LTSS Recipients *(1)	6,505	5,981	5,872	14,958	13,964	12,888	16,869	16,578	17,225	17,808
	Waiting for Medicaid Waiver *				574	491	206	200	1,113	898	356
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,400	152	878	DNF	1,045	1,078	1,064	1,051
Settings	Psychiatric Facility *(2)			10	43	69	425	376	259	253	DNF
Medicaid	Waiver Expenditures per Person			\$19,541	\$24,142	\$31,379	\$50,864	\$48,362	\$50,223	\$54,582	\$53,333
Recipients and	ICF/IID Expenditures per Person			\$51,212	\$72,792	\$216,630	\$183,157	\$183,845	\$171,805	\$176,976	\$181,689
Expenditures	Waiver Recipients per 100,000			43.9	147.2	142.5	153.0	183.3	201.0	201.9	215.9
	ICF/IID per 100,000			38.9	24.5	20.4	12.2	9.8	9.4	8.3	7.8

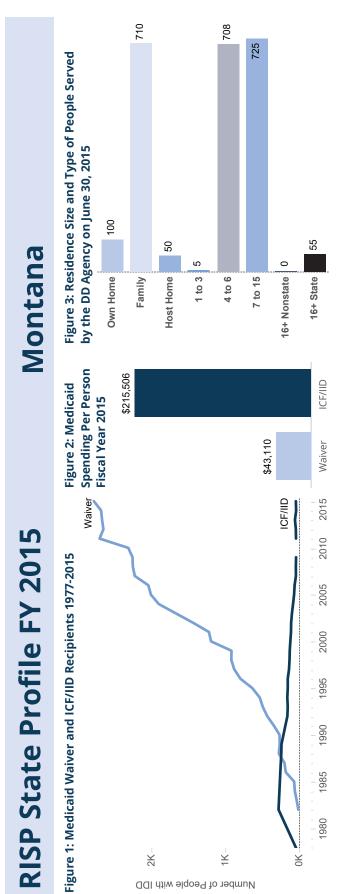
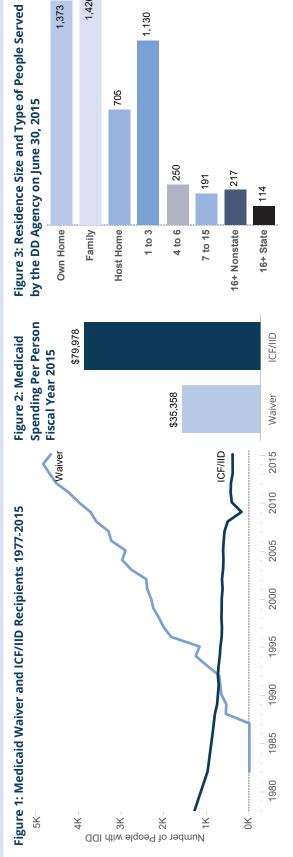


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				100	586	029	100	100	150	100
Individualized	Family				2,386	2,068	2,400	800	750	029	710
Semings	Host Home				207	181	240	42	45	43	20
	1 to 3				262	226	200	029	9	5	5
People in	4 to 6				226	286	380	661	504	536	708
Congregate	1 to 6	86	93	615	711	512	009	1,311	510	541	713
Semmes	7 to 15	339	415	523	488	398	400	415	632	632	725
	16+	340	273	422	130	62	55	55	53	51	55
People Served by	People Served by Caseload (known to the DD agency)								3,367	2,699	3,195
the DD Agency	LTSS Recipients *(1)	765	781	1,560	4,022	3,824	4,345	2,803	2,374	2,087	2,353
1	Waiting for Medicaid Waiver *				200	260	691	635	929	705	953
People in Non-DD	People in Non-DD Nursing Facility *(s)			232	205	163	DNF	80	88	114	92
Settings	Psychiatric Facility *(2)			_	0	_	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$21,670	\$27,829	\$28,619	\$42,448	\$34,060	\$34,240	\$44,731	\$43,110
Recipients and	ICF/IID Expenditures per Person			\$71,236	\$103,439	\$156,333	0	\$267,531	\$153,688	\$218,028	\$215,506
Experimines	Waiver Recipients per 100,000			43.9	133.7	216.2	235.5	265.4	264.6	263.7	270.9
	ICF/IID per 100,000			24.4	14.4	8.4		5.5	9.9	5.0	5.3



#### Nebraska



1,426

Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				841	622	1,132	1,322	1,330	1,385	1,373
Individualized	Family				233	210	904	1,130	1,347	1,302	1,426
settings	Host Home				168	244	404	574	708	730	705
	1 to 3				767	933	1,025	904	1,198	883	1,130
People in	4 to 6				681	494	520	658	447	200	250
Congregate	1 to 6	195	344	1,399	1,448	1,427	1,545	1,562	1,645	1,383	1,380
Settings	7 to 15	551	398	308	309	213	88	121	100	172	191
	16+	1,553	980	717	639	209	402	380	345	333	331
People Served by	People Served by Caseload (known to the DD agency)								8,537	8,431	8,592
the DD Agency	LTSS Recipients *(1)	2,299	1,722	2,424	3,638	3,480	4,476	5,396	5,477	5,324	5,433
	Waiting for Medicaid Waiver *				651	1,227	1,639	1,875	1,775	1,811	1,838
People in Non-DD	People in Non-DD Nursing Facility *(s)			613	115	117	379	307	205	228	177
Settings	Psychiatric Facility *(2)			0	0	0	0	0	2	_	2
Medicaid	Waiver Expenditures per Person			\$28,652	\$35,609	\$40,819	\$51,323	\$52,951	\$37,452	\$36,005	\$35,358
Recipients and	ICF/IID Expenditures per Person			\$42,086	\$75,404	\$96,500	\$83,283	\$130,002	\$83,396	\$81,743	\$79,978
Expenditures	Waiver Recipients per 100,000			42.9	135.5	165.3	219.0	244.2	250.8	257.0	245.5
	ICF/IID per 100,000			45.1	37.9	35.0	22.6	23.3	20.9	20.8	20.8



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

								2			
Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				707	1,293	1,348	1,530	1,597	1,635	1,662
Individualized	Family				1,447	2,418	3,621	3,826	3,879	4,122	4,371
Semas	Host Home				47	39	70	75	71	80	85
	1 to 3				0	0	0	10	0	0	0
People in	4 to 6				120	06	36	36	45	35	33
Congregate	1 to 6	61	116	389	120	06	36	46	45	35	33
Settings	7 to 15	20	25	15	39	0	0	9	0	0	0
	16+	166	160	177	140	107	107	152	170	174	181
People Served by	People Served by Caseload (known to the DD agency)								5,744	6,028	6,332
the DD Agency	LTSS Recipients *(1)	247	301	581	2,500	3,947	5,182	5,716	5,762	6,046	6,332
	Waiting for Medicaid Waiver *				188	407	109	188	620	739	712
People in Non-DD	People in Non-DD Nursing Facility *(s)			31	40	31	88	81	87	86	114
Settings	Psychiatric Facility *(2)			0	0	0	0	0	0	0	0
Medicaid	Waiver Expenditures per Person			\$16,563	\$15,403	\$32,379	\$44,517	\$47,680	\$43,985	\$49,786	\$49,085
Recipients and	ICF/IID Expenditures per Person			\$59,019	\$113,080	\$134,379	\$182,906	\$171,590	\$177,377	\$185,757	\$178,629
Experiments	Waiver Recipients per 100,000			10.5	39.8	54.9	6.09	59.9	61.6	66.1	67.1
	ICF/IID per 100,000			16.5	12.6	8.2	3.7	3.8	3.6	3.5	3.4



### **New Hampshire**

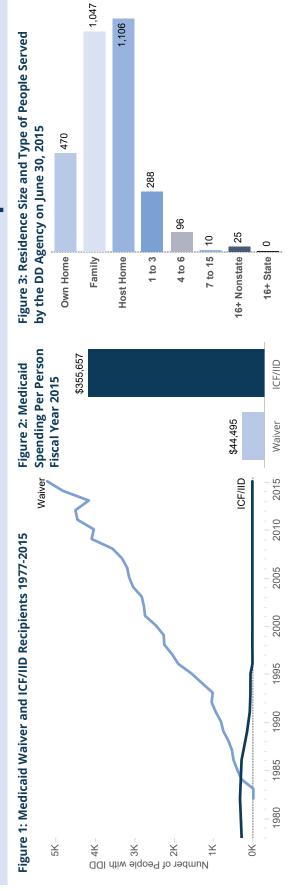


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				359	334	434	478	485	488	470
Individualized	Family				165	424	206	924	849	905	1,047
Settings	Host Home				952	1,016	1,139	933	1,194	1,204	1,106
	1 to 3				332	283	310	227	296	265	288
People in	4 to 6				65	78	75	62	80	84	96
Congregate	1 to 6	62	152	1,147	397	361	385	289	376	349	384
Settings	7 to 15	81	141	132	0	22	22	12	18	18	10
	16+	694	651	25	24	25	25	25	25	25	25
People Served by	People Served by Caseload (known to the DD agency)								4,415	4,913	5,235
the DD Agency	LTSS Recipients *(1)	837	944	1,304	1,897	2,182	2,511	2,749	2,947	2,986	3,042
	Waiting for Medicaid Waiver *				84	119	19	49	242	62	79
People in Non-DD	People in Non-DD Nursing Facility *(s)			26	84	87	61	84	85	79	108
Settings	Psychiatric Facility *(2)			_	0	0	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$41,047	\$40,300	\$40,366	\$43,152	\$42,493	\$47,488	\$43,202	\$44,495
Recipients and	ICF/IID Expenditures per Person			\$74,815	\$69,184	\$93,931	\$124,423	\$126,168	\$73,648	\$25,658	\$355,657
Experiornes	Waiver Recipients per 100,000			86.4	200.3	240.8	307.8	342.2	315.8	364.3	393.4
	ICF/IID per 100,000			8.2	1.9	1.9	1.9	1.9	1.9	1.9	1.9

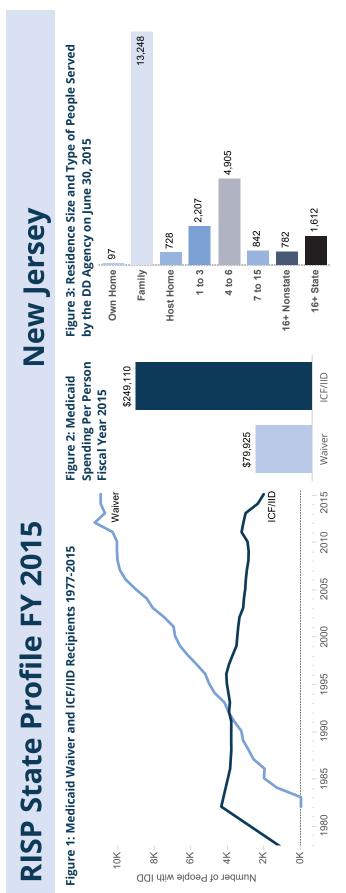


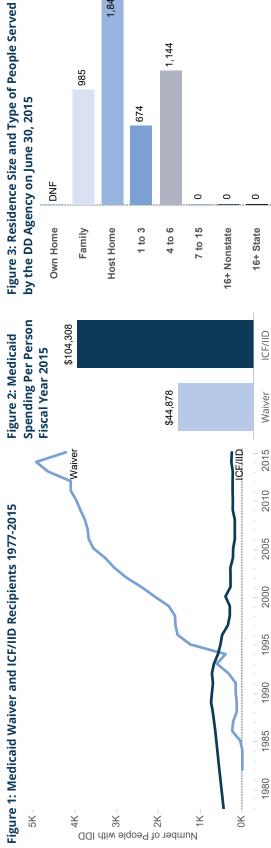
Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

								)			
Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				791	782	728	125	134	124	97
Individualized	Family				16,431	23,095	30,134	30,529	16,275	15,615	13,248
Semmes	Host Home				1,779	1,432	1,126	666	206	804	728
	1 to 3				1,094	1,404	3,598	2,100	2,133	2,210	2,207
People in	4 to 6				2,065	2,956	4,329	4,167	4,292	4,375	4,905
Congregate	1 to 6	280	1,076	3,954	3,159	4,359	7,927	6,267	6,425	6,585	7,112
Settings	7 to 15	197	439	0	842	782	931	1,437	945	922	842
	16+	8,836	7,216	4,932	3,587	3,783	3,671	3,240	3,534	2,846	2,394
People Served by	People Served by Caseload (known to the DD agency)								43,500	29,000	25,330
the DD Agency	LTSS Recipients *(1)	9,313	8,731	8,886	26,589	34,233	44,517	43,700	28,220	26,896	24,421
	Waiting for Medicaid Waiver *				5,012	3,384	DNF	DNF	3,932	3,765	3,664
People in Non-DD	People in Non-DD Nursing Facility *(s)			210	468	714	DNF	1,043	1,070	919	898
Settings	Psychiatric Facility *(2)			9	0	DNF	0	09	61	49	41
Medicaid	Waiver Expenditures per Person			\$25,035	\$42,973	\$43,995	\$55,351	\$65,316	\$65,968	\$75,146	\$79,925
Recipients and	ICF/IID Expenditures per Person			\$74,922	\$109,142	\$185,243	\$211,403	\$213,240	\$229,696	\$280,909	\$249,110
Experiments	Waiver Recipients per 100,000			47.1	81.9	104.1	114.7	127.4	120.7	122.8	122.5
	ICF/IID per 100,000			49.2	41.4	35.0	33.3	35.6	34.1	26.5	22.8





### New Mexico



1,844

Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				451	471	451	274	70	DNF	DNF
Individualized	Family				393	942	1,565	651	1,160	944	985
Settings	Host Home				219	391	422	0	1,915	1,808	1,844
	1 to 3				744	737	752	2,934	PD	PD	674
People in	4 to 6				224	206	363	134	PD	PD	1,144
Congregate	1 to 6	113	139	396	896	943	1,115	3,068	246	1,789	1,818
Settings	7 to 15	100	155	360	279	130	120	120	120	0	0
	16+	581	552	473	16	0	0	0	0	0	0
People Served by	People Served by Caseload (known to the DD agency)								11,534	10,674	11,328
the DD Agency	LTSS Recipients *(1)	794	846	1,229	2,326	2,877	3,673	4,222	3,511	5,663	5,860
	Waiting for Medicaid Waiver *				190	3,359	4,998	4,998	6,248	6,133	6,365
People in Non-DD	People in Non-DD Nursing Facility *(s)			88	94	110	103	109	96	66	100
Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$19,944	\$52,091	\$62,374	\$73,966	\$69,489	\$64,504	\$56,052	\$44,878
Recipients and	ICF/IID Expenditures per Person			\$49,249	\$68,680	\$96,016	\$108,309	\$106,937	\$109,070	\$97,692	\$104,308
Expenditures	Waiver Recipients per 100,000			10.3	115.7	185.2	193.3	197.3	223.6	237.0	202.9
	ICF/IID per 100,000			45.6	22.3	11.4	11.1	11.2	11.0	12.7	12.1



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				1,514	7,690	7,911	9,109	9,481	10,350	10,894
Individualized	Family				63,343	79,476	76,814	78,744	81,178	80,686	83,052
Settings	Host Home				4,287	3,322	2,471	2,307	2,178	2,059	1,949
	1 to 3				3,020	3,234	3,313	3,348	3,366	3,390	3,481
People in	4 to 6				5,855	8,769	11,420	11,697	11,784	12,067	12,201
Congregate	1 to 6	3,496	4,271	6,165	8,875	12,030	14,703	15,045	15,150	15,457	15,682
Settings	7 to 15	1,817	5,609	15,751	18,238	19,039	18,788	18,822	18,533	18,588	18,462
	16+	21,239	15,437	9,130	3,693	3,348	2,941	2,623	1,408	1,615	1,661
People Served by	People Served by Caseload (known to the DD agency)								128,271	128,635	131,789
the DD Agency	LTSS Recipients *(1)	26,552	25,317	31,046	99,950	124,905	123,628	128,551	128,949	129,217	131,914
	Waiting for Medicaid Waiver *				5,959	5,273	3,864	6,971	DNF	0	0
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,550	1,956	1,215	DNF	1,901	1,901	1,791	1,552
Settings	Psychiatric Facility *(2)			20	DNF	0	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			0	\$46,937	\$61,363	\$72,031	\$70,973	\$67,038	\$60,814	\$60,959
Recipients and	ICF/IID Expenditures per Person			\$92,299	\$210,643	\$317,721	\$450,043	\$444,470	\$380,254	\$214,260	\$205,740
Expenditures	Waiver Recipients per 100,000			0.0	190.2	267.4	341.5	393.7	404.5	408.0	423.0
	ICF/IID per 100,000			98.6	53.3	44.4	38.7	37.2	36.3	34.3	32.8



