



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

# **2012**



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

Research and Training Center on Community Living  
Institute on Community Integration/UCEDD





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

**2012**

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State profiles highlighting FISP project findings for FY 2012 can be downloaded from  
[https://fisp.umn.edu/FISP\\_final\\_w\\_appendix.pdf](https://fisp.umn.edu/FISP_final_w_appendix.pdf)

This project is funded through cooperative agreements from the Administration on Community Living, U.S. Department of Health and Human Services Grants #90DN0291-01 and #90DN0297 with supplemental support from the National Institute on Disability and Independent Living Rehabilitation Research, U.S. Department of Education 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.

**The recommended citation for this report is:**

Larson, S.A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Pettingell, S., Anderson, L.L., Moseley, C., Sowers, M., Fay, M.L., Smith, D., & Kardell, Y. (2014). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

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## ACRONYMS AND DEFINITIONS

<b>AHCA</b>	American Health Care Association
<b>AIDD</b>	Administration on Intellectual and Developmental Disabilities (formerly ADD)
<b>ACL</b>	Administration on Community Living
<b>ANCOR</b>	American Network of Community Options and Resources
<b>APDDA</b>	Association of Professional Developmental Disabilities Administrators
<b>CEHD</b>	College of Education and Human Development (University of Minnesota)
<b>CMS 64</b>	Centers for Medicare & Medicaid Services Quarterly Expense Report
<b>CMS</b>	Centers for Medicare & Medicaid Services
<b>DDSO</b>	Developmental Disabilities State Operations Office (New York)
<b>DSPD</b>	Division of Services for People with Disabilities
<b>FFP</b>	Federal Financial Participation
<b>FISP</b>	Supporting Individuals and Families Information Systems Project (University of MN)
<b>FMAP</b>	Federal Medical Assistance Percentage
<b>FY</b>	Fiscal Year (FY 2012 refers to July 1, 2011 to June 30, 2012)
<b>HCBS</b>	Home and Community-based Services (Medicaid)
<b>HCFA</b>	Health Care Financing Administration (now CMS)
<b>HSRI</b>	Human Services Research Institute
<b>ICF/IID</b>	Intermediate Care Facility for Individuals with Intellectual Disabilities (formerly ICF/MR)
<b>ICI</b>	Institute on Community Integration (University of MN)
<b>ID</b>	Intellectual Disabilities
<b>IDD</b>	Intellectual and Developmental Disabilities
<b>IDEA</b>	Individuals with Disabilities Education Act
<b>LTSS</b>	Long-term supports and services
<b>MA</b>	Medical Assistance
<b>MCO</b>	Managed Care Organization
<b>MFP</b>	Money Follows the Person
<b>NASDDDS</b>	National Association of State Directors of Developmental Disabilities Services
<b>NASUAD</b>	National Association of States United for Aging and Disabilities
<b>OBRA-87</b>	Omnibus Budget Reconciliation Act of 1987
<b>OSCAR</b>	Online Survey, Certification and Reporting system (maintained by CMS)
<b>PASRR</b>	Preadmission Screening and Resident Review
<b>QIDP</b>	Qualified Intellectual Disability Professional
<b>RISP</b>	Residential Information Systems Project (University of MN)
<b>RTC</b>	Research and Training Center on Community Living (University of MN)
<b>SNF</b>	Skilled Nursing Facilities
<b>SSA</b>	Social Security Administration
<b>UCEDD</b>	University Centers of Excellence in Developmental Disabilities

## ACKNOWLEDGEMENTS

This report is based on statistics gathered and analyzed as part of the National Residential Information Systems Project on Residential Services (RISP) and the Supporting Individuals and Families Information Systems Project (FISP). We are indebted to the more than 300 state and individual facility respondents who provided information for this report. This report would not be possible without their knowledge, expertise, and generous assistance. Some of these talented individuals are listed below.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) provides assistance with identifying state contacts, reviewing survey instruments, and reviewing and providing feedback on drafts of this report. Thanks to the state directors and data providers for the survey of state IDD agencies. Thanks also goes to the Association of Professional Developmental Disabilities Administrators (APDDA) and to data providers for the FY 2012 survey of state residential

facilities. APDDA provides assistance in identifying and contacting respondents for survey, presents results survey results to its membership, and provides input regarding changes to the survey instrument.

Thanks to all members of the RISP and FISP teams for their contributions to gathering and editing data, preparing the report, and providing technical support for the project website and other dissemination activities

The authors thank the Administration on Intellectual and Developmental Disabilities (AIDD), its Commissioner, Aaron Bishop and our Project Officer, Katherine Cargill-Willis, for ongoing support of these projects and their various activities. This project, co-sponsored through the Research and Training Center on Community Living is also greatly assisted by the National Institute on Disability and Rehabilitation Research, and our Project Officer, Dawn Carlson.

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## EXECUTIVE SUMMARY

This report describes the status of and trends in long-term supports and services (LTSS) for people with intellectual or developmental disabilities (IDD) in the United States on June 30, 2012 based on annual surveys of directors of state IDD agencies and large state residential facilities. The report is produced jointly by the University of Minnesota's *Supporting Individuals and Families Information Systems Project* (FISP) and *Residential Information Systems Project* (RISP). The FISP and RISP projects are Administration on Intellectual and Developmental Disabilities' (AIDD) data projects of national significance.

The FISP project, funded in 2011, focuses on supports for people with IDD and their families with an emphasis on people living with a family member or in an individualized setting. The RISP project chronicles the history of institutionalization, deinstitutionalization and the development of community-based LTSS for people with IDD. The RISP project began collecting data in 1977 and maintains longitudinal records dating back to the 1880 US Census on residential and in-home supports for people with IDD. RISP project reports were published periodically in a variety of formats between from 1977 to 1994, and in a consistent annual format between Fiscal Year 1995 through Fiscal Year 2011.

This joint FISP/RISP report is the first to be adapted to incorporate data collected specifically for the FISP project. The report has been reorganized to reflect current practices in supporting people with IDD and their families. Sections 1 and 2 describe individualized and congregate settings in which people with IDD live. Sections 3 and 4 describe utilization and expenditures for Medicaid's Home and Community-Based Supports Waiver (HCBS) program and Medicaid's Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) program. Section 5 highlights national longitudinal trends in the utilization of and expenditures for LTSS for people with IDD. Finally, sections 6 and 7 describe LTSS provided in state-operated IDD facilities serving 16 or more people with IDD.

The current RISP website <http://rtc3.umn.edu/risp/main/> has downloadable PDF copies of annual RISP reports from 1988 through 2011 and includes a build-a-report function allowing users to generate data tables comparing state and national trends over time for selected data elements. New websites for the RISP and FISP projects can be found at <http://rtc.umn.edu/fisp/> and <http://risp.umn.edu/>. The build-a-report functionality on the old website is being replaced with an interactive report generator



using the Tableau software platform. New data elements and new reports will be posted as they are developed. One of those new reports will describe the LTSS systems used in the US territories.

## Overview of Long-Term Supports and Services for People with IDD

In 2012, there were an estimated 4,677,319 total people with IDD in the United States based on the estimated total US population of 313,914,040, and prevalence estimates for people with IDD of 1.49%, (Larson et al, 2001; U.S. Bureau of the Census, 2014). As of June 30, 2012, state IDD agencies reported having an estimated 1,138,121 persons with IDD receiving LTSS under the auspices of or known to state IDD agencies (24% of the US population with IDD).

Of the persons with IDD known to or served under the auspices of state IDD agencies, an estimated 634,988 (56%) lived in the home of a family member; 207,128 (18%) lived in a group setting other than an Intermediate Care Facility for Individuals with



Of the 634,988 people with IDD living in the home of a family member, 242,163 (39%) received supports funded through a Medicaid HCBS Waiver authority. The rest, 392,825 (61%), were on the caseloads of state IDD agencies but may not have been receiving any Medicaid or state funded LTSS except perhaps case management. Some may have been using a Medicaid state plan service benefit such as personal care assistance or a family subsidy funded entirely by the state IDD agency.

Of the estimated 122,665 people living in a home they owned or leased, 118,576 (97%) lived with 3 or fewer people with IDD, and 4,089 (3%) lived with 4 to 6 people. The average number of people with IDD sharing a home owned or leased by a person with IDD was 1.2 per home.

An estimated 58,753 people lived in 35,830 host family or family foster care settings (93% of those settings were for 1 to 3 or people with IDD, 7% were for 4 to 6 people, and 0.1% were shared by 7 to 15 people). The average number of people with IDD per host home or foster family home was 1.6.

An estimated 68,781 people with IDD lived in 34,051 state or nonstate provider owned or leased settings shared by three or fewer people with IDD.

**Waiting Lists.** Directors of State IDD agencies reported that an estimated 110,039 people with IDD were waiting for residential services on June 30, 2012.

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*IN 2012, THERE WERE AN ESTIMATED 4,677,319 TOTAL PEOPLE WITH IDD IN THE UNITED STATES BASED ON THE ESTIMATED TOTAL US POPULATION OF 313,914,040, AND PREVALENCE ESTIMATES FOR PEOPLE WITH IDD OF 1.49%*

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Intellectual Disabilities (ICF/IID); 122,665 (11%) lived in homes owned or leased by a person with IDD; 85,384 (8%) lived in a state or nonstate ICF/IID; 58,753 (5%) lived in a host home or with a foster family; 28,064 (2%) lived in a nursing home; and 1,139 (0.1%) lived in state psychiatric facilities.

**Individualized settings.** An estimated 877,099 people with IDD (77%) lived in an individualized setting defined as the home of a family member (634,988 people) or a setting shared by three or fewer people with IDD. Individualized settings included homes owned or leased by the person with IDD (122,665), small host homes or foster homes (54,775), and small provider owned group homes (68,781).

This number only included people needing LTSS within the next 12 months who were not currently living in a LTSS setting other than the home of a family member. Using this definition, the number of people waiting for residential services in 2012 was higher than in 2011 (95,934) but lower than during the great recession in 2008 (114,916), 2009 (123,249), and 2010 (115,059). States would have to expand residential supports by an estimated 22% to provide non-family residential services to all of the people on the waiting list. The number of people with IDD estimated to be waiting for Medicaid 1915(c) Home and Community-Based Services Waiver services without regard to the urgency of the request or current living arrangement was 303,909 people in 2010 (Kaiser Family Foundation, 2014).

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*STATES WOULD HAVE TO EXPAND RESIDENTIAL SUPPORTS BY AN ESTIMATED 22% TO PROVIDE NON-FAMILY RESIDENTIAL SERVICES TO ALL OF THE PEOPLE ON THE WAITING LIST.*

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**Age of Medicaid ICF/IID and HCBS Waiver Service Recipients with IDD.** The FY 2012 survey asked states to report the number of Medicaid ICF/IID recipients by age and the number HCBS Waiver recipients with IDD by age and living arrangement (family home or other setting). In the first year of data collection between 31 and 46 states reported on one or more of the elements in this set of questions. The results for 2012 should be considered preliminary because non-reporting states may serve different proportions of children versus adults in ICF/IID facilities or through an HCBS Waiver funding authority.

In 46 reporting states, 7% of ICF/IID residents were 21 years old or younger and 93% were 22 years or older. In 39 reporting states, 26% of HCBS Waiver recipients were 21 years old or younger, and 74% were ages 22 years or older. Of the HCBS Waiver recipients whose place of residence was reported, 55% lived in the home of a family member and 45% lived in another type of setting.

In 33 reporting states, 89% of HCBS Waiver recipients 21 years or younger lived in the home of a family member and 11% lived in some other type of setting. In 31 reporting states, 42% of HCBS

Waiver recipients ages 22 or older lived in the home of a family member and 58% lived in another type of setting.

In 31 states reporting the age of both ICF/IID and HCBS Waiver recipients, 25% were 21 years old or younger and 75% were 22 years old or older.

**Expenditures by Age and Setting.** Average annual per person HCBS Waiver expenditures for people ages 21 years or younger ranged from less than \$10,000 to more than \$200,000 across the reporting states. Average annual per person HCBS expenditures for adults ranged from \$12,667 in Idaho to \$97,126 in the District of Columbia. Because the menu of services available through HCBS Waiver authorities and age of eligibility vary by waiver and by state, these averages are not directly comparable across states.

In 25 reporting states, average annual per person HCBS Waiver expenditures were \$17,671 for children ages 21 years or younger living in the home of a family member, \$54,988 for children living in some other type of setting, \$49,486 for adults ages 22 years or older living in the home of a family member and \$65,125 for adults living in some other setting. Again, these averages are not necessarily representative of all states because many states were not able to report this information for FY 2012.





### **Utilization of ICF/IID settings and HCBS Waiver-funded supports per 100,000 of the population.**

In 46 reporting states, there were 34.9 ICF/IID residents ages 22 years and older and 5.9 residents ages 21 years or younger per 100,000 of the population. In 36 reporting states there were 258.0 HCBS Waiver recipients with IDD ages 22 years or older and 186.9 recipients ages 21 years or younger per 100,000 of the population.

### **Long-Term Supports and Services Provided in Settings Other than the Home of a Family Member**

Of the people with IDD on the caseloads of state IDD agencies, 503,006 (44%) lived in a setting other than the home of a family member including an estimated 435,041 who received IDD services in one of 199,213 nonstate settings, and 38,761 who received services in one of 2,453 state operated IDD settings.

**Setting Size.** Among people with IDD who did not live with a family member 242,112 lived in a home shared by three or fewer people with IDD, 124,079 lived in a home shared by 4 to 6 people, 56,463 lived in a facility with 7 to 15 people with IDD and 50,671 lived in a facility with 16 or more people with IDD. In addition, 1,139 lived in a state psychiatric setting and 28,064 lived in a nursing home. Overall there were 2.35 people with IDD per non-family IDD setting.

Just over half (51%) of all people not living in the home of a family member shared a home with two or fewer other people with IDD. The proportion living in non-family settings shared by three or fewer people with IDD varied tremendously by state from a low of 6% in Mississippi to a high of 95% in Vermont. Six states supported 90% or more of people not living with a family member in a setting of three people or less (Vermont, New Hampshire, Georgia, New Mexico, Kentucky, and Colorado).

The utilization of LTSS settings other than the home of a family member was an estimated 150.9 people with IDD per 100,000 of the US population; including 116.7 per 100,000 who lived in settings with six or fewer people, 18.0 per 100,000 who lived in settings with 7 to 15 people, and 16.1 per 100,000 who lived in IDD facilities with 16 or more residents.

### **Medicaid-funded ICF/IID and HCBS Waiver Supports for People with IDD**

In 2012, the largest public programs funding long-term supports and services for people with IDD were Medicaid's Home and Community Based Waiver Services and Intermediate Care Facility for Individuals with Intellectual Disabilities programs.

On June 30, 2012, there were an estimated 680,610 HCBS Waiver recipients with IDD in the U.S. An estimated 340,702 (50%) lived in the home of a

family member, 173,698 (26%) lived in a nonstate group home, 93,924 (14%) lived in a home they owned or leased, 52,876 (8%) lived in a host home or with a foster family, 10,843 (2%) lived in a state operated group home, and 8,566 (1%) lived in another type of nonstate setting.

An estimated 85,384 people with IDD lived in 6,544 ICF/IID certified facilities including 21,891 (26%) who lived in ICF/IIDs with 6 or fewer residents, 18,459 (22%) who lived in facilities with 7 to 15 residents and 45,034 (53%) who lived in facilities with 16 or more residents.

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*TOTAL HCBS WAIVER EXPENDITURES FOR PEOPLE WITH IDD WERE \$29.5 BILLION IN 2012; AN AVERAGE OF \$45,219 PER YEAR PER HCBS WAIVER RECIPIENT (\$93.99 PER 100,000 OF THE US POPULATION).*

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Of the 27,440 people with IDD living in a state-operated ICF/IID, 1% lived in facilities with 6 or fewer residents, 3% lived in facilities with 7 to 15 residents, and 96% lived in facilities with 16 or more residents. Of the 57,944 people with IDD living in a nonstate ICF/IID, 37% lived in facilities with 1 to 6 residents, 30% lived in facilities with 7 to 15 residents and 32% lived in facilities with 16 or more residents.

Of the 184,940 people with IDD who lived in congregate settings with 1 to 6 residents, 12% lived in an ICF/IID. Of the 54,409 people who lived in settings with 7 to 15 residents, 33% lived in an ICF/IID. Of the 50,671 people who lived in settings with 16 or more residents 89% lived in an ICF/IID.

On June 30, 2012, 27.2 people with IDD per 100,000 of the population lived in an ICF/IID certified facility, and 219.3 people per 100,000 received supports through an HCBS Waiver.

## **Expenditures for Medicaid HCBS Waiver and ICF/IID Services**

Total HCBS Waiver expenditures for people with IDD were \$29.5 billion in 2012; an average of \$44,160 per year per HCBS Waiver recipient (\$93.99 per 100,000 of the US population).

Total ICF/IID expenditures for people with IDD were \$12.3 billion in 2012; an average of \$142,118

per average daily ICF/IID resident (\$39.21 per 100,000 of the US population).

While 89% of the combined HCBS Waiver plus ICF/IID recipients were supported by the HCBS Waiver program, only 71% of the combined expenditures were for HCBS Waiver recipients.

For state operated residential settings serving 1 to 6 people with IDD, the average per day per person costs were \$610 in ICF/IID facilities and \$495 in HCBS Waiver funded settings. For settings of 7 to 15 people average costs were \$577 in ICF/IID facilities and \$689 for HCBS Waiver funded settings. Per person per day costs for state operated facilities of 16 or more residents were \$650 for ICF/IID facilities and \$412 for HCBS Waiver funded facilities. Average daily costs per person were \$391 for people with IDD in other state operated IDD settings, and \$669 for people with IDD living in state operated psychiatric facilities.

The state Medicaid ratio compares the proportion of federal Medicaid ICF/IID plus HCBS Waiver expenditures for people with IDD in each state to the proportion of total federal income taxes the state paid. A ratio of 1.0 means the state proportion of federal Medicaid expenditures received is equal

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*TOTAL ICF/IID EXPENDITURES FOR PEOPLE WITH IDD WERE \$12.3 BILLION IN 2012; AN AVERAGE OF \$142,118 PER AVERAGE DAILY ICF/IID RESIDENT (\$39.21 PER 100,000 OF THE US POPULATION).*

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to the proportion it paid of all federal income taxes. The state benefit ratio ranged from 0.4 in Delaware and Nevada to 4.0 in West Virginia. While 33 states received proportionally more federal Medicaid expenditures than they paid in federal income taxes, 18 states had benefit ratios of less than 1.0.

## **Historical Trends in Long-Term Supports and Services for People with IDD**

The types of LTSS settings in which people with IDD live and funding for LTSS have been shifting for decades. Between 1998 and 2012, ongoing deinstitutionalization efforts and balancing initiatives successfully shifted the places where Medicaid LTSS are provided to people with IDD away from

congregate settings serving four or more people to individualized settings.

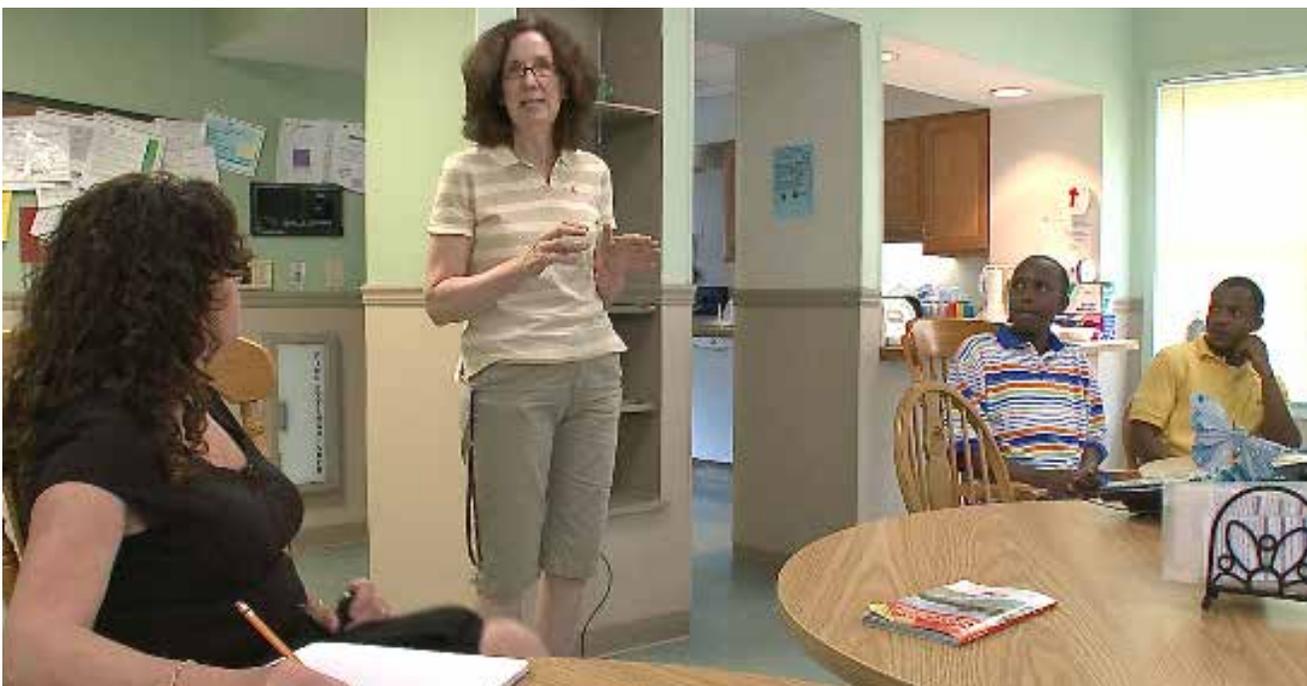
**Supports to People Living in the Home of a Family Member.** In 1998, 80,799 people with IDD lived in the home of a family member while receiving supports through a Medicaid HCBS Waiver while 242,093 people lived in a congregate LTSS setting of 4 or more people. In 2008, the number of people with IDD living in the home of a family member while receiving HCBS Waiver funded support (253,302) surpassed for the first time the number of people living in congregate LTSS with four or more people (251,150). By 2012, 340,702 lived in the home of a family member while receiving HCBS Waiver funded supports while 256,804 people with IDD lived in a congregate LTSS with four or more people.

**Non-Family Settings.** Between 1998 and 2012, both the size and type of non-family settings where people with IDD lived shifted. The number living in homes they owned or leased increased from 62,669 to 122,665, the number in other non-family settings with three or fewer people with IDD grew from 63,279 to 123,536; the number in settings with 4 to 6 people increased from 73,658 to 119,989; and the number in settings with 7 to 15 residents increased from 52,818 to 56,463. In comparison, the number living in nursing homes, psychiatric facilities or IDD facilities with 16 or more residents decreased from 115,265 to 80,352.

The effects of deinstitutionalization and the concomitant development of smaller community residential settings led to a decrease in the average size of LTSS settings in which people with IDD lived from 22.5 people per setting in 1977 to only 2.3 people per setting in 2012. The number of people living in any IDD facility with 7 or more residents declined from 227,380 in 1977 to 108,751 in 2012, while the number of people living in a non-family setting with 6 or fewer residents increased from 20,400 to 366,190.

**Large IDD Facilities.** Between 1977 and 2012, the number of people with IDD living in state operated IDD facilities with 16 or more residents declined from 154,638 to 28,120 (a decrease of 82%). The number living in nonstate IDD facilities with 16 or more residents declined from 53,718 to 24,168 (a decrease of 55%). We project that within the next five years there will be more people with IDD living in large non-state IDD facilities than there are in large state-operated IDD facilities.

**Medicaid Funding.** The Medicaid ICF/IID program was authorized in 1967 and by 1977 financed LTSS for 106,266 people with IDD. In 1993, 147,729 people lived in ICF/IID settings at an annual cost of \$9.2 billion compared to 86,604 people supported by an HCBS Waiver at an annual cost of \$2.2 billion. By 2012, 86,000 people lived in ICF/IID settings at an annual cost of \$12.3 billion and 688,410 people with



IDD received support through an HCBS Waiver at a total cost of \$29.5 billion.

In 1993, most ICF/IID residents (87%) lived in state operated facilities with 16 or more residents. By 2012, 46% of ICF/IID residents lived in nonstate settings with 15 or fewer residents. Despite shifts in the utilization of ICF/IID versus HCBS Waiver funded supports for people with IDD, the proportion of Medicaid expenditures going to ICF/IID and HCBS Waiver funded supports combined remained steady at between 9.0% and 10.3%.

The total number of people with IDD receiving HCBS Waiver funded LTSS was 1,381 in 1982, and increased rapidly to 39,838 in 1990; 291,255 in 2000; 592,070 in 2010; and 688,410 in 2012. Total HCBS Waiver expenditures for people with IDD increased from \$293.9 million in 1987 to \$827.5 million in 1990; \$9.6 billion in 2000; \$26.3 billion in 2010; and \$29.5 billion in 2012. Interestingly, while the inflation adjusted average cost per person increased for both ICF/IID and for HCBS Waiver services between 1993 and 2012, the overall average annual combined costs decreased from \$77,069 to \$55,191 as utilization of ICF/IID settings decreased and utilization of HCBS Waiver funded services increased.

## Utilization of IDD Facilities with 16 or More Residents

On June 30, 2012, 25.4 people with IDD per 100,000 of the U.S. population lived in state or non-state institutional settings serving 16 or more people. Utilization rates per 100,000 were 8.9 for people with IDD living in nursing homes, 8.4 for large state IDD facilities, 7.7 for large non-state IDD facilities, and 0.4 for psychiatric facilities.

**State-Operated Services.** On June 30, 2012, an estimated 38,761 people with IDD lived in 2,399 state-operated settings of all sizes in 42 states. Of those, 10,843 (28%) lived in an HCBS Waiver funded setting, 27,440 (71%) lived in an ICF/IID, and 478 (1%) lived in an IDD facility funded by another source.

In 2012, an estimated 1,119 people lived in 632 state settings with 1 to 3 residents, 4,267 people lived in 895 state settings with 4 to 6 residents, 6,394 people lived in 685 state IDD facilities with 7 to 15 residents, and 26,503 people lived in 178 state IDD facilities with 16 or more residents.

In 2012, all 632 state operated facilities with 1 to 3 residents were HCBS Waiver funded. Of the 895 homes with 4 to 6 residents, 70 were ICF/IID and 825 were HCBS Waiver-funded. Of the 685 facilities with 7 to 15 residents, 94 were ICF/IID and 591 were funded by an HCBS Waiver. All but 3 of the 178 facilities with 16 or more residents were certified as

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*BETWEEN 1980 TO 1990, THE AVERAGE DAILY POPULATION OF LARGE STATE FACILITIES DECREASED BY 36%, BETWEEN 1990 AND 2000 IT DECREASED BY 43%, BETWEEN 2000 AND 2010 IT DECREASED BY 36% AND BETWEEN 2010 AND 2012 IT DECREASED BY 10%. THE NUMBER OF PEOPLE IN LARGE STATE IDD FACILITIES PER 100,000 OF THE POPULATION DECLINED FROM 91.6 IN 1970 TO 57.8 IN 1980; 33.9 IN 1990; 17.0 IN 2000; 10.1 IN 2010; AND 8.4 IN 2012.*

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ICF/IID. Five states reported having state-operated IDD residences that were neither ICF/IID nor HCBS Waiver-funded.

In 2012, 1,075 people with IDD lived in state psychiatric facilities (4% of all people with IDD in state facilities). This is a decrease compared with the 16% of people with IDD living in in psychiatric facilities in 1950, but a slight increase from 3% in 2011.

**Facility Closures.** By June 30, 2012 of the 354 large state IDD facilities monitored by the RISP project and operating between 1960 and 2012, 207 had closed, converted to non-IDD settings or non-state settings or downsized to fewer than 16 residents including 8 that closed in 2012. Nine states reported plans to close an additional 14 large state facilities by 2020. Thirteen states had no open large state IDD facilities. Between 2010 and 2014 an estimated 6.6 large state-operated IDD facilities closed per year, up from 3.0 per year between 2005 and 2009.

**Changes in Average Daily Population.** The average daily population of state IDD facilities peaked at 194,650 in 1967. The average daily population decreased to 131,345 in 1980, 84,239 in 1990; 47,872 in 2000 and 28,146 on June 30, 2012.

Between 1980 to 1990, the average daily population of large state facilities decreased by 36%, between 1990 and 2000 it decreased by 43%, between 2000 and 2010 it decreased by 36% and between 2010 and 2012 it decreased by 10%. The number of people in large state IDD facilities per 100,000 of the population declined from 91.6 in 1970 to 57.8 in 1980; 33.9 in 1990; 17.0 in 2000; 10.1 in 2010; and 8.4 in 2012.

**Admissions, Discharges and Deaths.** During FY 2012 an estimated 1,141 people with IDD were admitted or readmitted to, 2,436 people were discharged from, and 747 people died while living in a large state IDD facility. Admissions to large state IDD facilities exceeded discharges plus deaths from 1950 (12,197 admissions, 6,672 discharges, and 2,761 deaths) until 1967 when there were 14,904 admissions, 11,665 discharges, and 3,635 deaths. In FY 2012, there were nearly three times as many discharges (2,353) and deaths (699) as admissions (1,077).

**Expenditures for Large State IDD Facilities.** The average annual per person expenditures for care in large state IDD facilities in inflation adjusted dollars increased from \$7,107 in 1950 to \$125,881 in 1990, \$151,813 in 2000, and \$237,149 in 2012.

## Characteristics of Individuals with IDD Living in Large State IDD Facilities

**Resident Characteristics.** The number of people with IDD in large state facilities declined from 31,101 in 2010 to 26,503 in 2012. Declines were reported in the number of people with each level of intellectual disability (mild from 3,707 to 3,038; moderate from 3,747 to 3,389; severe from 5,158 to 4,328; and profound from 18,489 to 15,373).

The proportion of people living in large state IDD facilities at each level of intellectual disability shifted between 1977 and 2012. As the proportion with mild or no intellectual disability increased from 10% to 11%, the proportion with moderate intellectual disability declined from 16% to 13%, the proportion with severe intellectual disability declined from 28% to 16%, and the proportion with profound intellectual disability increased from 46% to 58%.

The proportion of people with IDD in large state facilities who were 21 years or younger declined from 36% in 1977 and 5% in 2008 to 4% in 2012. In

2012, the majority of state IDD facility residents were between 40 and 62 years old (60%), and 17% were 63 years or older.

In 2012, 58% of residents had profound intellectual disabilities, 54% had a disorder requiring psychiatric attention and 52% had a behavior disorder requiring staff attention. While 57% of residents were able to walk without assistance, assistance or supervision was needed by 60% of residents for eating, 65% for dressing, and 56% for using the toilet. Only 43% of the residents were able to communicate their basic desires verbally and 69% were able to understand simple verbal requests.