### North Carolina

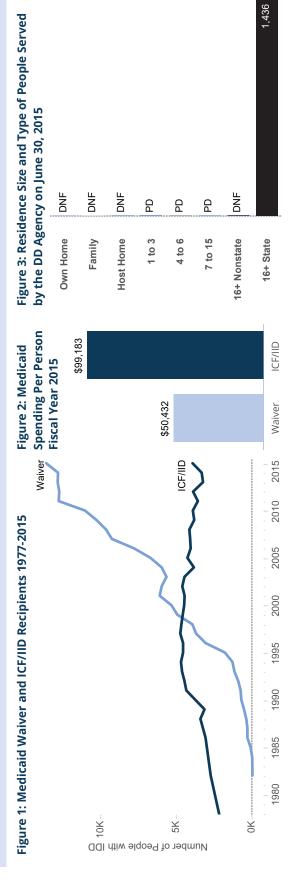


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

ate erved by gency			700-	1001	7000	2002	01.07	71.07	2013	2014	GL07
Settings Host Home Settings Host Home 1 to 3 People in Congregate Congregate To 15 People Served by Caseload (kn the DD Agency LTSS Recipie Waiting for M People in Non-DD Nursing Facil					294	2,292	1,486	1,536	1,536	DNF	DNF
People in Act Home 1 to 3  People in 4 to 6  Congregate 1 to 6  Settings 7 to 15  The Deople Served by Caseload (known DD Agency LTSS Recipie Waiting for M Deople in Non-DD Nursing Faciliary					7,193	17,058	13,389	13,765	13,765	DNF	DNF
People in Congregate Settings T to 6  People Served by Caseload (knuthe DD Agency LTSS Recipie Waiting for Menting Facility Construction Non-DD Nursing Facilit					358	295	1,128	1,400	1,400	DNF	DNF
People in Congregate Congregate T to 6 Settings T to 15 Tebes 16+ People Served by Caseload (knuthe DD Agency LTSS Recipie Waiting for M People in Non-DD Nursing Facili					1,491	DNF	DNF	DNF	PD	PD	PD
Congregate Settings 7 to 15 16+ People Served by Caseload (knumer DD Agency LTSS Recipie Waiting for M People in Non-DD Nursing Facili					5,747	DNF	1,526	DNF	PD	PD	PD
People Served by Caseload (knithe DD Agency LTSS Recipie Waiting for M People in Non-DD Nursing Facil		239	484	2,643	7,238	5,815	3,575	3,280	PD	PD	PD
People Served by Caseload (knuthe DD Agency LTSS Recipie Waiting for M People in Non-DD Nursing Facil		153	179	251	296	1,062	346	DNF	PD	PD	PD
People Served by Caseload (known the DD Agency LTSS Recipie Waiting for M People in Non-DD Nursing Facilia		4,032	3,778	3,134	2,543	2,468	2,170	DNF	PD	PD	PD
the DD Agency  LTSS Recipie  Waiting for M People in Non-DD Nursing Facil	own to the DD agency)								21,138	25,026	34,458
Waiting for M. People in Non-DD Nursing Facil	nts *(1)	4,424	4,441	6,028	18,522	28,990	22,094	26,727	21,824	24,399	28,975
People in Non-DD Nursing Facil	Waiting for Medicaid Waiver *				2,074	DNF	397	8,425	006'6	9,130	9,569
	ity *(s)			465	899	531	4,258	4,086	DNF	DNF	717
Settings   Psychiatric Facility *(2)	acility *(2)			4	0	91	DNF	86	92	92	DNF
Medicaid Waiver Expen	Waiver Expenditures per Person			\$16,450	\$34,107	\$39,530	\$54,831	\$48,422	\$34,266	\$58,661	\$50,432
	ICF/IID Expenditures per Person			\$57,292	\$87,802	\$103,802	\$124,544	\$134,533	\$65,334	\$140,706	\$99,183
Expenditures Waiver Recipi	Waiver Recipients per 100,000			11.6	9.99	77.8	116.3	131.3	131.1	129.5	136.1
ICF/IID per 100,000	0,000			65.0	56.2	49.6	41.4	40.3	33.2	33.8	39.5

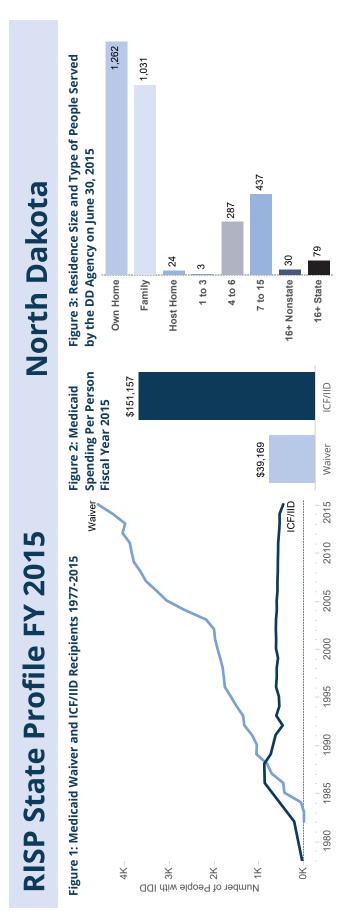


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Tvne	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
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People in	Own Home				996	1,070	1,267	1,126	1,159	1,241	1,262
Individualized	Family				393	269	206	1,225	1,159	1,037	1,031
Settings	Host Home				38	27	27	20	23	24	24
	1 to 3				0	0	0	0	0	0	8
People in	4 to 6				201	192	251	241	258	268	287
Congregate	1 to 6	23	12	965	201	192	251	241	258	268	290
settings	7 to 15	47	146	595	495	536	487	520	486	469	437
	16+	1,306	1,076	278	267	194	145	124	117	116	109
People Served by	People Served by Caseload (known to the DD agency)								4,175	5,062	4,970
the DD Agency	LTSS Recipients *(1)	1,376	1,234	1,838	2,360	2,588	3,084	3,356	3,202	3,155	3,153
	Waiting for Medicaid Waiver *				0	0	0	0	0	0	0
eople in Non-DD	People in Non-DD Nursing Facility *(s)			182	105	118	193	100	108	122	119
Settings	Psychiatric Facility *(2)			_	0	0	0	0	80	2	5
Medicaid	Waiver Expenditures per Person			\$14,046	\$21,675	\$18,683	\$25,336	\$31,933	\$35,531	\$39,473	\$39,169
Recipients and	ICF/IID Expenditures per Person			\$64,077	\$79,969	\$107,014	\$155,783	\$165,596	\$175,601	\$177,745	\$151,157
Experioritares	Waiver Recipients per 100,000			26.6	301.5	483.3	573.3	580.2	552.9	578.4	609.4
	ICF/IID per 100,000			8.66	97.3	95.8	86.1	79.9	75.2	73.7	61.2
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#### Ohio

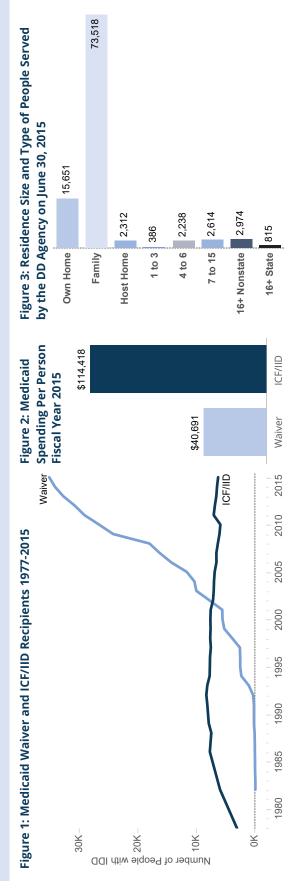


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				4,175	3,110	11,032	13,641	14,837	15,326	15,651
Individualized	Family				12,726	12,831	19,939	58,851	69,358	71,969	73,518
Serungs	Host Home				869	806	892	2,123	2,309	2,239	2,312
	1 to 3				DNF	DNF	DNF	873	392	390	386
People in	4 to 6				DNF	DNF	432	2,245	2,251	2,234	2,238
Congregate	1 to 6	620	1,347	3,707	2,415	2,660	3,623	3,118	2,643	2,624	2,624
Settings	7 to 15	768	1,587	2,993	2,772	2,609	2,817	2,618	2,660	2,668	2,614
	16+	9,429	7,938	6,907	5,483	4,752	3,861	4,364	4,116	3,984	3,789
People Served by	People Served by Caseload (known to the DD agency)								100,699	101,240	103,063
the DD Agency	LTSS Recipients *(1)	10,817	10,872	13,607	28,269	26,870	42,164	86,677	100,699	101,244	103,063
	Waiting for Medicaid Waiver *				6,816	DNF	DNF	DNF	31,630	29,660	30,526
People in Non-DD	People in Non-DD Nursing Facility *(s)			2,823	2,213	DNF	DNF	1,962	1,962	1,521	1,427
Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			0	\$31,651	\$40,623	\$40,984	\$40,194	\$40,183	\$40,133	\$40,691
Recipients and	ICF/IID Expenditures per Person			\$45,433	\$72,632	\$144,425	\$127,512	\$112,557	\$113,544	\$115,103	\$114,418
Expenditures	Waiver Recipients per 100,000			DNF	49.5	102.4	231.7	267.5	283.9	295.6	303.5
	ICF/IID per 100,000			75.1	67.7	2.09	51.9	0.09	57.7	56.5	54.8

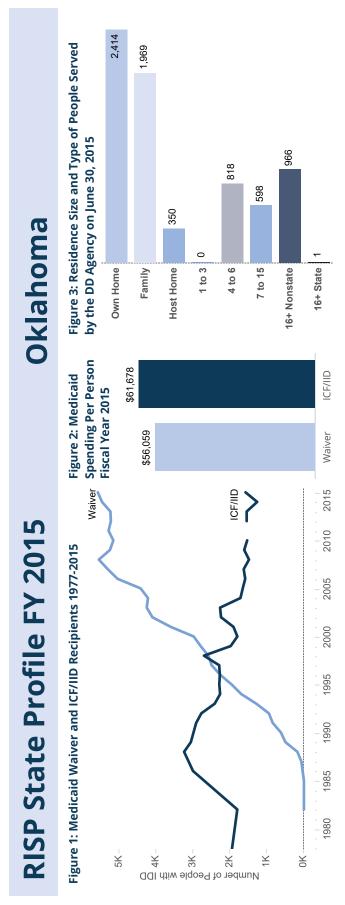


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,560	2,300	1,636	1,667	1,732	1,898	2,414
Individualized	Family				1,783	4,460	2,516	2,363	2,383	2,460	1,969
settings	Host Home				363	542	429	407	399	376	350
	1 to 3				9	21	0	0	0	0	0
People in	4 to 6				268	802	740	752	PD	PD	818
Congregate	1 to 6	11	9	720	574	823	743	752	PD	PD	818
Settings	7 to 15	19	98	283	222	326	461	574	PD	G G	598
	16+	3,082	2,920	3,852	1,678	1,270	1,091	1,009	PD	PD	296
eople Served by	People Served by Caseload (known to the DD agency)								14,347	14,550	13,809
the DD Agency	LTSS Recipients *(1)	3,112	3,012	4,855	6,180	9,721	6,876	7,087	6,837	908'9	7,115
	Waiting for Medicaid Waiver *				2,482	3,853	5,737	6,808	7,044	6,980	6,943
eople in Non-DD	People in Non-DD Nursing Facility *(s)			1,850	837	805	406	315	269	522	1,320
Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$14,002	\$49,491	\$47,916	\$54,334	\$52,451	\$53,048	\$55,197	\$56,059
Recipients and	ICF/IID Expenditures per Person			\$38,008	\$57,289	\$73,396	\$80,516	\$78,921	\$72,066	\$72,869	\$61,678
Experiginares	Waiver Recipients per 100,000			26.6	86.4	124.5	137.5	136.9	136.0	140.9	142.6
	ICF/IID per 100.000			918	52.2	46.7	40.9	40.6	40.2	326	40 4





Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
People in	Own Home				805	269	764	764	757	780	807
Individualized	Family				3,188	3,468	8,589	10,479	10,483	11,448	12,551
Settings	Host Home				1,278	1,967	2,655	3,273	3,272	3,401	3,494
	1 to 3				292	182	300	546	765	006	1,053
People in	4 to 6				1,858	1,924	1,720	2,018	2,259	2,216	2,230
Congregate	1 to 6	49	11	2,344	2,150	2,106	2,020	2,564	3,024	3,116	3,283
Settings	7 to 15	325	490	555	209	434	216	218	231	195	161
	16+	2,233	1,979	879	221	143	626	27	36	38	24
People Served by	People Served by Caseload (known to the DD agency)								22,074	23,212	24,701
the DD Agency	LTSS Recipients *(1)	2,607	2,480	3,778	8,151	8,815	14,870	17,520	17,803	18,978	20,320
	Waiting for Medicaid Waiver *				2,732	1,570	3,219	0	0	0	0
People in Non-DD	People in Non-DD Nursing Facility *(s)			452	96	168	6	195	0	0	161
Settings	Psychiatric Facility *(2)			0	0	0	0	0	0	0	0
Medicaid	Waiver Expenditures per Person			\$18,825	\$39,879	\$37,526	\$41,230	\$40,220	\$31,646	\$40,417	\$7,474
Recipients and	ICF/IID Expenditures per Person			\$127,146	\$408,664	\$251,996	\$39,678	0	0	0	0
Expenditures	Waiver Recipients per 100,000			74.5	170.2	243.4	326.1	381.2	451.3	426.2	172.1
	ICF/IID per 100,000			26.4	1.8	1.2	9.0	0.0	0.0	0.0	0.0

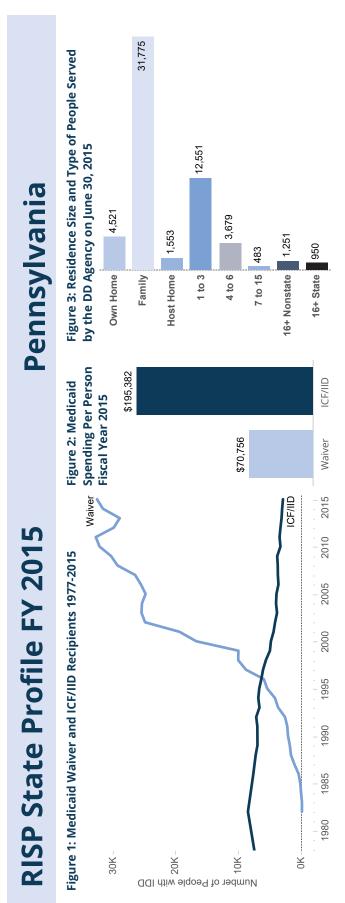


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,761	1,519	5,168	4,656	4,761	4,442	4,521
Individualized	Family				1,076	13,699	32,417	29,009	27,880	31,478	31,775
Settings	Host Home				3,600	1,600	1,434	1,590	1,589	1,480	1,553
	1 to 3				6,611	236	4,715	DNF	PD	PD	12,551
People in	4 to 6				1,835	8,065	3,838	DNF	PD	PD	3,679
Congregate	1 to 6	1,078	2,588	7,809	8,446	8,301	9,553	DNF	PD	PD	16,230
Settings	7 to 15	1,310	1,075	813	689	1,296	2,014	DNF	PD	PD	483
	16+	14,318	11,904	6,289	4,026	3,224	2,993	DNF	PD	PD	2,201
eople Served by	People Served by Caseload (known to the DD agency)								53,170	56,264	61,713
the DD Agency	LTSS Recipients *(1)	16,706	15,567	14,911	19,598	29,639	53,579	57,309	53,170	56,264	56,748
	Waiting for Medicaid Waiver *				3,442	5,149	1,613	1,979	5,814	7,360	5,493
eople in Non-DD	People in Non-DD Nursing Facility *(s)			209	2,573	DNF	DNF	1,549	1,549	1,625	1,919
Settings	Psychiatric Facility *(2)			0	170	0	0	77	99	64	115
Medicaid	Waiver Expenditures per Person			\$51,479	\$40,277	\$41,809	\$50,788	\$60,618	\$69,558	\$68,625	\$70,756
Recipients and	ICF/IID Expenditures per Person			\$65,671	\$100,509	\$142,243	\$174,983	\$172,884	\$175,097	\$181,040	\$195,382
Expelialities	Waiver Recipients per 100,000			19.5	137.0	200.3	253.7	234.8	227.6	247.9	254.9
	ICF/IID per 100,000			59.4	40.3	32.6	26.9		25.4	24.7	23.6



### **Rhode Island**

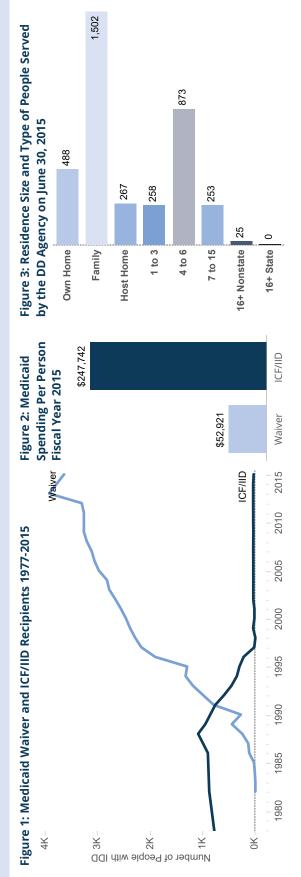


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				277	757	089	929	466	474	488
Individualized	Family				693	969	879	1,380	1,760	1,472	1,502
Settings	Host Home				22	65	166	183	229	247	267
	1 to 3				296	331	254	162	324	312	258
People in	4 to 6				774	817	927	949	957	913	873
Congregate	1 to 6	0	153	826	1,070	1,148	1,177	1,111	1,281	1,225	1,131
Settings	7 to 15	86	228	345	180	177	147	166	210	206	253
	16+	972	631	196	0	23	42	54	54	25	25
People Served by	People Served by Caseload (known to the DD agency)								3,641	3,648	4,016
the DD Agency	LTSS Recipients *(1)	1,070	1,012	1,367	2,577	2,866	3,091	3,614	4,000	3,649	3,666
	Waiting for Medicaid Waiver *				0	0	0	0	0	0	362
People in Non-DD	People in Non-DD Nursing Facility *(s)			40	162	91	92	44	66	168	9
Settings	Psychiatric Facility *(2)			0	0	0	0	0	0	DNF	0
Medicaid	Waiver Expenditures per Person			\$18,079	\$58,935	\$72,064	\$74,206	\$61,418	\$53,086	PD	\$52,921
Recipients and	ICF/IID Expenditures per Person			\$86,564	\$349,560	\$176,700	\$279,563	\$218,085	\$235,022	\$214,398	\$247,742
Expenditures	Waiver Recipients per 100,000			79.0	235.7	277.9	311.1	315.7	374.4		345.9
	ICF/IID per 100,000			76.3	1.7	3.7	3.9	4.0	4.0	4.0	3.0