The proportion of large public facility residents with specific conditions varied dramatically from state to state. For example, while 19% of residents were reported to have cerebral palsy overall, the proportion ranged from 1% in Utah to 57% in Wisconsin. The proportion with a psychiatric disorder was 54% overall, but ranged from 12% in Kentucky to 99% in South Dakota. The proportion of residents reported to have autism spectrum disorder was 17% overall, ranging from a low of 1% in Kentucky to a high of 63% in Connecticut. Overall 3% of residents were reported to have Alzheimer's disease ranging from 0% in Idaho, Illinois, and Nevada to 7% in Pennsylvania.



### **Involvement in the Criminal Justice System.**

In FY 2012, a small proportion people living in large state IDD facilities were involved with the criminal justice system. Overall, 4.7% had been placed in a facility due to behavior that led to criminal justice system involvement, 0.5% had been charged with a crime and had been court ordered to the facility for competency training, 5% had been found incompetent to stand trial, 0.4% were on parole, and 1.7% were otherwise under the jurisdiction of the criminal courts.

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*THERE WERE CLEAR DIFFERENCES BETWEEN THE CHARACTERISTICS OF PEOPLE LIVING IN LARGE STATE IDD FACILITIES ON JUNE 30, 2012 AND THOSE WHO WERE ADMITTED DURING 2012. ONLY 2% OF CURRENT RESIDENTS WERE AGES 18 YEARS OR YOUNGER COMPARED WITH 17% OF THOSE ADMITTED OR READMITTED. ONLY 2% OF CURRENT RESIDENTS WERE AGES 19 TO 21 YEARS COMPARED WITH 14% WHO WERE ADMITTED OR READMITTED, AND ONLY 19% OF CURRENT RESIDENTS WERE 22 TO 39 YEARS COMPARED WITH 44% OF THOSE ADMITTED OR READMITTED.*

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**Admissions and Readmissions.** In 2012, an estimated 1,077 people with IDD were admitted or readmitted to large state IDD facilities. Amongst newly admitted residents, 7% were 0-14 years, 28% were 15-21 years, and 44% were 22-39 years. The three older age groups (40-63+ years) made up the remaining 21%. Amongst people who were readmitted in 2012, none were 0-14 years, 12% were 15-21 years, 46% were 22-39 years, 18% were 40-54 years, and 16% were 55-63 years and older.

In FY 2012, 50% of all people who were newly admitted and 34% of those readmitted had mild or no intellectual disability. People with moderate intellectual disabilities were 26% of all new admissions plus readmissions; people with severe disabilities were 11%, and people with profound intellectual disabilities were 13%.

There were clear differences between the characteristics of people living in large state IDD

facilities on June 30, 2012 and those who were admitted during 2012. Only 2% of current residents were ages 18 years or younger compared with 17% of those admitted or readmitted. Only 2% of current residents were ages 19 to 21 years compared with 14% who were admitted or readmitted, and only 19% of current residents were 22 to 39 years compared with 44% of those admitted or readmitted. Similar differences were noted in levels of IDD. Only 11% of current residents had mild or no intellectual disability compared with 47% of those who were admitted or readmitted and only 13% of current residents had moderate intellectual disabilities compared with 26% of those admitted or readmitted. The mismatch in characteristics between newcomers and current residents is marked and points to potential challenges in adequately meeting the needs of both groups at the same time in the same facility.

Between 1985 and 2012 the proportion of people who were newly admitted to a large state facility from the home of a family member declined from 39% to 23% and the proportion admitted from an IDD facility with 16 or more residents declined from 26% to 14%. By contrast, the proportion admitted from a correctional facility increased from 2% to 12%, and the proportion admitted from a group IDD setting with 15 or fewer residents increased from 6% to 11%. Similarly there was a large reduction in people readmitted from the home of a family member (37% in 1985 and 12% in 2012). However there were increases in the proportion of readmissions from a correctional facility (0% in 1985 and 4% in 2012), mental health facilities (9% versus 19%), and nursing facilities (2% versus 7%).

**Discharges.** In 2012, an estimated 2,353 people were discharged from large state IDD facilities. Of those, 1% were 0-14 years, 11% were 15-21 years, 35% were 22-39 years, 27% were 40-54 years, and 25% were 55 years or older. Amongst the people who were discharged, 33% had no or mild intellectual disability, 22% had moderate disabilities, 15% had severe disabilities, and 28% had profound disabilities. Of the people who were discharged, 22% moved to another large state IDD, a correctional facility, a mental health facility, or a nursing home; 32% went to a group home with 1-6 residents; 8% went to a group home with 7-15 residents; and 10% moved to a private IDD residential facility with 16 or more residents.

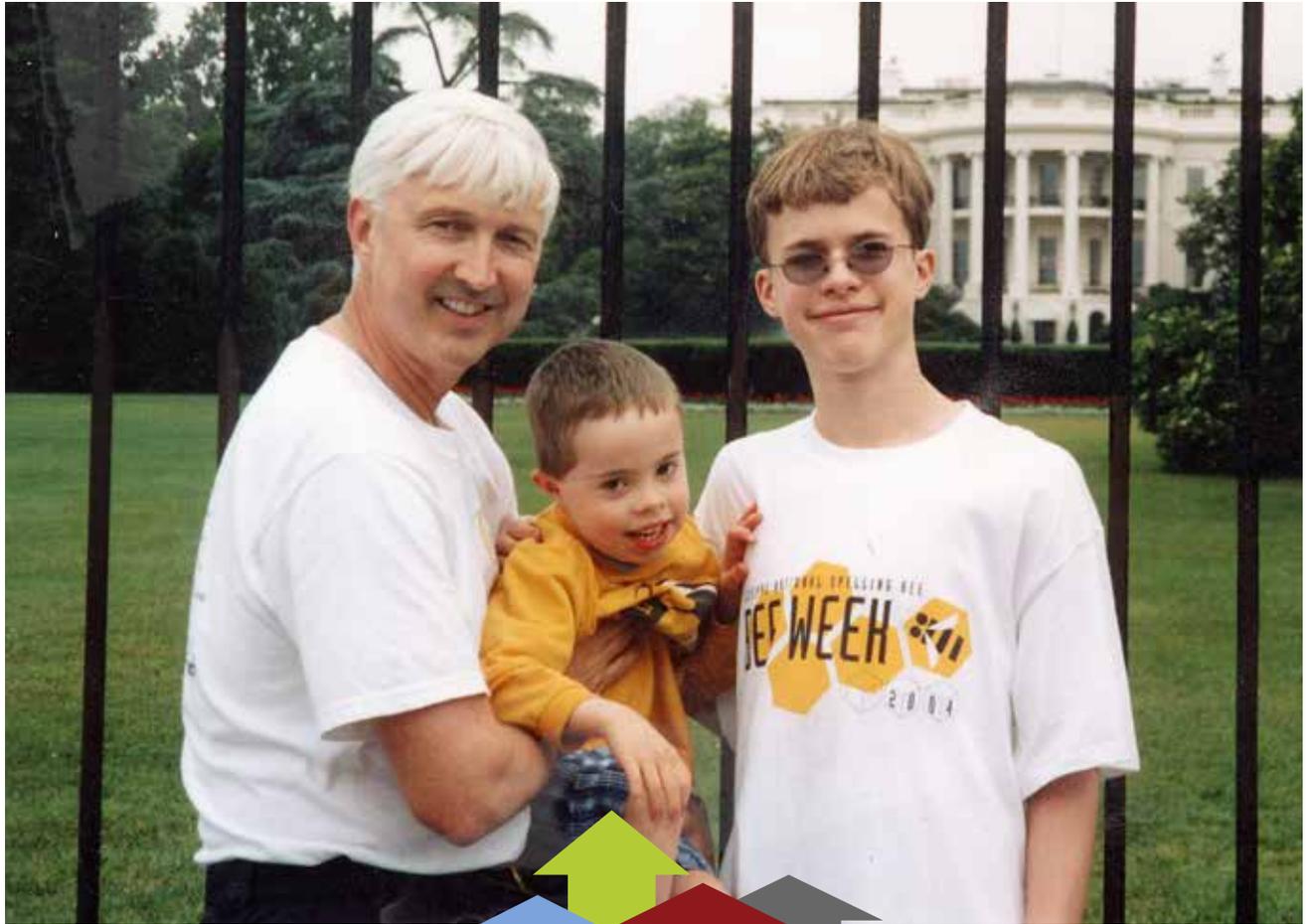
**Short Term Admissions.** In FY 2012, large state IDD facilities admitted an estimated 823 people for respite stays, 617 people for short-term evaluations, and 26 people for crisis housing support. On-site respite services were provided during FY 2012 to 1 person for every 32.2 residents; short-term evaluation to one person for every 43.0 residents; and crisis housing to 1 person for every 1,006 residents.

**Staff Characteristics and Outcomes.** In FY 2012, large state residential facilities employed an estimated 80,734 employees 59% of whom worked in direct support positions. Facilities reported employing 0.29 full-time equivalent doctors/nurses; 0.02 teachers/aides; 0.09 psychologist/other QMRP; 0.06 occupational, physical or speech therapy; 1.79 direct support workers; 0.17 administration/management; and 0.65 support personnel. There were 3.05 total workers per resident served. Personnel costs were 82% of the total operating budgets in 80 reporting facilities.

Direct support workers earned an average starting wage of \$11.99 and an average mean wage of \$14.67 per hour in 2012. Those workers on average had to work 27 hours per week to be eligible for paid leave time. Starting wages increased 25% and average wages increased 19% between 2002 and 2012.

In 2012, average turnover rates for direct support workers were 24%. A total of 22% of variability in DSP turnover rates could be accounted for by starting hourly wage and supervisor tenure. Direct support turnover was higher in facilities with lower wages, and in facilities with higher supervisor turnover. Vacancy rates increased from 6% in 2010 to 7% in 2012.

Frontline supervisors in large state facilities earned an average starting salary of \$33,118 and an average overall salary of \$38,062 in 2012. This represented a decline from 2010 where starting salaries were \$35,228 and average salaries were \$42,590. In 2012, turnover rates for supervisors were 14% and vacancy rates were 7% compared with turnover rates of 13% and vacancy rates of 8% in 2002.



## Introduction and Methodology

**FY 2012**



## INTRODUCTION

**Medicaid financed long-term** supports and services (LTSS) for persons with IDD have evolved over several decades. What was once an institutionally-focused system is now a multifaceted program of long-term services and supports primarily delivered in family homes and community-based settings. Institutional services still exist in most states but the numbers of people with IDD who live in them have steadily declined over time. Initially,

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*TODAY, MEDICAID PROVIDES FEDERAL FINANCIAL PARTICIPATION TO STATES TO SUPPORT PEOPLE WITH IDD LIVING IN THEIR OWN HOME, THE HOME OF A FAMILY MEMBER, A HOST HOME, A FOSTER HOME OR IN GROUP SETTINGS OF VARIOUS SIZES AND TYPES.*

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Medicaid financed LTSS for individuals with IDD were provided almost exclusively in large (mostly state-operated) institutions with a one size fits all set of services. Today, Medicaid provides federal financial participation to states for services to support people with IDD living in their own home, the home of a family member, a host home, a foster home or in group settings of various sizes and types. In some programs Medicaid LTSS funds support self-directed services through which people with disabilities receive resources and are given control over how those resources are used to meet their needs, within established state and federal parameters.

The Medicaid program<sup>1</sup> includes an array of different mechanisms (or “authorities”) through which states can request matching federal funds to provide LTSS to people with disabilities. 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 2012 the FMAP ranged from 50% to 74%. 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.

Under Medicaid, states are required to provide a set of mandatory benefits such as inpatient hospital and physician services to eligible recipients. Early and Periodic Screening, Diagnostic and Treatment services (EPSDT), and nursing facility services must be included in a state’s Medicaid State Plan. States can also choose to provide optional benefits such as case management, physical and occupational therapy, preventative health care, dental services, and private duty nursing to eligible individuals.

Medicaid State Plan options under which states can provide LTSS include:

- **1905(a)** - Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) - an optional Medicaid state plan benefit that enables states to provide comprehensive health care and rehabilitation services to individuals with IDD who need and receive active treatment services. ICF/IID services are by definition institutional and are provided under a prescriptive set of Federal regulations. Access to ICF/IID services for eligible individuals may not be limited and cannot be subject to waiting lists.
- **1905(a)** - Inpatient psychiatric services in an Institution for Mental Disease for people under age 21 or 65 years or older.
- **1905(a)** - State plan personal care.
- **1915(i)** – Home and Community-based Services State Plan Option - authorized under the Deficit Reduction Act of 2005, and amended through the 2010 Affordable Care Act. It provides HCBS benefits including LTSS to one or more specific populations and allows any or all HCBS to be self-directed.
- **1915(j)** – Self-Directed Personal Assistance Services - authorized under the Deficit Reduction Act of 2005. Eligible recipients can set their own provider qualifications and train their self-directed personal assistance services providers. Participants determine how much they will pay for a service, support or item. Allows recipients to 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.

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<sup>1</sup> Unless otherwise specified, 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>.

- **1915(k)** – Community First Choice (CFC) authorized by the Affordable Care Act in 2010, permits states to provide statewide home and community-based attendant care services and supports to individuals who need the level of supports once offered only in institutions. These services include assistance with 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 either an agency provider or self-directed mode.
- **1932(a)** – State Plan Amendment Authority for mandatory and voluntary managed care.
- **1945** Health Home State Plan Option - Provides enhanced integration and coordination of primary, acute, behavioral health, and long-term supports and services for individuals with chronic illness. Services include case management, care coordination and health promotion, comprehensive transitional care, individual and family support, referral to community and social supports and use of health information technology. Provides states a 90% FMAP for the first two years.

Medicaid Waiver authorities provide Federal Financial Participation (FFP) to states while allowing states to test new or existing ways to deliver and pay for LTSS in community-based settings including:

- **Section 1115** Research and Demonstration Projects - give states additional flexibility to design and improve their programs in areas such as expanding eligibility to individuals who are not otherwise Medicaid eligible, providing services not typically covered by Medicaid, using innovative service delivery systems that improve care, increase efficiency, and reduce costs.
- **1915(a)** – Voluntary managed care - a managed care option that individuals may choose to elect (are not required to enroll).
- **1915(a)/(c)** – Voluntary managed care program that incorporates home and community-based services in the contract.
- **1915(b)** - Renewable waiver authority for managed care. The 1915(b) waiver can be used to limit providers as well as to mandate enrollment for certain groups into managed care.
- **1915(b)/(c)** – Voluntary or mandatory managed

care program that includes home and community-based services. Allows targeted eligibility and mandated 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 - allow states to provide community-based LTSS in HCBS settings to specified populations. In this most widely used HCBS waiver authority, states can choose to provide comprehensive supports or can limit the amount or types of services for eligible recipients.

### Definition of Community Living

Community living and participation is a complex and evolving construct. In the 1970's, community living and participation simply meant, "not living in an institution." Over time the conceptualization of community living has broadened to include an array of lifelong community support alternatives for people with IDD and other disabilities. However for people with IDD "living in the community" does not necessarily mean that a person has a "life" in the community, that he or she actively participates in activities and events, interacts with family and friends and/or works in a regular job earning at least

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*IN THE 1970'S, COMMUNITY LIVING AND PARTICIPATION SIMPLY MEANT, "NOT LIVING IN AN INSTITUTION." OVER TIME THE CONCEPTUALIZATION OF COMMUNITY LIVING HAS BROADENED TO INCLUDE AN ARRAY OF LIFELONG COMMUNITY SUPPORT ALTERNATIVES FOR PEOPLE WITH IDD AND OTHER DISABILITIES.*

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minimum wage alongside people without disabilities. However, funders of services are increasingly seeking evidence of such outcomes.

Today community living and participation are conceptualized as having many critical elements such as: 1) where and with whom a person lives; 2) where a person works and how he or she earns money; 3) what a person does during the day; 4) the quality of relationships developed with others; 5) what and with whom a person does things of personal interest,



6) an individual's health (physical and emotional); 7) where and with whom they worship; 8) their interest and opportunity to engage in learning and personal growth; and 9) their ability to make informed decisions about their lives. Community living and participation for people with IDD is influenced by the availability and competence of those individuals who provide the ongoing support that they require, the design and funding of the service delivery system and state policies regarding the oversight, operation and funding of LTSS. The needs of a specific individual is influenced by personal characteristics and circumstances including cultural and linguistic variations (Hewitt, 2014).

In January 2014, the Centers for Medicare and Medicaid Services (CMS) issued a new definition and requirements for Home and Community-based Services (Final Regulation CMS-2249-F/CMS-2296-F; see [www.Medicaid.gov/HCBS](http://www.Medicaid.gov/HCBS) ) authorized under sections 1915(c) home and community-based waivers, 1915(i) State plan home and community-based services, and 1915(k) Community First Choice options. Under the Final Rule to be eligible for federal financial participation, home and community-based services must be provided in settings that have all of the following qualities based on the needs of the individual and included in their person-centered plan. This final rule became effective March 17, 2014.

- Be integrated in and provide support for full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in

community life, control personal resources, and receive services in the community, to the same degree as individuals not receiving Medicaid HCBS.

- Be selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residence. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
- Ensure an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
- Optimize individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- Facilitate individual choice regarding services and supports, and who provides them.
- In a provider-owned or controlled residential setting, the following additional conditions must be met:
  - » The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the

State, county, city, or other designated entity. Where landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

- » Each individual has privacy in their sleeping or living unit including:
  - Entrance doors can be locked by the individual, with only appropriate staff having keys.
  - Individuals sharing units have a choice of roommates within that setting.
  - Individuals have the freedom to furnish and decorate their sleeping or living units to the extent allowed by the lease or other agreement.
- » Ensure individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
- » Ensure individuals are able to have visitors of their choosing at any time.
- » Be physically accessible to the individual.
- » Any modification of the additional conditions specified above, must be supported by a specific assessed need and justified in the person-centered service plan.

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*THE IMPETUS TOWARD EXPANDING HCBS WAS BOLSTERED BY THE LANDMARK SUPREME COURT RULING IN THE CASE OF L.C. VS OLMSTEAD IN 1999 THAT AFFIRMED THE RIGHT OF ELIGIBLE PEOPLE WITH DISABILITIES TO RECEIVE PUBLIC SERVICES IN THE MOST INTEGRATED SETTINGS APPROPRIATE TO THEIR NEEDS.*

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These new regulations also define settings that are not home and community-based to include nursing facilities, Institutions for Mental Diseases, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), hospitals and other locations that have qualities of an institutional setting, as determined by the Secretary.

## **Evolution of the Medicaid Program**

Given its flexibility and potential for promoting individualization of services, the Medicaid program has emerged as the primary source of funding community services as an alternative to institutional care. When the HCBS 1915(c) Waiver program began in 1981, states were required to demonstrate reductions in the number of recipients of and total expenditures for institutional Medicaid-funded settings such as ICF/IID roughly equal to the increases in HCBS participants and expenditures. Those restrictions were relaxed and then dropped in 1994. The number of people with IDD receiving 1915(c) HCBS Waiver-funded supports increased from 1,381 in 1982 to 122,075 in 1994. The impetus toward expanding HCBS was bolstered by the landmark Supreme Court Ruling in the case of *L.C. vs Olmstead* in 1999 that affirmed the right of eligible people with disabilities to receive state services in the most integrated settings appropriate to their needs. By 2000, the number of people with IDD receiving HCBS Waiver-funded supports had climbed to 291,225.

Expansion of the HCBS Waiver programs continued as in 2001 Congress funded Real Choice Systems Change Grants for community living to help states change their LTSS systems to rely less on institutional services and to increase access to home and community-based services.

The Medicaid Money Follows the Person (MFP), enacted by 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. It is the largest demonstration program in the history of Medicaid designed to transform LTSS. The first 17 states received MFP demonstration grants in 2007. States use the grant funds to develop systems and services to help long-term residents of nursing facilities, Intermediate Care Facilities for Individuals with Intellectual Disabilities, and Institutions for Mental Disease (psychiatric hospitals) who want to move to home or community-based settings. By 2012, 37 states were participating in MFP and 30,141 people including 4,245 people with IDD had transitioned from institutional to community-based LTSS (Mathematica Policy Research, 2013). The CMS Balancing Incentive Payment (BIP) programs also offered states increased federal financing to expand

home and community-based services by providing an increased FMAP on all community-based services, in an effort to incentivize community-based services and to provide resources to increase community capacity.

Across populations more than 1.4 million participants received Medicaid-funded home and community-based services funded by Section 1915(c) waivers including an estimated 567,117 people with IDD in 2010 (Ng, Harrington, Musumeci, & Reaves, 2014). Across populations, an additional 807,659 people were receiving Medicaid Home Health State Plan Services, and 951,853 people were receiving Medicaid Personal Care State Plan Services (Ng, et al., 2014).

State plan home health services included skilled nursing services, therapy services, home health aide services for assistance with activities of daily living, and in 15 states, assistance with instrumental activities of daily living. State plan personal care services included assistance with instrumental activities of daily living in 30 states, transportation services in 13 states, and case management in 9 states (Ng, et al., 2014).

In FY 2012 total federal and state spending on Section 1915(c) programs across all population groups totaled \$39.3 billion accounting for 28.1% of all Medicaid LTSS funding and expenditures (Eiken, et al, 2014). Expenditures on Section 1915(c) programs for people with developmental disabilities totaled \$28.4 billion (72.1% of all 1915(c) spending). Across populations, Medicaid 1915(c) HCBS Waiver expenditures averaged \$26,218 per person, Medicaid Home Health State Plan Services expenditures averaged \$7,077 per person and Medicaid Personal Care State Plan Service expenditures averaged \$10,739 per person in 2010 (Ng, et al., 2014).

In 2012, an estimated 303,909 people with IDD were waiting to enroll in a 1915(c) HCBS Waiver. An estimated 94% of people with IDD waiting to enroll in a 1915 (c) HCBS Waiver received non-Waiver Services while waiting. The average time waiting was 47 months in 2012 (Ng, et al., 2014).

## **A Historical Perspective on Medicaid-funded Long-Term Supports and Services**

**State Institutions.** In 1848, the first state institution unit for persons with IDD was founded in a Massachusetts state school for children who were

blind. The number of people living in state institutions grew steadily reaching a peak of 228,500 people in 1967 (of those 194,650 lived in state-operated facilities for people with IDD; White et al, 1992).

**Medicaid Nursing Facilities.** Almost from the inception of Medicaid, states took advantage of financial incentives for placing persons with IDD in Medicaid-certified nursing facilities. As this continued, the advocacy community began to assert that many more people with IDD were living in nursing homes than were appropriately served in them (e.g., The Arc of the United States 1975). Congress responded to these and other criticisms of nursing facility care in the Omnibus Budget Reconciliation Act (OBRA) of 1987 (PL 100-203). Provisions of this legislation restricted criteria for admissions to Medicaid reimbursed nursing facilities, so that only those persons requiring the medical/nursing services offered would be admitted. Current residents not in need of nursing services

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*ALMOST FROM THE INCEPTION OF MEDICAID, STATES TOOK ADVANTAGE OF FINANCIAL INCENTIVES FOR PLACING PERSONS WITH IDD IN MEDICAID-CERTIFIED NURSING FACILITIES. AS THIS CONTINUED, THE ADVOCACY COMMUNITY BEGAN TO ASSERT THAT MANY MORE PEOPLE WITH IDD WERE LIVING IN NURSING HOMES THAN WERE APPROPRIATELY SERVED IN THEM.*

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were required to be moved to “more appropriate” residential settings, with the exception that individuals living in a specific nursing home for more than 30 months could stay if they so choose. In either case nursing facilities were required to assure that each person’s needs for “active treatment” (later termed “specialized services”) were met.

Despite state efforts to move persons with IDD out of nursing facilities as described in their required “alternative disposition plans” and the implementation of required preadmission screening and resident review (PASARR) provision, class action court cases established within a decade of the 1990 implementation deadline that the requirements of OBRA-87 were not always achieved (see Roland et al. v Cellucci et al., 1999, in Massachusetts; Olesky

et al. v. Haveman et al., 1999, in Michigan; Gettings, 1990). Other cases would likely have been filed for violation of OBRA-87 if the Supreme Court had not in their 1999 Olmstead Decision established a right to placement in the most integrated setting under its interpretation of the Americans with Disabilities Act of 1990. The US Department of Justice continues to file litigation based on both the Olmstead Decision and the PASRR provision (e.g., Steward v. Perry).

In 2005, to further reduce unnecessary institutionalization Congress authorized the Money Follows the Person (MFP) program to help states decrease the number of people with disabilities living in Medicaid institutions. The legislation provided a system of flexible and augmented financing for LTSS to assist states in moving people to smaller more integrated appropriate and preferred settings. Despite these efforts, the estimated number of people with IDD in Medicaid-certified nursing facilities on June 30, 2012 (28,064) was only 29% less than in 1986 (39,528), the year before OBRA 1987 nursing facility reform was enacted.



elderly, blind, disabled, or dependent people 21 years old or younger and their families.

Shortly after the introduction of federal reimbursement for skilled nursing care in 1965, government officials noted rapid growth in the number of people living in SNFs. Much of the increase was for people who were receiving far more medical care than they actually needed, at a greater cost than was needed, largely because of the incentives of placing people in facilities for which half or more of the costs were reimbursed through the federal Title XIX program. In 1967, a less medically oriented and less expensive form of long-term supports, the “Intermediate Care Facility” (ICF) program for elderly and disabled people 22 years or older, 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 combining the two programs was a hardly noticed, scarcely debated amendment that for the first time authorized Federal Financial Participation (FFP) for “intermediate care” provided in facilities specifically for people with IDD. These facilities were initially called Intermediate Care for People with Mental Retardation (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 was designed to: 1) provide substantial federal incentives for upgrading the physical environment and the quality of care and habilitation being provided in large state IDD facilities; 2) neutralize incentives for states to place persons

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*SHORTLY AFTER THE INTRODUCTION OF FEDERAL REIMBURSEMENT FOR SKILLED NURSING CARE IN 1965, GOVERNMENT OFFICIALS NOTED RAPID GROWTH IN THE NUMBER OF PEOPLE LIVING IN SNFs. MUCH OF THE INCREASE WAS FOR PEOPLE WHO WERE RECEIVING FAR MORE MEDICAL CARE THAN THEY ACTUALLY NEEDED, AT A GREATER COST THAN WAS NEEDED, LARGELY BECAUSE OF THE INCENTIVES OF PLACING PEOPLE IN FACILITIES FOR WHICH HALF OR MORE OF THE COSTS WERE REIMBURSED THROUGH THE FEDERAL TITLE XIX PROGRAM.*

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**The ICF/IID 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 states cover a portion of the total costs of providing services. Initially covered services were long-term medical supports offered in places such as Skilled Nursing Facilities (SNF) for people who met income standards and who were

with IDD in nonstate nursing homes and/or to certify their large state facilities as SNFs; and 3) provide a long-term supports program for care and habilitation in the form of active treatment for persons with IDD. It offered a mechanism for providing federal financial assistance to help states with rapidly increasing costs for large state facilities which were averaging real dollar increases of 14% per year in the five years prior to the passage of the ICF/IID legislation (Greenberg, Lakin, Hill, Bruininks, & Hauber, 1985).

The ICF/IID program began during a decade of rapid change. In 1975, PL 94-142 (Education of all Handicapped Children Act; now the Individuals with Disabilities Education Act) was passed mandating for the first time that all children, including children with IDD would have access to a free and appropriate public education. This gave people with IDD the right to receive a public education without moving into an institution. Many states made progress toward deinstitutionalizing their service systems during this period by restricting or prohibiting children from entering large state-operated facilities. This report will show the number of people 21 years old or younger living in large state-operated facilities peaked in 1965 when 91,592 of the 187,305 residents (49%) were children or youth (NIMH, 1966). By 1977, the number of people 21 years old or younger had declined to 54,098 of 151,532 residents (36%). By July 2012, children ages birth to 14 years were 20% of the US population (US Bureau of the Census, 2012 American Community Survey) but only 0.5% of large state facility populations and 7% of all admissions to large state facilities.

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*IN 1975, PL 94-142 (EDUCATION OF ALL HANDICAPPED CHILDREN ACT; NOW THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT) WAS PASSED MANDATING FOR THE FIRST TIME THAT ALL CHILDREN, INCLUDING CHILDREN WITH IDD WOULD HAVE ACCESS TO A FREE AND APPROPRIATE PUBLIC EDUCATION.*

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States overwhelmingly opted to certify their state institutions to participate in the ICF/IID program with two notable outcomes: 1) nearly every state acted to secure federal participation in paying for large state facility services for people with IDD, and

2) to maintain federal participation, most states were compelled to invest substantial state dollars to bring large state facilities into conformity with ICF/IID standards. Forty states had at least one ICF/IID certified state facility by June 30, 1977 (Krantz, Bruininks & Clumper, 1979). Nearly a billion state dollars were invested in facility improvement efforts in FYs 1978-1980 alone, primarily to meet ICF/IID standards (Gettings & Mitchell, 1980).

As expenditures for both state and private ICF/IID certified settings grew critics increasingly charged that the ICF/IID program 1) had created direct incentives for maintaining people in large state facilities by providing federal contributions to the costs of those facilities; 2) had diverted funds that could otherwise have been spent on community program development into facility renovations solely to obtain FFP; 3) had promoted the development of large private ICF/IID facilities for people leaving large state facilities (11,943 people were living in large private ICF/IID by June 1977); and 4) had promoted organizational inefficiency and individual dependency by promoting a single uniform standard for care and oversight of ICF/IID residents 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 residential opportunities jointly funded by the federal and state governments helped stimulate the development of ICF/IID services in smaller community settings. In 1981, the Health Care Financing Administration (HCFA), now the Centers for Medicare and Medicaid Services (CMS), promulgated a rule describing how ICF/IID services could be delivered in group homes for four to fifteen people with IDD.

**Community ICF/IID Group Homes.** In the late 1970s and the 1980s, ICF/IID services were expanded to include privately operated settings. Private residential facilities were not a focus at the time of original ICF/IID enactment in 1971, probably because: 1) most private facilities were already technically covered under the 1967 amendments to the Social Security Act authorizing private ICF programs, and 2) in 1971 large state facilities were by far the predominant model of residential care. Indeed, the 1969 Master Facility Inventory indicated a total population in nonstate IDD facilities of about 25,000, compared with a large state IDD facility population of 190,000 (Lakin, Bruininks, Doth, Hill, & Hauber, 1982).

Although Congressional debate about the ICF/IID program had focused on large state facilities, the statute did not specifically limit ICF/IID coverage to large state facilities or institutions. Participation in the ICF/IID program was (and remains) restricted to “four or more people in single or multiple units” (42 CFR 435.1010 (b)(2)). Although it cannot be determined whether Congress, in authorizing a “four or more bed” facility, purposely intended the ICF/IID benefit to be available in small settings, it does seem reasonable to suppose, in the absence of specific limitations, that Congress was more interested in improving the general quality of residential care than it was in targeting specific sizes of residential settings. ICF/IID regulations, first published in January 1974, also supported the option of developing smaller settings, delineating two categories of ICF/IID, those housing 16 or more people (“large”) and those housing 15 or fewer people (“community”) and providing several specifications that allowed greater flexibility in meeting ICF/IID standards in the smaller settings.

Despite the regulatory recognition of community ICF/IID, the numbers of facilities varied enormously among states and regions. In some DHHS regions hundreds of community ICF/IID were developed while other regions had none. By mid-1982 nearly half (46.4%) of the 1,202 community ICF/IID were located in Minnesota and New York and nearly two-thirds (65.1%) were located in Minnesota, New York, Michigan and Texas. These variations reflected what some states and national organizations considered a failure of HCFA to delineate clear and consistent policy guidelines for certifying community settings for ICF/IID participation and/or reluctance on the part of some regional HCFA agencies to support the option.

In 1981, the Health Care Financing Administration (now CMS) issued “Interpretive Guidelines” for certifying community ICF/IID in response to continued complaints from the states that there was a need to clarify policy regarding the certification of community ICF/IID. These guidelines did not change the existing standards for the ICF/IID program, but clarified how the existing standards could be applied to delivering the ICF/IID level of care in community settings with 4 to 15 residents. Publication of the 1981 guidelines was followed by substantially greater numbers of states exercising the option to develop community ICF/IID. Ironically, these guidelines were published in the same year (1981) that Congress enacted legislation that would give even greater

opportunity and flexibility to states to use Medicaid funding for community services through the Medicaid HCBS waiver authority (Section 2176 of P.L. 97-35).

**Home and Community-based Services.** Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance “non-institutional” services for Medicaid-eligible individuals. The Medicaid Home and Community-Based Services (HCBS) waiver program was designed to provide non-institutional, community services to people with disabilities (including older Americans) who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid

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*THE MEDICAID HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVER PROGRAM WAS DESIGNED TO PROVIDE NON-INSTITUTIONAL, COMMUNITY SERVICES TO PEOPLE WITH DISABILITIES (INCLUDING OLDER AMERICANS) WHO, IN THE ABSENCE OF ALTERNATIVE NON-INSTITUTIONAL SERVICES, WOULD REMAIN IN OR WOULD BE AT A RISK OF BEING PLACED IN A MEDICAID FACILITY.*

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facility (i.e., a Nursing Facility or an ICF/IID). State 1915(c) waiver plans target one or several Medicaid eligible populations such as people with IDD, older Americans, people with HIV/AIDS, people with Brain Injuries, children with specific disabilities, people with Autism Spectrum Disorders, adults with physical disabilities and others. Final regulations for the 1915(c) HCBS waivers were first published in March 1985. By 1987, the number of people 21 years old or younger in large state institutions (almost all of which were ICF/IID certified) had declined to 12,026 of the total 94,696 remaining residents (13%).

Since 1985, several additional Medicaid waiver authorities, regulations and interpretive guidelines have been added that allow states to expand the use of Medicaid-funded community services to reduce the need for institutional services. An increasing number of states are using 1115 demonstration authority to incorporate existing HCBS Waiver programs.



In June 2014, [www.Medicaid.gov](http://www.Medicaid.gov) listed more than 300 current waiver programs and 22 pending waiver programs in the 50 US States and the District of Columbia. Medicaid community-based LTSS available to eligible people with IDD include but are not limited to service coordination/case management, homemaker, home health aide, personal care, adult day services, day and residential habilitation, and respite care ([www.Medicaid.gov](http://www.Medicaid.gov), 2014). 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, Medicaid-funded LTSS for people with IDD are primarily delivered to people with IDD living in homes they own or lease or in homes shared with family members rather than in congregate facilities of any size.

**Medicaid Managed Long-Term Services and Supports.** Historically, Medicaid-funded LTSS were offered in a fee-for-service context. Since 2000, however, an increasing number of states have opted to use a capitated managed care model for LTSS. Section 1115 Research and Demonstration Projects allowed states the flexibility to test new or existing approaches to 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. Finally, Section 1915(a) and (b) Managed Care waivers 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) allowed 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

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*HISTORICALLY, MEDICAID-FUNDED LTSS WERE OFFERED IN A FEE-FOR-SERVICE CONTEXT. SINCE 2000, HOWEVER, AN INCREASING NUMBER OF STATES HAVE OPTED TO USE A CAPITATED MANAGED CARE MODEL FOR LTSS.*

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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 that the introduction of managed care contracting and operational strategies to long-term supports furnished to people with IDD

and other disabilities will 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 recent report from the National Council on Disabilities (Gettings, Moseley and Thaler, 2013) summarizes the growth of acute and long-term managed care and provides 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 should be addressed by managed care systems to ensure the needs of people with disabilities are adequately met. The American Network of Community Options and Resources (ANCOR) also published recent 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 2014).

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*IN CONTRAST TO TRADITIONAL OR MANAGED CARE SERVICE DELIVERY MODELS, SELF-DIRECTED MEDICAID OPTIONS ALLOW PARTICIPANTS OR THEIR LEGAL REPRESENTATIVES TO EXERCISE DECISION-MAKING AUTHORITY AND MANAGEMENT RESPONSIBILITY OVER SERVICES.*

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While individuals with IDD, families, advocates and other stakeholders continue to express concerns, many states see managed care as a way to gain additional control over the costs of long-term service delivery. In 2011, the vast majority of Medicaid recipients across all states and all eligible population groups (74.2%) were served through managed care arrangements for at least some of their Medicaid services. It is estimated that by the end of 2014, managed LTSS (MLTSS) programs, primarily serving elders and people with physical disabilities, will be operational in 26 states (Gettings et al, 2013). Currently managed long-term care for people with IDD exists in Arizona, Michigan, Wisconsin, North Carolina, Kansas Vermont, Texas, New York and California. Several additional states including Illinois,

Florida, Louisiana, Minnesota, Kentucky, Georgia, New Jersey, Hawaii, and Rhode Island are planning on introducing managed LTSS for people with IDD in the near future (NASUAD, 2014).

**Self-Directed Services.** In contrast to traditional or managed care service delivery models, 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 1915(c) Home and Community-Based Services waiver. As a result of the Affordable Care Act self-directed options can also be provided through 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. People receiving supports under these options can decide who provides waiver and state plan services and how those supports and services will be provided. In some cases people can decide how their budgeted Medicaid funds are spent. (Further descriptions of these options can be found at the [www.Medicaid.gov](http://www.Medicaid.gov) website).

## Methodology

This report describes the current status of Medicaid (and other funded) LTSS for people with IDD and provides longitudinal data to examine trends in the provision of those services.

## Funded Projects

**Supporting Individuals and Families Information Systems Project (FISP).** The FISP project was funded as an Administration on Intellectual and Developmental Disabilities (AIDD) Project of National Significance (PNS) in 2011 and is a collaboration between the University of Minnesota, the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS). The project is a comprehensive program of annual data collection and longitudinal data analysis, policy studies and broad-based dissemination to better understand and promote effective supports for families and for individuals who direct their own support. The data collection and reporting system build on existing capacity to capture progressively more sophisticated information about publicly funded supports for families and individuals.

The FISP uses common metrics and point-in-time data collection to gather information from states to help federal and state agencies understand the

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*THE [FISP] PROJECT IS A COMPREHENSIVE PROGRAM OF ANNUAL DATA COLLECTION AND LONGITUDINAL DATA ANALYSIS, POLICY STUDIES AND BROAD-BASED DISSEMINATION TO BETTER UNDERSTAND AND PROMOTE EFFECTIVE SUPPORTS FOR FAMILIES AND FOR INDIVIDUALS WHO DIRECT THEIR OWN SUPPORT. THE DATA COLLECTION AND REPORTING SYSTEM BUILD ON EXISTING CAPACITY TO CAPTURE PROGRESSIVELY MORE SOPHISTICATED INFORMATION ABOUT PUBLICLY FUNDED SUPPORTS FOR FAMILIES AND INDIVIDUALS.*

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current status and emerging trends in supporting families and individuals with intellectual and developmental disabilities (IDD) living in homes of their own or with family members (including consumer direction). As FISP continues, data will be used to compare and contrast services and expenditures targeting the person with IDD versus those targeting the family members with whom they reside, and to compare services for people 21 years old or younger versus services for people 22 years or older with IDD. In addition, to the extent possible it will collect and report on characteristics of consumer (or family) directed supports.

### **Residential Information Systems Project (RISP).**

The RISP project, also at the University of Minnesota, is an AIDD PNS that maintains longitudinal records of Medicaid-funded long-term supports and services (LTSS) for people with IDD. Annual 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 began collecting national data on residential supports for people with IDD in 1977 and references historical records dating back to the 1880 Census. It now works in conjunction with the FISP project to continue to capture the characteristics of LTSS for people with IDD.

In 1977 and 1982, the University of Minnesota surveyed all state and nonstate residential facilities for people with IDD (Bruininks, Hill & Thorsheim, 1982; Hauber, et al., 1984). Annual reports describing large state residential facilities were published beginning in 1983 but it wasn't until 1986 that data collection expanded to include state-operated settings with fewer than 15 residents and periodic surveys included nonstate settings in which people with IDD received supports. The RISP project began publishing annual reports covering both state and nonstate residential services in 1991. The project used essentially the same surveys from 1991 through 2011. The most recent major change in the RISP report was the addition for FY 1995 report of individual state profiles summarizing the status and trends in residential and community supports. The RISP project continues to monitor the annual status and longitudinal trends in residential services for people with IDD.

The RISP and FISP projects now housed at the University of Minnesota's Institute on Community Integration in the Research and Training Center on

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*THE RISP PROJECT, ALSO AT THE UNIVERSITY OF MINNESOTA, IS AN (AIDD) PROJECT OF NATIONAL SIGNIFICANCE (PNS) THAT MAINTAINS LONGITUDINAL RECORDS OF MEDICAID-FUNDED LONG-TERM SUPPORTS AND SERVICES (LTSS) FOR PEOPLE WITH IDD. ANNUAL 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.*

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Community Living. Employees of the University of Minnesota and our partners at HSRI and NASDDDS staff these projects. The Association of Professional Developmental Disabilities Administrators (APDDA) also assists with project activities related to the survey of state residential facilities. The NASDDDS Research Committee advises both projects. The FISP project has a national panel of expert advisors on supports for individuals and families.



**The FY 2012 report.** This report introduces the first FISP data element (age of service recipients) which was added to the annual survey program for FY 2012. Along with the new data elements, this report has been reorganized to emphasize supports to individuals and to the families with whom they live. The state profiles have been updated and tools have been added to assist long time RISP report readers find information that now appears in a different section of the report.

**Additional RISP and FISP Activities.** In addition to annual surveys of State Directors of Developmental Disabilities Services and bi-annual extended surveys of State Residential Facilities serving 16 or more people with IDD, RISP and FISP activities include policy studies, secondary data analyses using the National Core Indicators and other large data sets, dissemination of state-by-state information via project websites (including the RISP website, the FISP Website, [www.qualitymall.org](http://www.qualitymall.org) and <http://www.selfadvocacyonline.org/>), publications including this annual report, special reports, the NASDDDS's *Community Services Reporter*, presentations at conferences such as the Reinventing Quality Conference, and provision of tailored technical assistance.

FISP project activities also include developing instrumentation for assessing supports for individuals and families, policy analyses related to those supports, and supplemental studies that include policy reviews and analyses. Beginning with our FY 2013 report we will include summaries describing LTSS for people with IDD in the United

States Territories of American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and the United States Virgin Islands. Initial reports on the LTSS in the territories will be posted to each project's website as they are completed.

## Instrumentation

This report describes the results of two surveys for Fiscal Year 2012 which ran from July 1, 2011 through June 30, 2012. Point estimates reflect the status of services on June 30, 2012.

### Survey of State Directors of IDD Services

Designated project staff work with state DD directors and other data contacts throughout the year to gather and report data elements for this annual report. While some RISP/FISP respondents have been reporting data for the RISP project for many years, approximately one-third of the respondents each year are new to the project. The RISP/FISP data collection team is responsible for identifying new respondents if the director and/or data provider has changed, and for assisting respondents to complete the survey. The on-line survey includes information about what was reported in previous years to prompt the data provider to double check responses that vary dramatically for the current versus past years. Detailed contact reports are maintained for each state to track changes made to survey responses based on follow-up inquiries, and decisions about how to handle missing data elements. The annual survey of state directors is conducted in cooperation with the NASDDDS.

The FY 2012 survey of state IDD directors included 5 parts and includes several new questions.

**Part 1** asks about services provided to people with IDD in state owned or operated facilities. In previous years data were collected for ICF/IID funded settings and for other funded settings. In the FY 2012 the categories were expanded to ask about ICF/IID settings, HCBS Waiver-funded settings and facilities that were neither ICF/IID nor HCBS Waiver-funded.

**Part 2** asks for a description of nonstate LTSS service settings. Nonstate settings are classified into six types:

**Type I.** Nonstate ICF/IID.

**Type II.** A residence owned, rented or managed by the residential services provider, or the provider's agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD (group home).

**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 (host family/family foster care).

**Type IV.** 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 (own home).

**Type V.** A residence of person(s) with IDD which is also the home of related family members in which the person(s) with IDD and/or their family members receive supportive services such as respite care, homemaker services, personal assistance (family home),

**Type VI.** Other residential types. A place a person with IDD lives that is not one of the previously listed types.

States report on the number of people with IDD served, the number of settings in which those people lived and the number of HCBS Waiver recipients in each setting type.

**Part 3** asks for the total number of recipients and total annual state and federal expenditures for services provided to people with IDD through the 1915(c) HCBS Waiver or through other waiver authorities. In FY 2012 questions were added comparing the number of, ages of (21 years old or younger versus 22 years and older), and expenditures for HCBS Waiver recipients living either in the home of a family member or in another setting. Questions were also added to capture the age of ICF/IID recipients and expenditures for people living in ICF/IID settings.

**Part 4** requests the number of people with IDD on waiting lists for residential services as of June 30 of the Fiscal Year.

**Part 5** requests the number of people with IDD living in Medicaid-funded nursing homes on June 30 of the fiscal year.

Historically, the project surveys were fielded in paper format or as an Excel spreadsheet and responses were mailed, faxed or emailed to project staff for analysis. Since 2008, the survey of state IDD directors has also been available in an online format. In a password protected section of the project website, states can view their responses to previous years' surveys, enter data for the current year, and print out a copy of their completed survey. States can submit changes for the data reported in previous years at any time throughout the year if a correction is needed and can annotate their data to explain how a certain element was computed or to indicate they are making an estimate. Online resources for states include a set of operational definitions, a frequently asked questions document, a PDF version of the survey, and webinar slides and recordings describing how to complete the survey.

### Survey of Administrators of State Residential Facilities

Surveys of administrators of state residential facilities that serve 16 or more people with IDD have been collected annually since 1977 in cooperation with the Association of Professional Developmental Disabilities Administrators (APDDA). Each year data on current census, admissions, discharges and deaths are collected. Every other year (in even numbered Fiscal Years including FY 2012) a longer survey asks for demographic, diagnostic, functional and behavioral characteristics of the people served, numbers of people moving in and out of the

facilities, prior and post-discharge setting types, and administrative characteristics (e.g., expenditures, services offered to non-residents, wages and benefits and employee job classifications).

The survey sample includes large state-operated IDD residential facilities and IDD units (typically ICF/IID certified) within state psychiatric or other “mixed use” residential facilities with 16 or more residents with IDD. Facilities that closed, were repurposed and no longer serve people with IDD, or were downsized to fewer than 16 people with IDD as of June 30, 2012 were not surveyed. The FY 2012 survey of large state facilities was available in both online and paper formats.

While most items on the survey remain the same from year to year, several changes were incorporated into the FY 2012 survey. Questions about resident age and level of IDD were simplified and a response option was added to record cases for which age or level of IDD was not known. Formatting changes were incorporated for the setting size and type categories used to track where people entering

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*STATES VARY IN THE TYPES OF DATA MAINTAINED. MOST STATES HAVE DEVELOPED A SPECIFIC SET OF DATA QUERIES TO RESPOND TO THE ANNUAL RISP SURVEY BUT HAD TO ADD ANALYSES TO ANSWER THE FISP QUESTIONS ADDED IN FY 2012.*

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the facility lived prior to admission, and to track the places to which discharged residents moved to better reflect the current service delivery system. A question was added about the number of residents with Alzheimer’s or other dementia. Finally, job classifications for employees were collapsed and clarified. Some positions were combined while more detailed descriptions were provided for others. Survey data were analyzed using SPSS 21.0 software. Missing or inconsistent responses were clarified in follow-up phone calls and/or emails.

### **Other Data Sources**

In addition to the RISP and FISP surveys, longitudinal data are derived from the following sources: 1) state IDD and psychiatric facilities for the years

1950 to 1968 come from the National Institute of Mental Health’s surveys of “Patients in Institutions;” 2) state IDD facilities for FYs 1969 and 1970 come from surveys conducted by the Office on Mental Retardation Coordination, now the Administration on Intellectual and Developmental Disabilities; 3) large state IDD facilities for 1971 through 1977 come from the surveys of the National Association of Superintendents of Public Residential Facilities for People with Mental Retardation, now the APDDA; 4) psychiatric facilities for 1969 to 1977 come from the National Institute of Mental Health’s surveys of “Patients in State and County Mental Hospitals;” and, 5) large state IDD and psychiatric facilities for the years 1978 through 2012 come from the ongoing data collection of this project. Data on nursing home residents was derived from reports analyzing CMS data sets when the state did not provide it (American Health Care Association, 2013). Missing expenditure data for HCBS and ICF/IID services were pulled from a report describing analysis of Medicaid-funded LTSS by Truven (Eiken et al., 2014). Population, tax revenue, cost of living adjustments and federal Medicaid expenditure data were downloaded from US Census Bureau data bases or from the CMS Medicaid.gov website.

### **Study Limitations**

A variety of limitations are encountered when gathering state level policy data because states vary in the types of data maintained. Most states have developed a specific set of data queries to respond to the annual RISP survey but had to add analyses to answer the FISP questions added in FY 2012.

**Variations in Operational Definitions.** In a few states, the statistical systems were not wholly compatible with the operational definitions used for the RISP/FISP survey. Footnotes are used to indicate when additional information is available to explain a specific data element. The data collection task has been complicated by turnover of state IDD Directors and data analysts. An operational definition guide is available to states on the project website and RISP/FISP staff provide ongoing technical assistance to ensure consistency of reporting within states over time. For the FY 2012 survey a frequently asked questions guide was developed and webinars were used to explain key changes in the surveys to both state IDD agency respondents, and to large state facility survey respondents.

The setting type categories were defined in cooperation with state agencies to permit, to the extent possible, comprehensive annual data collection congruent with administrative data sets maintained in each state. However, states have hundreds of different names for residential programs with sometimes subtle differences from similarly named programs in other states. A few state data systems do not permit the requested breakdowns and some settings must be subsumed in the statistics of another setting type.

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*STATES HAVE HUNDREDS OF DIFFERENT NAMES FOR RESIDENTIAL PROGRAMS WITH SOMETIMES SUBTLE DIFFERENCES FROM SIMILARLY NAMED PROGRAMS IN OTHER STATES.*

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**Missing Data.** In most states substantial state effort is required to compile the requested data, sometimes including separate surveys of sub-state regions. Occasionally the demands of such data

collection activities preclude a state's reporting completely for a particular year. With the permission of states, data from the previous year are used to substitute for missing data when possible and appropriate. Footnotes indicate when a data element was the previous year's value. If data were not furnished by a state for two or more years in a row, "Did Not Furnish" (DNF) is noted on the table and that state is not included in the reported totals for the data element. Most tables include an estimated US total for which estimates were substituted for DNF responses. When used, estimates are based on historical trends, other data elements in the current year survey, and in some cases national averages. In general, the tables do not include estimated values for individual states. Exceptions are noted in the text and tables. Footnotes identify data elements for which additional information is available in the Appendix. When a state did not use a particular program, setting, or funding source an N/A (not applicable) is indicated on the table (e.g., on the average daily cost of large state-operated institutions table, states that had closed all of their large facilities have an N/A indicated).



## Definition of Key Terms

A few key terms used in this report are defined here. More detailed operational definitions for items on the annual survey of state IDD directors can be found in the Appendix.

**Individualized settings:** settings where three or fewer people with IDD live together while receiving federal- or state-funded long-term supports and services. People in individualized settings may live in a home they own or rent, the home of a family member, the home of a host or foster family, or in a small group home operated by a service-providing organization.

**Congregate settings:** settings where four or more people with IDD live together while receiving federal- or state-funded long-term supports and services. Congregate settings include all ICF/IID settings, nursing homes, psychiatric facilities, and other group settings serving four or more people with IDD.

**Intermediate Care Facilities for individuals with Intellectual Disability (ICF/IID):** 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 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 (Medicaid.gov).

**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.

**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.

**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. In settings classified as Own Home, the service recipient is able to remain in the home if the provider of services changes whereas in provider owned or operated facilities, changing the service provider requires the recipient to move to a new setting.

**Family Home:** A residence of person(s) with IDD which is also the home of related family members in which the person(s) with IDD and/or their family members receive supportive services (e.g. respite care, homemaker services, personal assistance).

**Host home/Foster Family:** A home owned or rented by an individual or family service provider in which they live and provide care for one or more unrelated persons with IDD.

**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.

**HCBS Waiver-funded supports:** supports provided to a person with IDD funded by one or more Medicaid Home and Community-based Services Waiver authority.

**Nursing home:** A 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.

**Waiting list:** Includes people with IDD who were living in homes of their own or with a family member on June 30, 2012 who were on waiting lists for in-home services or for residential services to live outside the family home. People waiting for residential services while living in the home of a family member may be receiving

other funded supports such as Medicaid State Plan services while they are on the waiting list. People are included only if they have requested residential services to begin within the next 12 months. The reported number of people waiting excludes persons with IDD who were living in a setting other than their own home or the home of a family member on June 30 of the fiscal year (e.g., people living in an ICF/IID who are waiting to move to an HCBS Waiver-funded setting were not counted).

**Psychiatric Facilities:** state residential facilities designed for persons with a primary diagnosis of a psychiatric disabilities, (for example a mental health facility) in which one or more residents

with a primary or dual diagnosis of 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 ICF/IID or the Medicaid HCBS Waiver programs.

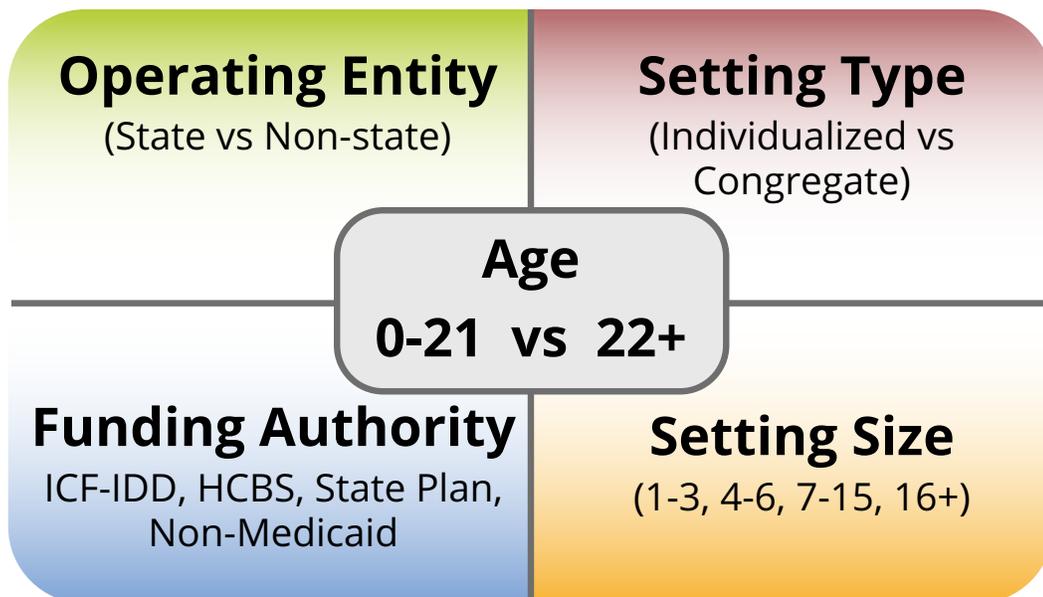
**Other nonstate-operated residence:** residential settings not staffed by state employees in which a person with IDD lives but that is not designated as a facility for persons with IDD (e.g., board care facilities, group homes serving other populations, provider owned housing with supports facility, or assisted living facilities).

### LTSS Dimensions

This report describes LTSS for people with IDD across several dimensions: setting type (own home, family home, host or foster home, group home and other), setting size (1-3, 4-6, 7-15, and 16 or more people), operating entity (state versus nonstate), age of service recipients (birth to 21 years versus 22 years and older), and funding authority (Medicaid HCBS

Waiver, Medicaid Intermediate Care Facilities for Persons with Intellectual Disabilities, other Medicaid, non-Medicaid; See diagram below). Data are collected about all individuals with IDD who receive LTSS under the auspices of state IDD directors. These individuals may only receive case management or service coordination and be waiting for other LTSS or they may already have federally or state funded LTSS.

## LONG TERM SUPPORTS AND SERVICES DIMENSIONS



## Report Organization

While we gather information about LTSS for people with IDD across all types of residential settings, we have reorganized the report to focus first on the most inclusive settings. The revised report sections are described below.

**Section 1.** This section provides a broad overview of residential and in-home LTSS for people 21 years old or younger and people 22 years or older with IDD and a policy analysis describing supports for families and individuals with IDD. It includes information about child and adult recipients of and expenditures for Medicaid HCBS Waiver and ICF/IID program funded supports. It includes state-by-state information about individualized LTSS offered to people living in their own homes, in the home of a family member, in a host home or family foster care setting, or in a group home setting that is shared by no more than three people with intellectual or developmental disabilities and about the number of people living with family members who are waiting for funding for residential LTSS. It is the FY 2012 report for the FISP project.

**Section 2.** This section describes congregate settings in which people with IDD receive LTSS including group IDD residential settings serving four or more people with IDD as well as nursing homes, psychiatric facilities, and other settings where people with IDD live that are not specifically designed for people with IDD.

**Section 3.** This section describes LTSS provided to people with IDD funded by a Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) or by a Medicaid Home and Community-based Support (HCBS) waiver funding authority.

**Section 4.** This section describes annual expenditures for HCBS waiver and ICF/IID funded supports.

**Section 5.** This section describes longitudinal trends in residential support and services for the nation as a whole across the dimensions of service.

**Section 6.** This section describes state-operated LTSS for people with IDD. It includes lists of large state-operated IDD facilities that remain open, and of those that have closed since 1960 and describes the progress made in deinstitutionalizing state-operated LTSS for people with IDD.

**Section 7.** This section shares the results from the FY 2012 bi-annual long-form survey of administrators of state-operated facilities with 16 or more residents including demographic characteristics of people living in those settings, types of services offered, and types of staff providing supports.

**State Profiles.** Two sets of state profiles have been developed. The first is in the FISP report. It summarizes by state key characteristics of LTSS provided in individualized settings and compares adult and child participants. The second at the end of the report describes historic trends in services by setting size and type, expenditures and participation in the Medicaid ICF/IID, HCBS Waiver-funded programs.

Data on elements previously included in the state profiles that were not included in this year's profiles are available upon request or through RISP and FISP project websites.

States that used FY 2011 data are noted on the table as are states that estimated the number of people using some other method. For FY 2012 received information about the living arrangements of at least some LTSS recipients with IDD from all 50 states and the District of Columbia.



Stock Photo



**SECTION ONE**

**In-Home and Residential Supports for  
Individuals with IDD and Families**

**FY 2012**



## SECTION 1: IN-HOME AND RESIDENTIAL SUPPORTS FOR INDIVIDUALS WITH IDD AND FAMILIES

**For more than 30 years, the RISP project** has gathered and reported on Medicaid-funded state and nonstate long-term supports and services (LTSS) for people with IDD including number of people receiving or waiting for services, types of settings in which service recipients lived, utilization of large state IDD facilities, and utilization and expenditures for Medicaid-funded Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and Medicaid 1915(c) Home and Community Based Services (HCBS) Waivers and services paid for by other Medicaid funding authorities.

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*GATHERING DATA ON THE FULL OF EXTENT AND ARRAY OF FAMILY SUPPORTS IS A COMPLEX AND DIFFICULT TASK AS INDIVIDUAL AND FAMILY SUPPORTS ARE BOTH FORMAL AND INFORMAL AND CUT ACROSS EDUCATIONAL, HEALTHCARE, AND SOCIAL SERVICE SYSTEMS.*

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When the FISP project began in 2011, we began adding elements to our ongoing data collection and reporting program to provide more information about supports for individuals with IDD and their families. Gathering data on the full of extent and array of family supports is a complex and difficult task as individual and family supports are both formal and informal and cut across educational, healthcare, and social service systems. We gathered information from our Family Advisory Panel and Technical Users Group about the most important new data elements and reviewed the lessons learned in previous attempts to expand data collection on supports for families and through the 30 years of the RISP project to plan our strategy. We identified data elements that can be provided by state directors of developmental disabilities services about supports to families and are now systematically incorporating those data elements into the annual data collection cycle over several years to expand the project scope at a pace that allows for both ongoing collection of RISP data elements and introduction of new elements without overburdening state respondents.



Section 1 includes a) operational definitions of categories of supports for families that could be used as a framework for expanding the program of data collection in future years<sup>2</sup>; b) a description of the status of Medicaid funded long-term supports and service people with IDD on June 30, 2012 with an emphasis on individualized supports and supports provided to people living in the homes of family members; and c) one page profiles for each state describing key findings related to supports for individuals and families.

### Medicaid-funded LTSS for Individuals and Families

While most people with IDD reside in the home of family members throughout their lives (Larson, Lakin, Anderson, Kwak, Lee and Anderson, 2001), the proportion of people with IDD living with family members who receive publicly funded LTSS has increased dramatically in recent years. In 2012, 337,371 recipients of Medicaid Home and

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<sup>2</sup> This description was originally published as: Agosta, J., Kardell, Y., Smith, D., & Aiken, F. (2013). Proposed categories for tracking HCBS services received by individuals living at home with family members. [Supporting Individuals and Families Information Systems Project Brief](#). Tulatin, OR: Human Services Research Institute.