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				641	269	899	899	662	663	664
Individualized	Family				12,258	13,306	12,238	12,427	12,361	12,735	13,437
Settings	Host Home				123	141	139	160	159	164	172
	1 to 3				209	217	368	328	335	361	370
People in	4 to 6				266	1,436	1,998	2,057	2,107	2,104	2,179
Congregate	1 to 6	6	က	927	1,604	1,953	2,366	2,385	2,442	2,465	2,549
Settings	7 to 15	135	191	973	1,028	910	897	890	891	865	867
	16+	3,982	3,519	2,291	1,193	933	191	745	721	701	673
eople Served by	People Served by Caseload (known to the DD agency)								31,474	32,399	34,373
the DD Agency	LTSS Recipients *(1)	4,126	3,713	4,191	16,847	17,812	17,075	17,481	17,236	17,592	18,363
	Waiting for Medicaid Waiver *				1,513	1,768	335	295	9,050	6,903	6,150
eople in Non-DD	People in Non-DD Nursing Facility *(s)			86	226	223	181	206	356	241	432
Settings	Psychiatric Facility *(2)			0	0	0	0	0	0	0	DNF
Medicaid	Waiver Expenditures per Person			0	\$25,423	\$32,895	\$29,356	DNF	\$29,689	\$29,911	\$29,326
Recipients and	ICF/IID Expenditures per Person			\$45,519	\$79,013	\$94,295	\$100,695	\$114,938	\$170,338	\$84,471	\$116,963
Expenditures	Waiver Recipients per 100,000			0.0	108.9	112.2	166.9		178.6	178.9	195.9
	ICF/IID per 100.000			9 06	54.2	40.2	30.2	27.8	26.4	25.0	24.2



### South Dakota

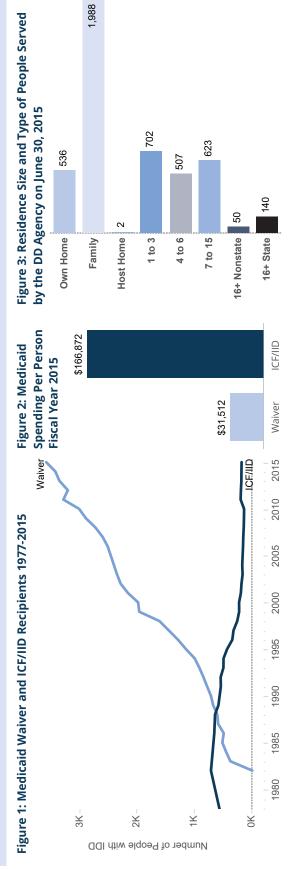


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

D.	оше	1161	202	200	2000		2010				
р	оте					2007		4-04	204	1	207
D					009	265	527	222	569	555	536
					551	761	1,033	1,161	1,656	1,738	1,988
	ome				24	7	2	4	4	_	2
					435	268	725	747	744	754	702
					157	304	514	404	406	431	202
Colligregate 1 to 6		10	00	555	265	872	1,239	1,151	1,150	1,185	1,209
Settings 7 to 15		242	471	739	650	586	416	585	649	647	623
16+		925	736	378	196	185	144	199	191	190	190
People Served by Caselo	People Served by Caseload (known to the DD agency)								4,219	4,316	4,550
the DD Agency LTSS F	LTSS Recipients *(1)	1,177	1,215	1,672	2,613	3,008	3,364	3,822	4,219	4,316	4,545
Waiting	Waiting for Medicaid Waiver *				12	2	2	0	0	0	0
People in Non-DD Nursing Facility *(s)	g Facility *(s)			225	187	185	144	134	96	93	88
Settings Psychi	Psychiatric Facility *(2)			_	15	21	31	31	0	0	0
Medicaid	Waiver Expenditures per Person			\$16,921	\$25,093	\$29,62\$	\$31,893	\$31,645	\$31,257	\$31,345	\$31,512
	ICF/IID Expenditures per Person			\$48,534	\$77,919	\$126,015	\$170,305	\$150,624	\$153,675	\$161,201	\$166,872
Waiver	Waiver Recipients per 100,000			112.1	263.8	317.9	370.7	385.8	397.9	402.4	418.4
ICF/IID	ICF/IID per 100,000			78.1	30.6	21.8	17.7	23.9	22.6	22.3	21.8

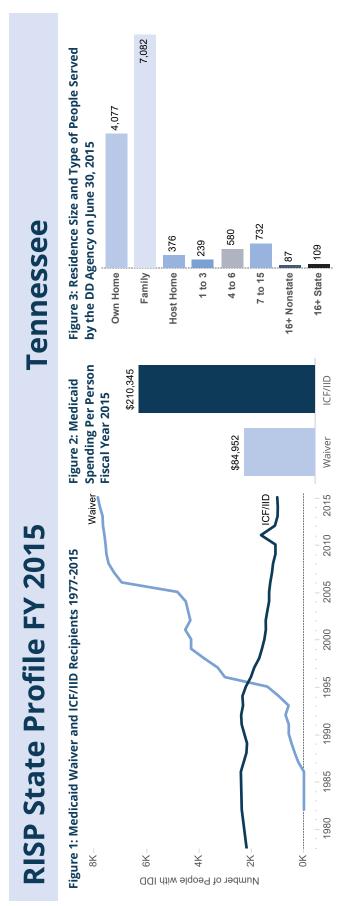


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,670	2,420	3,347	3,647	3,807	3,982	4,077
Individualized	Family				3,575	3,363	3,950	2,928	2,788	2,737	7,082
Settings	Host Home			161	246	240	317	338	336	344	376
	1 to 3				28	309	233	233	259	220	239
People in	4 to 6				307	371	357	258	609	909	280
Congregate	1 to 6	210	343	654	335	089	610	791	898	826	819
Settings	7 to 15	495	729	1,401	1,127	892	649	733	929	899	732
	16+	2,500	2,456	2,167	1,047	806	528	351	253	226	196
People Served by	People Served by Caseload (known to the DD agency)								20,624	20,341	21,799
the DD Agency	LTSS Recipients *(1)	3,205	3,528	4,383	8,000	8,401	9,401	9,219	8,708	8,783	13,282
	Waiting for Medicaid Waiver *				910	1,491	1,158	1,654	7,165	6,494	6,277
People in Non-DD	People in Non-DD Nursing Facility *(s)			883	892	895	369	420	646	614	292
Settings	Psychiatric Facility *(2)			5	0	29	35	11	DNF	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$19,672	\$37,100	\$73,704	\$75,936	\$78,659	\$81,194	\$82,385	\$84,952
Recipients and	ICF/IID Expenditures per Person			\$42,017	\$155,340	\$217,565	\$207,079	\$200,917	\$220,444	\$211,419	\$210,345
Expellullules	Waiver Recipients per 100,000			11.7	83.9	89.9	119.4	119.0	118.5	119.1	119.4
	ICF/IID per 100,000			48.1	26.6	81.1	17.1	17.2	15.5	15.3	15.5





### **Texas**

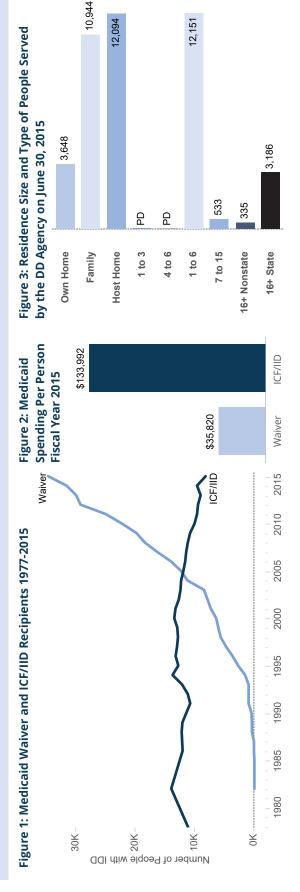


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

ced         Family         2,282         2,396         3,605           red         Family         1,798         3,277         5,080           Host Home         1,053         3,168         5,665           1 to 6         101         76         1,987         7,265         8,153         4,420           a to 6         101         76         1,987         7,265         8,153         4,420           roc by         Caseload (known to the DD agency)         14,370         14,634         9,660         7,961         6,568         5,657           roch by         Caseload (known to the DD agency)         14,370         14,634         9,660         7,961         6,568         5,657           Inch by         Caseload (known to the DD agency)         14,905         15,763         12,440         20,341         24,251         24,394           Inch by         Nusing Facility *(s)         14,905         15,763         12,440         20,341         24,251         24,394           Inch by         Nusing Facility *(s)         August         August         August         August         August         August         August           Inch by         August         August         August         August <th>Category</th> <th>Туре</th> <th>1977</th> <th>1982</th> <th>1991</th> <th>2000</th> <th>2005</th> <th>2010</th> <th>2012</th> <th>2013</th> <th>2014</th> <th>2015</th>	Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
Family	People in	Own Home				2,282	2,396	3,605	3,485	4,316	2,936	3,648
Host Home         Host Home         1,053         3,168         5,665           Ito 3         1,400         DNF         DNF         DNF           A to 6         10 6         10 6         10 6         DNF         4,420           Ito 6         1 to 6         10 1         76         1,987         7,265         8,153         4,420           Brved by Caseload (known to the DD agency)         14,370         14,634         9,660         7,961         6,568         5,057           Brved by Caseload (known to the DD agency)         14,370         14,634         9,660         7,961         6,568         5,057           Brved by Caseload (known to the DD agency)         14,370         14,634         9,660         7,961         6,568         5,057           Non-DD Nursing Facility *(s)         Non-Brved Recipients *(1)         14,905         15,763         12,440         20,941         24,251         24,394           Non-DD Psychiatric Facility *(s)         Non-Brved Recipients per Person         \$1,4767         \$4,199         DNF         DNF           Raiver Expenditures per Person         \$41,055         \$542,034         \$60,981         \$8.5           Maiver Recipients per 100,000         \$60,00         \$60,000         \$60,000	Individualized	Family				1,798	3,277	5,080	9,238	9,645	10,397	10,944
teach         4 to 6         1400         DNF         DNF         DNF         DNF         A420         A430         A430         A430         A430	Settings	Host Home				1,053	3,168	5,665	9,738	11,090	10,637	12,094
te         4 to 6         101         76         1,987         7,265         B,153         4,420           7 to 15         7 to 15         434         1,053         793         582         689         567           16+         16+         434         1,053         793         582         689         567           16+         16+         14,370         14,634         9,660         7,961         6,568         5,057           gency         Caseload (known to the DD agency)         14,370         14,634         9,660         7,961         6,568         5,057           gency         LTSS Recipients *(1)         14,305         15,763         12,440         20,941         24,251         24,394           Non-DD         Nursing Facility *(s)         3,258         2,919         1,145         DNF           Non-DD         Psychiatric Facility *(s)         3,258         2,919         1,145         DNF           Non-DD         Psychiatric Facility *(s)         \$1,055         \$54,108         \$67,570         \$96,981         \$8.5           Auiver Expenditures per Person         \$41,055         \$54,188         \$67,570         \$96,981         \$8.5           Auiver Recipients per 100,000		1 to 3				1,400	DNF	DNF	DNF	B	PD	PD
teal of to 6         1 to 6         1 to 6         1 to 6         1 to 6         4 420         4 420           7 to 15         7 to 15         4 34         1,053         793         582         689         567           strod by ared by Gaseload (known to the DD agency)         14,370         14,634         9,660         7,961         6,568         5,057           Bency         LTSS Recipients *(1)         14,905         15,763         12,440         20,941         24,251         24,394           Non-DD         Nursing Facility *(s)         14,905         15,763         12,440         20,941         24,251         24,394           Non-DD         Nursing Facility *(s)         0         0         0         0         0         0           Psychiatric Facility *(s)         0         0         0         0         0         0         0           Raiver Expenditures per Person         \$41,055         \$54,105         \$62,034         \$34,128         \$41,022           Avaiver Recipients per 100,000         \$66,981         \$66,981         \$66,981         \$66,981         \$66,981	People in	4 to 6				5,865	DNF	4,420	DNF	PD	PD	PD
Pro15         7 to 15         434         1,053         793         582         689         567           stroed by Gaseload (known to the DD agency)         LTSS Recipients *(1)         14,370         14,634         9,660         7,961         6,568         5,057           Waiting for Medicaid Waiver *         Waiting for Medicaid Waiver *         14,905         15,763         12,440         20,941         24,251         24,394           Non-DD Nursing Facility *(s)         Nursing Facility *(s)         3,258         2,919         1,145         DNF           Naiver Expenditures per Person         \$14,767         \$42,034         \$34,128         \$41,022           s and Lies*         Waiver Recipients per 100,000         \$6.56         \$3.9         \$8.5	Congregate	1 to 6	101	92	1,987	7,265	8,153	4,420	11,283	12,357	11,886	12,151
16+   14,370   14,634   9,660   7,961   6,568   5,057     Caseload (known to the DD agency)   14,905   15,763   12,440   20,941   24,251   24,394     Valiting for Medicald Walver*   14,905   15,763   12,440   20,941   24,251   24,394     Non-DD   Nursing Facility*(2)   3,258   2,919   1,145   DNF   DNF     Psychiatric Facility*(2)   0 0 0 0 0     Walver Expenditures per Person   \$41,055   \$54,188   \$67,570   \$96,981   \$1,000     ICF/IID Expenditures per 100,000   \$6.6   \$	Settings	7 to 15	434	1,053	793	582	689	292	222	551	553	533
Parked by   Caseload (known to the DD agency)   14,905   15,763   12,440   20,941   24,251   24,394     LTSS Recipients *(1)		16+	14,370	14,634	9,660	7,961	6,568	5,057	4,361	4,047	3,738	3,521
Boncy         LTSS Recipients *(1)         14,905         15,763         12,440         20,941         24,251         24,394           Non-DD         Nursing Facility *(s)         Non-DD         Nursing Facility *(s)         DNF         DNF           Non-DD         Nursing Facility *(s)         0         0         0         0         0           Psychiatric Facility *(s)         waiver Expenditures per Person         \$14,767         \$42,034         \$34,128         \$41,022           S and Ires *         Waiver Recipients per 100,000         \$41,055         \$54,188         \$67,570         \$96,981         \$8.5	People Served by	Caseload (known to the DD agency)								DNF	DNF	DNF
Non-DD Nursing Facility *(s)         Waiting for Medicaid Waiver *         4,199         DNF	the DD Agency	LTSS Recipients *(1)	14,905	15,763	12,440	20,941	24,251	24,394	40,596	41,902	41,079	42,780
Non-DD Psychiatric Facility *(s)         Nursing Facility *(s)         1,145         DNF           Psychiatric Facility *(2)         0         0         0         0           Waiver Expenditures per Person Lires *         \$14,767         \$42,034         \$34,128         \$41,022           Avaiver Recipients per Person Lires *         \$41,055         \$54,188         \$67,570         \$96,981         \$8.5		Waiting for Medicaid Waiver *				4,199	DNF	DNF	DNF	DNF	DNF	DNF
Psychiatric Facility *(2)         0         3         0         3         0         2 <th>People in Non-DD</th> <th>Nursing Facility *(s)</th> <th></th> <th></th> <th>3,258</th> <th>2,919</th> <th>1,145</th> <th>DNF</th> <th>1,936</th> <th>1,934</th> <th>1,881</th> <th>2,227</th>	People in Non-DD	Nursing Facility *(s)			3,258	2,919	1,145	DNF	1,936	1,934	1,881	2,227
waiver Expenditures per Person         \$14,767         \$42,034         \$34,128         \$41,022           s and lcF/IID Expenditures per Person         \$41,055         \$54,188         \$67,570         \$96,981         \$85,981           values*         Waiver Recipients per 100,000         \$66,981         \$85,983         \$85,983	Settings	Psychiatric Facility *(2)			0	0	0	0	0	DNF	DNF	DNF
ICF/IID Expenditures per Person         \$41,055         \$54,188         \$67,570         \$96,981           Waiver Recipients per 100,000         5.6         30.7         53.9         88.5	Medicaid	Waiver Expenditures per Person			\$14,767	\$42,034	\$34,128	\$41,022	\$36,270	\$36,813	\$36,422	\$35,820
Waiver Recipients per 100,000 5.6 30.7 53.9	Recipients and	ICF/IID Expenditures per Person			\$41,055	\$54,188	\$67,570	\$96,981	\$108,735	\$119,283	\$112,535	\$133,992
	Expenditures	Waiver Recipients per 100,000			9.6	30.7	53.9	88.5	112.0	113.2	117.0	126.0
62.1 84.5 52.2		ICF/IID per 100,000			62.1	84.5	52.2	39.9	36.3	34.1	35.7	29.8