Community Based Waiver-funded services lived with family members compared with 105,682 in 2000. Relatively little is known about these individuals and their families and the LTSS they receive or the related costs (See Braddock, et al, 2013 for an exception). The FISP project aims to provide more national and state by state information about in-home services and supports provided to families of individuals with IDD.

## Defining Supporting Families

Despite efforts to conceptualize “family support” to date there is no unified, single operational definition of what constitutes supports to families to guide national and state-by-state efforts to gather and summarize data about supports for families. In 2011, a group supported by the Administration on Intellectual and Developmental Disabilities (AIDD) met at the Wingspread Conference Center in Wisconsin and deliberated over family support policy and practice. They developed the following working definition of family support

Family support is a comprehensive and coordinated set of strategies that are designed to ensure that families who are assisting family members with intellectual disabilities/developmental disabilities (IDD) have access to person-centered and family-centered resources, supports, services, and other assistance. These strategies are directed to the family unit, but ultimately benefit the individual with IDD (Hecht & Reynolds, 2011).

The Wingspread construct asserts that family support consists of a variety of flexible paid and unpaid, professional and nonprofessional, specialized and generic services that are provided to the family as the primary beneficiary such as:

- Family-centered planning,
- Cash assistance,
- Professionally provided services and supports,
- Information and training,
- In-kind assistance from other individuals or entities,
- Peer mentoring and family-to-family supports,
- Assistive technology, home modifications, goods or products,

- Service coordination,
- Emergency assistance and crisis support, and
- Any combination of resources that are provided to families who have minor or adult members with IDD living in the family’s home.

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*THE WINGSPREAD CONSTRUCT ASSERTS THAT FAMILY SUPPORT CONSISTS OF A VARIETY OF FLEXIBLE PAID AND UNPAID, PROFESSIONAL AND NONPROFESSIONAL, SPECIALIZED AND GENERIC SERVICES THAT ARE PROVIDED TO THE FAMILY AS THE PRIMARY BENEFICIARY.*

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We used this definition of family support as a starting point for our effort to categorize services that individuals receive while living home with families. Using this definition or others like it, however, to collect accurate, reliable and consistent data regarding the Medicaid-funded services provided to individuals with IDD living at home with family is a challenging task. Consider that:

- There is no unified operational definition of what constitutes family support and, therefore, services counted as family support can vary from state to state;
- States vary in the ways they fund and provide supports to families;
- Currently, none of the national data collection projects specific to IDD request comprehensive information on the types of in-home or family support services people receive;
- Medicaid HCBS Waiver services are provided to “Medicaid beneficiaries” (in this instance people with IDD) and few of those services treat the family as the primary beneficiary; and
- Efforts to support individuals with IDD and their families cut across multiple state agencies, and may involve supports offered outside the public sector.

## Categorizing Supports for Individuals and Families

A primary aim for data collection on supports for families is to separate in-home services and supports being provided to individuals with IDD living in the

home of a family member, designed to benefit the individual, from services and supports being provided to families of such individuals that are designed to benefit the family. To fulfill this goal, we begin by

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*A PRIMARY AIM FOR DATA COLLECTION ON SUPPORTS FOR FAMILIES IS TO SEPARATE IN-HOME SERVICES AND SUPPORTS BEING PROVIDED TO INDIVIDUALS WITH IDD LIVING IN A FAMILY HOME, DESIGNED TO BENEFIT THE INDIVIDUAL, FROM SERVICES AND SUPPORTS BEING PROVIDED TO FAMILIES OF SUCH INDIVIDUALS THAT ARE DESIGNED TO BENEFIT THE FAMILY.*

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defining a set of categories that capture the primary services available to individuals living in the home of a family member or own home. In addition to the Wingspread report, three other key resources were reviewed to identify and categorize the services provided to families that have an individual with IDD living in the home of a family member. Those resources included:

### **Taxonomy of Home and Community-Based Services – Thomson Reuters (Eiken et al., 2011).**

Thomson Reuters, Mathematica, and the Centers for Medicare and Medicaid developed a taxonomy to catalogue services provided through 1915 (c) Home and Community-Based Service waivers. The directed content analysis involved review and categorization of HCBS services based on payment claims submitted by states to CMS in 28 states. The analysis was further refined utilizing input from several key national associations, CMS staff, state staff in ten states, other experts in the field, and responses received subsequent to a presentation of the taxonomy at the fall 2010 CMS HCBS Waiver conference. The final taxonomy included 66 services within 17 categories.

### **Taxonomy Family Support Services – State of the States in Developmental Disabilities (Braddock & Hemp, 2008)**

In 2008, the State of the States in Developmental Disabilities project published an expansion of their



2004 taxonomy of family support services. The taxonomy was developed to guide data collection and provide a better summary of family support services. Their final taxonomy was comprised of 11 subcategories of 61 individual family support services. The result was reviewed by the Research Committee of NASDDDS as a possible framework for organizing state-by-state data collection on family supports.

### **Review of HCBS Supports Waivers – Human Services Research Institute (Smith, Agosta, & Fortune, 2007)**

Under subcontract to the Research Triangle Institute through the U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy, HSRI worked to better understand the “supports” waivers utilized in 17 states and whether demand for Medicaid services from this cohort of recipients has been moderated as a result of them. HSRI collected and reviewed data pertaining to supports waiver programs in 17 states in 2006. The final report offers a profile of the HCBS waivers in operation in each of 17 states, and provides analysis of the findings.

**Table A1:** Comparison of service categories identified in three taxonomies of HCBS Services

<b>Taxonomy of Home and Community-Based Services Thomson Reuter (28 states)</b>	<b>Review of HCBS Supports Waivers HSRI (17 states)</b>	<b>Taxonomy of Family Support Services Coleman Institute</b>
• Case Management	• Case Management/ Service Coordination	• Case Management/ Service Coordination
• Caregiver Support including respite	• Family and Caregiver Training • Respite	• Family Training Counseling • Respite
• Nursing • Other Health and Therapeutic Services	• Clinical Services • Health Related	• Nursing and Home Health Services • Health and Related Professional Services
• Services Supporting Participant Direction • Rent and Food Expenses for Live-In Caregiver	• Supports of Participant Direction (Support Broker) • Financial Management Services	• Supports of Participant Direction (Support Broker) • Financial Services (Subsidies, Vouchers, Loans)
• Home-Based Services	• In-Home Services	• In-Home Support Services
• Non-Medical Transportation	• Transportation	• Transportation
• Day Services • Supported Employment	• Day Supports • Supported Employment	• Education and Habilitation (Day Services)
• Equipment, Technology, and Modifications • Home Delivered Meal	• Environmental Accessibility Adaptations • Equipment/ Supplies • Person Directed Goods and Services	• Assistive and Medical Technology • Other (e.g. Home Repair, Special Diets, Clothing)
• Other Mental Health and Behavioral Services		• Other Mental Health and Behavioral Services
• Round-the-Clock Services (group living, shared living, in-home residential habilitation) • Community Transition Services • Participant Training • Other Services (Housing coordination, interpreters)		• Recreational Leisure

There is considerable overlap across the three taxonomies but there are also important differences (See [Table A1](#)). Services referred to across all three include: Case management and service coordination, respite, day supports or services, in-home services, health related services, supports of participant direction, transportation and equipment, medical technology, and supplies. Services included in two of the three taxonomies include: Supported employment, nursing, respite, family and caregiver training or counseling, financial services, and other mental health and behavioral services. Services included in one of the three taxonomies include: Round-the-clock services, home delivered meals, rent and food expenses for live-in caregiver, caregiver support, participant training, community transition services, clinical services, environmental accessibility

adaptations, person directed goods and services, and recreational leisure services.

### Service Category Description

The next objective was to identify the specific services about which states would report. We began by reviewing the RISP data to identify states that serve the highest percentages of people receiving LTSS under the auspices of state DD agencies who lived in the home of a family member. In 2010 these states were Arizona, California, Mississippi, Louisiana, North Carolina and West Virginia.

Next, the HCBS services these states provide were reviewed and classified into the categories described in the taxonomies. Each service was accounted for, adding confidence to the analysis.

Finally, the list of services was narrowed based on the following criteria:

- If a service is directed at the caregiver, it was retained.
- If a service is offered exclusively in the family home, it was retained.
- If a service is offered exclusively in other residential settings, it was set aside (e.g., residential habilitation available to residents of staffed community homes).
- Preference is given to services that are highly utilized or high in aggregate cost.

When these criteria are applied to the three taxonomies, ten service categories emerged:

- Family Caregiver Support

- Behavior Supports
- Respite
- Medical Supports
- Personal Care Supports
- Participant-Directed Supports
- Habilitation
- Transportation
- Day Services
- Environmental Modifications and Technology

While some of these services are also provided in other residential settings, our purpose was to identify services available to families and to individuals living in the home of a family member. [Table A2](#) provides a description and examples of services in each category.

**Table A2: Supports for Individuals and Families Categories**

Service Category	Brief description	Example Services
<b>Family Caregiver Support</b>	Services provided to help the <b>family</b> provide supports to the individual	<i>Home delivered meals, home health aide, homemaker/chore, caregiver counseling, care giver training</i>
<b>Respite</b>	Temporary relief from/for the family caregiver	<i>Respite (in home, out of home), individual support (day or night)</i>
<b>Personal Care Supports</b>	Direct one-to-one services to the individual provided in or out of home to provide instrumental support, community integration or skill training	<i>Companion services, personal care/ assistance</i>
<b>Habilitation</b>	Services to direct skills development and training to the individual at home	<i>Home-based habilitation</i>
<b>Day Services</b>	Services provided to support the individual in community-based activities (i.e., supported employment, day programs, education)	<i>Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, early start programs</i>
<b>Behavior Supports</b>	Supports to prevent or reduce behavior related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions.	<i>Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment</i>
<b>Medical Supports</b>	Supports for individuals with medical complications. Includes clinical services, such as OT, PT, and speech therapies as well as in home nursing services.	<i>OT, PT, speech and language therapies, skilled and private nursing, clinic services</i>
<b>Participant Directed Supports</b>	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.	<i>Financial management services, participant training, goods and services, other, interpreter</i>
<b>Transportation</b>	Supports to transport an individual to a community-based activity, including day services, employment services, or other community-based activities.	<i>Community transportation services, non-medical transportation</i>
<b>Environmental Modifications and Technology</b>	Services to accommodate physical disabilities (e.g., ramps, bathroom modifications, etc.), modification or repair to a vehicle, or other adaptive equipment, augmentative communication devices, personal emergency response systems, (etc.)	<i>Personal emergency response systems, home and vehicle modifications, adaptive equipment</i>

In subsequent years we will continue to work both with the project's Family Advisory Committee and the Technical Advisory Group (the NASDDDS Research Committee) to identify and prioritize questions about these services that can be answered in our annual survey of state DD directors.

### **FY 2012 Survey of State IDD Directors: Living Arrangements for People with IDD**

State IDD Directors reported an estimated 1,138,121 persons with IDD in their IDD systems on June 30, 2012 (See [Table 1.1](#)). Of those, an estimated 634,988 lived in the home of a family member, 122,665 lived in a home they owned or leased, 58,753 lived in the home of a host or foster family, and 253,751 lived in a nonstate group setting (including 57,944 who lived in an ICF/IID, 180,743 who lived in an IDD setting other than an ICF/IID, and 15,064 who lived in a group setting not specifically designed for people with IDD). An additional 39,900 people with IDD lived in state-operated residences (including 27,440 who lived in a state ICF/IID, 10,843 who lived in an HCBS Waiver-funded setting, 478 who lived in a group setting not funded by the ICF/IID or the HCBS Waiver

programs, and 1,139 who lived in a state psychiatric facility). Finally, 28,064 people with IDD lived in a nursing home.

### **Defining Individualized LTSS Settings**

This report classifies the places in which people with IDD live while receiving LTSS as either individualized or congregate living arrangements. Individualized settings included a person's own home, the home of a family member, a host or foster family home, or a group setting shared by three or fewer people with IDD (See [Figure 1.1](#)). Congregate settings are those shared by four or more people with IDD and include group IDD settings not certified as an ICF/IID; ICF/IID settings, and group settings with four or more people not specifically designed for people with IDD such as nursing homes and psychiatric facilities).

### **Overview of Types of Living Arrangements**

Of the people with IDD identified by state IDD agencies on June 30, 2012, 56% lived in the home of a family member, 10% lived in a home they owned or leased with no more than two other people with IDD, 6% lived in a group setting shared by three or fewer people with IDD, and 5% lived in a host family



or foster home shared by three or fewer people with IDD. An additional 23% lived in congregate settings (including 12% who lived in an IDD group setting shared by four or more people with IDD that was not certified as an ICF/IID, 7% who lived in an ICF/IID, and 3% who lived in a nursing home, psychiatric facility or some other group setting not specifically designed only for people with IDD).

The proportion of people living in each type of setting varied dramatically by state both in percentage and in actual numbers (see [Table 1.1](#)). In all states but Mississippi, most people with IDD lived in an individualized setting. In Mississippi, there were more people living in state-operated ICF/IID facilities (2,033 people) than in any other type of setting. In 32 states, the most commonly reported living arrangement for people with IDD was the home of a family member. The most common living arrangement was a host family or foster home in Idaho (1,694 people), New Hampshire (933), and Texas (9,738). The most common living arrangement

in 14 states was an IDD group home shared by three or fewer people with IDD. In Iowa, the number of people living in their own home or the home of a family member was not reported so the largest

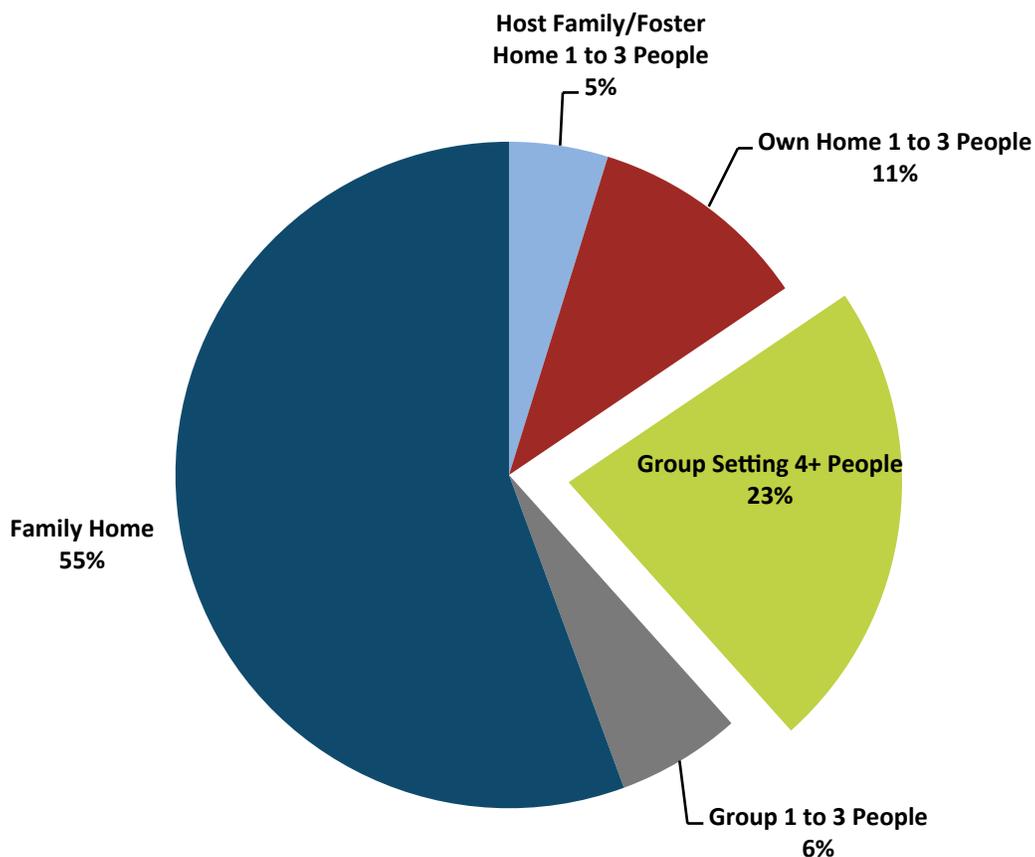
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*IN 32 STATES THE MOST COMMONLY REPORTED LIVING ARRANGEMENT FOR PEOPLE WITH IDD WAS THE HOME OF A FAMILY MEMBER. THE MOST COMMON LIVING ARRANGEMENT WAS A HOST FAMILY OR FOSTER HOME IN IDAHO (1,694 PEOPLE), NEW HAMPSHIRE (933), AND TEXAS (9,738).*

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reported group (1,558 people) lived in nonstate ICF/IID facilities. Finally, in New Mexico most people lived in a non-specified nonstate setting (1,802) or in a nonstate ICF/IID (1,096).

**Figure 1.1** Estimated Number of People with IDD in Individualized versus Congregate Settings as of June 30, 2012



**Table 1.1** Living Arrangement for People with IDD Receiving Medicaid Funded or Non-Medicaid Funded Long-Term Supports and Services Under the Auspices of State IDD Programs as of June 30, 2012

Setting Type	Nonstate Operated						State Operated					Nursing Home	Reported Total	Estimated Total
	Own home	Family home	Host Family / Foster	Group (Non-ICF/IID)	ICF/ IID	Nonstate Other	ICF/ IID	HCBS Funded	State Other IDD	Psychiatric				
AL	127	1,895 <sup>e</sup>	166	3,412 <sup>e</sup>	41	0	0	0	0	0	854	6,495	6,495	
AK	473	292	218	428	0	0	0	0	0	0*	10	1,421	1,421	
AZ	439	27,983	1,281	2,590	35	0	113	59	0	0	73	32,573	32,573	
AR	642	1,994	560	1,068	516	0	951	0	0	0	597	6,328	6,328	
CA	23,097	140,887	3,892	21,409	7,044	0	1,682	0	0	0	1,157	199,168	199,168	
CO	1,020 <sup>e</sup>	5,807 <sup>e</sup>	2,204 <sup>e</sup>	1,138 <sup>e</sup>	21	980 <sup>e</sup>	322	270*	0	0	95	11,857	11,857	
CT	1,349	1,381*	458	3,427	372	0	612	624	0	0	376*	8,599	8,599	
DE	20	2,428	132	765	0	0	66	15	0 <sup>e</sup>	3 <sup>e</sup>	29	3,458	3,458	
DC	19	715	81	894	363	21	0	0	0	0	6	2,099	2,099	
FL	5,883	37,082	7,254	7,600	2,005	1,059	781	0	118	28	308	62,118	62,118	
GA	1,366	5,495	1,044	2,063	0	51	300	0	0	0	1,095 <sup>e*</sup>	11,414	11,414	
HI	123	2,202	669	155	79	0	0 <sup>e</sup>	0	0	0	53	3,281	3,281	
ID	942	1,182	1,694 <sup>e</sup>	243 <sup>e</sup>	438 <sup>e*</sup>	0	47	0	0	0	49 <sup>e</sup>	4,595	4,595	
IL	DNF	DNF	244	9,850	6,416	0 <sup>e</sup>	1,928	0	0	0	1,094 <sup>e*</sup>	19,532	30,173	
IN	5,136 <sup>e</sup>	6,888 <sup>e</sup>	207	555 <sup>e</sup>	3,839	0	0 <sup>e</sup>	0	0	106	1,553	18,284	18,284	
IA	DNF <sup>e</sup>	DNF <sup>e</sup>	4	766	1,558	0	444	68	0	0	634	3,474	14,838	
KS	DNF	2,811	82	5,004 <sup>e*</sup>	175 <sup>e</sup>	0	334 <sup>e*</sup>	0	0	0	262 <sup>e*</sup>	8,668	9,045	
KY	261 <sup>e*</sup>	1,135 <sup>e</sup>	761 <sup>e</sup>	2,475 <sup>e</sup>	136 <sup>e</sup>	0	149 <sup>e</sup>	0	0	0	273	5,190	5,190	
LA	2,468	15,946	0	0	3,756	0	848 <sup>e</sup>	0	0	16	511 <sup>e</sup>	23,545	23,545	
ME	541 <sup>e</sup>	1,563 <sup>e</sup>	793 <sup>e</sup>	2,068 <sup>e</sup>	189 <sup>e</sup>	55 <sup>e</sup>	0	0	0	3 <sup>e</sup>	49 <sup>e</sup>	5,261	5,261	
MD	2,014	2,215	208	5,653	0	0	54	0	0	0	241 <sup>e*</sup>	10,385	10,385	
MA	638 <sup>e</sup>	21,000 <sup>e</sup>	2,807*	7,423 <sup>e</sup>	0	0 <sup>e</sup>	594	1,171	0	0*	367	34,000	34,000	
MI	7,571	25,772	600	11,210	0	1,784	0	0	0	0	609 <sup>e*</sup>	47,546	47,546	
MN	1,384*	10,332	1,438	8,569	1,630	1,594*	89	332	0	0 <sup>e</sup>	218	25,586	25,586	
MS	15 <sup>e</sup>	1,087	0	160 <sup>e*</sup>	732 <sup>e*</sup>	0	2,033 <sup>e</sup>	212 <sup>e</sup>	17 <sup>e</sup>	0	140 <sup>e</sup>	4,396	4,396	
MO	3,984	8,089	20	2,554	80	0	510 <sup>ed</sup>	211	0	376	1,045 <sup>e*</sup>	16,869	16,869	
MT	100	800 <sup>e*</sup>	42 <sup>e</sup>	1,726*	0	0	55	0	0	0	80 <sup>e</sup>	2,803	2,803	
NE	1,322	1,130	574	1,630	289	0	144	0	0	0	307	5,396	5,396	
NV	1,530	3,826	75	0	56	100	48	0	0	0	81	5,716	5,716	

**Table 1.1** Living Arrangement for People with IDD Receiving Medicaid Funded or Non-Medicaid Funded Long-Term Supports and Services Under the Auspices of State IDD Programs as of June 30, 2012

Setting Type	Nonstate Operated						State Operated					Nursing Home	Reported Total	Estimated Total
	Own home	Family home	Host Family / Foster	Group (Non-ICF/IID)	ICF/ IID	Nonstate Other	ICF/ IID	HCBS Funded	State Other IDD	Psychiatric				
NH	478	924	933	301	25	0	0	0	4	0	84	2,749	2,749	
NJ	125	30,529	999	7,156	719	589	2,434	46 <sup>e</sup>	0	60	1,043 <sup>e</sup>	43,700	43,700	
NM	274 <sup>e</sup>	651 <sup>ed</sup>	0 <sup>ed</sup>	1,096 <sup>e</sup>	230 <sup>e</sup>	1,802 <sup>ed</sup>	4 <sup>ed</sup>	56 <sup>ed</sup>	0 <sup>e</sup>	0 <sup>ed</sup>	109 <sup>ed</sup>	4,222	4,222	
NY	9,109 <sup>e</sup>	78,744 <sup>e</sup>	2,307	21,873	5,566	0 <sup>e</sup>	1,722	7,329	0	0	1,901 <sup>e*</sup>	128,551	128,551	
NC	1,536 <sup>e</sup>	13,765 <sup>e</sup>	1,400 <sup>e</sup>	1,842 <sup>e</sup>	2,506 <sup>e</sup>	0	1,424	0	82	86	4,086	26,727	26,727	
ND	1,126	1,225	20	326	465	0	94	0	0	0	100	3,356	3,356	
OH	13,641	58,851	2,123	2,658	5,792	516	1,134	0	0	0	1,962 <sup>e*</sup>	86,677	86,677	
OK	1,667	2,363	407	786	1,314	0	235	0	0	0	315	7,087	7,087	
OR	764	10,479	3,273	2,701	0	0	0	108	0	0	195 <sup>*</sup>	17,520	17,520	
PA	4,656 <sup>e</sup>	29,009 <sup>e</sup>	1,590	10,750	2,313	6,259 <sup>e</sup>	1,106	0	0	77	1,549 <sup>e*</sup>	57,309	57,309	
RI	676	1,380	183	1,077	21	0	21	212	0	0	44	3,614	3,614	
SC	668	12,427	160	2,707	568	0	745	0	0	0	206	17,481	17,481	
SD	557	1,161	4	1,736	59	0	140	0	0	31	134	3,822	3,822	
TN	3,647	2,928	338	767	828	0	280	0	0	11	420	9,219	9,219	
TX	3,485	9,238	9,738	6,732	5,670	0	3,797	0	0	0	1,936 <sup>e*</sup>	40,596	40,596	
UT	985	1,814 <sup>e</sup>	269	1,391 <sup>e</sup>	594	0	207	0	0	0	167 <sup>e*</sup>	5,427	5,427	
VT	248	1,725	1,300	131	6	0	0	0	0	0	32	3,442	3,442	
VA	1,235	1,445	801	4,971	378	0	948	0	0	312	933	11,023	11,023	
WA	6,370 <sup>e</sup>	11,148 <sup>e</sup>	96	2,045	53	245 <sup>e</sup>	576	130	257	22 <sup>e*</sup>	294	21,236	21,236	
WV	32 <sup>*</sup>	2,994	156	1,265 <sup>*</sup>	562 <sup>e*</sup>	0	0	0	0	0	329 <sup>e*</sup>	5,338	5,338	
WI	4,307 <sup>e</sup>	11,524 <sup>e</sup>	5,085	2,470	505 <sup>e</sup>	9	390	0	0	0	34 <sup>e</sup>	24,324	24,324	
WY	216	744	63	1,127	0	0	79	0	0	8	25 <sup>e*</sup>	2,262	2,262	
<b>Reported US Total</b>	118,266	617,005	58,753	180,743	57,944	15,064	27,440	10,843	478	1,139	28,064	1,115,739	1,138,121	
<b>Estimated US Total</b>	122,665	634,988	58,753	180,743	57,944	15,064	27,440	10,843	478	1,139	28,064	1,138,121		

<sup>e</sup>2011 data <sup>e</sup>Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix



States with the highest proportion people with IDD living in each setting type were:

- Family Home (Arizona, 86%, California, 71%, Delaware, 70%, New Jersey, 70%, and South Carolina, 71%)
- Own home (Arkansas, 33%, Indiana, 28%, North Dakota, 34%; Tennessee, 40%; and Washington, 30%)
- Host/Foster (Idaho, 37%, New Hampshire, 34%, Texas, 24%, Vermont, 38% and Wisconsin, 21%)
- Nonstate group setting other than ICF/IID (Alabama, 53%, Illinois, 50%, Kansas, 58%, Maryland, 54%, Montana, 62%, and Wyoming 50%)
- Nonstate ICF/IID (District of Columbia, 17%, Illinois, 33%, Indiana, 21%, Iowa, 45%, and Oklahoma 19%).
- Other nonstate setting (Colorado, 8%, Michigan, 4%, Minnesota, 6%, New Mexico, 43%, and Pennsylvania, 11%)
- State ICF/IID facility (Arkansas, 15%, Illinois, 10%, Iowa, 13%, Mississippi, 46%, Texas, 9%, and Virginia, 9%)
- State HCBS IDD group setting (Connecticut, 7%, Massachusetts, 3%, Mississippi, 5%, New York, 6%, and Rhode Island, 6%)
- State psychiatric facility (Washington, 1%)
- Nursing home (Alabama, 13%, Arkansas, 9%, Georgia, 10%, Iowa, 18%, and North Carolina, 15%)

## Utilization of Individualized Settings

**Own Home.** On June 30, 2012, there were an estimated 122,665 people with IDD living in 99,019 homes owned or leased by the person or a roommate with IDD (“own home settings”; See [Table 1.2](#)). An estimated average of 1.2 people with IDD lived together in own home settings. All but three states reported the number of people living in own home settings. However, 21 states were not able to report the number of own home settings. Nine states estimated the number of settings to be equal to the number of people with IDD living in own home settings.

States reporting the largest numbers of people with IDD living in own home settings were California (23,097 people), Ohio (13,641), New York (9,109), and Washington (6,370). States reporting the fewest people with IDD living in own home settings were Montana (100), Delaware (20), the District of Columbia (19), and Mississippi (15).