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

			_								
Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				448	612	885	985	1,006	1,158	1,244
Individualized	Family				1,387	1,614	1,843	1,814	1,828	2,009	2,139
Settings	Host Home				143	247	263	269	278	307	339
	1 to 3				782	816	893	606	925	1,093	1,135
People in	4 to 6				240	311	341	348	353	400	415
Congregate	1 to 6	89	20	782	1,022	1,127	1,233	1,257	1,278	1,493	1,550
Settings	7 to 15	95	145	340	160	160	172	162	162	71	74
	16+	1,217	1,155	948	748	754	739	773	760	814	763
People Served by	People Served by Caseload (known to the DD agency)								6,512	968'9	7,234
the DD Agency	LTSS Recipients *(1)	1,380	1,350	2,070	3,908	4,514	5,135	5,427	5,350	5,851	6,161
	Waiting for Medicaid Waiver *				1,303	244	1,822	1,834	1,886	1,821	1,914
People in Non-DD	People in Non-DD Nursing Facility *(s)			283	191	248	96	167	92	81	34
Settings	Psychiatric Facility *(2)			0	0	0	0	0	0	0	0
Medicaid	Waiver Expenditures per Person			\$16,207	\$23,573	\$26,854	\$34,643	\$36,007	\$37,432	\$36,078	\$36,657
Recipients and	ICF/IID Expenditures per Person			\$74,849	\$70,184	\$72,435	\$73,959	\$96,976	\$78,989	\$81,094	\$86,178
Expelialiares	Waiver Recipients per 100,000			85.5	141.1	155.2	155.1	151.3	150.0	167.9	174.9
	ICF/IID per 100,000			54.2	33.9	32.2	28.2	28.1	28.4	28.5	28.1



# **RISP State Profile FY 2015**

### Vermont

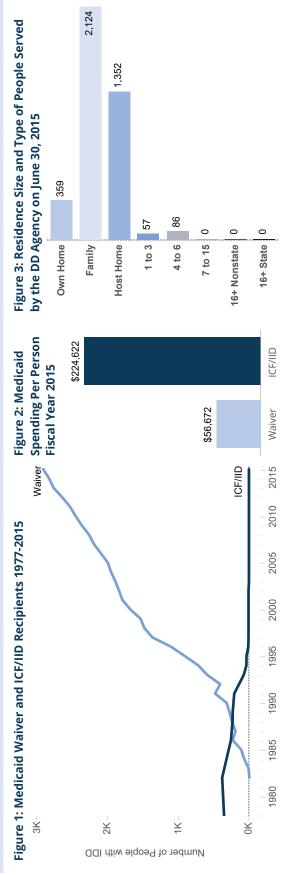


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

People in Individualized	7 6	1161	1982	1991	2000	2002	2010	2012	2013	2014	2015
	Own Home				147	184	236	248	283	317	329
	Family				1,003	1,285	1,734	1,835	1,900	1,915	2,124
Settings	Host Home				813	626	1,237	1,300	1,307	1,319	1,352
`	1 to 3				30	42	26	47	29	56	22
People in	4 to 6				73	73	75	06	81	85	86
ate	1 to 6	262	322	504	103	115	131	137	148	141	143
Settings	7 to 15	143	120	0	0	0	0	0	0	0	0
`	16+	517	356	160	0	0	0	0	0	0	0
People Served by	People Served by Caseload (known to the DD agency)								4,245	4,283	4,408
the DD Agency	LTSS Recipients *(1)	922	798	664	2,066	2,563	3,238	3,442	3,638	3,692	3,978
	Waiting for Medicaid Waiver *				7	0	0	0	367	295	182
People in Non-DD	People in Non-DD Nursing Facility *(s)			91	42	27	28	32	32	34	30
Settings	Psychiatric Facility *(2)			_	0	DNF	DNF	0	0	0	0
Medicaid	Waiver Expenditures per Person			\$21,144	\$35,638	\$46,017	\$54,040	\$53,461	\$54,388	\$56,065	\$56,672
	ICF/IID Expenditures per Person			\$92,297	\$138,446	\$157,468	DNF	\$211,131	\$191,744	\$212,504	\$224,622
- samminedva	Waiver Recipients per 100,000			85.5	276.6	321.5	393.1	423.2	442.0	452.1	465.9
_	ICF/IID per 100,000			37.9	2.0	1.0	1.0	1.0	1.0	1.0	1.0



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				1,463	1,735	1,656	1,235	209	216	252
Individualized	Family				2,896	3,213	1,071	1,445	1,445	3,247	3,252
Settings	Host Home				430	351	578	801	1,285	1,373	1,491
	1 to 3				DNF	DNF	1,093	372	477	523	229
People in	4 to 6				DNF	DNF	1,240	2,166	2,523	2,824	3,028
Congregate	1 to 6	123	161	223	00	DNF	2,333	2,538	3,000	3,347	3,705
Settings	7 to 15	153	281	394	75	DNF	411	594	1,060	1,097	1,010
	16+	4,441	3,778	2,667	1,785	DNF	2,646	3,165	963	789	654
People Served by	People Served by Caseload (known to the DD agency)								10,018	18,054	19,517
the DD Agency	LTSS Recipients *(1)	4,717	4,220	3,284	6,657	DNF	8,695	11,023	7,973	9,967	10,142
	Waiting for Medicaid Waiver *				1,316	2,028	4,395	4,649	6,672	8,576	10,339
People in Non-DD	People in Non-DD Nursing Facility *(s)			1,993	1,272	762	864	933	935	1,563	836
Settings	Psychiatric Facility *(2)			6	140	148	345	312	312	DNF	DNF
Medicaid	Waiver Expenditures per Person			\$810	\$31,186	\$43,142	\$60,885	\$61,761	\$55,803	\$66,506	\$58,538
Recipients and	ICF/IID Expenditures per Person			\$56,732	\$98,041	\$126,770	\$176,590	\$49,302	\$270,991	\$204,652	\$201,104
Expellulues	Waiver Recipients per 100,000			5.2	65.5	66.3	110.8	119.2	124.5	133.3	148.2
	ICE/IID per 100.000			42.7	26.4	23.9	19.1	16.2	13.5	110	0





## Washington

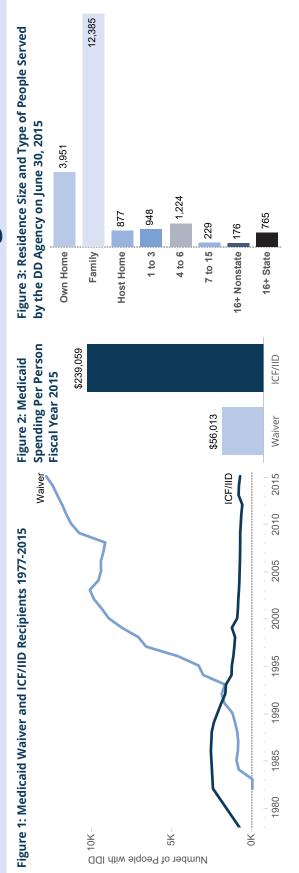


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

3,488 3,724 3 7,030 12,994 14 521 2,465 2.14 1102 194 3,549 309 1,753 2 347 473 402 260 307 3,979 3,067 2,046 1,344 1,201 1 1) 4,428 3,734 6,518 14,896 20,193 21 10 Waiver* 1) 4,428 3,734 6,518 14,896 20,193 21 10	Category	Туре	1977	1982	1991	2000	2005	2010	2012	2013	2014	2015
Family         Family         7,030         12,994         14           Host Home         103         12,994         14           4 to 6         103         178         42           4 to 6         102         194         3,549         309         1,753         2           7 to 15         347         473         402         260         307         1,701         1           7 co 15         3,979         3,067         2,046         1,344         1,201         1           16+         3,979         3,067         2,046         1,344         1,201         1           16+         4,428         3,734         6,518         14,896         20,193         21           LTSS Recipients *(1)         4,428         3,734         6,518         14,896         20,193         21           Nating for Medicaid Waiver *         4,428         3,734         6,518         14,896         20,193         21           Psychiatric Facility *(s)         700         462         365         365         365           Waiver Expenditures per Person         \$1,7427         \$20,462         \$36,706         \$36           Waiver Recipients per 100,000         <	People in	Own Home				3,488	3,724	3,727	6,370	6,307	3,701	3,951
Host Home         521         2,465         214           1 to 3         4 to 6         178         42           4 to 6         1 to 6         131         1,711         2           1 to 6         1 to 6         102         194         3,549         309         1,753         2           7 to 15         3,979         3,067         2,046         1,344         1,201         1           1 G*         1 to 4         3,979         3,067         2,046         1,344         1,201         1           1 Caseload (known to the DD agency)         4,428         3,734         6,518         14,896         20,193         21           Waiting for Medicaid Waiver*           DD Nursing Facility *(s)         700         462         365           Psychiatric Facility *(s)         700         462         \$365           Waiver Expenditures per Person         \$17,427         \$20,462         \$36,706         \$37           Waiver Recipients per Person         \$81,681         \$140,429         \$156,544         \$150,5         1	Individualized	Family				7,030	12,994	14,442	11,148	10,075	11,495	12,385
1 to 3         1 to 3         178         42           4 to 6         1 to 6         102         194         3,549         309         1,753         2           1 to 6         1 to 6         347         473         402         260         307         1,753         2           1 c+         1 to 15         3,979         3,067         2,046         1,344         1,201         1           1 caseload (known to the DD agency)         4,428         3,734         6,518         14,896         20,193         21           Waiting for Medicaid Waiver *           DD         Nursing Facility *(s)         700         462         365           Psychiatric Facility *(s)         700         462         365           Waiver Expenditures per Person         \$17,427         \$20,462         \$36,706         \$37           ICF/IID Expenditures per Person         \$81,681         \$140,429         \$156,544         \$150,5         1           Waiver Recipients per 100,000         34.6         152.4         150.5         1	Settings	Host Home			521	2,465	214	129	96	891	828	877
4 to 6         110 to 6         110 to 6         110 to 6         110 to 6         11711         2           1 to 6         1 to 6         347         473         402         260         307         260         307         307         307         307         307         307         307         307         307         307         307         307         307         307         307         307         1100         307         308         307         308         307         308		1 to 3				178	42	89	DNF	257	1,586	948
to 6         102         194         3,549         309         1,753         2           7 to 15         7 to 15         347         473         402         260         307         307           16+         16+         3,979         3,067         2,046         1,344         1,201         1           Caseload (known to the DD agency)         4,428         3,734         6,518         14,896         20,193         21           Waiting for Medicaid Waiver *         Waiting Facility *(s)         DNF         DNF         DNF         DNF           Psychiatric Facility *(s)         700         462         365         365         365           Psychiatric Facility *(s)         2         0         0         0         0           Waiver Expenditures per Person         \$17,427         \$20,462         \$36,706         \$37           Waiver Recipients per 100,000         341,642         \$156,544         \$156,541	People in	4 to 6				131	1,711	2,015	DNF	1,866	737	1,224
To 15         347         473         402         260         307           16+         16+         3,979         3,067         2,046         1,344         1,201         1           LTSS Recipients *(1)         4,428         3,734         6,518         14,896         20,193         21           Waiting for Medicaid Waiver *(1)         A,428         3,734         6,518         14,896         20,193         21           Psychiatric Facility *(2)         700         462         365         96         365         96           Psychiatric Facility *(2)         2         0         0         0         0         0           Waiver Expenditures per Person         \$17,427         \$20,462         \$36,706         \$33           Waiver Recipients per 100,000         34,6         150,5         1	Congregate	1 to 6	102	194	3,549	309	1,753	2,104	DNF	2,123	2,323	2,172
16+         3,979         3,067         2,046         1,344         1,201         1           Osseload (known to the DD agency)         4,428         3,734         6,518         14,896         20,193         21           LTSS Recipients *(1)         Waiting for Medicaid Waiver *         DNF         DNF         DNF         DNF           Nursing Facility *(s)         Psychiatric Facility *(s)         700         462         365         365           Psychiatric Facility *(s)         Waiver Expenditures per Person         \$17,427         \$20,462         \$36,706         \$37           Waiver Recipients per 100,000         34.6         152.4         150.5         1	Settings	7 to 15	347	473	402	260	307	169	DNF	284	120	229
value         Caseload (known to the DD agency)         4,428         3,734         6,518         14,896         20,193         21           LTSS Recipients *(1)         Waiting for Medicaid Waiver *         LTSS Recipients *(1)         DNF         DNF         DNF           DN Nursing Facility *(s)         Psychiatric Facility *(2)         2         0         0         0           Psychiatric Facility *(2)         Waiver Expenditures per Person         \$17,427         \$20,462         \$35,706         \$37           ICF/IID Expenditures per Person         \$81,681         \$140,429         \$158,544         \$195           Waiver Recipients per 100,000         34.6         152.4         150.5         1		16+	3,979	3,067	2,046	1,344	1,201	1,061	DNF	1,092	1,129	941
LTSS Recipients *(1)         4,428         3,734         6,518         14,896         20,193         21           Waiting for Medicaid Waiver *         Waiting for Medicaid Waiver *         DNF         DNF         DNF         DNF           DD Nursing Facility *(s)         Psychiatric Facility *(s)         2         0         0         0         0         0         0         0         0         0         0         0         0         0         452         \$35,706         \$37         \$20,462         \$35,706         \$37         \$415,427         \$20,462         \$35,706         \$37         Waiver Recipients per 100,000         341,681         \$140,429         \$158,544         \$195         1	People Served by	Caseload (known to the DD agency)								39,937	40,809	42,374
Non-DD Nursing Facility *(s)         DNF         DNF	the DD Agency	LTSS Recipients *(1)	4,428	3,734	6,518	14,896	20,193	21,632	21,236	20,772	19,596	20,507
Non-DD Nursing Facility *(s)         Nursing Facility *(s)         700         462         365           Psychiatric Facility *(2)         2         0         0         0           Waiver Expenditures per Person ts and ures *         (F/IID Expenditures per Person ures *         \$17,427         \$20,462         \$36,706         \$37           Waiver Recipients per 100,000         34.6         152.4         150.5         1		Waiting for Medicaid Waiver *				DNF	DNF	DNF	DNF	1,081	1,270	1,033
Psychiatric Facility *(2)         2         0         0           Waiver Expenditures per Person ures.*         Waiver Recipients per Person ures.*         \$17,427         \$20,462         \$36,706         \$37           Waiver Recipients per 100,000         34,681         \$140,429         \$158,544         \$195	People in Non-DD	Nursing Facility *(s)			700	462	365	329	294	0	0	0
Waiver Expenditures per Person         \$17,427         \$20,462         \$36,706         \$37           ICF/IID Expenditures per Person         \$81,681         \$140,429         \$158,544         \$195           Waiver Recipients per 100,000         34.6         152.4         150.5         1	Settings	Psychiatric Facility *(2)			2	0	0	0	22	37	37	38
ICF/IID Expenditures per Person         \$81,681         \$140,429         \$158,544         \$195           Waiver Recipients per 100,000         34.6         152.4         150.5         1	Medicaid	Waiver Expenditures per Person			\$17,427	\$20,462	\$36,706	\$37,018	\$46,302	\$47,060	\$48,323	\$56,013
Waiver Recipients per 100,000 34.6 152.4 150.5 1	Recipients and	ICF/IID Expenditures per Person			\$81,681	\$140,429	\$158,544	\$195,388	\$213,619	\$193,173	\$222,930	\$239,059
	Experioring	Waiver Recipients per 100,000			34.6	152.4	150.5	168.7	172.5	175.0	176.8	179.8
38.9 16.1 12.7		ICF/IID per 100,000			38.9	16.1	12.7	10.8	9.1	12.4	11.9	10.7



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

. (				, , ,			0,00	0,00	0,00		-100
Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				203	737	753	32	0	0	0
Individualized	Family				875	2,343	2,846	2,994	3,027	3,051	3,051
Settings	Host Home				549	335	165	156	105	103	103
	1 to 3				187	128	218	1,165	1,248	1,016	PD
People in	4 to 6				287	170	171	DNF	311	PD	222
Congregate	1 to 6	24	29	446	474	298	389	DNF	1,559	PD	1,238
settings	7 to 15	32	24	409	428	555	200	DNF	726	PD	425
	16+	950	978	373	0	29	47	DNF	78	PD	0
People Served by	People Served by Caseload (known to the DD agency)								4,524	4,524	4,524
the DD Agency	LTSS Recipients *(1)	1,006	1,031	1,228	2,529	4,327	4,700	5,338	5,517	5,566	5,030
	Waiting for Medicaid Waiver *				218	210	409	646	832	977	977
People in Non-DD	People in Non-DD Nursing Facility *(s)			211	40	DNF	DNF	329	268	279	183
Settings	Psychiatric Facility *(2)			2	7	22	0	0	31	31	DNF
Medicaid	Waiver Expenditures per Person			\$24,310	\$45,057	\$47,540	\$55,553	\$68,330	\$74,696	\$83,123	\$70,658
Recipients and	ICF/IID Expenditures per Person			\$23,085	\$106,055	\$106,992	\$131,226	\$116,483	\$118,919	\$121,499	\$133,521
Experiores	Waiver Recipients per 100,000			22.9	107.6	200.8	238.1	239.7	242.2	274.5	275.4
	ICF/IID per 100,000			37.8	24.6	28.3	25.7		30.5	29.9	27.4



## **RISP State Profile FY 2015**

### Wisconsin

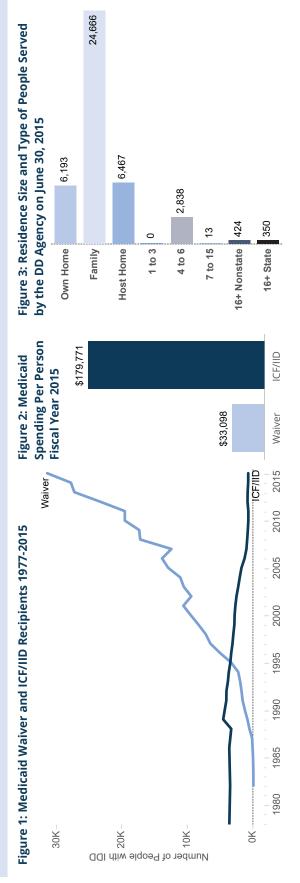


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				5,062	5,677	5,823	4,307	5,444	5,320	6,193
Individualized	Family				5,633	2,152	7,663	11,524	13,904	21,393	24,666
Settings	Host Home				2,578	3,390	1,280	5,085	5,367	5,800	6,467
	1 to 3				0	0	0	0	0	0	0
People in	4 to 6				780	1,016	2,858	2,465	2,596	2,561	2,838
Congregate	1 to 6	194	324	4,655	780	1,016	2,858	2,465	2,602	2,561	2,838
Settings	7 to 15	096	1,282	1,510	807	1,083	2,040	28	31	22	13
	16+	4,494	4,079	4,059	2,840	1,755	722	867	846	692	774
People Served by	People Served by Caseload (known to the DD agency)								30,765	31,297	41,007
the DD Agency	LTSS Recipients *(1)	5,648	5,685	10,224	17,700	15,073	20,386	24,324	28,194	35,939	40,985
	Waiting for Medicaid Waiver *				2,250	DNF	4,783	924	2,252	2,169	1,890
People in Non-DD	People in Non-DD Nursing Facility *(s)			966	471	88	153	34	34	28	22
Settings	Psychiatric Facility *(2)			2	0	0	0	0	0	0	0
Medicaid	Waiver Expenditures per Person			\$18,340	\$28,596	\$33,071	\$35,420	\$36,561	\$33,504	\$35,159	\$33,098
Recipients and	ICF/IID Expenditures per Person			\$41,217	\$88,901	\$108,328	\$188,655	\$176,258	\$185,235	\$197,658	\$179,771
Expendimes	Waiver Recipients per 100,000			33.2	178.0	234.6	344.9	408.6	475.7	483.5	545.1
	ICF/IID per 100,000			83.3	53.4	32.9	13.5	15.6	15.3	13.7	13.6



Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

			_								
Category	Туре	1977	1982	1991	2000	2002	2010	2012	2013	2014	2015
People in	Own Home				292	102	253	216	202	155	390
Individualized	Family				510	748	933	744	932	885	1,002
settings	Host Home				69	142	84	63	100	29	65
	1 to 3				87	107	276	DNF	PD	PD	PD
People in	4 to 6				263	393	495	DNF	PD	PD	PD
Congregate	1 to 6	28	17	222	350	200	771	1,036	PD	PD	PD
Settings	7 to 15	70	93	180	29	125	87	91	PD	PD	PD
	16+	584	519	290	106	120	83	62	PD	PD	PD
People Served by	People Served by Caseload (known to the DD agency)								2,035	2,102	2,110
the DD Agency	LTSS Recipients *(1)	682	629	692	1,394	1,737	2,211	2,262	2,125	1,888	2,178
	Waiting for Medicaid Waiver *				0	0	120	387	587	513	317
People in Non-DD	People in Non-DD Nursing Facility *(s)			49	40	45	45	25	21	20	22
Settings	Psychiatric Facility *(2)			0	0	0	0	80	6	9	4
Medicaid	Waiver Expenditures per Person			\$6,768	\$36,006	\$41,068	\$42,463	DNF	\$47,947	\$52,403	\$42,405
Recipients and	ICF/IID Expenditures per Person			\$140,278	\$15,146	\$208,355	\$222,932	\$364,021	\$218,226	\$232,689	\$275,184
Experimines	Waiver Recipients per 100,000			27.2	248.3	360.7	377.6	373.0	349.3	310.4	360.0
	ICF/IID per 100,000			13.0	21.5	17.3	14.7	13.7	15.4	12.8	11.9



## RISP Profile FY 2015

## **United States**

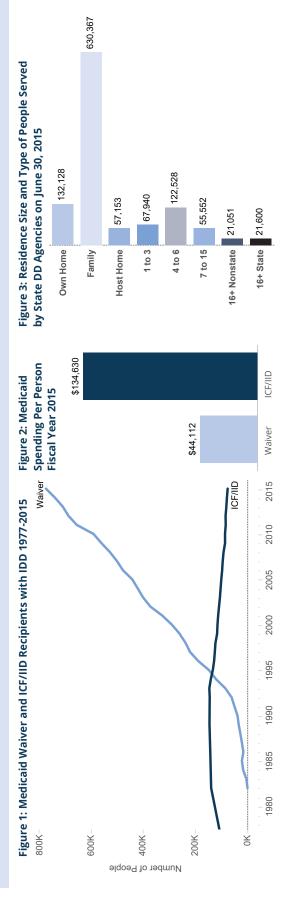


Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

People in ndividualized Family Settings Host H Host H People in 4 to 6 Congregate 1 to 6 Settings 7 to 15	Own Home Family		7061	1881	1996	2000	2002	2010	2012	2013	2014	2015
lized ate	lly				46,608	73,147	101,143	127,455	122,665	127,664	132,128	139,985
ate					590,180	391,859	533,048	592,180	634,988	662,691	630,367	698,566
ate	Host Home				24,675	37,367	35,386	40,060	58,753	63,059	57,153	61,715
ate	3		15,702			33,360	49,037	62,584	68,781	59,058	67,940	92,576
ate	6		17,486			67,146	107,573	105,290	116,159	122,262	122,528	119,831
	0	20,400	33,188	108,479	100,915	124,469	156,610	167,874	184,940	181,320	190,468	212,407
4	15	20,024	30,515	53,475	56,389	52,802	52,888	55,682	56,409	62,709	55,552	56,372
10+		207,356	180,146	127,408	95,336	82,582	990,79	57,028	50,671	48,903	43,565	42,490
People Served Case	Caseload (known to the DD agency)									1,297,378	1,374,398	1,464,459
2	LTSS Recipients *(1)	247,780	243,849	289,362	914,103	762,226	946,141	1,040,279	1,138,121	1,134,193	1,164,396	1,211,535
Waiti	Waiting for Medicaid Waiver *				87,187	71,922	73,828	115,059	79,102	245,955	209,874	199,641
People in Nurs	Nursing Facility *(s)	42,242	40,538	39,208	30,591	32,195	30,027	31,832	28,064	24,021	21,011	24,257
Non-DD Settings Psychiatric Facility *(2)	hiatric Facility *(2)	15,524	7,865	1,594	1,269	488	392	873	1,139	2,709	2,775	3,504
Medicaid	Waiver Expenditures per Person	0	\$901	\$22,319	\$24,783	\$33,142	\$38,679	\$44,396	0	\$43,365	\$43,154	\$44,112
Recipients and ICF/I	ICF/IID Expenditures per Person	\$5,798	\$14,886	\$55,636	\$73,926	\$85,040	\$119,162	\$146,999	\$143,996	\$144,609	\$133,748	\$134,630
	Waiver Recipients per 100,000		0.9	20.2	71.5	103.4	149.7	191.8	219.3	225.0	234.8	241.1
ICF/I	ICF/IID per 100,000	48.2	8.09	58.2	48.7	41.4	34.4	28.4	27.2	25.3	24.4	24.1

All U.S. data are estimates with imputed values for missing data. Settings by size include ICF/IID, group homes, and nonstate other, but if nonstate other data is DNF it is assumed to be zero. \* See state notes and the RISP FY2015 report for further explanation. (1) Long Term Supports and Service (LTSS) recipients may include imputed values to replace DNF; up until 2012 people in psychiatric and nursing homes not served directly by the DD agency may be part of LTSS recipients. (2) Psychiatric Facility data prior to 2013 was only for state facilities, after 2013 it includes people in state and nonstate operated facilities when available, see report for details. Updated 10/25/2017







**SECTION SIX** 

**APPENDICES** 

**FY 2015** 

### APPENDIX A: REFERENCES, RESOURCES AND DATA SOURCES

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- Larson, S.A. (2015). University of Minnesota data on the estimated number of people with IDD by state (Fact Sheet). Alexandria, VA: National Association of State Directors of Developmental Disabilities Services. http://www.nasddds.org/uploads/documents/University\_of\_Minnesota\_Data\_on\_the\_Estimated\_Number\_of\_People\_with\_IDD\_by\_State.pdf
- Larson, S.A., & Byun, S.Y. (2005). Prevalence
  Estimates of ID/DD Among Young Children
  from the NHIS-D. Fact Sheet. Minneapolis:
  University of Minnesota, Institute on Community
  Integration, Research and Training Center on
  Community Living. http://rtc.umn.edu/nhis/
  factsheets/fs0104.html

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Larson, S.A., (2003, June). Analysis of Prevalence of Intellectual and/or Developmental Disabilities in the South Census Bureau Region Based on the 1994/1995 National Health Interview Survey - Disability Supplement. (Unpublished Data). Minneapolis: University of Minnesota, Institute on Community Integration.

Larson, S.A., Hallas-Muchow, L., & Dean, K. (2014). Medicaid funded Long-Term Supports and Services for People with Intellectual and Developmental Disabilities State compared with the U.S. Totals on June 30, 2011. Minneapolis, MN: Residential Information Systems Project, Institute on Community Integration, University of Minnesota. Interactive Visualization published to https://risp.umn.edu/. RISP (2015). Changes in the size and type of residence for people with IDD who did not live in the home of a family member: US estimates between 1998 and 2012. Minneapolis, MN: Residential Information Systems Project, Institute on Community Integration, University of Minnesota. Interactive Visualization published to https://risp.umn.edu/.

Pettingell, S., Dean, K., & Larson, S.A. (2016). *Medicaid long-term supports and services for people with intellectual or developmental disabilities*. Chart Gallery. https://risp.umn.edu/viz

### **FISP Infographics for FY 2014**

- What is the diagnosis of adults and children with intellectual or developmental disabilities who live with their families?
- Who are family caregivers?
- What are the support needs of adults and children with intellectual or developmental disabilities who live with their families?
- How do adults with intellectual or developmental disabilities living with families spend their day?
- Do people with intellectual or developmental disabilities have social connections?
- Who gets services from state developmental disability agencies?
- Where do people with intellectual or developmental disabilities live?
- How has where people with intellectual or developmental disabilities live changed between 1998 and 2014?
- Who receives Medicaid funded waiver supports?
- How does the average annual cost of providing Medicaid Waiver services to people with IDD differ by age and living arrangement?

### **Learn More Products**

- How many people are known to state IDD agencies?
- What are the ages of people who receive home and community based services in their family homes?
- How many people with IDD are waiting for long-term supports and services?

### FISP/UIC RTC on Family Support Co-branded briefs

- Sibling Caregiver Experience Less Choice and Control
- Family Experiences with Long-term Supports and Services for Family Members
- Family-Outcomes of Long-term Supports and Services for Family Members with Intellectual and Developmental Disabilities



### Other Data Sources

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

- Data on state IDD and psychiatric facilities for 1950 to 1968 from the National Institute of Mental Health's surveys of "Patients in Institutions;"
- Data on state IDD facilities for FYs 1969 and 1970 from surveys conducted by the Office on Mental Retardation Coordination, now AIDD;
- Data on large state IDD facilities for 1971 through 1977 from surveys of the National Association of Superintendents of Public Residential Facilities for People with Mental Retardation, now the APDDA; and
- Data on psychiatric facilities for 1969 to 1977 come from the National Institute of Mental Health's surveys of "Patients in State and County Mental Hospitals."

### **Medicaid Waiver Expenditures**

1982-1991	Smith & Gettings (1991). <i>The Waiver Program and Services for People with Developmental Disabilities: An Update</i> . Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.
1992	Burwell, B. (1993). Personal Communication with K. Charlie Lakin.
2010	Eiken, S, Burwell, B., Gold, L. & Sredl, K. (2011). <i>Medicaid 1915(c) Waiver Expenditures: 2011 Update Period</i> . Cambridge, MA: Thompson Reuters.
2012	Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., and Saucier, P. (2015). <i>Medicaid Expenditures for long-term services and supports in FFY 2012</i> . Cambridge, MA: Thomson Reuters; Washington, DC: Centers for Medicaid and Medicare Services.
2013	Eiken, S., Sredl, K., Burwell, B., & Saucier, P. (2015). <i>Medicaid expenditures for long-term services and supports (LTSS) in FY 2013: Home and Community-Based Services were a majority of LTSS spending</i> . Ann Arbor, MI: Truven Health Analytics. Downloaded from https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf July 2015.

### **ICF/IID Expenditures**

State ICF/IID expenditures are reported by states to CMS annually, and are compiled by a CMS contractor. Until FY 2010, the contractor released its preliminary report within 12 months of the end of the fiscal year. CMS stopped releasing preliminary Medicaid expenditure reports in FY 2011. Final data are now released 18 to 24 months after the end of a fiscal year and are usually not available in time to be included in the RISP reports.

The RISP project reported ICF/IID expenditures based on preliminary data from the CMS contractor through FY 2010. For FY 2011, the State of the States Project of National Significance at the University of Colorado (Boulder) provided ICF/IID expenditure data for the RISP report. Since FY 2012, total annual ICF/IID expenditures have been reported by states on the annual RISP survey.

1980-1989	Eiken, S. (personal communication, April 15, 2015).
1990-1991	Burwell, B. (1992, January). Medicaid Long Term Expenditures for FY 1991. Lexington, MA: Systemetrics/McGraw-Hill.
1992	Burwell, B. (1994, February). Medicaid Long Term Expenditures in FY 1993. Cambridge, MA: SysteMetrics A MEDSTAT Division.

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1993	Burwell, B. (1999, April). <i>Medicaid Long Term Expenditures in FY 1998</i> . Cambridge, MA: The MEDSTAT Group.
1994-1999	Burwell, B. (1999, April). <i>Medicaid Long Term Expenditures in FY 1999</i> . Cambridge, MA: The MEDSTAT Group. Medicaid ICF-MR expenditures by state FY 1995 to FY 2000: Data from the HCFA 64 report. The Medstat Group.
2000	Burwell, B. (2001). <i>Table B Medicaid ICF-MR expenditures by state FY 1995 to FY 2000: Data from the HCFA 64 report</i> . The Medstat Group.
2001-2003	Burwell, B., Sredl, K., Eiken, S. (2007). <i>Medicaid Long-Term Care Expenditures in FY 2006</i> . Cambridge, MA: Thomson Reuters.
2004	Eiken, S., Sredl, K., Burwell, B., and Gold, L. (2010, August). <i>Medicaid Long-Term Care Expenditures in FY 2009</i> . Cambridge, MA: Thomson Reuters.
2005	Eiken, S., Sredl, K., Burwell, B., and Gold, L. (2011, October). <i>Medicaid Expenditures for Long-Term Services and Supports: 2011 Update</i> . Cambridge, MA: Thomson Reuters.
2006	Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2013, October). <i>Medicaid Expenditures for Long Term Services and Supports in 2011.</i> Truven.
2007-2011	Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2015, April). <i>Medicaid Expenditures for Long-Term Services and Supports in FFY 2012</i> . Truven.

### Supplemental Data

When a state is unable to furnish data for a particular year, the value the reported for the previous year is used in the RISP report. If a data element has not been furnished for more than two consecutive years, external data sources are consulted. If no other data source can be found, a DNF (Did not furnish) designator is noted in the RISP report.

For Medicaid Waiver and ICF/IID expenditures, DNF's are replaced with data from Truven Group (e.g., Eiken, 2015, 2016). See Appendix A for the full citations. When possible, historic data that was drawn from the Truven group data are also updated.

Missing data on nursing home residents and ICF/IID recipients come from analysis of CMS CASPER data by the American Health Care Association (2015a, 2015b, and 2015c). ■



### Appendix B: FY 2015 Surveys and Operational Definitions

Appendix B includes the print version of the FY 2015 RISP survey of state IDD agencies, operational definitions and instructions for that survey, and the print version of the FY 2015 survey of administrators of public residential facilities. Most states used the online version of these surveys. Print versions are reproduced here to provide the context and questions asked in each survey.

### RISP/FISP Survey FY 2015 (July 1, 2014 – June 30, 2015)

(February 2016 Edition)

**About:** This is a survey of the University of Minnesota's Residential Information Systems Project (RISP) and the Supporting Individuals and Families Information Systems Project (FISP). It is part of a 40-year longitudinal study tracking the types and sizes of residential and in home supports provided to people with Intellectual or Developmental Disabilities (IDD). The survey is fielded annually in conjunction with the National Association of State Directors of Developmental Disabilities Services (NASDDDS). It serves as the basis for your state's representation in FISP and RISP national reports, thus complete responses are important to ensure that your state's system is accurately portrayed.

**Timelines:** FY 2015 surveys are due June 30, 2016. Late responses may not be included in our FY 2015 annual report. Questions reference June 30, 2015 or the period from July 1, 2014 through June 30, 2015.

**Target Population:** This survey asks about people with IDD receiving Medicaid or state-funded long-term supports or services (LTSS) as well as those known to the state IDD agency waiting for LTSS.

### **Key Changes for FY 2015:**

- We reorganized how some items appear on the screen to help you double check your totals. If you enter a total that is not the sum of the parts, you will get an error message and will be asked to note why in the Notes tab.
- Instructions have been added to clarify some items based on feedback from FY 2013 and 2014.
- In Part 5, questions about nursing homes and psychiatric settings have been reorganized, and a question about children and youth in nursing homes added.
- Part 6 was added asking about the total number of children and youth with IDD who live in congregate settings in your state. This item is used for the Centers for Disease Control's Healthy People 2020 monitoring.
- A validation checking tool was added for staff to automate proofing the data you submitted. Error messages were built in when that tool detects a response requiring further explanation.
- Your project staff member can download an excel spreadsheet summarizing your responses on request. This tool is in beta testing for FY 2015. It will be made available to all users in future surveys.

**Instructions:** This survey should be completed by the state director of developmental disability services or his or her designee. Please consult your state's Medicaid office or other relevant state agencies as needed to provide accurate responses. Your assigned 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.

Be sure to click the save and continue button on each screen before you move to another section of the survey so that your data entries are saved.

### 2015

Answer each question, entering 0's when applicable. Partial information is preferred to no information. If you are unable to answer a question, select DNF "Did not furnish" code in the Date and Code tab.