Of the people with IDD not living in the home of a family member (503,199), an estimated 24% lived in an own home setting. The proportion was highest in Nevada (81%), Washington (63%), Tennessee (58%), North Dakota (53%), and Ohio (49%). The proportion of those not living with a family member who lived in their own home was lowest in Mississippi (0.5%), New Jersey (1%), Delaware (2%), the District of Columbia (2%), and Alabama (3%)

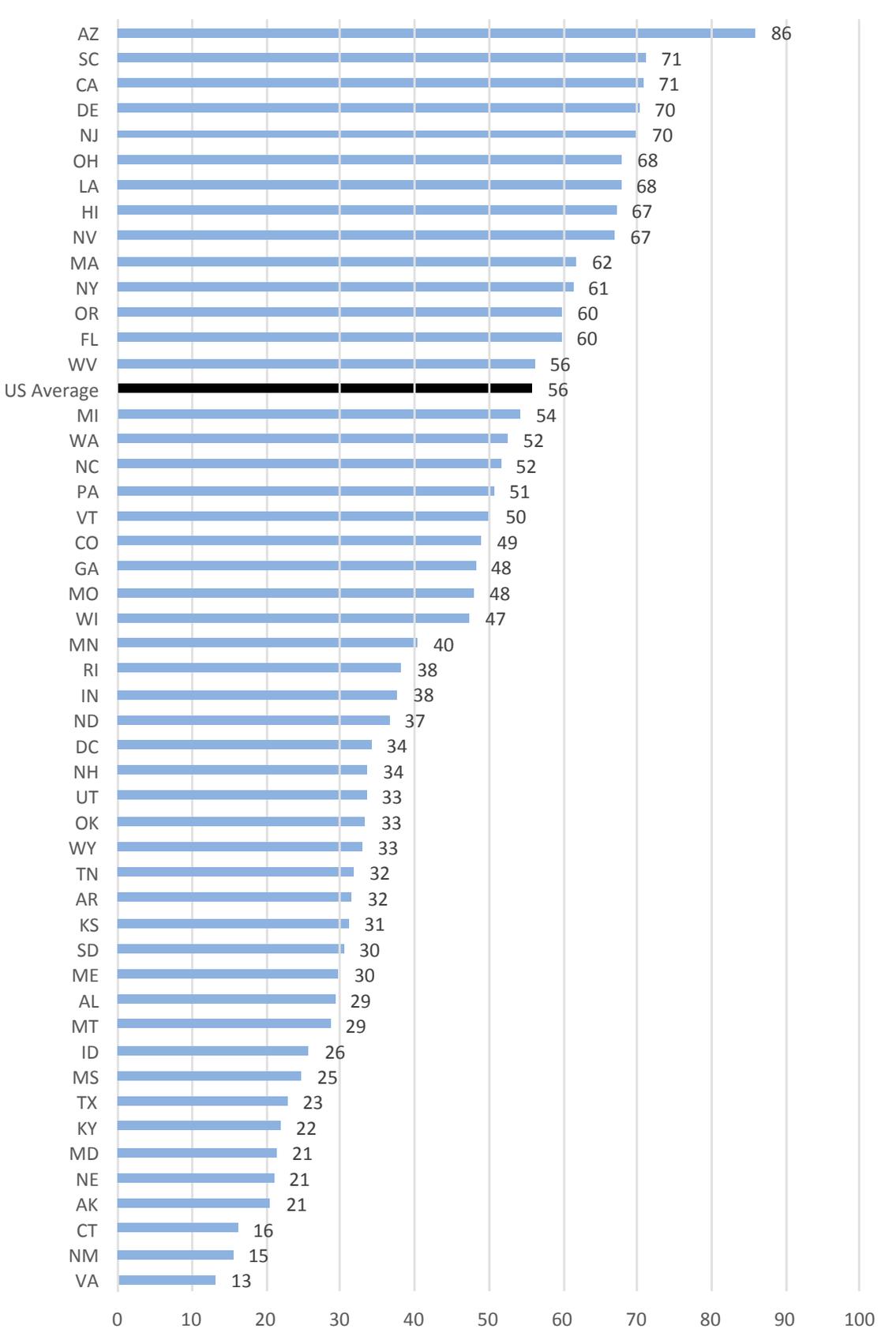


Table 1.2 People with IDD Living in Homes They Own or Lease by State on June 30, 2012

State	Homes Owned/ Leased by PWIDD	People in Own Home By Size		People w/IDD Per Home	Total Not Living with Family	% Not with Family Living in Own Home
		1 to 3	4 to 6			
<b>N States</b>	<b>30</b>	<b>42</b>	<b>42</b>	<b>30</b>	<b>49</b>	<b>42</b>
AL	120	127	0	1.1	4,600	3%
AK	473	473	0	1.0	1,129	42%
AZ	278	439	0	1.6	4,590	10%
AR	591	590	52	1.1	4,334	15%
CA	23,097	23,097	0	1.0	58,281	40%
CO	DNF	1,020 <sup>e</sup>	0	DNF	6,050	17%
CT	1,312	1,349	0	1.0	7,218	19%
DE	DNF	20	0	DNF	1,030	2%
DC	18	19	0	1.1	1,384	1%
FL	DNF	5,883	0	DNF	25,036	23%
GA	1,366	1,362	4	1.0	5,919	23%
HI	123	123	0	1.0	1,079	11%
ID	DNF	942 <sup>e</sup>	0	DNF	3,413	28%
IL	DNF	DNF	DNF	DNF	DNF	DNF
IN	2,859 <sup>e</sup>	5,067 <sup>e</sup>	278 <sup>e</sup>	1.9	11,396	47%
IA	DNF	DNF	DNF	DNF	DNF	DNF
KS	DNF	DNF	DNF	DNF	5,857	DNF
KY	261	261 <sup>e*</sup>	0	1.0	4,055	6%
LA	DNF	2,468	0	DNF	7,599	32%
ME	DNF	541 <sup>e</sup>	0	DNF	3,698	15%
MD	1,840	1,997	17	1.1	8,170	25%
MA	DNF	DNF	DNF	DNF	13,000	DNF
MI	DNF	DNF	DNF	DNF	21,774	DNF
MN	DNF <sup>e</sup>	1,384 <sup>e</sup>	0 <sup>e</sup>	DNF	15,254	9%
MS	5	15 <sup>e</sup>	0	3.0	3,309	0%
MO	1,532	3,984	0	2.6	8,780	45%
MT	75	100 <sup>e*</sup>	0	1.3	2,003	5%
NE	1,204	1,318	4	1.1	4,266	31%
NV	848	921	609	1.8	1,890	81%
NH	478	478	0	1.0	1,825	26%
NJ	125	125	0	1.0	13,171	1%
NM	274 <sup>ed</sup>	274 <sup>ed</sup>	0 <sup>ed</sup>	1.0	3,571	8%
NY	DNF	9,109 <sup>e</sup>	0	DNF	49,807	18%
NC	DNF	DNF	DNF	DNF	12,962	DNF
ND	1,126	1,126	0	1.0	2,131	53%
OH	10,903	12,817	824	1.3	27,826	49%
OK	998	1,606	61	1.7	4,724	35%
OR	DNF	764	0	DNF	7,041	11%
PA	DNF	4,656	0	DNF	28,300	16%
RI	676	676	0	1.0	2,234	30%
SC	71 <sup>*</sup>	668	0	9.4	5,054	13%
SD	535	557	0	1.0	2,661	21%
TN	1,841	3,647	0	2.0	6,291	58%
TX	DNF	DNF	DNF	DNF	31,358	DNF
UT	897	985	0	1.1	3,613	27%
VT	230	248	0	1.1	1,717	14%
VA	DNF	349	886	DNF	9,578	13%
WA	4,574 <sup>e</sup>	5,753 <sup>e</sup>	617 <sup>e</sup>	1.4	10,088	63%
WV	DNF	DNF	DNF	DNF	2,344	DNF
WI	DNF	4,307	0	DNF	12,800	34%
WY	DNF	DNF	DNF	DNF	1,518	DNF
<b>Reported US Total</b>	<b>58,730</b>	<b>101,645</b>	<b>3,352</b>	<b>1.8</b>	<b>475,728</b>	<b>22%</b>
<b>Estimated US Total</b>	<b>99,019</b>	<b>118,576</b>	<b>4,089</b>	<b>1.2</b>	<b>503,133</b>	<b>24%</b>

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix <sup>^</sup> Imputed value

**Figure 1.2** Proportion of People with IDD on the Caseloads of State IDD Agencies Who Live in the Home of a Family Member



**Table 1.3** Number of People with IDD Receiving Services While Living in the Home of a Family Member on June 30, 2012

State	People In Family Home	Estimated All People with IDD	% in Family Homes
<b>N States</b>	<b>49</b>	<b>51</b>	<b>49</b>
AL	1,895 <sup>e</sup>	6,495	29
AK	292	1,421	
AZ	27,983	32,573	86
AR	1,994	6,328	
CA	140,887	199,168	71
CO	5,807 <sup>e</sup>	11,857	
CT	1,381 <sup>*</sup>	8,599	16
DE	2,428	3,458	
DC	715	2,099	34
FL	37,082	62,118	
GA	5,495	11,414	48
HI	2,202	3,281	
ID	1,182	4,595	26
IL	DNF	30,173	
IN	6,888 <sup>e</sup>	18,284	38
IA	DNF <sup>*</sup>	14,838	
KS	2,811	9,045	31
KY	1,135 <sup>e</sup>	5,190	
LA	15,946	23,545	68
ME	1,563 <sup>e</sup>	5,261	
MD	2,215	10,385	21
MA	21,000 <sup>e</sup>	34,000	
MI	25,772	47,546	54
MN	10,332	25,586	
MS	1,087	4,396	25
MO	8,089	16,869	
MT	800 <sup>e*</sup>	2,803	29
NE	1,130	5,396	
NV	3,826	5,716	67
NH	924	2,749	
NJ	30,529	43,700	70
NM	651 <sup>ed</sup>	4,222	
NY	78,744 <sup>e</sup>	128,551	61
NC	13,765 <sup>e</sup>	26,727	
ND	1,225	3,356	37
OH	58,851	86,677	
OK	2,363	7,087	33
OR	10,479	17,520	
PA	29,009 <sup>e</sup>	57,309	51
RI	1,380	3,614	
SC	12,427	17,481	71
SD	1,161	3,822	
TN	2,928	9,219	32
TX	9,238	40,596	
UT	1,814 <sup>e</sup>	5,427	33
VT	1,725	3,442	
VA	1,445	11,023	13
WA	11,148 <sup>e</sup>	21,236	
WV	2,994	5,338	56
WI	11,524 <sup>e</sup>	24,324	
WY	744	2,262	33
<b>Reported Total</b>	<b>617,005</b>	<b>1,138,121</b>	<b>54</b>
<b>Est Total</b>	<b>634,988</b>	<b>1,138,121</b>	<b>56</b>

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix

**Home of a family member.** On June 30, 2012, an estimated 634,988 people with IDD (56%) known to or receiving services under the auspices of a state IDD agency were living in the home of a family member (see Table 1.3). Two states were not able to furnish the number people with IDD living in the home of a family member (Illinois and Iowa).

States reporting the largest number of people with IDD living in the home of a family member were California (140,887), New York (78,744), Ohio (58,851), Florida (37,082), and New Jersey (30,259). States reporting the fewest people with IDD living in the home of a family member were Montana (800), Wyoming (744), the District of Columbia (715), New Mexico (651), and Alaska (292).

States reporting the greatest proportion people with IDD in the homes of family members were Arizona (86%), South Carolina (71%), California (71%), Delaware (70%), and New Jersey (70%; See Figure 1.2). Hawaii, Louisiana, Massachusetts, Nevada, New York, and Ohio also reported more than 60% of the people known to or served under the auspices of the state IDD agency lived in the home of a family member. States reporting the smallest proportion of people living in the home of a family member were Nebraska (21%), Alaska (20%), Connecticut (16%), New Mexico (15%), and Virginia (13%).

**Host family or foster family.** On June 30, 2012 states reported that 58,753 people with IDD lived in 35,830 host family or family foster care settings (See Table 1.4). Overall, an estimated 93% of people with IDD living in host family or family foster care settings lived in homes serving 3 or fewer people, 7% in homes serving 4 to 6 people, and 0.1% (54 people) in settings with 7 to 15 people. An average of 1.6 people with IDD lived in each host home or family foster care settings (ranging from a high of 9.4 people in Kentucky to a low of 1.0 in Arkansas, Georgia, Iowa, Minnesota, North Dakota, Oklahoma, and Utah).

States with the largest number of host family/foster care residential settings were Illinois (7,372), Minnesota (1,438), Ohio (1,837), Wisconsin (1,626) and New York (1,287). States serving the greatest number of people with IDD in host family/foster care settings were Texas (9,738), Florida (7,254), Wisconsin (4,972), California (3,892 people), and Oregon (3,273).

Table 1.4 Host Family/Foster Care Setting and Residents by State and Setting Size on June 30, 2012

State/ Setting Size	Number of Host Family/Foster Care Settings					Number of Residents					People per site
	1-3	4-6	1-6	7-15	Total	1-3	4-6	1-6	7-15	Total	
<b>N States</b>	<b>39</b>	<b>42</b>	<b>41</b>	<b>48</b>	<b>40</b>	<b>44</b>	<b>44</b>	<b>49</b>	<b>49</b>	<b>51</b>	<b>37</b>
AL	57	0	57	0	57	166	0	166	0	166	2.9
AK	73 <sup>e</sup>	0	73 <sup>3e</sup>	0	73 <sup>e</sup>	218	0	218	0	218	3.0
AZ	969	0	969	0	969	1,281	0	1,281	0	1,281	1.3
AR	560	0	560	0	560	560	0	560	0	560	1.0
CA	DNF	0	0	0	DNF	3,892	0	3,892	0	3,892	DNF
CO	DNF	0 <sup>e</sup>	DNF	0 <sup>e</sup>	DNF	2,204 <sup>e</sup>	0 <sup>e</sup>	2,204 <sup>e</sup>	0 <sup>e</sup>	2,204 <sup>e</sup>	DNF
CT	296	1	297	1	298	445	6	451	7	458	1.5
DE	101	0	101	0	101	132	0	132	0	132	1.3
DC	56	0	56	0	56	81	0	81	0	81	1.4
FL	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	7,254	DNF
GA	1,043	0	1,043	0	1,043	1,044	0	1,044	0	1,044	1.0
HI	306	145	451	0	451	525 <sup>e</sup>	144	669	0	669	1.5
ID	378	162	540	0	540 <sup>e</sup>	531	1,163 <sup>e</sup>	1,694 <sup>e</sup>	0	1,694 <sup>e</sup>	3.1
IL	DNF	DNF	DNF	0	DNF	229	15	244	0	244	DNF
IN	148	1	149	0	149	203	4	207	0	207	1.4
IA	4	0	4	0	4	4	0	4	0	4	1.0
KS	DNF	0 <sup>e</sup>	DNF	0	DNF	82	0	82	0	82	DNF
KY	81 <sup>e</sup>	0	81 <sup>e</sup>	0	81 <sup>e</sup>	761 <sup>e</sup>	0	761 <sup>e</sup>	0	761 <sup>e</sup>	9.4
LA	0	0	0	0	0	0	0	0	0	0	DNF
ME	691	2 <sup>e</sup>	693 <sup>e</sup>	0	693 <sup>e</sup>	782 <sup>e</sup>	11 <sup>e</sup>	793 <sup>e</sup>	0	793 <sup>e</sup>	1.1
MD	197	0	197	0	197	208	0	208	0	208	1.1
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	2,807	DNF
MI	DNF	DNF	DNF	0	DNF	DNF	DNF	600	0	600	DNF
MN	DNF	DNF	1,438 <sup>e</sup>	0	1,438 <sup>e</sup>	DNF	DNF	1,438	0	1,438	1.0
MS	0	0	0	0	0	0	0	0	0	0	DNF
MO	14	0	14	0	14	20	0	20	0	20	1.4
MT	40 <sup>e</sup>	0	40	0	40	42 <sup>e</sup>	0 <sup>e</sup>	42 <sup>e</sup>	0	42 <sup>e</sup>	1.1
NE	485	0	485	0	485	574	0	574	0	574	1.2
NV	58	1	59	0	59	71	4	75	0	75	1.3
NH	815	1	816	1	817	923	4	927	6	933	1.1
NJ	500 <sup>e</sup>	0	500	0	500	999	0	999	0	999	2.0
NM	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	DNF
NY	1,073	214	1,287	0	1,287	1,618	689	2,307	0	2,307	1.8
NC	DNF	DNF	DNF	0	DNF	DNF	DNF	1,400	0	1,400 <sup>e</sup>	DNF
ND	20	0	20	0	20	20	0	20	0	20	1.0
OH	1,827	5	1,832	4	1,837	2,058	31	2,089	34	2,123	1.2
OK	407	0	407	0	407	407	0	407	0	407	1.0
OR	455	434	889	0	889	DNF	DNF	3,273	0	3,273	3.7
PA	1,237	0	1,237	0	1,237	1,590	0	1,590	0	1,590	1.3
RI	168	0	168	0	168	183	0	183	0	183	1.1
SC	128	0	128	0	128	160	0	160	0	160	1.3
SD	2	0	2	0	2	4	0	4	0	4	2.0
TN	267	0	267	0	267	338	0	338	0	338	1.3
TX	DNF	DNF	DNF	0	DNF	DNF	DNF	9,738	0	9,738	DNF
UT	268 <sup>e</sup>	0	268	0	268	269	0	269	0	269	1.0
VT	1,150	0	1,150	0	1,150	1,300	0	1,300	0	1,300	1.1
VA	DNF	DNF	DNF	0	DNF	782	19	801	0	801	DNF
WA	91	0	91	0	91	96	0	96	0	96	1.1
WV	DNF	DNF	DNF	DNF	DNF	156	0	156	0	156	DNF
WI	1,626 <sup>e</sup>	0	1,626	0	1,626	4,972	0	4,972	0	5,085	3.1
WY	DNF	0	DNF	0	DNF	63	0	63	0	63	DNF
<b>Reported US Total</b>	<b>15,591</b>	<b>966</b>	<b>17,995</b>	<b>6</b>	<b>18,002</b>	<b>29,993</b>	<b>2,090</b>	<b>48,532</b>	<b>47</b>	<b>58,753</b>	<b>3.3</b>
<b>Estimated US Total</b>	<b>34,504</b>	<b>1,326</b>	<b>35,830</b>	<b>7</b>	<b>35,839</b>	<b>54,755</b>	<b>3,831</b>	<b>58,586</b>	<b>54</b>	<b>58,753</b>	<b>1.6</b>

<sup>a</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish \* See state notes in Appendix

Table 1.5 State and Nonstate Group Settings and Residents by Residence Size on June 30, 2012

State	Number of Group Settings						Number of Residents					
	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total
<b>N States</b>	<b>37</b>	<b>37</b>	<b>36</b>	<b>38</b>	<b>41</b>	<b>36</b>	<b>41</b>	<b>38</b>	<b>43</b>	<b>42</b>	<b>44</b>	<b>42</b>
AL	724	92	816	77	0	893	2,110	527	2,637	816	0	3,453
AK	212	158	370	7	11	388	300	128	428	0	0	428
AZ	633	271	904	3	3	910	1,463	1,166	2,629	25	143	2,797
AR	84	13	97	98	26	221	111	53	164	867	1,504	2,535
CA	DNF	DNF	DNF	125	88	213	DNF	DNF	25,593	1,152	3,390	30,135
CO	DNF	20	DNF	33	2	DNF	2,118	110	2,228	207	296	2,731
CT	748	522	1,270	43	6	1,319	1,431	2,654	4,085	338	612	5,035
DE	135	120	255	4	2	261	283	474	757	23	66	846
DC	455	98	553	0	0	553	789	489	1,278	0	0	1,278
FL	DNF	DNF	DNF	DNF	DNF	DNF	696	6,343	7,039	1,642	2,764	11,445
GA	1,824	61	1,885	1	2	1,888	DNF	DNF	DNF	DNF	DNF	DNF
HI	0	58	58	1	0	59	0	227	227	7	0	234
ID	0	DNF	DNF	DNF	37	37	0	DNF	DNF	DNF	141	DNF
IL	DNF	DNF	DNF	DNF	DNF	DNF	403	4,366	4,769	8,202	5,223	18,194
IN	0	359	359	319	3	681	0	1,657	1,657	2,447	290	4,394
IA	6	117	123	92	24	239	18	467	485	920	1,431	2,836
KS	DNF	DNF	DNF	DNF	2	DNF	1,910	DNF	DNF	DNF	334	DNF
KY	128	11	144	3	4	151	2,372	103	2,475	6	279	2,760
LA	0	494	494	15	12	521	0	3,035	3,035	181	1,388	4,604
ME	686	174	860	11	DNF	DNF	1,304	775	2,079	116	117	2,312
MD	1,548	406	1,954	32	2	1,988	3,660	1,757	5,417	236	54	5,707
MA	DNF	DNF	DNF	DNF	5	DNF	DNF	DNF	7,809	799	580	9,188
MI	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MN	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MS	141	38	179	81	13	278	184	128	312	652	2,173	3,137
MO	181	235	416	124	12	552	468	1,156	1,624	1,108	623	3,355
MT	215	100	315	50	1	366	650	661	1,311	415	55	1,781
NE	646	137	783	16	5	804	904	658	1,562	121	380	2,063
NV	10	7	17	1	44	62	10	36	46	6	152	204
NH	168	14	182	2	1	186	227	62	289	12	25	326
NJ	1,050	1,038	2,088	DNF	DNF	DNF	2,100	4,167	6,267	1,437	3,240	10,944
NM	2,185	30	2,215	14	0	2,229	2,934	134	3,068	120	0	3,188
NY	1,848	2,312	4,160	2,029	78	6,267	3,348	11,697	15,045	18,822	2,623	36,490
NC	329	1,128	1,457	72	20	1,550	DNF	DNF	3,280	DNF	DNF	DNF
ND	0	45	45	64	2	111	0	241	241	520	124	885
OH	662	473	1,135	302	92	1,529	873	2,245	3,118	2,618	4,364	10,100
OK	0	226	226	58	22	306	0	752	752	574	1,009	2,335
OR	241	477	718	28	16	762	546	2,018	2,564	218	27	2,809
PA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
RI	81	208	289	23	3	315	162	949	1,111	166	54	1,331
SC	122	514	636	108	5	749	328	2,057	2,385	890	745	4,020
SD	502	81	583	61	2	646	747	404	1,151	585	199	1,935
TN	100	117	227	91	5	323	233	558	791	733	351	1,875
TX	DNF	DNF	DNF	49	22	DNF	DNF	DNF	11,283	555	4,361	16,199
UT	615	72	685	18	14	717	909	348	1,257	162	773	2,192
VT	37	20	57	0	0	57	47	90	137	0	0	137
VA	DNF	DNF	DNF	DNF	DNF	DNF	372	2,166	2,538	594	3,165	6,297
WA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WV	DNF	DNF	DNF	DNF	DNF	DNF	1,165	DNF	DNF	DNF	DNF	DNF
WI	0	506	506	4	8	518	0	2,465	2,465	28	867	3,360
WY	DNF	DNF	DNF	DNF	1	DNF	DNF	DNF	1,036	91	79	1,206
<b>Reported US Total</b>	<b>16,316</b>	<b>10,752</b>	<b>27,061</b>	<b>4,059</b>	<b>595</b>	<b>28,649</b>	<b>37,305</b>	<b>75,765</b>	<b>158,310</b>	<b>49,665</b>	<b>48,602</b>	<b>256,577</b>
<b>Estimated US Total</b>	<b>34,051</b>	<b>25,603</b>	<b>59,686</b>	<b>6,196</b>	<b>1,057</b>	<b>66,808</b>	<b>68,781</b>	<b>116,159</b>	<b>184,940</b>	<b>56,409</b>	<b>50,671</b>	<b>292,498</b>

<sup>o</sup>2011 data <sup>a</sup>Estimate <sup>DNF</sup>Did not furnish \* See state notes in Appendix

<sup>1</sup>This table includes ICF/IID, HCBS Waiver and other funded State and Nonstate IDD group settings of all sizes. Excludes people living with family members, in a host/foster setting, or home they own or lease. Also excluded are people living in nursing homes and psychiatric settings.



**Group IDD settings.** Group IDD settings included state and nonstate settings that were funded by ICF/IID, HCBS Waiver or other sources but do not include family homes, own home settings, host home/foster family settings, nursing homes or psychiatric facilities (See Table 1.5). (See Table 1.5)

An estimated 292,498 people with IDD lived in one of 66,808 group IDD settings (an average of 4.4 people with IDD per home). An estimated 34,051 settings were shared by three or fewer people with IDD, 25,603 were shared by four to six people, 6,196 were shared by seven to fifteen people, and 1,057 were shared by 16 or more people. Three states reported the number of people living in group IDD settings of 6 or fewer people but were not able to report separately on settings with 1 to 3 people versus settings with 4 to 6 people.

In all, 68,781 people with IDD lived in group IDD settings with three or fewer people, 116,159 lived with four to six people, 56,409 lived with 7 to 15 people, and 50,671 shared a large residential facility with 16 or more people with IDD. Of the people living in group IDD settings, 68,781 (24%) lived in individualized settings (shared by three or fewer people with IDD) while 223,239 people (76%) lived in congregate settings (shared by four or more people).

The size of group IDD settings varied by state. Overall, an estimated 64% of people in group IDD settings lived with six or fewer people ranging from a low of 6% in Arkansas to a high of 100% in Alaska, the District of Columbia, and Vermont. More than 95% of people in group IDD settings in Hawaii (97%) and New Mexico (96%) lived with six or fewer people



On average, 17% of group facility residents with IDD lived in settings with 16 or more residents. States with the highest proportion of people with IDD living in settings with 16 or more people were Arkansas (59%), Iowa (50%), Mississippi (69%), Nebraska (75%) and Virginia (50%). Six states reported not having any group facilities serving 16 or more people with IDD (Alabama, Alaska, the District of Columbia, Hawaii, New Mexico, and Vermont).

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*THE PROPORTION OF PEOPLE WITH IDD LIVING IN GROUP SETTINGS WHO LIVED IN SETTINGS OF 1 TO 6 PEOPLE VARIED ACROSS STATES FROM A LOW OF 6% IN ARKANSAS TO A HIGH OF 100% IN ALASKA, THE DISTRICT OF COLUMBIA, AND VERMONT.*

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## Persons Waiting for Residential Supports and Services

States reported the number of people with IDD who were on waiting lists for but not receiving residential services on June 30, 2012. Guidelines about who to count included:

- a.) The person must require residential services within the next 12 months
- b.) The person cannot already be living in a LTSS setting other than the home of a family member (i.e., do not count people living in IDD group homes who are waiting to move to another group home).
- c.) The person can be living in the home of a family member and be waiting for residential supports.
- d.) All people with IDD known to or receiving LTSS under the auspices of the state's IDD agency were considered. Some received no LTSS through the state IDD agency, some received only case management supports, and still others may have received LTSS supports funded by a Medicaid State Plan program such as personal care attendant services.

In FY 2012, 41 states that provided LTSS to 503,133 people with IDD reported the number of people waiting for services (see Table 1.6). Altogether 77,353 people with IDD were waiting for residential supports in the 41 states. Ten states reported that

**Table 1.6** Persons with IDD on a Waiting List For, But Not Receiving Residential Services on June 30, 2012

State	People with IDD on Waiting List	Estimated People in Non-Family Settings	% Growth Required to Serve those Waiting in Non-Family Settings
<b>N States</b>	<b>41</b>	<b>49</b>	<b>39</b>
AL	2,901 <sup>e</sup>	4,600	63.1
AK	461	1,129	40.8
AZ	79	4,590	1.7
AR	2,180	4,334	50.3
CA	0	58,281	0.0
CO	1,794	6,050	29.7
CT	612 <sup>+</sup>	7,218	8.5
DE	17	1,030	1.7
DC	0	1,384	0.0
FL	4,311 <sup>e</sup>	25,036	17.2
GA	2,735	5,919	46.2
HI	0	1,079	0.0
ID	0	3,413	0.0
IL	12,076 <sup>+</sup>	DNF	DNF
IN	DNF	11,396	DNF
IA	0	DNF	DNF
KS	DNF	5,857	DNF
KY	802 <sup>+</sup>	4,055	19.8
LA	DNF	7,599	DNF
ME	85 <sup>e</sup>	3,698	2.3
MD	4,065	8,170	49.8
MA	DNF	13,000	DNF
MI	DNF	21,774	DNF
MN	2,718 <sup>+</sup>	15,254	17.8
MS	DNF	3,309	DNF
MO	200	8,780	2.3
MT	635	2,003	31.7
NE	1,875	4,266	44.0
NV	188	1,890	9.9
NH	49	1,825	2.7
NJ	DNF	13,171	DNF
NM	4,998 <sup>de</sup>	3,571	140.0
NY	6,971	49,807	14.0
NC	8,425 <sup>e</sup>	12,962	65.0
ND	0	2,131	0.0
OH	DNF	27,826	DNF
OK	6,808	4,724	144.1
OR	0	7,041	0.0
PA	1,979	28,300	7.0
RI	0	2,234	0.0
SC	295	5,054	5.8
SD	0	2,661	0.0
TN	1,654	6,291	26.3
TX	DNF	31,358	DNF
UT	1,834	3,613	50.8
VT	0	1,717	0.0
VA	4,649	9,578	48.5
WA	DNF	10,088	DNF
WV	646	2,344	27.6
WI	924 <sup>+</sup>	12,800	7.2
WY	387	1,518	25.5
<b>Reported Total</b>	<b>77,353</b>	<b>480,751</b>	<b>16.1</b>
<b>Est US total</b>	<b>110,039</b>	<b>503,133</b>	<b>21.9</b>

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>+</sup> See state notes in Appendix

they did not keep waiting lists or that they had no people waiting for residential services as of June 30, 2012 (California, District of Columbia, Hawaii, Idaho, Iowa, North Dakota, Oregon, Rhode Island, South Dakota, and Vermont). Including estimates for states that did not report waiting list information, we estimate a national total of 110,039 people with IDD were waiting for residential services on June 30, 2012. States with the largest waiting lists numerically were Illinois (12,076), North Carolina (8,425), New York (6,971), Oklahoma (6,808), New Mexico (4,998), Virginia (4,649), Florida (4,311), and Maryland (4,065).

The total number of people waiting for residential services in 2012 (110,039) was higher than in 2011 (95,934) but lower than in 2008 through 2010 (when the waiting list ranged from 114,916 to 123,249; See Figure 1.3).

The number of people waiting for supports was compared to the number of people with IDD receiving Medicaid-funded supports in non-family settings on June 30, 2012 to estimate the amount of growth required to provide non-family residential services to all people with IDD on waiting lists for residential services. To serve all of the people waiting for residential supports in non-family settings, states would have to expand the capacity of non-family residential supports by 30%. States that would have to increase their capacity proportionately the most to meet the identified need were Oklahoma (the current system would have to grow by 144%), New Mexico (140%), Alabama (63%) and Arkansas (50%).

### Ages of ICF/IID and HCBS Waiver Recipients with IDD

The FY 2012 survey asked about the number of people 21 years old or younger or 22 years or older receiving Medicaid ICF/IID or HCBS Waiver funded services. For HCBS Waiver recipients the survey also asked for the ages for those who lived in the home of a family member versus those who lived in any other setting. As anticipated based on pilot work done by NASDDDS, only 24 states reported complete age information for FY 2012.

**Age of ICF/IID residents.** A total of 45 states and the District of Columbia reported the ages of 77,049 (90%) of the estimated 85,384 total people living in ICF/IID settings on June 30, 2012 (see Table 1.7 and Figure 1.4). Michigan and Oregon reported having no ICF/IID facilities. An estimated 5,011 ICF/IID residents

(7%) were 21 years old or younger, and 72,038 (93%) were 22 years or older. The number of people living in ICF/IID settings ages birth to 21 years ranged from 0 in Delaware, Hawaii, Montana, New Jersey, Rhode Island, Tennessee, Vermont and Wisconsin to 731 in Indiana and New York. Other states with more than 100 people 21 years or younger living in an ICF/IID included California, Florida, Iowa, Louisiana, North Carolina, Ohio, Oklahoma, Pennsylvania, and Texas. In New Hampshire all 25 ICF/IID residents were 21 years old or younger, and in Alaska 10 of 17 (59%) were 21 years old or younger (all lived in out-of-state facilities).

**Age of HCBS Waiver Recipients.** A total of 38 states and the District of Columbia reported the ages of 545,726 (80%) HCBS waiver recipients with IDD. Of those, 142,958 (26%) were 21 years or younger and 402,768 (74%) were 22 years or older. The number of people 21 years or younger who were HCBS Waiver recipients ranged from 13 in the District of Columbia, and 124 in Maine, to 41,625 in California. Other states with 6,000 or more people 21 years old or younger receiving HCBS Waiver funded supports were Arizona (15,583), New York (20,887), Ohio (5,899) and Texas (5,735). The proportion who were 21 years old or younger ranged from less than 6% in

the District of Columbia, Illinois, Maine, Maryland, and Tennessee to 55% in Alaska and 63% in Arizona.