**Note:** The FISP and RISP projects make national estimates by estimating a value for each item marked DNF. We strongly prefer to get estimates from the states rather than by extrapolating them or estimating them using another process. Historical trends are described in our annual report. If you are unable to furnish a data point, the charts and graphs developed for your state may not be a fully accurate summary.

- If your answer is an estimate, select the "estimate" code in the Date and Code tab.
- If you use a different time period for any question, indicate the alternate date in the Date and Code tab.
- Use the Note tab to add comments to explain any unusual changes from FY 2014 to FY 2015. Relevant comments will be published with state summaries and in other FISP or RISP reports.
- For any question you answer using data from a date other than June 30, 2015 (FY 2015), please provide the data date.
- Add an explanatory notes as needed to understand your response (especially if you are reporting a number that is significantly different from previous years.

### Tips for using the Online Survey:

- The system automatically tracks all entries by log in ID. Each person should have his or her own user name and password. Please do not use another person's ID to log in.
- You can view data from previous years by selecting the previous date tab.
- If you notice inaccuracies in data from previous years please let your RISP staff team member know so we can update the database and use updated data for subsequent reports.
- Definitions for selected terms can be viewed by moving your cursor over the "?" symbol highlighted in blue.
- The FISP/RISP project team member assigned to your state is listed on the "contact us" section.
- Click on the Ask a Question button to submit guestions to project staff.

Thank you for your ongoing support of these Administration on Intellectual and Developmental Disabilities Projects of National Significance.

Sherri Larson and the FISP RISP Team



### FY 2015 SURVEY

### **General Instructions**

Your assigned FISP/RISP project team member is available by phone or email to answer your questions throughout the year and will contact you by phone or email during the editing process if we find missing or possibly incorrect information, or notice a change in a trend that has not been explained in your comments.

**Sample Frame:** This survey focuses on people with Intellectual or Developmental Disabilities (IDD) who are on the caseloads of your state IDD agency.

The sample frame includes

- People with IDD receiving Medicaid or state-funded long-term supports or services (LTSS), and
- People with IDD on the caseloads of the state IDD agency who do not currently receive Medicaid or statefunded long-term supports and services (They may or may not be on a waiting list for services) and
- People with IDD receiving Medicaid funded employment or day services

The sample frame does not include people with IDD not on the caseload of the state IDD agency.

For example, it does not include people receiving services exclusively through a non-Medicaid agency such as

- educational services,
- · child welfare services,
- vocational rehabilitation services
- income supports
- unless those individuals also receive case management or at least one other services under auspices of the state IDD agency

**Time Frame:** Questions ask about the number of people in a particular group on June 30, 2015, or services or expenditures for services delivered in FY 2015 (July 1, 2014 and June 30, 2015). If you provide data based any other period, please specify the time period or date you used.

**Key Changes for FY 2015**: The strategy we use to gather and verify totals has changed for many of the questions. Please verify that your totals equal the sum of the relevant parts. In Part 5, questions about nursing homes and psychiatric settings have been reorganized, and a question about children and youth in nursing homes added. Finally, a question was added about the total number of children and youth with IDD who live in congregate settings in your state. This item is used for the Centers for Disease Control's Healthy People 2020 monitoring.

This survey was designed to be completed on the RISP project website but is provided here as a convenience to respondents. Please see the website version of the survey to see what your state reported for each item in previous years.

Background	State:
background	State.

For this question, please include all people on the state IDD agency caseload receiving or waiting for long-term supports and services.

Long-term supports and services assist an individual with ongoing disability-related support needs such as residential supports, in-home supports, personal care assistance, family supports, day or employment supports, case management, 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 and other similar services provided under the auspices of the state IDD agency.

### Funded by the following funding authorities

- Medicaid Waiver including 1115 demonstration waivers; 1915 (a), (b), (b/c) managed care waivers; and 1915(c) home and community based services waivers,
- Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities,
- Other Medicaid State Plan including 1915(i) Home and Community Based Service, 1915(k) Community First Choice, and Targeted Case Management
- State funded IDD programs (such as family support)
- Include people with IDD of all ages living in
- State operated or nonstate settings

### Settings of any size

Settings of any type such as group homes, nursing homes, psychiatric facilities, IDD facilities, a host family or family foster care, a home owned or rented by one or more persons with IDD, the home of a family member, or settings such as assisted living settings, board and care facilities, intentional communities, communes, or farm collectives shared by groups of people with disabilities.

Please provide an unduplicated count.



### **B1.** People with IDD on caseload of State IDD Agency

B1. On June 30, how many people with IDD were on the caseload of the state IDD Agency? (Include IDD who receive Medicaid funded long-term supports and services, receive no services, receive stalong-term supports or services or who are waiting for services).  1. IDD Caseload: Ages 21 years or younger 2. IDD Caseload: Ages 22 years or older 3. IDD Caseload: Total all ages		
B1b. Of the people you listed as being on the state IDD agency caseload, how many were receiving Medicaid or state-funded long-term support or service as of June 30, 2015?	one or	more
Number of long-term supports and services recipients with IDD		
(Note: Parts 1 and 2 of the survey ask about the living arrangements of the people you report here	.)	
B2. Medicaid Funding Authority for Long-Term Supports and Services (LTSS) for people with IDD		
Funding authorities used to support people with IDD receiving long-term supports and services by cat (Medicaid Waiver, Medicaid State Plan, Other). Select yes or no for each funding authority.  (Please respond "yes" or "no" to each item.)		
B2. Which <u>Medicaid Waiver</u> authorities does your state use to provide long-term supports and services to people with IDD?	Yes	No
1. 1115 Demonstration waiver		
2. 1915(a) (b) and (b/c) Managed care waiver with long-term support and services		
3. 1915 (c) Home and Community Based services Waiver		
Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care was supports and services; and 1915 (c) Home and Community Based Waivers.  B3. Medicaid State Plan Funding Authority for Long-Term Supports and Services (LTSS) for people was (Please respond yes or no to each item.)		
Which Medicaid <u>State Plan</u> funding authorities does your state use to provide long-term supports and services to people with IDD?	Yes	No
1. ICF/IID (Intermediate Care Facilities for Individuals with Intellectual Disability)		
2. 1915(i) State plan Home and Community Based Waiver Services		
3. 1915(k) Community First Choice		
4. Targeted Case Management		
"Medicaid State Plan" funding authorities include 1915(j), 1915(k) and Targeted Case Management.		
B4. Non-Medicaid Funding Authority for Long-Term Supports and Services (LTSS)		
Non-Medicaid Funding Authorities (e.g., State-funded family support or cash subsidy programs) used long-term supports and services to people with IDD. If you answer yes, please describe the funding auuse.	-	
Does your state use <u>non-Medicaid</u> funding authorities to provide long-term supports and services to people with IDD?	Yes	No
1. Non-Medicaid Funding Authority		
Background Section Respondent Name: Phone: Em	ail·	
	u	

### Part 1: State-Operated Facilities and Units

### 1A. State Operated IDD facilities with 15 or fewer residents on June 30, 2015

Please report the number of state-operated facilities with 1 to 15 residents by setting size and funding authority on June 30, 2015. Facility size refers to the total number of people with IDD living in the same facility or on the same campus.

	P1.1 Number of State		tate Operated IDI Funding Authority	,
	Operated IDD <i>facilities</i>	P1-2.		P1-4 Other
	<b>/homes</b> (Total All funding	Medicaid		Funding
Facility Size (People with IDD)	authorities)	Waiver	P1-3 ICF/IID	Authority
1. Facilities w/ 1-6 people				
2. Facilities w/ 1-3 people				
3. Facilities w/4-6 people				
4. Facilities w/7 to 15 people				
5. Total Facilities with 1 to 15				
people				

<sup>\*</sup>Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

Mark 0 if there were no facilities of a certain size or funded by a certain funding authority. Write DNF in the cell if you are unable to provide a count. Use an "e" to designate estimated numbers.

### 1B. People with IDD living in State Operated IDD facilities with 15 or fewer residents on June 30, 2015

- Do not include people admitted solely for respite or for short-term (90 days or less) crisis or assessment purposes.
- Report people living in state-operated IDD facilities with 16 or more residents in the Part 1C.

	P1-5 <b>People</b> in	Number of <b>People</b>	with IDD in State-O	perated IDD
	State Operated IDD	Facilities by Fundir	ng Authority	
	facilities (Total All	P1-6. Medicaid		
Facility Size (People with IDD)	Funding Sources)	Waiver	P1-7. ICF/IID	P1-8. Other
1. 1 to 6 residents Total				
2. 1 to 3 residents				
3. 4 to 6 residents				
4. 7 to 15 residents				
5. Total people in facilities				
with 15 or fewer residents				

<sup>\*</sup>Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

Mark 0 if there were no people with IDD living in state operated facilities of a specific size funded by a specific funding authority. Write DNF in the cell if you are unable to provide a count. Use an "e" to designate estimated numbers.



**1C State Operated** IDD facilities and facilities with IDD units with **16 or more people** with IDD living in them on June 30, 2015

- Multiple units located on a single campus should be counted as one facility even if there are two or more units on the campus. Multiple units located on different campuses should be counted separately.
- Questions P1-9 through P1-10 refer to June 30, 2015.
- Questions P1-11 through P1-16 refer to Fiscal Year 2015 (July 1, 2014 through June 30, 2015).
- Questions about nursing homes and psychiatric facilities have been moved to Part 5 of the survey

	Fur	nding Auth	nority	
			Non-	Total All
	Medicaid		Medicaid	funding
State Operated IDD facilities/units with 16 or more residents	Waiver	ICF/IID	funded	Authorities
P1-9. Number of <b>settings</b> (Campuses with multiple units or buildings of any size housing a combined 16 or more people with IDD should be counted as a single facility)				
P1-10. <b>People</b> with IDD on June 30, 2015				
P1-11. <b>ADMISSIONS/READMISSIONS</b> –people who moved into the facility during FY 2015. Do not include short-term respite or crisis admissions of 90 days or less. Report short-term admissions on Question P1-13.				
P1-12. <b>DISCHARGES</b> – people who moved out of the facility during FY 2015 excluding transfers to other large state facilities. Report deaths on Question P1-13.				
P1-13. <b>DEATHS</b> – people who died while a resident of the facility between July 1, 2014 and June 30, 2015				
P1.14. Average daily residents FY 2015				
P1.15. Short-term <b>respite or crisis admissions</b> (90 days or less)				
P1-16. PER DIEM (average daily cost of care per resident)				

<sup>\*</sup>Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

Use an "e" to designate estimated numbers; "DNF" to designate data you are not able to furnish; "0" if there are no settings funded by the funding authority. Use N/A for question 8 if there are no state facilities in a given funding authority.

Part 1 Respondent Name:	Phone:	Email:	
Comments (If you used a date other	than June 30, 2015, ple	ase indicate th	e item and the date used).

### Part 2. Nonstate Living Arrangements for People with IDD on June 30, 2015

- Report living arrangements for people with IDD receiving one or more Medicaid or state funded longterm support or service (including targeted case management).
- Long-term supports and services assist an individual with needing ongoing supports such as residential
  supports, in-home supports, personal care assistance, family supports, day or employment supports, case
  management, 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 and other similar services.

Exclude respite care placements, nursing homes and psychiatric facilities on this table.

State Residence:  1-6 Total  1-6 Total  1-6 Settings*  1-7-15 16+ Settings*  1-7-15 16+ Total  1-6 Total  1-7-15 16+ Tot		2A. N	. Number of Nonstate <b>residential settings</b> by facility size	Nonstate <b>resic</b> facility size	resider	ıtial set	tings by	2B. Num	ber of <b>pe</b>	2B. Number of <b>people with IDD</b> in Nonstate residential settings by facility size	facility si	onstate r	esidential	2C. Number of Medicaid
1-3 4-6 Total 7-15 16+ Settings* 1-3 4-6 Total 7-15 16+	•									(2.00				Waiver
	Type of Nonstate Residence:	2-3	4-6	1-6 Total	7-15	16+	Total Settings*	ζ.	4-6	1-6 Total	7-15	16+	Total Peonle*	recipients in Nonstate
Type II. A residence owned, rented or managed by the residential services providers a gent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD. On NOT include ICF/IID facilities in this row.P.24, R.25, R.26  Type III. A home owned or rented by an individual and and then support for residents with IDD e.g., host family in which they live and provide care for one or more persons with IDD g.g., host family family foster care). R.2-7, R.2-8, R.2-9  Type III. A home owned or rented by one or more persons with IDD as the persons (s) own home in which personal sussistance, instruction, supervision and other support is provided as needed. Do NOT include people with IDD living in the home of related family members and other support is provided as needed. Do NOT include people with IDD and/or their family members also the home of related family members also the home of related family members home or more personal sustitutes. P.2-13, R.2-14, R.2-14.  Type V. A residence of personal sustitutes of their family members home or more personal sustitutes becopie with IDD who receive at portions and or their family members home or the actions. P.2-13, R.2-14.  Type V. Or their residential types (please specify).  Please record Of fyou do not have other Nonstate receive options for people with IDD. R.2-15.  Type R.2-15, R.2-17.	Type I. Nonstate ICF/IID (Intermediate Care Facilities for Individuals with Intellectual Disabilities) P2-1. P2-2													
the residential services provides 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 in hour include ICF/IID facilities in this row, 12-4, 12-5, 12-6.  Type III. 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 ea, host family in which they live and provide care for one or more unrelated persons with IDD as the persons with IDD as the persons with IDD as the persons yith IDD as the persons yith IDD as the persons job with IDD as the persons instruction, supervision and other support is provided as needed. Do NOT include people with IDD living in the home of a family members in which the personal assistance, Instruction and other support is provided as needed. Do NoT include people with IDD and/or their family members in which the personal assistance, ION occur people with IDD and/or their family members in which the personal assistance). Only count people with IDD who receive at least one funded long-term support or services, personal assistance). Only count people with IDD who receive at least one funded long-term support or services, personal assistance. Don's IDD who receive at least one funded long-term support or services us as asset management or in home supports. 22-12, 12-14.  Type VI. Other residential types (please specify).  Please record Of if you do not have other Nonstate record Of if you do not have other Nonstate asset asset members. The personal assistance is asset asset as a service and asset are ordered or personal assistance. The personal asset are asset as a service and asset as a service and a service	Type II. A residence owned, rented or managed by													
which staff provide care, instruction, supervision, and other support for residents with IDD. Do NOT include ICP/IID facilities in this row, P2, P2-6  Type III. A home owned or rented by an individual or family in which they live and provide care for one or more	the residential services provider, or the provider's agent, to provide housing for persons with IDD in													
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15, P2-16, P2-17	residential service options for people with IDD. P2-													
	15, P2-16, P2-17													

\*Totals should equal the sum of 1-6, 7-15, and 16+. Please provide the totals even if you are unable to provide all of the size breakdowns. Size refers to the number of people with IDD living together. Use an "e" to designate estimated numbers, "DNF" to designate data you are not able to furnish, and "0" for none. Please do not make entries in the blacked out cells.

Data date (if other than June 30, 2014):

\_\_Comments:



### Part 3: Fiscal Year Expenditures for People with IDD by Funding Authority, Age and Living Arrangement

- Data from this part will be used to calculate average per person expenditures for the fiscal year.
- Report the number of people based on their age as of June 30, 2015
- Report total expenditures for July 1, 2014 through June 30, 2015
- Include both state and nonstate service recipients.

<u>Part 3A.</u> On June 30, 2015, how many **people** with IDD received long-term supports and services by age and funding authority?

		Number of	People by Funding	Authority	
		Medicaid			
	Medicaid	State Plan -	Other Medicaid	State-Funded	No LTSS
P3-1-2. Recipient Age	Waiver	ICF/IID	State Plan	(Non-Medicaid)	funding
a. 21 years or younger					
b. 22 years and older					
Total					

<sup>\*</sup>Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

Other Medicaid State Plan funding authorities include 1915(j), 1915 (k) and Targeted Case Management. Use an "e" to designate estimated numbers, "DNF" to designate data you are not able to furnish, and "0" for none.

<u>Part 3B.</u> Combined **FY 2015** (July 1, 2014 through June 30, 2015) long-term support and services **Federal and State Expenditures** for people with IDD by age and funding authority

	Total Fe	deral and Stat	e Expenditures by Funding Au	uthority
		Medicaid		
		State Plan -		State-Funded
P3-3-4. Recipient Age	Medicaid Waiver	ICF/IID	Other Medicaid State Plan	(Non-Medicaid)
a. 21 years or younger	\$	\$	\$	\$
b. 22 years and older	\$	\$	\$	\$
Total	\$	\$	\$	\$

<sup>\*</sup>Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

Other Medicaid State Plan funding authorities include 1915(j), 1915 (k) and Targeted Case Management. Use an "e" to designate estimated numbers, "DNF" to designate data you are not able to furnish, and "0" for none.

<u>Section 3C.</u> Medicaid Waiver Recipients and Expenditures for People with IDD by Age and Living Arrangement on June 30, 2015.

	Medicaid Waiver*	Total FY 2015 Federal plus State Medicaid
Age and Residence Type	Recipients with IDD	Waiver* expenditures
P3-5. Recipients 21 years or younger		
1. Number living in the home of a		
family member (Type V)		\$
2. Number living in any other setting		\$
3.Total		\$
P3-6. Recipients 22 years and older		
1. Number living in the home of a		
family member (Type V)		\$
2. Number living in any other setting		\$
3.Total		\$
*Medicaid Waiver authorities include 111	5 Demonstration Waivers: 1	1915 (a) (b) (b/c) Managed care with long-

<sup>\*</sup>Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

Use an "e" to designate estimated numbers, "DNF" to designate data you are not able to furnish, and "0" for none.