**Place of Residence for HCBS Waiver Recipients by Age.** Thirty states and the District of Columbia reported both age and residence type for 470,538 HCBS Waiver recipients with IDD. Six states reported the number of HCBS Waiver Recipients by age but could not report on the places people 22 years or older lived and eight states could not report on the places people 21 years old or younger lived. Massachusetts reported no people 21 years old or younger living in the home of a family member received HCBS funded services, and New Hampshire reported no people 21 years old or younger receiving HCBS funded services lived in settings other than the home of a family member.

Of the 470,538 HCBS Waiver recipients whose age was reported, 115,394 (25%) were 21 years or younger living in the home of a family member, 143,623 (31%) were 22 years or older living in the home of a family member, 14,586 (3%) were 21 years or younger living in a non-family setting, and 196,935 (42%) were 22 years or older living in a non-family setting (See [Figure 1.4](#)).

**Figure 1.3** Change in People with IDD on a Waiting List For, But Not Receiving Residential Services 1999 through 2012

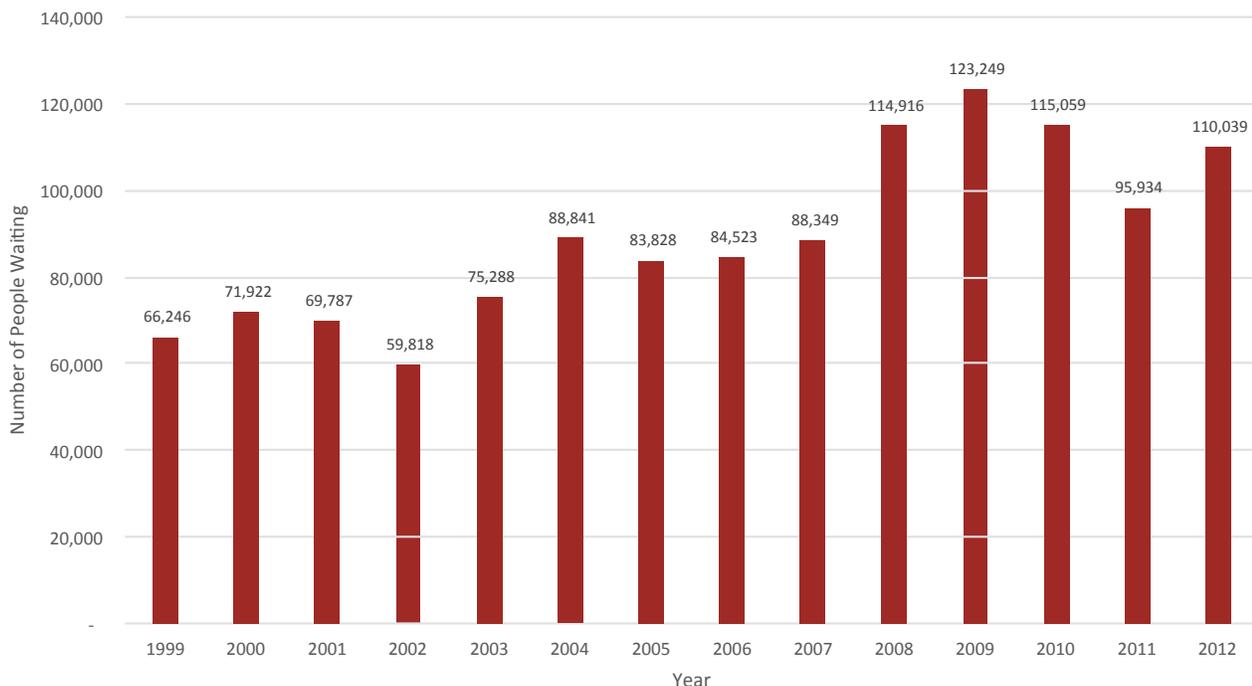


Table 1.7 Ages of HCBS Waiver and ICF/IID Recipients by Setting Type and State for FY 2012

State	HCBS Waiver Recipients						ICF/IID Residents		All HCBS plus ICF/IID recipients	
	Family Home		Non-Family		Total HCBS		Birth to 21 years	22 years or older	Birth to 21 years	22 years or older
	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older				
<b>N states</b>	<b>33</b>	<b>31</b>	<b>33</b>	<b>31</b>	<b>39</b>	<b>39</b>	<b>46</b>	<b>46</b>	<b>36</b>	<b>36</b>
AL	DNF	DNF	DNF	DNF	DNF	DNF	1	40	DNF	DNF
AK	247 <sup>e</sup>	45	563	627	810	672	10*	7	820	679
AZ	14,958	5,387	625	3,647	15,583	9,034	3	134	15,586	9,168
AR	DNF	DNF	DNF	DNF	1,073	2,964	DNF	DNF	DNF	DNF
CA	39,482	26,432	2,143	29,811	41,625	56,243	145	6,660	41,770	62,903
CO	540	2,356	146	5,105	686	7,461	4	182	690	7,643
CT	395	807	95	5,094	490	5,901	4	989	494	6,890
DE	DNF	DNF	DNF	DNF	DNF	DNF	0	65	DNF	DNF
DC	6	502	6	965	12	1,467	1	362	13	1,829
FL	4,759	11,151	1,010	11,698	5,769	22,849	129	2,677	5,898	25,526
GA	812	10,544	30*	218	842	10,762	30	218	872	10,980
HI	579	923	16	1,026	595	1,949	0	79	595	2,028
ID	182 <sup>e</sup>	1,000 <sup>e</sup>	218 <sup>e</sup>	1,260 <sup>e</sup>	400 <sup>e</sup>	2,260 <sup>e</sup>	92	476	492	2,736
IL	1,287	DNF	245	DNF	1,532	16,823*	17	8,327	1,549	25,150
IN	2,086 <sup>e</sup>	4,802 <sup>e</sup>	232 <sup>e</sup>	5,666 <sup>e</sup>	2,318 <sup>e</sup>	10,468 <sup>e</sup>	731	3,108	3,049	13,576
IA	DNF	DNF	DNF	DNF	3,279	8,080	299	1,717	3,578	9,797
KS	DNF	DNF	DNF	DNF	1,018	6,777	DNF	DNF	DNF	DNF
KY	DNF	DNF	DNF	DNF	DNF	DNF	24	499 <sup>e</sup>	DNF	DNF
LA	2,981	6,822	0	154 <sup>e</sup>	2,981	6,976 <sup>e</sup>	556	4,048	3,537	11,024
ME	61 <sup>e</sup>	1,068 <sup>e</sup>	63 <sup>e</sup>	2,909 <sup>e</sup>	124 <sup>e</sup>	3,977 <sup>e</sup>	5 <sup>e</sup>	197 <sup>e</sup>	129	4,174
MD	60	110	190	7,887	250	7,997	2	52	252	8,049
MA	0 <sup>e</sup>	DNF	157	DNF	157*	11,830	DNF	DNF	DNF	DNF
MI	DNF	DNF	DNF	DNF	DNF	DNF	N/A	N/A	DNF	DNF
MN	3,410	3,220	699	10,623	4,109	13,843	88	1,543	4,197	15,386
MS	DNF	DNF	DNF	DNF	DNF	DNF	93 <sup>e</sup>	1,319 <sup>e</sup>	DNF	DNF
MO	1,200	3,353	478	6,010	1,678	9,363	1	589	1,679	9,952
MT	620	180	415	1,453	1,035	1,633	0	55	1,035	1,688
NE	DNF	DNF	DNF	DNF	DNF	DNF	30	388	DNF	DNF
NV	50	404	119	1,079	169	1,483	7	97	176	1,580
NH	300	624	0	1,888	300*	2,512*	25	0	325	2,512
NJ	DNF	DNF	DNF	DNF	DNF	DNF	0	2,333 <sup>e</sup>	DNF	DNF
NM	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	19,907	21,126	980	29,999	20,887	51,125	731	6,522	21,618	57,647
NC	DNF	DNF	DNF	DNF	5,429	7,371	338	3,592 <sup>e</sup>	5,767	10,963
ND	1,067	158	57	1,415	1,124	1,573	96	463	1,220	2,036
OH	5,313	11,363	586	13,610	5,899	24,973	432	6,544	6,331	31,517
OK	506	1,857	259	2,601	765	4,458	129	1,592	894	6,050
OR	3,584	6,895	1,540	5,334	5,124	12,229	N/A*	N/A	5,124	12,229
PA	DNF	DNF	DNF	DNF	DNF	DNF	129	3,290	DNF	DNF
RI	DNF	DNF	DNF	DNF	DNF	DNF	0	21	DNF	DNF
SC	DNF	DNF	DNF	DNF	1,407	6,987	53 <sup>e</sup>	1,260 <sup>e</sup>	1,460	8,247
SD	727	396	133	1,959	860	2,355	89	110	949	2,465
TN	228	1,896	169 <sup>e</sup>	5,387 <sup>e</sup>	397 <sup>e</sup>	7,283 <sup>e</sup>	0	1,077	397	8,360
TX	3,363	5,875	2,372	17,583	5,735	23,458	543 <sup>e</sup>	8,608 <sup>e</sup>	6,278	32,066
UT	646	1,047	538	2,088	1,184	3,135	68	733	1,252	3,868
VT	DNF	DNF	DNF	DNF	DNF	DNF	0	6	DNF	DNF
VA	DNF <sup>e</sup>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	1,284	3,566	311	6,737	1,595	10,303	17	612	1,612	10,915
WV	1,423	1,521	62	1,359	1,485	2,880	88	474	1,573	3,354
WI	3,331	8,193 <sup>e</sup>	129	11,743 <sup>e</sup>	3,460	19,936 <sup>e*</sup>	0	895 <sup>e</sup>	3,460	20,831
WY	DNF	DNF	DNF	DNF	772	1,378	1	78	773	1,456
<b>Reported Total</b>	<b>115,394</b>	<b>143,623</b>	<b>14,586</b>	<b>196,935</b>	<b>142,958</b>	<b>402,768</b>	<b>5,011</b>	<b>72,038</b>	<b>145,444</b>	<b>445,274</b>

Note: This table includes only people for whom age and residence type are known. Age was not reported for 134,885 HCBS recipients (20%) or for 8,335 ICF/IID residents (10%).

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix

The proportion of HCBS waiver recipients living in the home of a family member who were 21 years or younger ranged from a low of 1% in the District of Columbia, to a high of 87% in North Dakota. Other states in which fewer than 10% of HCBS Waiver recipients living in the home of a family member were 21 years or younger included Georgia (7%) and Maine (5%). Other states in which more than 50% of HCBS Waiver recipients living in the home of a family member were 21 years or younger included: Alaska (85%), Arizona (74%), California (60%), Minnesota (51%), Montana (78%) and South Dakota (65%).

*OVERALL 45% OF ALL HCBS WAIVER RECIPIENTS LIVING IN THE HOME OF A FAMILY MEMBER AND 7% OF ALL HCBS WAIVER RECIPIENTS WHO LIVED IN A SETTING OTHER THAN THE HOME OF A FAMILY MEMBER WERE 21 YEARS OR YOUNGER.*

The proportion of HCBS Waiver recipients living in settings other than the home of a family member ages birth to 21 years ranged from a low of 0% in Louisiana and New Hampshire, to more than 10% in Alaska (47%), Montana (22%), Oregon (22%), Idaho

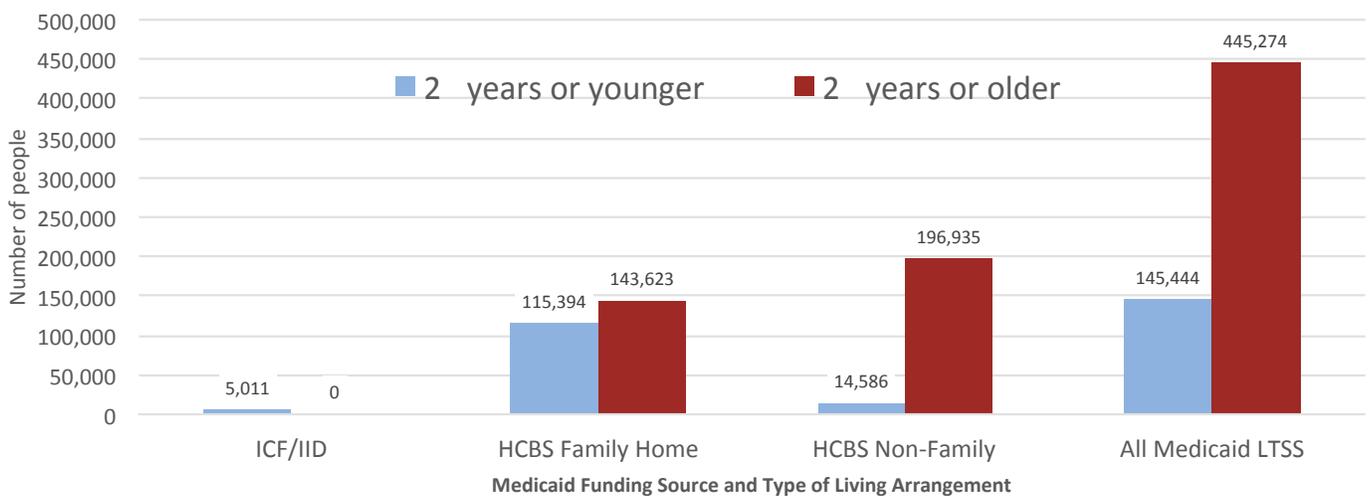
(15%), Georgia (12%), Texas (12%), and Utah (20%). In all of the reporting states the majority of HCBS Waiver recipients living in non-family settings were people 22 years or older.

### Discussion

Of the 590,718 Medicaid LTSS recipients in 39 reporting states, 25% were 21 years old or younger. However, only 7% of ICF/IID residents were 21 years old or younger compared with 26% of HCBS Waiver recipients. HCBS Waiver recipients who were 21 years old or younger were much more likely to live in the home of a family member than were people 22 years or older (80% compared with 35%). As we will see in the next section, HCBS Waiver expenditures are heavily influenced by both age and living arrangement.

US estimated totals for recipients and expenditures by age and living arrangement were not reported on [Table 1.7](#) because too few states were able to report all of the component information. [Figure 1.4](#) only includes 31 states. The FY 2012 results should be considered preliminary and exploratory. The information is helpful because it was not available previously, but should be used with caution for making policy decisions until a higher proportion of states are able to respond.

**Figure 1.4** Residence Type for Medicaid HCBS Waiver Funded LTSS Recipients and ICF/IID Residents by Age (21 Years or Younger versus 22 years or older) on June 30, 2012 (31 States)



## Expenditures for HCBS Waiver Recipients by Age and Setting Type

The final set of age questions on the FY 2012 survey asked states for total expenditures (federal plus state) for HCBS Waiver Recipients with IDD by age and setting type (See [Table 1.8](#)). Analyses of expenditures by setting type can be found later in the report. Here we only include those states that reported expenditures by both age and setting type.

### HCBS Waiver Expenditures by Recipient Age.

In 31 reporting states, 13% of all HCBS Waiver expenditures were people 21 years or younger and 87% of expenditures were for people 22 years old or older. The proportion spent on people 21 years old or younger ranged from 5% or less in Georgia (5%), Colorado (4%), Tennessee (4%), the District of Columbia (3%), and New Hampshire (2%) to more than 20% in Arizona (36%), North Carolina (35%), Montana (25%), Arkansas (29%), and Hawaii (23%).

### HCBS Waiver Expenditures by Recipient Age and Living Arrangement.

In 24 reporting states, 69% of HCBS Waiver expenditures were for people 22 years or older living in settings other than the home of a family member, 19% were for people 22 years or older living in the home of a family member, 9% were for people 21 years old or younger living in the home of a family member, and 5% were for people 21 years old or younger living in a setting other than the home of a family member. Twenty-two states spent the largest amount on people 22 years or older living in non-family settings (ranging from 41% in Hawaii to 88% in California). Two states reported spending the largest proportion of HCBS Waiver dollars on people 22 years or older living in the home of a family member (Georgia, 94%; and Louisiana, 85%).

The only state to spend more than 25% of their HCBS Waiver dollars on people 21 years old or younger living in the home of a family member was Arizona (30%). Other states with more than 20% of their HCBS Waiver expenditures for people 21 years old or younger living in the home of a family member were Georgia (22%) and Hawaii (22%). States spending more than 10% of their total HCBS Waiver dollars on people 21 years old or younger living in a setting other than the home of a family member were Arkansas (25%), Montana (18%), Oregon (16%) and Utah (12%).

## Annual per Person HCBS Waiver Expenditures for People with IDD by Age and Living Arrangement.

In 24 reporting states, the average annual per recipient HCBS Waiver expenditures for people with IDD were as follows: people 21 years old or younger living in the home of a family member \$17,671, people 21 years old or younger living in a setting other than the home of a family member \$54,988, people 22 years or older living in the home of a family member \$49,466, and people 22 years or older living in a setting other than the home of a family member \$65,125 (See [Figure 1.5](#)). Regardless of age, annual per person expenditures were higher for people with IDD living in a setting other than the home of a family member than for those living with a family member. Across setting types, annual per person HCBS Waiver expenditures were higher for people 22 years or older than for people 21 years old or younger.

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*THE ONLY STATE TO SPEND MORE THAN 25% OF THEIR HCBS WAIVER DOLLARS ON CHILDREN LIVING IN THE HOME OF A FAMILY MEMBER WAS ARIZONA (30%). OTHER STATES WITH MORE THAN 20% OF THEIR HCBS WAIVER EXPENDITURES FOR CHILDREN LIVING IN THE HOME OF A FAMILY MEMBER WERE GEORGIA (22%) AND HAWAII (22%).*

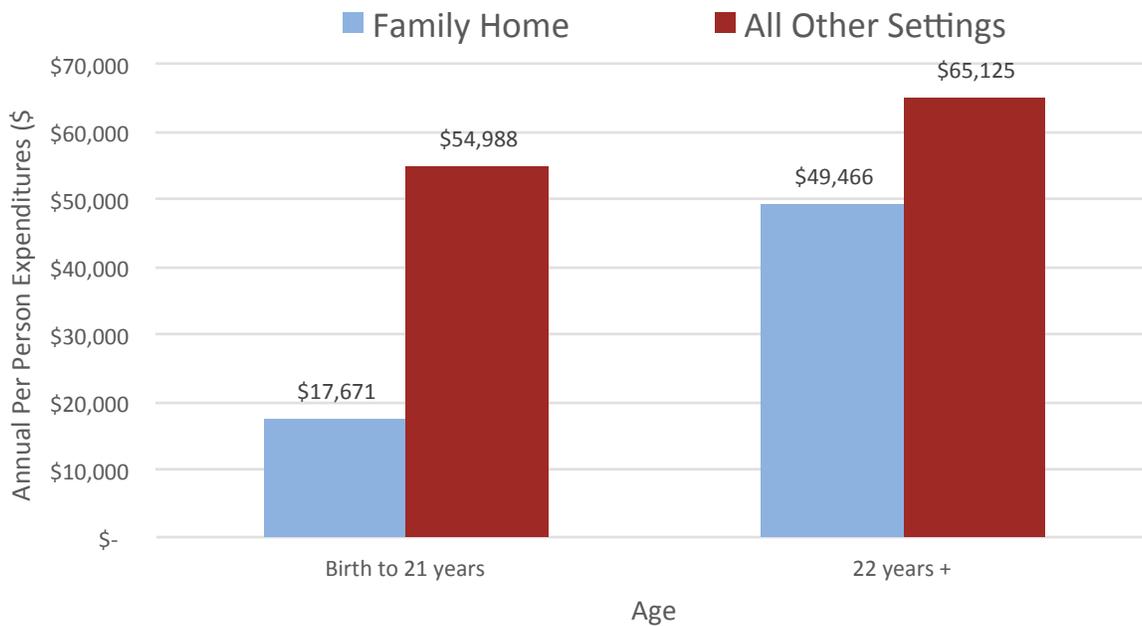
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Average annual per recipient HCBS Waiver expenditures were higher for people 22 years or older than for people 21 years old or younger in all of the reporting states except for the District of Columbia and Connecticut which reported spending the same per person regardless of age or living arrangement (See [Table 1.8](#)).

### Discussion on HCBS Waiver Expenditures by Age and Setting Type.

There was considerable variation in HCBS Waiver Expenditures by state, age and setting type. Not enough states responded to the age and setting type questions to make US estimates for total expenditures by age and living arrangement for FY 2012. The reporting states had higher per person expenditures for people 22 years or older than for people 21 years old or younger and lower per person expenditures for people with IDD living in the home

**Figure 1.5** Average Annual Per Person Medicaid HCBS Waiver Expenditures by Age and Setting Type FY 2012 (24 States)



of a family member than for people with IDD living in any other setting type. These age and setting variations must be taken into account as states develop statistical models for the purpose of making HCBS Waiver allocations. Other factors not measured in this study that may also contribute to differences in HCBS expenditures may include individual characteristics such as level and type of disability and support intensity as well as differences due to policy regarding the types or amounts of service available to different subgroups of participants. See Section 4 of this report for overall average annual per recipient HCBS Waiver expenditures by state, and for US estimated totals.

**Utilization of HCBS Waiver and ICF/IID LTSS by Age per 100,000 of the Population.** In 39 states that reported the ages of HCBS Waiver recipients, there were 181 HCBS recipients with IDD per 100,000 of the US population ages birth to 21 years, and 223 per 100,000 of the US population ages 22 years and older. States with the highest utilization rate for HCBS Waiver services for people 21 years old or younger were Arkansas (152), Montana (134), North Dakota (272), South Dakota (135) and Wyoming (273).

In the 46 states that reported ages of ICF/IID residents, there were 6 ICF/IID residents per 100,000 of the population 21 years or younger, and 35 ICF/

IID residents 22 years and older per 100,000 of the population. States with the highest utilization rates for ICF/IID services for people 21 years old or younger were Indiana (37), Iowa (33), Louisiana (40), North Dakota (47), and South Dakota (35). States with the highest utilization rates for ICF/IID services for people 22 years or older were Illinois (91), Iowa (79), Louisiana (126), North Dakota (93) and Ohio (70).

Overall, in the 36 reporting states the combined utilization rate for HCBS Waiver and ICF/IID services was 187 per 100,000 for people 21 years old or younger and 256 per 100,000 for people 22 years or older. States with the highest combined utilization of HCBS Waiver and ICF/IID per 100,000 for people 21 years old or younger were Arkansas (157), Montana (134), North Dakota (320), South Dakota (171), and Wyoming (274). States with the highest combined utilization of HCBS Waiver and ICF/IID per 100,000 for people 22 years or older were the District of Columbia (141), Iowa (96), Louisiana (133), North Dakota (157) and Wyoming (102).

**Discussion of HCBS Waiver and ICF/IID Utilization per 100,000 of the Population by Age.** The utilization per 100,000 of the population for both HCBS Waiver services and ICF/IID services was higher for people 22 years or older than for people 21 years old or younger. The proportional difference

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OVERALL, IN THE 36 REPORTING STATES THE COMBINED UTILIZATION RATE FOR HCBS WAIVER AND ICF/IID SERVICES WAS 187 PER 100,000 FOR PEOPLE 21 YEARS OLD OR YOUNGER AND 256 PER 100,000 FOR PEOPLE 22 YEARS OR OLDER. STATES WITH THE HIGHEST COMBINED UTILIZATION OF HCBS WAIVER AND ICF/IID PER 100,000 FOR PEOPLE 21 YEARS OLD OR YOUNGER WERE ARKANSAS (157), MONTANA (134), NORTH DAKOTA (320), SOUTH DAKOTA (171), AND WYOMING (274). STATES WITH THE HIGHEST COMBINED UTILIZATION OF HCBS WAIVER AND ICF/IID PER 100,000 FOR PEOPLE 22 YEARS OR OLDER WERE THE DISTRICT OF COLUMBIA (141), IOWA (96), LOUISIANA (133), NORTH DAKOTA (157) AND WYOMING (102)

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in utilization for people 21 years old or younger compared with people 22 years or older was smaller for HCBS Waiver services (19%) than for ICF/IID

services (84%). The advantage of looking at utilization as referenced to the population as a whole is that it allows a more direct comparison of states of different sizes. The utilization rates reported on [Table 1.9](#) only include states that provided information by age and therefore may be different than the rates would be if they were calculated based on all states. In future years, we expect to have a clearer picture of national utilization. Overall utilization rates for HCBS Waiver and ICF/IID services can be found in Section 3 of this report.

### State Profiles for LTSS Provided in Individualized Settings

The companion report to this one, the FY 2012 FISP report <https://fisp.umn.edu/>, includes state profiles focusing on the provision of individualized services (LTSS provided in a person's own home, family home, host or foster family home, and provider owned settings with 3 or fewer people with IDD), comparing differences in Medicaid LTSS for people 21 years old or younger and people 22 years or older, and for HCBS Waiver Services provided in the home of a family member compared with LTSS provided in any other type of setting.



Table 1.8 Total Annual and Per Person HCBS Waiver Expenditures Reported by Age and Family Home Versus Other Settings FY 2012<sup>1</sup>

State	Total Annual HCBS Waiver Expenditures (\$)						Annual Per Person HCBS Waiver Expenditures (\$)					
	Family Home		All Other		HCBS Waiver Total		Family Home		All Other		HCBS Waiver Total	
	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older
<b>N States</b>	<b>26</b>	<b>23</b>	<b>26</b>	<b>23</b>	<b>31</b>	<b>31</b>	<b>27</b>	<b>23</b>	<b>26</b>	<b>24</b>	<b>31</b>	<b>31</b>
<b>AL</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>AK</b>	3,212,032 <sup>e</sup>	784,401	18,950,931	52,267,022	22,162,963	53,051,422	13,004	17,431	33,661	83,360	27,362	78,946
<b>AZ</b>	189,098,944	137,128,158	41,058,299	273,499,896	230,157,243	410,628,054	12,642	25,455	65,693	74,993	14,770	45,454
<b>AR</b>	DNF	DNF	DNF	DNF	35,850,171	137,284,356	DNF	DNF	DNF	DNF	33,411	46,317
<b>CA</b>	297,443,758	401,188,723	80,936,599	1,327,920,085	378,380,357	1,729,108,808	7,534	15,178	37,768	44,545	9,090	30,744
<b>CO</b>	8,698,697	25,759,689	5,201,035	291,350,254	13,899,732	317,109,943	16,109	10,934	35,624	57,072	20,262	42,502
<b>CT</b>	32,964,430 <sup>*</sup>	67,347,583 <sup>*</sup>	7,928,154 <sup>*</sup>	425,115,969 <sup>*</sup>	40,892,584 <sup>*</sup>	492,463,552 <sup>*</sup>	83,454	83,454	83,454	83,454	83,454	83,454
<b>DE</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>DC</b>	1,014,516	19,331,328	3,697,319	123,152,981	4,711,835	142,484,309	169,086	38,509	616,220	127,620	392,653	97,126
<b>FL</b>	45,075,346	213,492,176	62,217,031	533,594,795	107,292,377	747,086,971	9,472	19,146	61,601	45,614	18,598	32,697
<b>GA</b>	19,456,644	381,521,517	708,573	5,148,962 <sup>*</sup>	20,165,217	386,670,479	23,961	36,184	23,619	23,619	23,949	35,929
<b>HI</b>	23,032,620	37,526,411	636,480	41,714,082	23,669,100	79,240,493	39,780	40,657	39,780	40,657	39,780	40,657
<b>ID</b>	2,371,704 <sup>e</sup>	12,902,160 <sup>e</sup>	2,844,271 <sup>e</sup>	15,724,776 <sup>e</sup>	5,215,975 <sup>e</sup>	28,626,936 <sup>e</sup>	13,031	12,902	13,047	12,480	13,040	12,667
<b>IL</b>	17,339,171	DNF	21,774,000	DNF	39,113,171	552,346,871 <sup>e</sup>	13,473	DNF	88,873	DNF	25,531	32,833
<b>IN</b>	29,090,182	75,987,886	13,410,588	371,481,905	42,500,770	447,469,791	13,945	15,824	57,804	65,563	18,335	42,746
<b>IA</b>	DNF	DNF	DNF	DNF	68,124,305	319,455,540	DNF	DNF	DNF	DNF	20,776	39,537
<b>KS</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>KY</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>LA</b>	57,199,881	347,048,740	0	2,999,264 <sup>e</sup>	57,199,881	350,048,004 <sup>e</sup>	19,188	50,872	N/A	19,476	19,188	50,179
<b>ME</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>MD</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>MA</b>	DNF	DNF	DNF	DNF	DNF	DNF	N/A	DNF	DNF	DNF	DNF	DNF
<b>MI</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>MN</b>	131,130,871	140,883,919	60,536,733	844,470,333 <sup>*</sup>	191,667,604	985,354,253 <sup>*</sup>	38,455	43,753	86,605	79,495	46,646	71,181
<b>MS</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>MO</b>	13,107,642	54,500,996	49,906,161	416,452,037	63,013,803	470,953,033	10,923	16,254	104,406	69,293	37,553	50,299
<b>MT</b>	6,200,000 <sup>e</sup>	1,800,000 <sup>e</sup>	16,600,000 <sup>e</sup>	66,271,419 <sup>e</sup>	22,800,000 <sup>e</sup>	68,071,419 <sup>e</sup>	10,000	10,000	40,000	45,610	22,029	41,685
<b>NE</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>NV</b>	2,386,870 <sup>e</sup>	19,190,433 <sup>e</sup>	5,680,750 <sup>e</sup>	51,508,650 <sup>e</sup>	8,067,620 <sup>e</sup>	70,699,083 <sup>e</sup>	47,737	47,501	47,737	47,737	47,737	47,673

Table 1.8 Total Annual and Per Person HCBS Waiver Expenditures Reported by Age and Family Home Versus Other Settings FY 2012<sup>1</sup>

State	Total Annual HCBS Waiver Expenditures (\$)						Annual Per Person HCBS Waiver Expenditures (\$)					
	Family Home		All Other		HCBS Waiver Total		Family Home		All Other		HCBS Waiver Total	
	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older	Birth to 21 years	22 years or older
<b>N States</b>	<b>26</b>	<b>23</b>	<b>26</b>	<b>23</b>	<b>31</b>	<b>31</b>	<b>27</b>	<b>23</b>	<b>26</b>	<b>24</b>	<b>31</b>	<b>31</b>
<b>NH</b>	4,762,828	DNF	0	DNF	4,762,828	187,261,873	15,876	DNF	N/A	N/A	15,876	74,547
<b>NJ</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>NM</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>NY</b>	289,203,580	644,834,478	98,840,505	3,693,285,082	388,044,085	4,338,119,560	14,528	30,523	100,858	123,114	18,578	84,853
<b>NC</b>	DNF	DNF	DNF	DNF	218,351,070	401,454,234	DNF	DNF	DNF	DNF	40,219	54,464
<b>ND</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>OH</b>	88,157,578	261,238,847	31,692,371	851,170,358	119,849,949	1,112,409,205	16,593	22,990	54,083	62,540	20,317	44,544
<b>OK</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>OR</b>	13,477,367	58,817,177	88,613,211	378,379,455	102,090,577	437,196,633	3,760	8,530	57,541	70,937	19,924	35,751
<b>PA</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>RI</b>	DNF	DNF	DNF <sup>0</sup>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>SC</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>SD</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>TN</b>	9,120,000 <sup>e</sup>	86,558,471 <sup>e</sup>	16,543,538 <sup>e</sup>	491,876,196 <sup>e</sup>	25,663,538 <sup>e</sup>	578,434,667 <sup>e</sup>	40,000	45,653	97,891	91,308	64,644	79,423
<b>TX</b>	103,793,250	135,538,903	90,144,476	729,350,757	193,937,726	864,889,660	30,863	23,070	38,004	41,480	33,817	36,870
<b>UT</b>	7,574,234	17,596,082	18,195,618	112,148,794	25,769,852	129,744,876	11,725	16,806	33,821	53,711	21,765	41,386
<b>VT</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>VA</b>	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
<b>WA</b>	26,273,620 <sup>e</sup>	78,310,421 <sup>e</sup>	23,599,451 <sup>e</sup>	422,712,062 <sup>e</sup>	49,873,071 <sup>e</sup>	501,022,483 <sup>e</sup>	20,462	21,960	75,882	62,745	31,268	48,629
<b>WV</b>	DNF	DNF	DNF	DNF	55,081,512	248,780,069	DNF	DNF	DNF	DNF	37,092	86,382
<b>WI</b>	37,141,901	DNF	6,141,299	DNF	43,283,200	812,090,808	11,150	DNF	47,607	DNF	12,510	40,735
<b>WY</b>	DNF	DNF	DNF	DNF	13,640,845	84,855,661	DNF	DNF	DNF	DNF	17,669	61,579

<sup>0</sup> 2011 data <sup>e</sup> Estimate DNF Did not furnish \* See state notes in the Appendix 1The HCBS Waiver totals columns include data from states that could not provide breakdowns by type of residence. Use this table only for expenditures by age and setting analyses.

Table 1.9 Adults and Children Receiving Medicaid HCBS Waiver or ICF/IID services by Age per 100,000 of the US population on June 30, 2012<sup>1</sup>

State	State Population by Age in 100,000s		HCBS Waiver Recipient per 100,000		ICF/IID Residents per 100,000		HCBS Waiver + ICF/IID Recipients per 100,000	
	Birth to 21 years	22+ years	Birth to 21 years	22+ years	Birth to 21 years	22+ years	Birth to 21 years	22+ years
<b>N States</b>	<b>51</b>	<b>51</b>	<b>39</b>	<b>39</b>	<b>46</b>	<b>46</b>	<b>36</b>	<b>36</b>
AL	14.0	34.2	DNF	DNF	0.1	1.2	DNF	DNF
AK	2.3	5.0	152.2	26.8	4.3	1.4	156.5	28.2
AZ	19.9	45.6	39.4	4.3	0.2	2.9	39.5	7.3
AR	8.7	20.8	14.1	6.9	DNF	DNF	DNF	DNF
CA	115.1	265.3	3.1	0.8	1.3	25.1	4.4	25.9
CO	15.2	36.7	3.0	5.5	0.3	5.0	3.2	10.5
CT	9.9	26.0	5.0	8.7	0.4	38.1	5.4	46.8
DE	2.6	6.6	DNF	DNF	0.0	9.9	DNF	DNF
DC	1.6	4.8	4.9	64.7	0.6	76.0	5.6	140.7
FL	50.0	143.1	2.3	1.1	2.6	18.7	4.9	19.8
GA	30.7	68.5	0.9	2.3	1.0	3.2	1.9	5.5
HI	3.8	10.1	41.7	18.9	0.0	7.8	41.7	26.7
ID	5.2	10.8	15.0	19.4	17.8	44.1	32.8	63.5
IL	37.8	90.9	1.1	2.0	0.4	91.6	1.5	93.6
IN	19.7	45.7	6.0	5.0	37.1	68.0	43.1	73.0
IA	9.0	21.7	40.1	17.2	33.1	79.1	73.2	96.3
KS	8.9	19.9	12.8	17.1	DNF	DNF	DNF	DNF
KY	12.6	31.2	DNF	DNF	1.9	16.0	DNF	DNF
LA	13.8	32.2	15.6	6.7	40.2	125.7	55.8	132.5
ME	3.3	10.0	11.1	40.1	1.5	19.8	12.6	59.9
MD	16.7	42.2	0.9	4.5	0.1	1.2	1.0	5.7
MA	18.0	48.4	0.5	5.0	DNF	DNF	DNF	DNF
MI	28.4	70.5	DNF	DNF	0.0	0.0	DNF	DNF
MN	15.7	38.1	16.7	9.5	5.6	40.5	22.3	50.0
MS	9.2	20.6	DNF	DNF	10.1	64.0	DNF	DNF
MO	17.4	42.8	5.5	5.1	0.1	13.8	5.6	18.9
MT	2.8	7.3	134.2	30.9	0.0	7.6	134.2	38.4
NE	5.7	12.9	DNF	DNF	5.3	30.2	DNF	DNF
NV	8.0	19.5	2.6	3.9	0.9	5.0	3.5	8.8
NH	3.5	9.7	24.6	26.6	7.2	0.0	31.8	26.6
NJ	24.8	63.9	DNF	DNF	0.0	36.5	DNF	DNF
NM	6.3	14.5	DNF	DNF	DNF	DNF	DNF	DNF
NY	53.9	141.8	7.2	2.5	13.6	46.0	20.7	48.6
NC	28.4	69.1	6.7	1.5	11.9	52.0	18.6	53.5
ND	2.0	5.0	272.4	63.8	47.3	93.3	319.7	157.1
OH	33.0	82.5	5.4	3.7	13.1	79.4	18.5	83.0
OK	11.6	26.6	5.7	6.3	11.2	59.9	16.9	66.2
OR	10.7	28.3	45.1	15.2	0.0	0.0	45.1	15.2
PA	34.7	92.9	DNF	DNF	3.7	35.4	DNF	DNF
RI	2.9	7.6	DNF	DNF	0.0	2.8	DNF	DNF
SC	13.5	33.7	7.7	6.2	3.9	37.4	11.6	43.6
SD	2.5	5.8	135.1	69.7	35.3	18.9	170.4	88.7
TN	18.5	46.1	1.2	3.4	0.0	23.4	1.2	26.8
TX	85.1	175.5	0.8	0.8	6.4	49.0	7.2	49.8
UT	10.7	17.9	10.3	9.8	6.4	41.1	16.7	50.9
VT	1.6	4.6	DNF	DNF	0.0	1.3	DNF	DNF
VA	23.2	58.6	DNF	DNF	DNF	DNF	DNF	DNF
WA	19.6	49.4	4.2	4.2	0.9	12.4	5.0	16.6
WV	4.8	13.7	64.3	15.2	18.3	34.5	82.6	49.7
WI	16.4	40.9	12.9	11.9	0.0	21.9	12.9	33.8
WY	1.7	4.1	273.3	82.6	0.6	19.1	273.9	101.7
<b>Reported Total</b>	<b>915.4</b>	<b>2,223.8</b>	<b>181.0</b>	<b>223.1</b>	<b>5.9</b>	<b>34.9</b>	<b>186.9</b>	<b>258.0</b>

<sup>1</sup> Only 38 states were able to report residence type by age recipients FY 2012.

<sup>2</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix

Source: <http://factfinder2.census.gov/faces/nav/jsf/pages/searchresults.xhtml?refresh=t>



**SECTION TWO**

**LTSS Provided in Congregate  
Settings for People with IDD**

**FY 2012**



## SECTION 2: LTSS PROVIDED IN CONGREGATE SETTINGS FOR PEOPLE WITH IDD

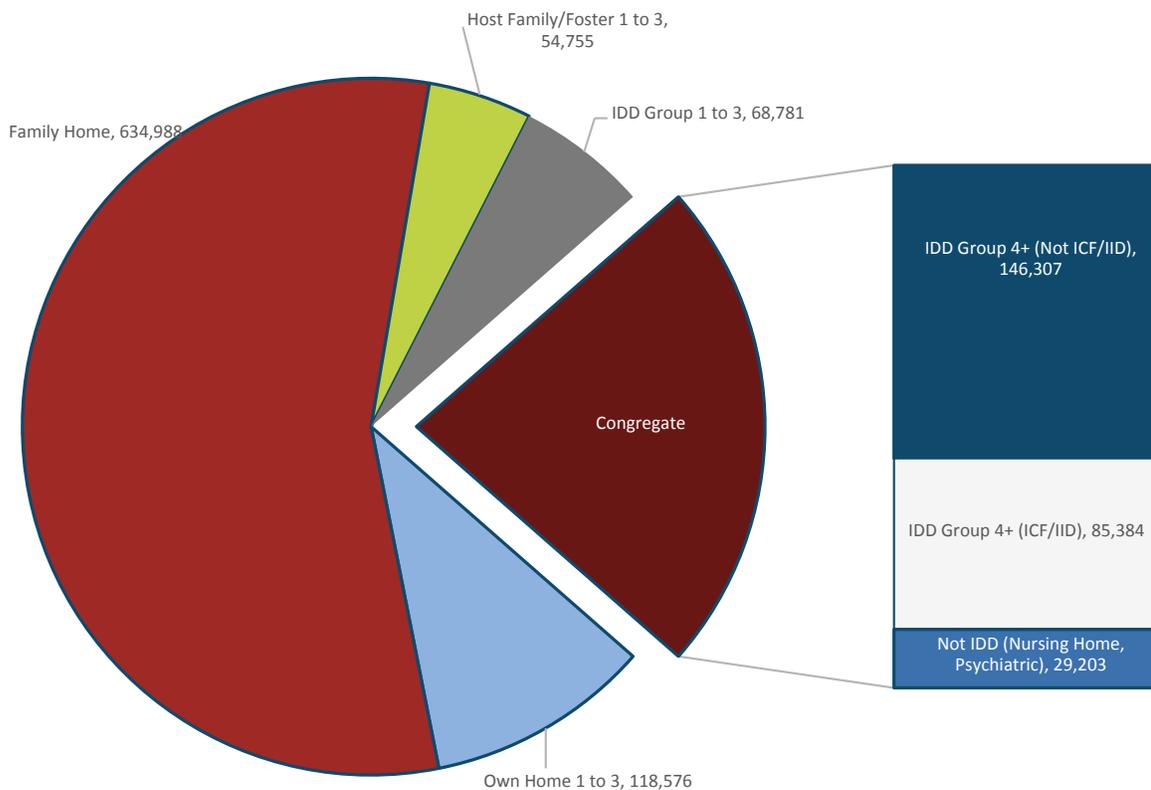
**Section 1 described people known to or served under the auspices of state IDD agencies** with IDD living in a home of their own, with a family member, in a host family/foster home or in a group setting shared by no more than three people with IDD. The remaining sections of this report focus on people with IDD living in congregate settings (See [Figure 2.1](#)). Of the 1,138,121 people with IDD known to or receiving LTSS under the auspices of state IDD agencies, 503,113 people lived in a setting other than the home of a family member including 28,064 who lived in nursing homes, 1,139 who lived in state psychiatric facilities, and 478 who lived in state operated settings not funded by the ICF/IID or HCBS Waiver programs. This section excludes people with IDD in nursing homes, state psychiatric facilities or in other funded (not ICF/IID or HCBS Waiver) state operated IDD settings.

Table footnotes designate instances when the state provided an estimated value, used data from 2011, or provided additional information about the numbers they reported. Additional state specific information can be found in the Appendix.

### LTSS Settings Other Than Family Homes

Residential settings vary in operating organization (state or non-state), funding authority (Medicaid ICF/IID, Medicaid HCBS Waiver, or other Medicaid), setting size (1 to 3, 4 to 6, 7 to 15 or 16+), and whether the setting was specific to people with IDD or was designed for another population. In Section 2, we discuss differences by operating entity, setting size and whether the setting was IDD specific. In Section 3 we compare settings by funding authority used to finance services.

**Figure 2.1** Individualized and Congregate Living Arrangements for People with IDD Receiving Medicaid or Non-Medicaid Funded Long-Term Supports and Services Under the Auspices of State IDD Programs on June 30, 2012 (Estimated Totals)



[Table 2.1](#) shows the number of state and non-state places people with IDD lived by size. This table includes people living in group IDD settings, host or foster family homes or in a home owned or leased by a person with IDD but does not include people with IDD living in the home of a family member, nursing home or state-operated psychiatric facility.

On June 30, 2012, there were an estimated 201,454 residential settings for people with IDD in the United States. Of those, an estimated 199,213 were operated by a non-state entity and 2,241 were operated by a state entity. An estimated 166,764 settings were shared by no more than 3 people with IDD (referred to as individualized settings in Section 1) while an estimated 27,738 were shared by 4 to 6 people, 6,203 were shared by 7 to 15 people and 1,057 were shared by 16 or more people with IDD.

While all but one of the states reported the number and size of state-operated settings for people with IDD, only 28 states reported the sizes of all non-state-operated settings (see the first row of the table for the number of states reporting each item). Estimated US totals were computed using historical trends, national distributions of settings sizes, and other information provided by the state such as the number of settings by funding mechanism. States reported a total of 157,042 IDD residential settings. We estimate the US total for June 2012 was 201,454 settings.

Altogether, 9 states reported having no state-operated IDD residential settings, and 27 reported having between 1 and 10 state IDD facilities. Of the remaining states, 6 had 11 to 30 state-operated IDD settings, 4 had 31 to 100 settings and 4 had 101 or more settings.

## People with IDD Receiving Supports in Non-Family Settings

[Table 2.2](#) shows the number of people with IDD living in state and non-state IDD residential settings. An estimated 473,802 people with IDD lived in a non-family IDD residential setting in the United States on June 30, 2012. Of those, an estimated 435,041 (92%) lived in non-state IDD settings and 38,761 (8%) lived in state-operated IDD settings. The majority lived in settings shared by 6 or fewer people with IDD (366,190; 77%) while 56,463 (12%) lived in settings shared by 7 to 15 people with IDD, and 50,671 (11%) lived in settings shared by 16 or more people with

IDD. Of the people with IDD who lived in a setting shared by 6 or fewer people with IDD, 240,992 (67%) lived in individualized settings with shared by 3 or fewer people and 119,812 (33%) lived in congregate settings shared by 4 to 6 people with IDD.

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*THE PROPORTION OF PEOPLE WITH IDD IN SETTINGS OF VARIOUS SIZES DIFFERED FROM STATE TO STATE. THE PROPORTION LIVING IN CONGREGATE SETTINGS SHARED BY 16 OR MORE PEOPLE WITH IDD RANGED FROM 0 IN ALABAMA, ALASKA, THE DISTRICT OF COLUMBIA, HAWAII, NEW MEXICO AND VERMONT TO 69% IN MISSISSIPPI.*

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The proportion of people with IDD in settings of various sizes differed from state to state. The proportion living in congregate settings shared by 16 or more people with IDD ranged from 0 in Alabama, Alaska, the District of Columbia, Hawaii, New Mexico and Vermont to 69% in Mississippi. Arkansas, Virginia, New Jersey, Louisiana, Oklahoma, and Utah reported that between 20% and 40% of people with IDD lived in settings shared by 16 or more people with the remaining states reporting that fewer than 20% of people with IDD lived in settings of 16 or more people.



**Table 2.1** State and Nonstate IDD Residential Settings<sup>1</sup> for Persons with IDD on June 30, 2012

Size	Nonstate Residential Settings						State Residential Settings						Total Settings					
	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total	1-3	4-6	1-6	7-15	16+	Total
N States	28	35	29	38	41	28	50	50	50	50	51	50	28	34	29	38	40	28
AL	901	92	993	77	0	2,063	0	0	0	0	0	0	901	92	993	77	0	2,063
AK	758	158	916	7	11	1,850	0	0	0	0	0	0	758	158	916	7	11	1,850
AZ	1,875	265	2,140	0	1	4,281	5	6	11	3	2	16	1,880	271	2,151	3	3	4,297
AR	1,224	24	1,248	98	21	2,615	0	0	0	0	5	5	1,224	24	1,248	98	26	2,620
CA	DNF	DNF	28,695	125	83	28,903	0	0	0	0	5	5	DNF	DNF	28,695	125	88	28,908
CO	DNF	4	DNF	0	0	DNF	0	16	16	33	2	51	DNF	DNF	DNF	33	2	DNF
CT	2,108	483	2,591	26	0	5,208	248	40	288	18	6	312	2,356	523	2,879	44	6	5,520
DE	DNF	118	DNF	4	1	DNF	3	2	5	0	1	6	DNF	120	DNF	4	2	DNF
DC	529	98	627	0	0	1,254	0	0	0	0	0	0	529	98	627	0	0	1,254
FL	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	2	3	DNF	DNF	DNF	DNF	DNF	DNF
GA	4,229	65	4,294	1	0	8,589	0	0	0	0	2	2	4,229	65	4,294	1	2	8,591
HI	429	203	632	1	0	1,265	0	0	0	0	0	0	429	203	632	1	0	1,265
ID	DNF	DNF	DNF	DNF	36	DNF	0	0	0	0	1	1	DNF	DNF	DNF	DNF	37	DNF
IL	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	8	8	DNF	DNF	DNF	DNF	DNF	DNF
IN	2,938	429	3,367	319	3	7,056	0	0	0	0	0	0	2,938	429	3,367	319	3	7,056
IA	DNF	DNF	DNF	92	22	DNF	6	14	20	0	2	22	DNF	DNF	DNF	92	24	DNF
KS	DNF	DNF	DNF	DNF	0	DNF	0	0	0	0	2	2	DNF	DNF	DNF	DNF	DNF	DNF
KY	470	11	486	0	2	969	0	0	0	3	2	5	470	11	486	3	4	974
LA	DNF	494	DNF	14	8	DNF	0	0	0	1	4	5	DNF	494	DNF	15	12	DNF
ME	DNF	176	DNF	11	DNF	DNF	0	0	0	0	0	0	DNF	176	DNF	11	DNF	DNF
MD	3,581	410	3,991	31	0	8,013	0	0	0	1	2	3	3,581	410	3,991	32	2	8,016
MA	DNF	DNF	DNF	DNF	0	DNF	DNF	DNF	DNF	DNF	5	DNF	DNF	DNF	DNF	DNF	5	DNF
MI	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	DNF	DNF	DNF	DNF	DNF	DNF
MN	DNF	DNF	DNF	DNF	DNF	DNF	6	98	104	0	0	104	DNF	DNF	DNF	DNF	DNF	DNF
MS	59	2	61	0	7	129	87	36	123	81	6	215	146	38	184	81	13	344
MO	1,663	226	1,889	124	6	3,908	64	9	73	0	6	79	1,727	235	1,962	124	12	3,987
MT	330	100	430	50	0	910	0	0	0	0	1	1	330	100	430	50	1	911
NE	2,334	138	2,472	15	2	4,961	0	0	0	1	3	4	2,334	138	2,472	16	5	4,965
NV	767	157	924	1	43	1,892	0	0	0	0	1	1	767	157	924	1	44	1,893
NH	1,461	15	1,476	3	1	2,956	0	0	0	0	0	1	1,461	15	1,476	3	1	2,957
NJ	1,673	1,031	2,704	DNF	DNF	DNF	2	7	9	13	7	29	1,675	1,038	2,713	DNF	DNF	DNF
NM	2,442	24	2,466	14	0	4,946	17	6	23	0	0	23	2,459	30	2,489	14	0	4,969
NY	DNF	2,109	DNF	1,500	32	DNF	71	417	488	529	46	1,063	DNF	2,526	DNF	2,029	78	DNF
NC	DNF	DNF	DNF	72	16	DNF	0	2	2	0	4	7	DNF	DNF	DNF	72	20	DNF
ND	1,146	45	1,191	64	1	2,447	0	0	0	0	1	1	1,146	45	1,191	64	2	2,448
OH	13,187	683	13,870	306	82	28,128	0	0	0	0	10	10	13,187	683	13,870	306	92	28,138
OK	1,389	242	1,631	58	20	3,340	0	0	0	0	2	2	1,389	242	1,631	58	22	3,342
OR	DNF	888	DNF	28	16	DNF	0	23	23	0	0	23	DNF	911	DNF	28	16	DNF
PA	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	5	5	DNF	DNF	DNF	DNF	DNF	DNF
RI	889	179	1,068	22	1	2,159	36	29	65	1	2	68	925	208	1,133	23	3	2,227
SC	321	514	835	108	0	1,778	0	0	0	0	5	5	321	514	835	108	5	1,783
SD	1,039	81	1,120	61	1	2,302	0	0	0	0	1	1	1,039	81	1,120	61	2	2,303
TN	2,208	92	2,310	91	3	4,704	0	25	25	0	2	27	2,208	117	2,335	91	5	4,731
TX	DNF	DNF	DNF	49	9	DNF	0	2	2	0	13	15	DNF	DNF	DNF	49	22	DNF
UT	1,780	72	1,850	18	13	3,733	0	0	0	0	1	1	1,780	72	1,850	18	14	3,734
VT	1,417	20	1,437	0	0	2,874	0	0	0	0	0	0	1,417	20	1,437	0	0	2,874
VA	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	5	5	DNF	DNF	DNF	DNF	DNF	DNF
WA	DNF	DNF	DNF	DNF	DNF	DNF	19	19	38	0	3	42	DNF	DNF	DNF	DNF	DNF	DNF
WV	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	DNF	DNF	DNF	DNF	DNF	DNF
WI	DNF	506	DNF	4	6	DNF	0	0	0	0	2	2	DNF	506	DNF	4	8	DNF
WY	DNF	DNF	DNF	DNF	0	DNF	0	0	0	0	1	1	DNF	DNF	DNF	DNF	1	DNF
<b>Reported US Total</b>	<b>53,147</b>	<b>10,154</b>	<b>87,714</b>	<b>3,394</b>	<b>447</b>	<b>154,856</b>	<b>564</b>	<b>751</b>	<b>1,315</b>	<b>684</b>	<b>178</b>	<b>2,186</b>	<b>53,711</b>	<b>10,905</b>	<b>89,029</b>	<b>4,078</b>	<b>625</b>	<b>157,042</b>
<b>Estimated US Total</b>	<b>166,132</b>	<b>26,843</b>	<b>193,008</b>	<b>5,518</b>	<b>879</b>	<b>199,213</b>	<b>632</b>	<b>895</b>	<b>1,527</b>	<b>685</b>	<b>178</b>	<b>2,453</b>	<b>166,764</b>	<b>27,738</b>	<b>194,535</b>	<b>6,203</b>	<b>1,057</b>	<b>201,666</b>

<sup>1</sup>2011 data \* Estimate <sup>DNF</sup> Did not furnish \* See state notes in Appendix 1 This table excludes people in family homes, nursing homes, and psychiatric settings. It includes people in Nonstate "other" settings. Size information was not collected for state "other" settings. Totals include people with IDD in state "other" IDD settings.



Table 2.2 People with IDD in State and Nonstate IDD Residential Settings other than Family Home1by Setting Size June 30, 2012

State	Nonstate Residential Settings						State Residential Settings						All Settings						
	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	51	51	51	51	51	51	51	51	51	51	51	51	51	51	51	51	51	51	51
AL	2,403	527	2,930	816	0	3,746	0	0	0	0	0	0	2,403	527	2,930	816	0	0	3,746
AK	991	128	1,119	0	0	1,119	0	0	0	0	0	0	991	128	1,119	0	0	0	1,119
AZ	3,167	1,143	4,310	0	35	4,345	16	23	39	25	108	172	3,183	1,166	4,349	25	143	143	4,517
AR	1,261	105	1,366	867	553	2,786	0	0	0	0	951	951	1,261	105	1,366	867	1,504	3,737	
CA	DNF	DNF	52,582	1,152	1,708	55,442	0	0	0	0	1,682	1,682	DNF	DNF	52,582	1,152	3,390	57,124	
CO	5,342	21	5,363	0	0	5,363	0	89	89	207	296	592	5,342	110	5,452	207	296	5,955	
CT	2,963	2,440	5,403	203	0	5,606	262	220	482	142	612	1,236	3,225	2,660	5,885	345	612	6,842	
DE	428	466	894	23	0	917	7	8	15	0	66	81	435	474	909	23	66	998	
DC	889	489	1,378	0	0	1,378	0	0	0	0	0	0	889	489	1,378	0	0	1,378	
FL	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	781	899	DNF	DNF	DNF	DNF	DNF	DNF	
GA	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	300	300	DNF	DNF	DNF	DNF	DNF	DNF	
HI	648	371	1,019	7	0	1,026	0	0	0	0	0	0	648	371	1,019	7	0	1,026	
ID	1,473	DNF	DNF	DNF	94	DNF	0	0	0	0	47	47	1,473	DNF	DNF	DNF	141	DNF	
IL	DNF	DNF	DNF	8,202	3,295	DNF	0	0	0	0	1,928	1,928	DNF	DNF	DNF	8,202	5,223	DNF	
IN	5,072	1,928	7,000	2,447	290	9,737	0	0	0	0	0	0	5,072	1,928	7,000	2,447	290	9,737	
IA	DNF	DNF	DNF	920	987	DNF	18	50	68	0	444	512	DNF	DNF	DNF	920	1,431	DNF	
KS	DNF	DNF	DNF	DNF	0	DNF	0	0	0	0	334	334	DNF	DNF	DNF	DNF	334	DNF	
KY	3,394	103	3,497	0	136	3,633	0	0	0	6	143	149	3,394	103	3,497	6	279	3,782	
LA	2,468	3,035	5,503	172	549	6,224	0	0	0	9	839	848	2,468	3,035	5,503	181	1,388	7,072	
ME	2,627	786	3,413	116	117	3,646	0	0	0	0	0	0	2,627	786	3,413	116	117	3,646	
MD	5,865	1,774	7,639	236	0	7,875	0	0	0	0	54	54	5,865	1,774	7,639	236	54	7,929	
MA	DNF	DNF	DNF	DNF	0	DNF	DNF	DNF	923	262	580	1,765	DNF	DNF	DNF	DNF	580	DNF	
MI4	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	DNF	DNF	DNF	DNF	DNF	DNF	
MN	DNF	DNF	DNF	DNF	DNF	DNF	15	406	421	0	0	421	DNF	DNF	DNF	DNF	DNF	DNF	
MS	93	16	109	66	732	907	106	112	218	586	1,441	2,262	199	128	327	652	2,173	3,169	
MO	4,297	1,120	5,417	1,108	113	6,638	175	36	211	0	510	721	4,472	1,156	5,628	1,108	623	7,359	
MT	792	661	1,453	415	0	1,868	0	0	0	0	55	55	792	661	1,453	415	55	1,923	
NE	2,796	662	3,458	113	244	3,815	0	0	0	8	136	144	2,796	662	3,458	121	380	3,959	
NV	1,002	649	1,651	6	104	1,761	0	0	0	0	48	48	1,002	649	1,651	6	152	1,809	
NH	1,628	66	1,694	18	25	1,737	0	0	0	0	0	4	1,628	66	1,694	18	25	1,741	
NJ	3,220	4,125	7,345	1,437	806	9,588	4	42	46	0	2,434	2,480	3,224	4,167	7,391	1,437	3,240	12,068	
NM	3,172	110	3,282	120	0	3,402	36	24	60	0	0	60	3,208	134	3,342	120	0	3,462	
NY	13,889	10,289	24,178	13,687	990	38,855	186	2,097	2,283	5,135	1,633	9,051	14,075	12,386	26,461	18,822	2,623	47,906	
NC	DNF	DNF	6,216	DNF	DNF	DNF	0	0	0	0	1,424	1,506	DNF	DNF	6,216	DNF	DNF	DNF	
ND	1,146	241	1,387	520	30	1,937	0	0	0	0	94	94	1,146	241	1,387	520	124	2,031	
OH	15,748	3,100	18,848	2,652	3,230	24,730	0	0	0	0	1,134	1,134	15,748	3,100	18,848	2,652	4,364	25,864	
OK	2,013	813	2,826	574	774	4,174	0	0	0	0	235	235	2,013	813	2,826	574	1,009	4,409	
OR	DNF	DNF	6,493	218	27	6,738	0	108	108	0	0	108	DNF	DNF	6,601	218	27	6,846	
PA	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	1,106	1,106	DNF	DNF	DNF	DNF	DNF	DNF	
RI	985	799	1,784	152	21	1,957	36	150	186	14	33	233	1,021	949	1,970	166	54	2,190	
SC	1,156	2,057	3,213	890	0	4,103	0	0	0	0	745	745	1,156	2,057	3,213	890	745	4,848	
SD	1,308	404	1,712	585	59	2,356	0	0	0	0	140	140	1,308	404	1,712	585	199	2,496	
TN	4,218	461	4,679	733	168	5,580	0	97	97	0	183	280	4,218	558	4,776	733	351	5,860	
TX	DNF	DNF	24,496	555	574	25,625	0	10	10	0	3,787	3,797	DNF	DNF	24,506	555	4,361	29,422	
UT	2,163	348	2,511	162	566	3,239	0	0	0	0	207	207	2,163	348	2,511	162	773	3,446	
VT	1,595	90	1,685	0	0	1,685	0	0	0	0	0	0	1,595	90	1,685	0	0	1,685	
VA	1,503	3,071	4,574	594	2,217	7,385	0	0	0	0	948	948	1,503	3,071	4,574	594	3,165	8,333	
WA	DNF	DNF	DNF	DNF	DNF	DNF	54	76	130	0	576	963	DNF	DNF	DNF	DNF	DNF	DNF	
WV	DNF	DNF	DNF	DNF	DNF	DNF	0	0	0	0	0	0	DNF	DNF	DNF	DNF	DNF	DNF	
WI	9,279	2,465	11,744	28	477	12,249	0	0	0	0	390	390	9,279	2,465	11,744	28	867	12,639	
WY	DNF	DNF	1,315	91	0	1,406	0	0	0	0	79	79	DNF	DNF	1,315	91	79	1,485	
Reported US Total	167,830	77,648	319,084	43,318	22,099	384,501	915	3,548	5,386	6,394	26,503	38,761	168,745	81,196	324,470	49,712	48,602	423,262	
Estimated US Total	240,993	119,812	360,805	50,069	24,168	435,042	1,119	4,267	5,386	6,394	26,503	38,761	242,112	124,079	366,191	56,463	50,671	473,803	

## People with IDD Living in Nursing Facilities or State Psychiatric Facilities

[Table 2.3](#) shows the number of people with IDD reported or estimated to be living in state-operated psychiatric facilities, nursing homes, or other non-IDD settings. Estimates from the American Health Care Association (AHCA) based on their analysis of CMS's Online Survey, Certification and Reporting (OSCAR) data network (2013) were used for states

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*WHILE CMS DECLINED TO SPECIFY A SPECIFIC SETTING SIZE MAXIMUM TO QUALIFY AS A COMMUNITY SETTING UNDER THE 2014 HCBS WAIVER RULES, WE KNOW FROM PREVIOUS RESEARCH THAT PEOPLE WITH IDD HAVE THE BEST OUTCOMES WHEN THEY LIVE IN HOMES THEY SHARE WITH THREE OR FEWER OTHER PEOPLE WITH IDD.*

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that did not report the number of people with IDD in nursing homes. This table also includes state-by-state estimates of the number of people with IDD known to or served under the auspices of state IDD

agencies. Altogether, 1,139 people with IDD (0.1%) lived in a state-operated psychiatric facility, 28,054 (2.5%) lived in a nursing home, and 15,055 (1.3%) lived in a non-IDD state or non-state congregate setting

The proportion persons with IDD living in a nursing home ranged from less than 1% in Alaska, Arizona, California, Colorado, Delaware, the District of Columbia, Florida, Maine, Minnesota, Vermont and Wisconsin to 15% in North Carolina. The proportion living in any of the three non-IDD settings ranged from less than 1% in Alaska, Arizona, California, Delaware, and Wisconsin to 16% in North Carolina.