**Home of a family member** = nonstate Type V (family home);

**Other** settings include nonstate Types II (group home), III (host/foster), IV (own home), and VI (other); and state Medicaid Waiver settings

Part 3 Respondent Name:	Phone:	Email:
Data Date if other than June 30, 2015:		
Comments:		

### Part 4: People with IDD waiting for Medicaid-funded residential or in-home long-term supports or services on June 30, 2015

- Include people who were living in homes of their own or with a family member who
  - o are waiting for in-home supports or residential services to live outside the family home
  - o are not receiving but are waiting for one or more Medicaid funded long-term support or service
  - are receiving a state funded or Medicaid State Plan services but are waiting for Medicaid
     Waiver funding
- Do not include people with IDD living in an ICF/IDD facility or in another Medicaid funded non-family setting.

P4-1 How many people with IDD were waiting for HC services on June 30, 2015?	BS funded in-hom	ne or residential long-term supports or	
P4-2 On June 30, of the people with IDD waiting for Medicaid-funded long-term supports and services, how many were receiving Targeted Case Management (TCM) Services?			
P4-3 On June 30, of the people with IDD waiting for Medicaid-funded long-term supports and services, how many were waiting to live in a setting other than the home of a family member?			
Part 4 Respondent Name: Data Date if other than June 30, 2015:		Email:	
Comments:			

Status and Trends: Residential Services for Persons with Intellectual and Developmental Disabilities



### Part 5. Nursing homes and Psychiatric Facilities

Nursing I	Homes
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### Congregate settings are:

- · Non-family residential setting (state or nonstate settings of any size, type or funding authority)
- In which two or more individuals with IDD live
- In which rotating (or shift) staff members provide supports and services.

### Do not include children and youth who:

- Live with birth or adoptive parents or other family members
- Live in family "foster care" settings in which no shift staff work
- Live only part of the year in a residential PreK-12 school
- Live in correctional facilities
- Live in nursing facilities (report those individuals in the nursing home section)
- Receive only respite services from a congregate care facility
- Live in other states (do count children who live in your state whose services are paid by another state)

P6-1. How many children and youth with IDD (birth to 21 years) lived in a congregate setting located in your state on June 30, 2015? \_\_\_\_\_\_

Part 6 Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_ Email: \_\_\_\_\_

Data Date if other than June 30, 2015: \_\_\_\_\_

Comments:

Contact Libby Hallas-Muchow (hall0342@umn.edu) if you have questions. We encourage states to enter their data in the RISP project website (http://rtc.umn.edu/risp/main/). Log in to complete your survey and to view resource documents including operational definitions, FAQ's and webinar slides. Otherwise, return your survey to RISP team, 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. Email: rtc@umn.edu.

National Survey by the ASSOCIATION OF PUBLIC AND PRIVATE DEVELOPMENTAL DISABILITIES ADMINISTRATORS and the UNIVERSITY OF MINNESOTA of

# Public Residential Facilities and Special Units for Persons with Intellectual Disabilities and Related Developmental Disabilities (IDD) Short Form

Fiscal Year 2015 (July 1, 2014 - June 30, 2015)

Please complete and mail, fax or email the survey by *March 15, 2016* and send to:

**RISP Project** 

210A Pattee Hall, 150 Pillsbury Dr. SE

Minneapolis, MN 55455-0223

hall0324@umn.edu

Fax: 612-625-6619

If you have questions about the survey, please contact:

Sherri Larson Phone: (612) 624-6024 Email: <a href="mailto:larso072@umn.edu">larso072@umn.edu</a>
Libby Hallas-Muchow Phone: (612) 625-9700 Email: <a href="mailto:hall0324@umn.edu">hall0324@umn.edu</a>
Faythe Aiken Phone: (503) 924-3783, ext. 24 Email: <a href="mailto:faiken@hsri.org">faiken@hsri.org</a>
Brittany Taylor Phone: (503) 924-3783, ext. 16 Email: <a href="mailto:btaylor@hsri.org">btaylor@hsri.org</a>

This project is funded through a cooperative agreement from the Administration on Community Living, U.S. Department of Health and Human Services Grant #90DN0297 with supplemental support from the National Institute on Disability and Independent Living Rehabilitation Research Grant #H133B130006. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not therefore necessarily represent official ACL or NIDRR policy.



### **Facility Contact Information**

Please fill in the following:
Facility Name:
City Facility is located in:
State Facility is located in:
First Name of Person completing this survey:
Last Name of Person completing this survey:
Phone Number:
Email Address:
Has the facility been renamed?
What is the previous name of the facility?
Total Residents
A state residential facility consists of one or more units on a single campus or adjoining property that together serve 16 or more residents with a primary diagnosis of intellectual disability or developmental disabilities (IDD), is staffed by state employees and that provides 24 hour services.  DO NOT include residents living in group homes on non-adjacent property for any of the questions.
What is the Total number of residents (including all units and all diagnoses) as of June 30, 2015?
Current Residents
For the following questions about Current Residents, count ONLY residents with a primary diagnosis of intellectual and/or developmental disabilities (IDD) who lived in IDD units.
Please <b>DO NOT include</b> people who were admitted only for respite, short-term evaluation or treatment, or crisis housing.
2. For Fiscal Year 2014 (July 1, 2014 to June 30, 2015):
a. Number of residents at beginning of year (July 1, 2014)
b. Deaths
c. Average daily population of residents with IDD
d. Number of residents at end of year (June 30, 2015)

3. Of the residents with IDD who lived in the facility on June 30, 2015, please indicate how many residents were in the following Levels of Intellectual Disability. (Your total should equal your response in Question 2d.)

	Number of Individuals with IDD
IDD Level	(Lived in the facility on June 30, 2015)
None	
Mild	
Moderate	
Severe	
Profound	
Unknown	
Total	

4. Of the residents with IDD who lived in the facility on June 30, 2015, please indicate how many residents were in each of the following age groups. (Your total should equal your response to question 2d.)

Chronological Age	Number of Individuals with IDD (Lived in the facility on June 30, 2015)
0-14	
15-18	
19-21	
22-39	
40-54	
55-62	
63+	
Unknown	
Total	



5.		egories? (Please count each person on	ly onc	acility on June 30, 2015, how many fall into the following se. Your total should equal your response to Question 2d.
		Please check the box if race information	on is r	
		Race		Number of Individuals with IDD (Lived in the facility on June 30, 2015)
	-		/hite	
	-	Black or African Ame	rican	
	•	Native American or American In	ıdian	
			Asian	
		Native Hawaiian and Other Pacific Isla	nder	
		C	ther	
		Two or more r	aces	
		Unkn	iown	
		-	Total	
	Questio	Please check the box if ethnicity infor	matio:	
			,	Number of Individuals with IDD (Lived in the facility on June 30, 2015)
		Ethnicity	(	Lived in the Jacinty on June 30, 2013)
		Hispanic or Latino		
		Not Hispanic or Latino		
		Unknown		
		1 2 331	Poad	Imissions and Discharges
		New Aumissions,	Reau	amissions and discharges
		lowing questions about New Admission I and/or developmental disabilities (IDE		unt ONLY residents with a primary diagnosis of olived in IDD units.
	ease <b>DO</b> ousing.	NOT include people who were admitte	d only	y for respite, short-term evaluation or treatment, or crisis
Ρl	ease <b>DO</b>	NOT include deaths.		
7.	For Fisc	al Year 2015 (July 1, 2014 to June 30, 20	۰ 015), ۱	what was the number of New admissions?
3.	For Fiscal Year 2015 (July 1, 2014 to June 30, 2015), what was the number of Readmissions?			
Э.	For Fiscal Year 2015 (July 1, 2014 to June 30, 2015), what was the number of Discharges?			what was the number of Discharges?
		А	dmin	istration
10.		record the following budgetary informa t of a psychiatric or other type of facili		or the period July 1, 2014 to June 30, 2015 (If this is an ease report for IDD units only).
	What w	as the average per diem cost from July	1, 201	14 to June 30, 2015 \$
		("Average per diem cost" means the	avera	age cost of care of one resident for one day.)

		Closure	
11. Is your facility scheduled for closure?	Yes	No	
If yes, by what year is it closing?		Which month is it closing?	

Thank you for your continued support of this survey.

Please fax, mail, or email your survey to the person listed on the front page of this survey or complete the on-line version by March 15, 2016.



# RISP OPERATIONAL DEFINITIONS Abbreviations and Acronyms

FISP Supporting Individuals and Families

Information Systems Project (University of Minnesota)

FY Fiscal Year (e.g., FY 2012 refers to

July 1, 2011 to June 30

**HCBS** Medicaid Home and Community

**Based Services Waiver** 

**HSRI** Human Services Research Institute

**ICF/IID** Intermediate Care Facility for

Individuals with Intellectual Disabilities (formerly ICF/MR)

**IDD** Intellectual and/or Developmental

Disabilities

**LTSS** Long-term supports and services

**NASDDDS** National Association of State

Directors of Developmental

**Disabilities Services** 

**RISP** Residential Information Systems

Project (University of MN)

**RTC** Research and Training Center on

Community Living (University of MN)

#### **Definitions**

#### **IDD - Intellectual or Developmental Disabilities**

American Association on Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability is a disability 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. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.

Congress in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 defined developmental disabilities as a severe, chronic disability of an individual that:

Related conditions: Some states define eligibility for IDD services to include people with a related condition that results in the need for the same type, intensity and duration of support as needed by a person with intellectual disabilities. Common related conditions include autism, cerebral palsy, Down syndrome, Spina Bifida, Hydrocephalus and epilepsy. Several states offer different programs to people with certain related conditions such as autism spectrum disorder. States choose whether to include the diagnosis of any of the listed conditions or other similar conditions (such as Fragile X syndrome) as one basis for eligibility for IDD services.

Nursing home: A state or nonstate Medicaid-funded institutional setting 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.

**Psychiatric Facilities:** residential facilities designed for persons with psychiatric disabilities (for example a mental health facility or Institution for Mental Disease) in which one or more people with IDD lives.

Other state-operated settings: state-operated facilities or units within facilities that are specifically designated to serve people with IDD that are funded with resources other than the Medicaid ICF/IID or HCBS programs.

Other nonstate-operated residence: nonstate settings in which a person with IDD lives that is not a group home, ICF/IID, foster family, host home, or own home setting. This could include for example, board care facilities, disability specific intentional communities or farms or assisted living facilities.

**Long-term supports and services:** institutional or community-based supports provided to assist an individual with ongoing health or other support needs related to their disability (see table below).

## **Long-Term Supports and Services Categories**

Service Category	Brief description	Example Services
Family Caregiver Support	Services provided to help the family provide supports to the individual	Home delivered meals, home health aide, homemaker/chore, caregiver counseling, care giver training
Respite	Temporary relief from/for the family caregiver	Respite (in home, out of home), individual support (day or night)
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	Companion services, personal care/assistance
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.	Home-based habilitation
Case Management	Services to assist an individual or family 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	Case Management, Service Coordination
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.	Residential Habilitation, Group Home, Semi- Independent Living Services, Supported living services, Shared Living, Corporate foster care, Host home, Family foster care
Day Services	Services provided throughout the day to support the individual in community-based activities (i.e., supported employment, day programs, education)	Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, early start programs
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
Medical Supports	Long-term supports for individuals with medical complications. Includes clinical services, such as OT, PT, and speech therapies as well as in home nursing services.	OT, PT, speech and language therapies, skilled and private nursing, clinic services
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.	Financial management services, participant training, goods and services, other, interpreter
Transportation	Supports to transport an individual to a community-based activity, including day services, employment services, or other community-based activities.	Community transportation services, non- medical transportation
Environmental Modifications and Technology	Services to accommodate physical disabilities	Personal emergency response systems, home modifications (such as ramps, bathroom modifications), vehicle modifications or repairs, other adaptive equipment, augmentative communication devices



**Operating Entities.** Services are classified as being operated by state agencies or by nonstate entities.

- State-operated: staffed by state employees or operated by a state agency.
- Nonstate-operated: long-term supports or services provided to people with IDD by staff who are not state employees. Organizations providing nonstate-operated LTSS may be for profit or not-for-profit or they may be a nonstate governmental entity such as a county.

**Setting Size**. The size category is based on the number of people with IDD who live in the setting or on the campus. Size categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, and 16 or more people. Homes or facility units that are clustered on a single campus or at a single address such as a large state operated IDD facility are counted as one facility and are categorized based on the total number of people living on the campus or at the address.

Partial or missing data: Provide as much information as you can. Do not leave any questions blank. Partial information is preferred to no information. If you are not able to answer a question, mark the question DNF "Did not furnish". The FISP and RISP projects make national estimates by estimating a value for each item marked DNF. We strongly prefer to get estimates from the states rather than by extrapolating them or estimating them using another process. Historical trends are described in our annual report for many items. If you are unable to furnish a data point, the charts and graphs developed for your state may not be a fully accurate summary.

### **Background Section (Items B1-B3)**

Include all people with IDD who are on the <u>caseloads</u> of the state IDD agency.

- People getting no IDD services but known to the IDD agency
- People with IDD receiving targeted case management, state IDD Agency program funding, or Medicaid funded supports (through ICF/IID, HCBS, State Plan).
- We are asking for the administrative prevalence of IDD in your state.
- We are only interested in the people with IDD who are in your silo for at least something. People who

only get public education, income supports, child protection, vocational rehabilitation but are not getting services administered through the state IDD agency would not be included.

### **Funding Authorities**

The FISP/RISP survey asks specifically about utilization and expenditures for people with IDD under four broad categories of funding authorities:

- Medicaid Waiver Authorities (including 1115
   Demonstration, 1915(a) (b) and (b/c) Managed care
   with long-term support and services and 1915 (c)
   Home and Community Based services Waivers)
- ICF/IID Intermediate Care Facilities for Individuals with Intellectual Disabilities
- Other Medicaid State Plan long-term supports and services (including 1915(i) State plan Home and Community Based Waiver Services; 1915(k) Community First Choice; and Targeted Case Management)
- Non-Medicaid State-funded LTSS for people with IDD (e.g., family support program) operated state IDD agencies.

#### **Medicaid Waiver Authorities**

Information about Federal Medicaid Authorities comes from the Guide to Federal Medicaid Authorities Used in Restructuring Medicaid Health Care Delivery or Payment http://www.medicaid.gov. Additional analyses by NASDDDS.

Under the Social Security Act, there are certain provisions that give the Secretary of Health and Human Services the authority to waive otherwise applicable provisions of the statute. These provisions broadly refer to Medicaid waivers, though they can vary in their purpose and scope. Within a given state, an individual may be enrolled in one or more waiver programs.

Unless otherwise specified please include all 1115 Demonstration Waivers, 1915 (a)(b) (b/c) and (c) through which services for people with IDD are funded when asked about "Medicaid Waiver Authorities".

**1115 Demonstration Waivers** Section 1115 of the Social Security Act gives the Secretary of Health and Human Services authority to approve experimental,

pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. The purpose of these demonstrations, which give States additional flexibility to design and improve their programs, is to demonstrate and evaluate policy approaches such as:

- Expanding eligibility to individuals who are not otherwise Medicaid or CHIP eligible
- · Providing services not typically covered by Medicaid
- Using innovative service delivery systems that improve care, increase efficiency, and reduce costs

For this survey, please only include 1115 demonstration waivers that provide HCBS (modeled upon state plan or waiver) to individuals with IDD.

**1915(a)** States can implement a voluntary managed care program simply by executing a contract with companies that the state has procured using a competitive procurement process. CMS must approve the state's contract in order to make payment. A few states are utilizing 1915(a) authority for the delivery of institutional and community-based long-term services and supports.

For this survey, only include 1915(a) contracts that facilitate the provision of home or community based services (state plan or waiver) to individuals with IDD.

**1915(b)** States can implement a managed care delivery system using the 1915(b) waiver authority. Under a 1915(b) waiver, participating states may require people who are dually eligible for Medicaid and Medicare, American Indians, and children with special health care needs to enroll in a managed care delivery system. 1915(b) waivers are typically used to allow the use of a managed care delivery system for traditional Medicaid State Plan services. Some 1915(b) waivers allow for the provision of community-based services to eligible individuals by using savings that the state has garnered through the introduction of managed care (1915(b)(3) services). In addition, states may allow contracted managed care entities to provide HCBS as costeffective alternatives to other services, such as institutional services. When States use managed care for the delivery of State Plan and HCBS to eligible individuals, the 1915(b) waiver is usually operated concurrently with a 1915(c) HCBS or other HCBS authority.

For this survey, only include 1915(b) waivers that facilitate the provision of home or community based services (state plan or waiver, including 1915(b)(3) services) to individuals with IDD.

1915(b)/(c) States can provide traditional long-term care benefits (like home health, personal care, and institutional services), as well as non-traditional home and community-based "1915(c)-like" services (like homemaker services, adult day health services, and respite care) using a managed care delivery system, rather than fee-for-service. They accomplish this goal by operating a 1915(c) waiver concurrently with 1915(b) waiver (or any of the Federal managed care authorities). The managed care delivery system authority is used to mandate enrollment into a managed care entity providing HCBS services or to limit the number or types of providers delivering HCBS services.

For this survey, please only include 1915(b)/(c) concurrent waivers that facilitate the provision of home or community based services to individuals with IDD.

1915(c) 1915(c) is also known as the Home and Community Based (HCBS) waiver program.

States can offer a variety of services under an HCBS to individuals needing an institutional level of care. Services include but are not limited to case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community. 1915(c) waivers can target specific populations, and each waiver includes a specified set of covered services

#### **Medicaid State Plan Services**

State Plan refers to the full array of Medicaid Services available under a number of provisions of the Social Security Act. The majority of these services are identified in 1905(a) of the Act, but other provisions that have been added to the State Plan include 1915(i), 1915(j) and 1915(k). Other Medicaid State Plan Services include 1915(i) and 1915(k) and Targeted Case Management.



ICF/IID - Intermediate Care Facilities for Individuals with Intellectual Disabilities ICF/ IID is an optional institutional Medicaid benefit that enables States to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and

individualized health care and rehabilitation services to individuals to promote their functional status and independence. Although it is an optional benefit, all States offer it, if only as an alternative to home and community-based services waivers for individuals at the ICF/IID level of care.

#### **Other Medicaid State Plan**

**1915(i)** States can offer a variety of services under a State Plan Home and Community-Based Services (HCBS) benefit. People must meet State-defined targeting and needs-based criteria. States may offer the same array of services that are available under 1915(c) such as respite, case management, supported employment, environmental modifications, and others. States may not limit the number of eligible individuals who receive 1915(i) services.

For this survey, only include 1915(i) SPAs that include individuals with IDD (either through programs targeted specifically to individuals with IDD or programs broadly targeted that are likely to include individuals with IDD).

1915(k) 1915(k) is the "Community First Choice Option" and permits States to provide home and community-based attendant services to Medicaid enrollees with disabilities under their State Plan. Community-based attendant services must include services and supports to assist in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, and/or cueing. The following services may be provided at the State's option: transition costs such as rent and utility deposits, first month's rent and utilities, purchasing bedding, basic kitchen supplies, and other necessities required for transition from an institution; and services that increase independence or substitute for human assistance to the extent that expenditures would have been made for the human assistance, such as non-medical transportation services or purchasing a microwave.

For this survey, please include all 1915(k) SPAs. By statutory construction, 1915(k) SPA services must be

available to individuals with IDD meeting and ICF/IID level of care.

Targeted Case Management Authorized by section 6052 of the Deficit Reduction Act of 2005. Case management services help beneficiaries gain access to needed medical, social, educational, and other services. "Targeted" case management services are aimed specifically at special groups of enrollees such as those with developmental disabilities or chronic mental illness. Case management services are comprehensive and coordinated, and include an assessment of an eligible individual, development of a specific care plan, referral to services, and monitoring and follow-up activities. It also includes contact with family members to help a Medicaideligible individual access services covered by Medicaid. (CMS Fact Sheet November 30, 2007 Medicaid Definition of Covered Case Management Services Clarified. Downloaded October 13, 2015 from https://www.cms.gov/Regulations-and-Guidance/ Legislation/DeficitReductionAct/downloads/CM Fact Sheet.pdf)

For this survey, only include TCM SPAs targeted to individuals with IDD.

#### **Other State Plan LTSS**

- State plan home health, personal care services, or optional rehabilitation services
- The Program of All-Inclusive Care for the Elderly (PACE)
- Home and community care services defined under Section 1929(a)
- Private duty nursing authorized under Section 1905 (a)(8) provided in home and communitybased settings
- Affordable Care Act, Section 2703, State Option Health Homes for Enrollees with Chronic Conditions

**Medicaid Waiver authorities** include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

**Medicaid State Plan services**: supports provided to people with IDD funded by a state's Medicaid State Plan.

 Institutional State Plan services include Intermediate Care Facilities for Individual with Intellectual Disabilities, nursing facilities, inpatient psychiatric

- facilities for person under age 21, and mental hospital services for persons age 65 years or older
- Home and community based state plan services offered in home or community settings include 1915i state plan home and community based services, 1915k community first choice.
- Other state plan funded long-term supports and services include targeted case management, personal care, home health, rehabilitation services, adult day care, private duty nursing, and PACE. The RISP 2013-2015 surveys include specific questions about the use of targeted case management for people with IDD.

#### Parts 1 and 2

When reporting the number of residents or facilities with 6 or fewer residents

- Please separate facilities with 1-3 residents versus those with 4 to 6 residents whenever possible.
- If it is not possible to distinguish between settings of 1-3 residents and those with 4-6 residents, please note DNF "data not furnished" for the 1-3 and 4-6 columns, and report the total in the 1-6 column.

#### **Part 1. State-Operated Facilities**

- State-operated: staffed by state employees or operated by a state agency.
  - Do not include people who stay in residential facilities for short-term respite only.
  - Do not include people admitted for 90 days or less for short-term crisis or assessment purposes except in the item asking specifically about short-term admissions.
- Setting types
  - Large IDD facilities and other large facilities with IDD units (16+ residents live on the campus).
    - Multiple units with or without separate licenses located on a single institution campus are considered one facility
    - Include ICF/IID units designed or licensed specifically for people with IDD that are located on the grounds of a state operated nursing home or psychiatric facility with 16 or more residents
  - IDD facilities with 15 or fewer residents.
    - Only include IDD facilities <u>not</u> located on the grounds or campus of a large state facility.

- No more than 15 people live at this address/in this facility/on the campus
- Funding Authorities: Classify state operated settings based on how services in that setting are funded
  - Medicaid Waiver Authorities (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers)
  - ICF/IID Intermediate Care Facilities for Individuals with Intellectual Disabilities
  - State funded (non-Medicaid) residential facilities with 15 or fewer residents in which people with IDD live and receive services under the auspices of the state IDD agency such as transition or half-way houses, board and care, assisted living facilities that do not have a designated IDD unit, and state operated housing with services.

**Section 1A** State Operated IDD facilities with 15 or fewer residents

- The number of Medicaid Waiver plus ICF/IID plus state-funded facilities of each size should sum to the total number of state operated facilities of that size.
- Mark 0 if there were no facilities of a certain size or funded by a certain funding authority. Do not leave any of the questions blank.

**Section 1B** People living in State-Operated IDD facilities with 15 or fewer residents

- Number of people with IDD living in the state operated IDD facilities reported in Section 1A.
- We will use the number of people together with the matching number of facilities of a specific size and funding authority to compute the average number of people per facility
- Mark 0 if there were no people with IDD living in state operated facilities of a specific size funded by a specific funding authority.
- Write DNF if you are unable to provide a count.
- Use an "e" to designate estimated numbers.

**Section 1C** State-Operated IDD facilities with 16 or more people with IDD

 SETTINGS number of different campuses serving 16 or more people with IDD. Campuses with multiple units or buildings of any size housing a combined 16 or more people with IDD should be counted as a single facility.



- RESIDENTS with IDD at the end of Fiscal Year 20xx (6/30/20xx).
- ADMISSIONS/READMISSIONS The number of people with IDD admitted during Fiscal Year 20xx (7/1/20xx to 6/30/20xx),
  - Include admissions or readmissions from a hospital, nursing home or other long-term care setting.
  - Exclude transfers between large state operated IDD facilities
  - Exclude people admitted only for respite care and crisis services lasting 90 days or less
- DISCHARGES the number of residents with IDD who were released from state facilities during Fiscal Year 20xx (7/1/20xx to 6/30/20xx).
  - 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 only for respite care or crisis services lasting 90 days or less
- DEATHS the number of residents with IDD who died while on the rolls between July 1, 2014 and June 30, 2015
  - Include any people who died prior to being discharged from the facility even if their death occurred during a temporary stay in a hospice, hospital, nursing home or other facility.
- AVERAGE DAILY RESIDENTS with IDD in FY 2015.
  - This is an aggregate average. It should include all people with IDD living in all large state IDD facilities or specialized IDD units during the year.
  - Please use a running average if you have it.
  - If you do not provide a response, this will be computed as the average of the residents with IDD in the facility at the beginning of the year (as reported on your FY 2012 survey) and the residents with IDD in the facility at the end of the year as reported above
- SHORT-TERM RESPITE OR CRISIS ADMISSIONS
  - Report the total number of admissions for respite care plus the total number of admissions for crisis services that were for stays of 90 days or less.
  - People with multiple respite or crisis services stays during a year should be counted for each stay.
- PER DIEM (average daily cost of care per resident) in Fiscal Year 20xx

 If a facility has more than one per diem rate, provide the average per diem paid across all residents with IDD.

# Part 2. Nonstate Living Arrangements for People with IDD by Size and Type

- "Nonstate" living arrangements include all living arrangements for people with IDD on your state IDD agency caseload that were not reported in Part 1 of the survey.
- Include people with IDD who receive case management or long-term support services while living in homes of their own or in the home of a family member.
- Include people with IDD receiving services funded by the following funding authorities:
  - Medicaid Waiver services through an 1115 demonstration waiver, 1915 (a) (b) (b/c) or any 1915(c) waiver,
  - State Plan: ICF/IID, 1915(i), 1915 (k), or targeted case management
  - Non-Medicaid state funded residential settings
- Include only people who received at least one LTSS service under the authority of the state IDD agency
- Total number of settings by type should equal the sum of settings with 1 to 6 people, 7 to 15 people and 16 or more people.
- Total number of people by type should equal the sum of people living in settings with 1 to 6 people,
   7 to 15 people and 16 or more people.
- Provide the total number of settings of each type and the total number of people with IDD in each setting type even if you are unable to provide a breakdown showing the size of places in which people lived.
- Setting type
  - Type I Intermediate Care Facilities for individuals with Intellectual Disability (ICF/IID)): A group home operated under the authority of the ICF/IID Medicaid State-Plan benefit that enables states to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence.
    - Includes all ICF-IDD settings except those staffed by state employees (reported in Part 1).
    - Multiple units on a campus or at a single address should be counted as a one facility

- Type II Group Home: A residence of any size 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.
  - Under the 2014 Medicaid HCBS Rule, all people receiving home and communitybased services must have legal protections such as a lease or rental agreement when living in settings owned or operated by a provider organization. If the person is renting or leasing a home owned or operated by a provider of residential or in-home services regardless of the number of people living together, the setting is classified as a group home.
  - Includes organizations operated by a public entity other than the state (county, municipality) unless the employees are considered "state" employees
  - It is a Type II facility unless it meets the criteria for another setting type
- Type III Host home/Foster Family: A home owned or rented by an individual or family service provider in which the provider lives and provide care for one or more unrelated persons with IDD.
- Type IV Own home: A home owned or rented by one or more persons with IDD as the person(s)' own home in which personal assistance, instruction, supervision and other support is provided as needed.
  - It is a Type IV setting only if
    - A person with IDD holds title or lease in his or her own name; or is named on the lease.
    - each unit/apartment or house has separately keyed entrance doors
    - each unit has a different mailbox number or separate address
    - The person with IDD could continue to live in the home but discontinue services from a particular provider or substitute services from an alternative provider
    - The person with IDD decides which people if any will live in his/her home (with legal guardian assistance as needed)
- **Type V Family Home:** A home owned or leased by a family member in which the person with IDD and one or more family members live.

- Include people receiving supportive services such as respite care, homemaker services, personal assistance, personal care assistance, behavioral supports, community inclusion support, certified nursing assistant care, inhome nursing, parent training or education.
- Type IV Other Nonstate Setting: A nonstate residence other than those described in Type I through Type V. If you report people with IDD living in other residential settings, please describe those settings.
  - Unless the state specifically reports having people in these settings, we will assume them to be zero setting and zero people.
  - Include settings in which people with IDD on the caseload of the state IDD agency live such as
    - Residential School
    - Commune, farm, or other type of intentional community
    - Hospital
    - Board care
    - Transition half-way houses
    - Housing with supports
    - Assisted living
- Only count each person one time. Do not count them as living in the home of a family member and in one of the other types of settings. Report the place the person is living on June 30 of the Fiscal Year.
- Include people with IDD on the caseload of the state IDD agency whose living arrangement is unknown.

**Part 2C.** Waiver Recipients by setting type. Number of people with IDD who live in each type of nonstate setting (other than ICF-IDD) who received Medicaid Waiver services through an 1115 demonstration waiver, 1915 (a) (b) (b/c) or any 1915(c) waiver.

• The number of Medicaid Waiver recipients may be the same as or less than the total number of people living in a setting type but should not be more than the total number living in a setting type.

#### Part 3. Age and Expenditures

- For FY 2015 people with IDD born on or after June 30, 1994 should be counted in the 21 years or younger category, those born before June 30, 1994 should be counted in the 22 years or older category.
- Please use recipient and expenditure data from the same date in this section because we will



compute average annual expenditure per person for each funding authority and age group based responses to 3A and 3B. If you are using a date other than June 30 of the fiscal year, please specify the date you used.

The following funding authorities are used for Part 3

- Medicaid Waiver Authorities (including 1115
   Demonstration, 1915(a) (b) and (b/c) Managed care
   with long-term support and services and 1915 (c)
   Home and Community Based services Waivers).
- ICF/IID Intermediate Care Facilities for Individuals with Intellectual Disabilities
- Other Medicaid State Plan services (including 1915(i) State plan Home and Community Based Waiver Services; 1915(k) Community First Choice; and Targeted Case Management)
- Non-Medicaid State-funded LTSS for people with IDD (e.g., family support program) operated state IDD agencies.
- No LTSS funding –People with IDD who are on the caseloads of the state IDD agency who were not receiving long-term supports and services from one or more of the listed funding authorities as of June 30 of the fiscal year.

# P3-1 Age of People with IDD on State IDD Agency Caseloads on June 30, 2015

Use an "e" to designate estimated numbers; "DNF" to designate data you are not able to furnish; "0" for none.

- Report the total number of people with IDD on the state IDD agency caseload by age for each funding authority.
- Individuals receiving services through more than one funding authority and their expenditures should be counted in each of the categories in use on June 30, 2015.

# P3-2 Total State and Federal Expenditures for People with IDD by Age and Funding Authority

 Total state portion plus federal match dollars for Medicaid Home and Community Based Services during the fiscal year.

Section 3C Medicaid Waiver Recipients and Expenditures for People with IDD by Age and Living Arrangement (Family Home versus all other HCBS funded settings)

- Section 3C asks for information about the subset of people with IDD on the caseloads of state IDD agencies who were receiving supports under one of the Medicaid Waiver Authorities (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers)
- To respond to Section 3C you will need a break down of recipient and expenditures by age and living arrangement.
- Living arrangements in Section 3C collapse all living arrangements into two categories
  - People with IDD receiving supports funded by a Medicaid Waiver Authority living in the home of a family member (reported in Type V in Section 2)
  - All other people with IDD receiving supports funded by a Medicaid Waiver Authority (including those in Medicaid Waiver stateoperated settings plus those in nonstate setting types II, III, IV, V, and VI whose supports were funded by a Medicaid Waiver Authority)
- Please double check your math

### **Part 4. Waiting List**

The waiting list question changed in FY 2013. Previously we asked for the number of people living with a family member waiting to move to a setting other than the home of a family member as of June 30 who had requested services to begin *within 12 months*. That is now the third question.

- The first question asks about people with IDD who were eligible for and waiting for services funded by a Medicaid Waiver Authority (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers).
  - People waiting for Medicaid Waiver-funded supports may be receiving other supports funded by Medicaid State Plan or state only funding while they wait for services
  - Do not include people with IDD living in an ICF/IDD facility or in another non-family setting on June 30.
- The second question asks for the subset of people with IDD reported to be waiting for services in question 1 who were receiving Targeted Case Management State Plan services while waiting for services under a Medicaid Waiver Authority.
- The third question asks for the subset of people with IDD reported in the first question who

requested funding for services to be delivered in a setting other than the home of a family member. This is the same as the waiting list question for FY 2012 and earlier.

 Count those living with in a family home or own home who are looking to move to a non-family setting. Do not count people who are in a nonfamily setting who wish to move.

### **Part 5. Nursing homes and Psychiatric Facilities**

- Do not include people reported in Part 1 or 2 as living in a special unit for people with IDD within a nursing home or psychiatric facility.
- Do include people with IDD who have a PASSAR screening.

### **Special designators**

- "I" imputed. If you do not provide a value for an item, we will use a set of decision rules to estimate a value for developing US estimates. In most instances, DNF will be noted for your state for the data element in paper and online reports. We may publish the imputed value designated as such for certain summary tables.
- "o" Other source. Missing data were replaced with values from a source other than the state IDD agency (Note the specific source when this is used).
- "e" Estimate The exact number is not available.
  - The number recorded is the best estimate of the correct count.
  - If you do not have an estimate for the designated Fiscal Year, but do have a value for the previous fiscal year please use the data from the previous year and note the date for the value reported.
- · "DNF" Data not furnished
  - If the exact number is not known, and the estimate or report used in the previous year is not likely to reflect accurately the actual number please note this as DNF.
  - Use this designation only when necessary because the United States Estimated totals require us to impute a value for missing data.
- "Date" If your data source is from a data other than the one specified, please note the data for which the data were provided.
- "N/A" Not applicable Noted only when reporting Per Diem for state operated services if a size or funding authority is not used by the state.

- Note: (Respondent) Open ended comment box for each section or subsection to record explanations provided by the state during proofing, or with more detail than in the record for individual data elements.
  - If you use a definition that differs from the one specified, please describe what you provided.
  - Please add comments as needed to explain any unusual changes from FY 2012 to FY 2014.
     Relevant comments will be published with state summaries and in other FISP or RISP reports.
  - If you notice that data from previous years is inaccurate, please let your staff team member know so we can update the database and use updated data for subsequent reports we generate.

# Administrative categories (for use by project staff only)

# Completion status (auto generated by the system)

- "No data" have been provided for the section
- "Partial data" have been provided
- "Complete data" have been provided for all items in the section

### Approval status (Manually changed by project staff)

- Not approved data have been submitted for one or more item in the section but project staff has not reviewed the data for accuracy and completeness.
- Locked data are in the process of being verified by project staff. States may request changes but those changes have to be entered by project staff.
- Verified data in the section have been reviewed for arithmetic errors, completeness, accuracy and consistency with other data elements and against the prior year.
- Published data have been translated into tables for the report and those tables have been reviewed for arithmetic errors, completeness, accuracy and consistency with other data elements, against trends over time, and with US estimated Totals and reports from other states and are ready to be released for public use.