## Estimated Size of Non-Family Settings in which People with IDD Receive LTSS

While CMS declined to specify a specific setting size maximum to qualify as a community setting under the 2014 HCBS Waiver rules previous research suggests that people with IDD have the best outcomes when they live in homes they share with three or fewer other people with IDD (c.f., Ticha, Hewitt, Nord, and Larson, 2013).

[Table 2.4](#) shows the average setting size of non-family settings, the average number of people with IDD sharing a setting, and the proportion of people



**Table 2.3** Number and Percent of People with IDD living in Settings Not Specifically Designated for People with IDD on June 30, 2012

State	State Psychiatric	Nursing Home	Not IDD Specific	All Settings	% in Nursing Home	% in Non/IDD Settings
N States	51	51	51	51	51	51
AL	0	854	0	6,495	13%	13%
AK	0*	10	0	1,421	1%	1%
AZ	0	73	0	32,573	0%	0%
AR	0	597	0	6,328	9%	9%
CA	0	1,157	0	199,168	1%	1%
CO	0	95	980 <sup>e</sup>	11,857	1%	9%
CT	0	376*	0	8,599	4%	4%
DE	3 <sup>e</sup>	29	0	3,458	1%	1%
DC	0	6	21	2,099	0%	1%
FL	28	308	1,177	62,118	0%	2%
GA	0	1,095 <sup>e*</sup>	51	11,414	10%	10%
HI	0	53	0	3,281	2%	2%
ID	0	49 <sup>e</sup>	0	4,595	1%	1%
IL	0	1,094 <sup>e*</sup>	0 <sup>e</sup>	30,173	4%	4%
IN	106	1,553	0	18,284	8%	9%
IA	0	634	0	14,838	4%	4%
KS	0	262 <sup>e*</sup>	0	9,045	3%	3%
KY	0	273	0	5,190	5%	5%
LA	16	511 <sup>e</sup>	0	23,545	2%	2%
ME	3 <sup>e</sup>	49 <sup>e</sup>	55 <sup>e</sup>	5,261	1%	2%
MD	0	241 <sup>e*</sup>	0	10,385	2%	2%
MA	0*	367	0 <sup>e</sup>	34,000	1%	1%
MI	0	609 <sup>e*</sup>	1,784	47,546	1%	5%
MN	0 <sup>e</sup>	218	1,594*	25,586	1%	7%
MS	0	140 <sup>e</sup>	17	4,396	3%	4%
MO	376	1,045 <sup>e*</sup>	0	16,869	6%	8%
MT	0	80 <sup>e</sup>	0	2,803	3%	3%
NE	0	307	0	5,396	6%	6%
NV	0	81	100	5,716	1%	3%
NH	0	84	4	2,749	3%	3%
NJ	60	1,043 <sup>e</sup>	589	43,700	2%	4%
NM	0 <sup>ed</sup>	109 <sup>ed</sup>	1,802 <sup>ed</sup>	4,222	3%	45%
NY	0	1,901 <sup>e*</sup>	0 <sup>e</sup>	128,551	1%	1%
NC	86	4,086	82	26,727	15%	16%
ND	0	100	0	3,356	3%	3%
OH	0	1,962 <sup>e*</sup>	516	86,677	2%	3%
OK	0	315	0	7,087	4%	4%
OR	0	195*	0	17,520	1%	1%
PA	77	1,549 <sup>e*</sup>	6,259 <sup>e</sup>	57,309	3%	14%
RI	0	44	0	3,614	1%	1%
SC	0	206	0	17,481	1%	1%
SD	31	134	0	3,822	4%	4%
TN	11	420	0	9,219	5%	5%
TX	0	1,936 <sup>e*</sup>	0	40,596	5%	5%
UT	0	167 <sup>e*</sup>	0	5,427	3%	3%
VT	0	32	0	3,442	1%	1%
VA	312	933	0	11,023	8%	11%
WA	22 <sup>e*</sup>	294	502 <sup>e</sup>	21,236	1%	4%
WV	0	329 <sup>e*</sup>	0	5,338	6%	6%
WI	0	34 <sup>e</sup>	9	24,324	0%	0%
WY	8	25 <sup>e*</sup>	0	2,262	1%	1%
<b>Estimated US Total</b>	<b>1,139</b>	<b>28,064</b>	<b>15,542</b>	<b>1,138,121</b>	<b>2%</b>	<b>4%</b>

<sup>e</sup> 2011 data <sup>e</sup> Estimate DNF Did not furnish \* Estimated from AHCA report

with IDD who lived in settings with 3 or fewer or 6 or fewer people. For FY 2012 all of the states reported the total number of people with IDD known to or receiving LTSS under auspices of a state IDD agency or director. For some states however, estimates were used for the total number of non-family settings.

An estimated 473,802 people with IDD lived in settings other than the home of a family member on June 30, 2012. The average number of people sharing a non-family residence was 2.35 in FY 2012. Overall, 51% of all people with IDD not living with a family member shared a home with 3 or fewer people with IDD, and 77% shared a home with 6 or fewer people.

There were huge differences between states in the proportion of people with IDD living in a non-family residence who shared a home with 3 or fewer people with IDD (See [Figure 2.2](#)). Seven states reported that 89% or more of people with IDD in non-family settings lived in a residence shared by 3 or fewer people with IDD (Vermont, New Hampshire, Georgia, New Mexico, Kentucky, Colorado, and Alaska), 24 states reported the proportion to be between 51% and 74%, 11 states reported the proportion to be 40 to 50%, 3 states reported the proportion to be between 30% and 35% (Louisiana, Iowa, and Arkansas), and 3 states reported that only 20% to 30% of people with IDD lived in individualized settings (New York, New Jersey, and South Carolina). By contrast, fewer than 20% of the people with IDD in non-family settings in Mississippi, Illinois and Virginia lived in a setting shared by three or fewer people. In fact 90% of people with IDD in Mississippi reported on by the state IDD agency lived in congregate settings of 7 or more people as did 65% in Illinois.

## Utilization of Non-Family Residences per 100,000 of the State Population

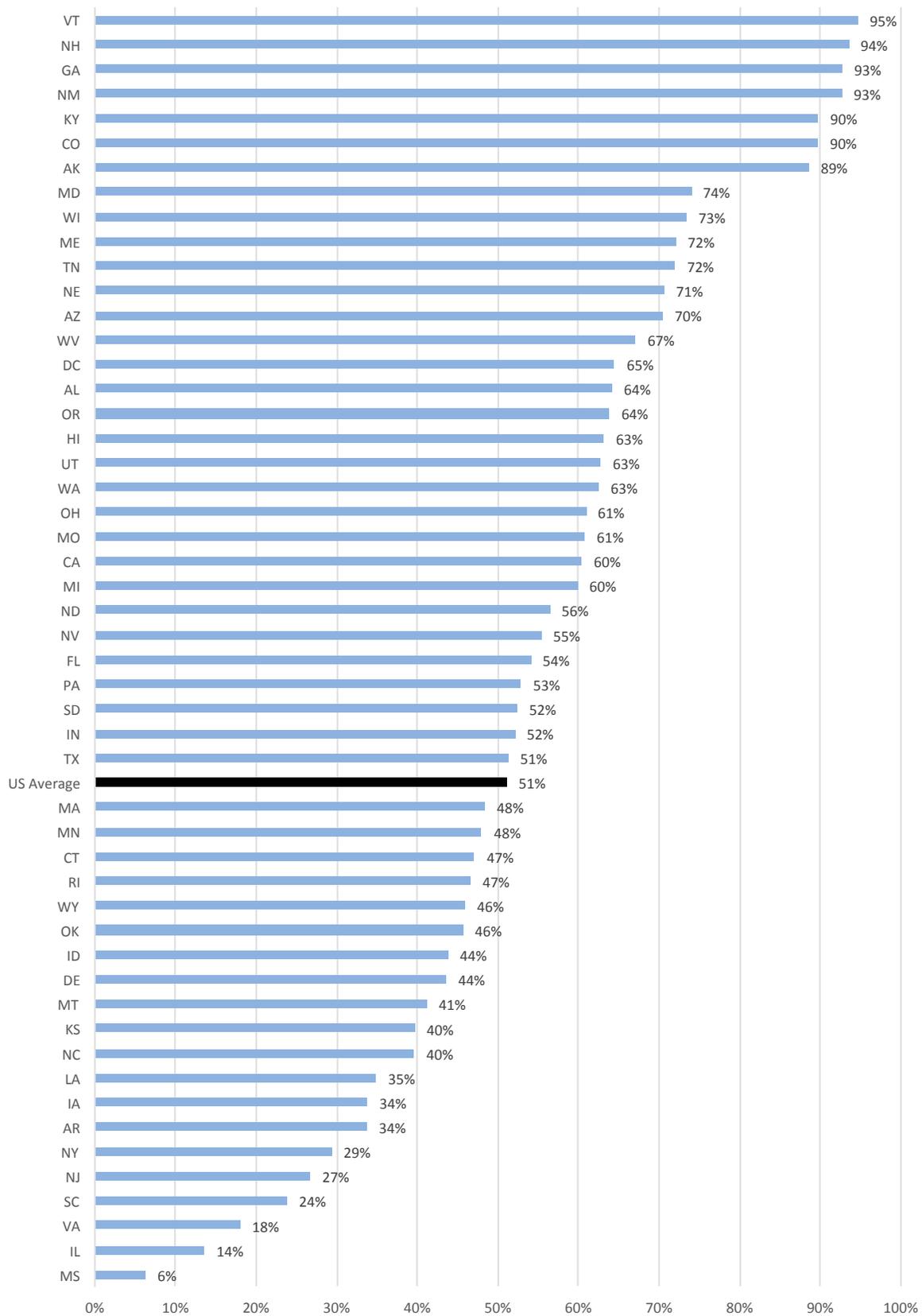
[Table 2.4](#) and [Figure 2.2](#) indexed the size of residential settings in terms of the proportion of people with IDD living in settings shared by three or fewer or six or fewer people with IDD. Another way to compare state utilization residential settings for people with IDD is to compare the number of people with IDD living in a setting type or size to the total state population.

**Table 2.4** Estimated Size of Non-Family Long-Term Support and Service Settings for Persons with IDD on June 30, 2012

State	Estimated Totals		% in Settings with		
	Settings <sup>1</sup>	People	People Per Setting	1-3 People	1-6 People
AL	1,070	3,746	3.50	64%	78%
AK	935	1,119	1.20	89%	100%
AZ	2,157	4,517	2.09	70%	96%
AR	1,372	3,737	2.72	34%	37%
CA	31,282	57,124	1.83	60%	92%
CO	3,245	5,955	1.83	90%	92%
CT	2,929	6,842	2.34	47%	86%
DE	379	998	2.63	44%	91%
DC	627	1,378	2.20	65%	100%
FL	11,716	24,700	2.11	54%	82%
GA	4,297	4,824	1.12	93%	94%
HI	633	1,026	1.62	63%	99%
ID	1,447	3,364	2.33	44%	87%
IL	2,983	20,613	6.91	14%	35%
IN	3,693	9,737	2.64	52%	72%
IA	1,739	4,687	2.70	34%	50%
KS	1,536	5,972	3.89	40%	92%
KY	493	3,782	7.67	90%	92%
LA	2,524	7,072	2.80	35%	78%
ME	2,044	3,646	1.78	72%	94%
MD	4,025	7,929	1.97	74%	96%
MA	4,078	12,633	3.10	48%	89%
MI	9,908	21,165	2.14	60%	88%
MN	7,524	15,036	2.00	48%	92%
MS	283	3,169	11.20	6%	10%
MO	2,107	7,359	3.49	61%	76%
MT	481	1,923	4.00	41%	76%
NE	2,493	3,959	1.59	71%	87%
NV	969	1,809	1.87	55%	91%
NH	1,481	1,741	1.18	94%	97%
NJ	2,867	12,068	4.21	27%	61%
NM	2,503	3,462	1.38	93%	97%
NY	14,937	47,906	3.21	29%	55%
NC	3,652	8,790	2.41	40%	71%
ND	1,257	2,031	1.62	56%	68%
OH	14,269	25,864	1.81	61%	73%
OK	1,711	4,409	2.58	46%	64%
OR	2,270	6,846	3.02	64%	96%
PA	13,294	26,674	2.01	53%	77%
RI	1,159	2,190	1.89	47%	90%
SC	948	4,848	5.11	24%	66%
SD	1,184	2,496	2.11	52%	69%
TN	2,436	5,860	2.41	72%	82%
TX	11,181	29,422	2.63	51%	83%
UT	1,882	3,446	1.83	63%	73%
VT	1,437	1,685	1.17	95%	100%
VA	2,170	8,333	3.84	18%	55%
WA	5,360	9,772	1.82	63%	87%
WV	601	2,015	3.35	67%	76%
WI	5,634	12,639	2.24	73%	93%
WY	463	1,485	3.21	46%	89%
<b>Estimated US Total</b>	<b>201,666</b>	<b>473,803</b>	<b>2.35</b>	<b>51%</b>	<b>77%</b>

<sup>1</sup> 2011 data \* Estimate <sup>DNF</sup> Did not furnish \* See state notes in Appendix 1  
Excludes people in family homes, nursing homes, and psychiatric settings.  
Estimates are used for all missing data on this table.

**Figure 2.2** Percent of People with IDD Living in Non-Family Settings Who Live with Three or Fewer People With IDD by State on June 30, 2012



**Table 2.5** Persons with IDD in Non-Family Residential Settings Per 100,000 of State General Population by Size of Residential Setting, June 30, 2012

State	*State Population (100,000)	Residence Size			Total in Non-Family Settings
		1-6	7-15	16+	
<b>N States</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>
AL	48.2	60.8	16.9	0.0	77.7
AK	7.3	153.0	0.0	0.0	153.0
AZ	65.5	66.4	0.4	2.2	68.9
AR	29.5	46.3	29.4	51.0	126.7
CA	380.4	138.2	3.0	8.9	150.2
CO	51.9	105.1	4.0	5.7	114.8
CT	35.9	163.9	9.6	17.0	190.6
DE	9.2	99.1	2.5	7.2	108.8
DC	6.3	217.9	0.0	0.0	217.9
FL	193.2	DNF	DNF	DNF	127.9
GA	99.2	DNF	DNF	DNF	48.6
HI	13.9	73.2	0.5	0.0	73.7
ID	16.0	DNF	DNF	8.8	210.8
IL	128.8	DNF	63.7	40.6	160.1
IN	65.4	107.1	37.4	4.4	148.9
IA	30.7	DNF	29.9	46.5	152.5
KS	28.9	DNF	DNF	11.6	206.9
KY	43.8	79.8	0.1	6.4	86.3
LA	46.0	119.6	3.9	30.2	153.7
ME	13.3	256.8	8.7	8.8	274.3
MD	58.8	129.8	4.0	0.9	134.7
MA	66.5	DNF	DNF	DNF	190.1
MI	98.8	DNF	DNF	DNF	214.1
MN	53.8	DNF	DNF	DNF	279.5
MS	29.8	11.0	21.8	DNF	106.2
MO	60.2	93.5	18.4	10.3	122.2
MT	10.1	144.6	41.3	5.5	191.3
NE	18.6	186.4	6.5	20.5	213.4
NV	27.6	59.8	0.2	5.5	65.6
NH	13.2	128.3	1.4	1.9	131.8
NJ	88.6	83.4	16.2	36.5	136.1
NM	20.9	160.2	5.8	0.0	166.0
NY	195.7	135.2	96.2	13.4	244.8
NC	97.5	63.7	DNF	DNF	90.1
ND	7.0	198.2	74.3	17.7	290.3
OH	115.4	163.3	23.0	37.8	224.0
OK	38.1	74.1	15.0	26.4	115.6
OR	39.0	169.3	5.6	0.7	175.6
PA	127.6	DNF	DNF	DNF	209.0
RI	10.5	187.6	15.8	5.1	208.5
SC	47.2	68.0	18.8	15.8	102.6
SD	8.3	205.4	70.2	23.9	299.5
TN	64.6	74.0	11.4	5.4	90.8
TX	260.6	94.0	2.1	16.7	112.9
UT	28.6	87.9	5.7	27.1	120.7
VT	6.3	269.2	0.0	0.0	269.2
VA	81.9	55.9	7.3	38.7	101.8
WA	69.0	DNF	DNF	DNF	141.7
WV	18.6	DNF	DNF	DNF	108.6
WI	57.3	205.1	0.5	15.1	220.7
WY	5.8	228.1	15.8	13.7	257.6
<b>US Estimate</b>	<b>3139.1</b>	<b>116.7</b>	<b>18.0</b>	<b>16.1</b>	<b>150.9</b>

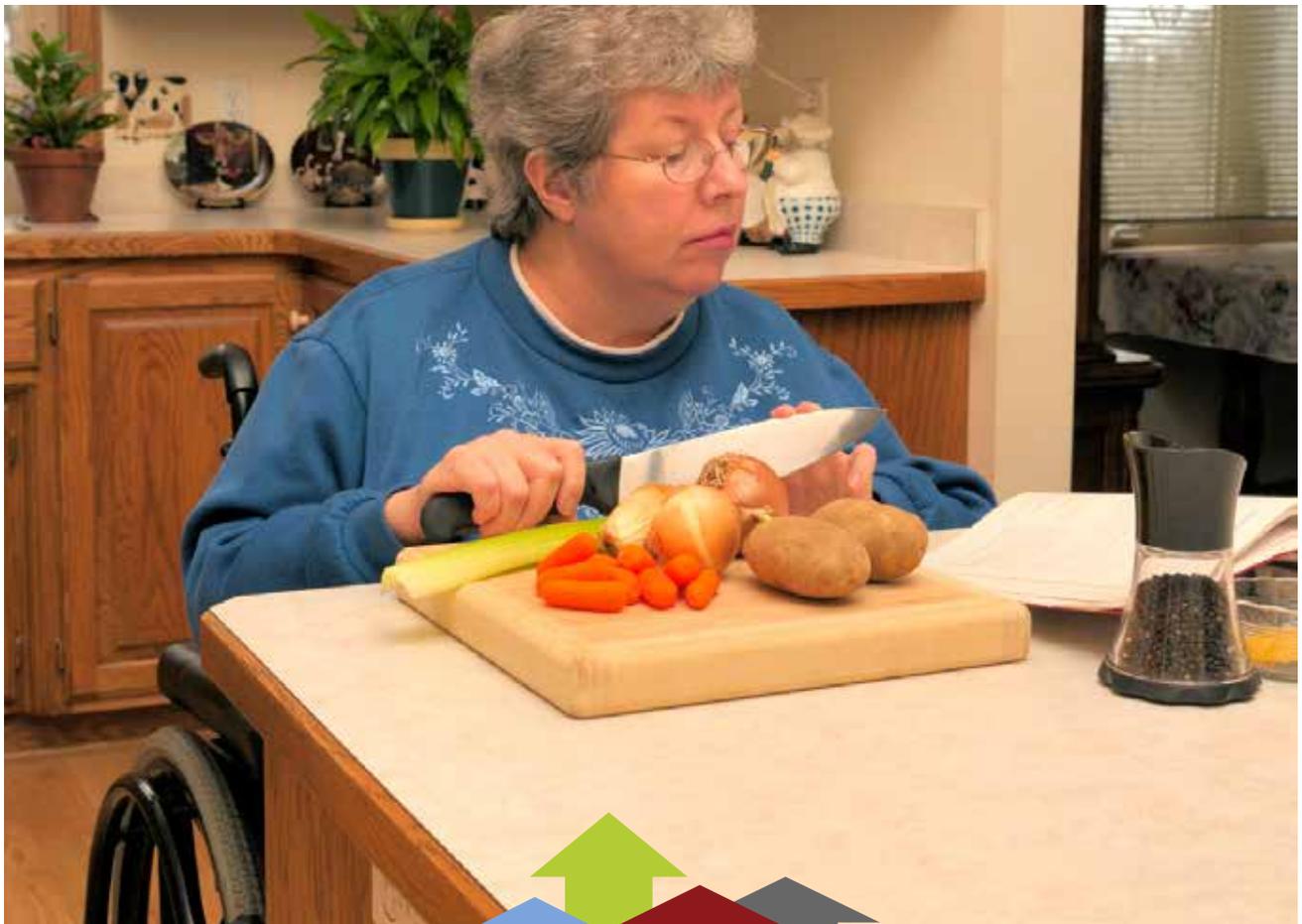
† 2011 data ° Estimate DNF Did not furnish \* See state notes in Appendix

Table 2.5 shows the estimated total number of people with IDD receiving LTSS in settings shared by six or fewer people, seven to fifteen people or 16 or more people per 100,000 of a state's population. Nationally, 148.5 people with IDD received LTSS while living in non-family settings per 100,000 of the population. The national average for non-family settings with 1 to 6 people was 114.8, for non-family settings with 7 to 15 people was 17.7 and for non-family settings with 16 or more people 15.9.

Overall, rates of providing LTSS to people with IDD in non-family settings varied by state from a low of 26.1 people per 100,000 in Wyoming to highs of 299.5 per 100,000 in South Dakota, and 290.3 per 100,000 in North Dakota. Altogether, 9 states provided LTSS to people with IDD in non-family settings for fewer than 100 people with IDD per 100,000 of the population. In addition to Wyoming, those states included Alabama (77.7), Arizona (68.9), Georgia (48.6), Hawaii (73.7), Kentucky (86.3), Nevada (65.6), North Carolina (90.1) and Tennessee (90.8). Fifteen states reported non-family LTSS utilization rates of 200 or more people with IDD per 100,000, and 27 states reported utilization rates of between 100 and 200 people with IDD per 100,000 of the state population.

States with the highest utilization rates for settings of 16 or more people with IDD per 100,000 of the state's population were Arkansas (51.0), Illinois (40.5), Iowa (46.5), Ohio (37.8) and Virginia (38.7). States reporting the highest utilization rates for settings shared by 7 to 15 people with IDD included Illinois (63.7), Montana (41.3), New York (96.2), North Dakota (74.3), and South Dakota (70.2). States with the highest utilization rate for non-family settings of 1 to 6 people with IDD were the District of Columbia (217.9), Maine (256.8), South Dakota (205.4), Vermont (269.2) and Wisconsin (205.1)





Stock Photo



### **SECTION THREE**

# **LTSS provided in Medicaid Home and Community-based Waiver Settings or Intermediate Care Facilities for Individuals with Intellectual Disabilities**

**FY 2012**



## SECTION 3: LTSS PROVIDED IN MEDICAID HOME AND COMMUNITY-BASED WAIVER SETTINGS OR INTERMEDIATE CARE FACILITIES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

**Sections 1 and 2 described** all people with IDD known to or receiving LTSS under the auspices of state IDD agencies including people receiving supports 24 hours a day 7 days a week, as well as people who received only a few hours of paid support per week. Sections 1 and 2 also included people with IDD known to the state IDD system who

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*OF THE 1,134,662 PEOPLE WITH IDD KNOWN TO STATE IDD SYSTEMS, AN ESTIMATED 677,151 (60%) RECEIVED LTSS FUNDED THROUGH AN HCBS WAIVER AUTHORITY (PRIMARILY 1915(C) WAIVERS) AND AN ESTIMATED 85,384 (8%) LIVED IN A MEDICAID FUNDED ICF/IID SETTING.*

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were receiving only case management services, who received LTSS funded solely by state dollars or who might need but were on a waiting list for Medicaid-funded LTSS.

Section 3 describes the subgroup of people with IDD who received LTSS in an ICF/IID or funded by a

Medicaid Waiver authority. Of the 1,138,121 people with IDD known to state IDD agencies, an estimated 680,610 (60%) received LTSS funded through an HCBS Waiver authority (primarily 1915(c) Waivers) and an estimated 85,384 (8%) lived in a Medicaid ICF/IID setting. The funding source for LTSS received, if any, for the remaining 372,127 people with IDD known to or receiving service under the auspices of state IDD agencies was not captured in the FY 2012 data collection (or in any previous year). More information about the funding authorities under which IDD LTSS are provided will be requested beginning with the FY 2013 survey of state IDD directors.

### Living Arrangements for People with IDD Receiving HCBS Funded Supports

Each state operates one or more HCBS Waiver-funded programs each of which has a target population, service array and funding parameters. Of the estimated 677,151 people with IDD receiving LTSS funded by one or more Medicaid Waiver Authorities on June 30, 2012, an estimated 10,843 (2%) lived in a state-operated group home, 173,698 (26%) lived in a nonstate group home, 52,876 (8%)



**Table 3.1** Total HCBS Waiver Recipients with IDD by Type of Residential Setting on June 30, 2012

State	State Group Home	Nonstate Group Home	Host/ Foster Home	Person's Own Home	Family Home	Other Nonstate	Reported Total
<b>N States</b>	<b>51</b>	<b>46</b>	<b>45</b>	<b>43</b>	<b>44</b>	<b>50</b>	<b>43</b>
AL	0	3,412 <sup>e</sup>	166	131	1,895 <sup>e</sup>	0	5,604
AK	0	428	218	473	292	0	1,411
AZ	59	2,550	1,256	411	20,345	0	24,621
AR	0	1,054	530	514	1,953	0	4,051
CA	0	20,568	1,062	10,139	65,532	0	97,301
CO	270	1,138 <sup>e</sup>	2,204 <sup>e</sup>	816 <sup>e</sup>	2,896 <sup>e</sup>	980 <sup>e</sup>	8,304
CT	624	3,186	374	1,349	1,202	0	6,735
DE	15	721	125	4	2	0	867
DC	0	872	78	17	536	6	1,509
FL	0	7,406	7,254 <sup>e</sup>	4,410	9,521	644	29,235
GA	0	DNF	DNF	DNF	DNF	DNF	DNF
HI	0	147 <sup>e</sup>	628 <sup>e</sup>	103 <sup>e</sup>	1,587 <sup>e</sup>	0	2,465
ID	0	0	DNF	DNF	1,182	0	DNF
IL	0	9,416	239	DNF	DNF	0 <sup>e</sup>	DNF
IN	0	555 <sup>e</sup>	207	5,136 <sup>e</sup>	6,888 <sup>e</sup>	0	12,786
IA	68	DNF	DNF	DNF <sup>e</sup>	DNF <sup>e</sup>	0	DNF
KS	0	5,004	82	DNF	DNF	0	DNF
KY	0	2,412 <sup>e</sup>	740 <sup>e</sup>	69 <sup>e*</sup>	1,076 <sup>e</sup>	0	4,297
LA	0	0	0	2,366	11,641	0	14,007
ME	0	1,998 <sup>e</sup>	782 <sup>e</sup>	541 <sup>e</sup>	1,129 <sup>e</sup>	19 <sup>e</sup>	4,469
MD	0	DNF	DNF	DNF	DNF	0	DNF
MA	1,171	DNF	DNF	DNF	DNF	0	DNF
MI	0	10,842	535	6,828	22,064	1,232	41,501
MN	332	8,565	1,356	1,289	6,630	1,021	19,193
MS	212	160 <sup>e</sup>	0 <sup>e</sup>	15 <sup>e</sup>	1,087	0	1,474
MO	211	2,530	0	3,958	4,553	0	11,252
MT	0	1,726 <sup>e</sup>	42	100	800	0	2,668
NE	0	1,630	574	1,322	1,130	0	4,656
NV	0	0	36	1,150	454	12	1,652
NH	0	348	1,081	459	924	0	2,812
NJ	46	5,863 <sup>e</sup>	680 <sup>e</sup>	0 <sup>0</sup>	4,754 <sup>e</sup>	0	11,343
NM	56	1,096 <sup>ed</sup>	0 <sup>ed</sup>	274 <sup>ed</sup>	651 <sup>ed</sup>	1,802 <sup>ed</sup>	3,879
NY	7,329	21,762	2,294	5,033	41,011	0 <sup>e</sup>	77,429
NC	0	DNF	DNF	DNF	DNF	0	DNF
ND	0	326	20	1,126	1,225	0	2,697
OH	0	2,658	897	10,099	14,397	168	28,219
OK	0	786	407	1,667	2,363	0	5,223
OR	108	2,729	3,273	764	10,479	0	17,353
PA	0	10,673	1,567	2,294 <sup>e</sup>	12,848 <sup>e</sup>	2,581 <sup>e</sup>	29,963
RI	212	1,077	183	676	1,380	0	3,528
SC	0	2,677	156	618	4,943	0	8,394
SD	0	1,714	4	374	1,123	0	3,215
TN	0	767	338	3,647	2,928	0	7,680
TX	0	6,732	9,738	3,485	9,238	0	29,193
UT	0	1,392	267	967	1,693	0	4,319
VT	0	131	1,300	191	673	0	2,295
VA	0	3,636	801	1,235	1,445	0	7,117
WA	130	1,506	91	5,341	4,848 <sup>e</sup>	92 <sup>e</sup>	12,008
WV	0	1,265	156	32	2,994	0	4,447
WI	0	2,470	5,085	4,307 <sup>e</sup>	11,524 <sup>e</sup>	9	23,395
WY	0	1,127 <sup>e</sup>	63	216	744	0	2,150
<b>US Total</b>	<b>10,843</b>	<b>157,055</b>	<b>46,889</b>	<b>83,946</b>	<b>296,580</b>	<b>8,566</b>	<b>603,879</b>
<b>Est US Total</b>	<b>10,843</b>	<b>173,698</b>	<b>52,876</b>	<b>93,924</b>	<b>340,702</b>	<b>8,566</b>	<b>680,610</b>
<b>Est Percent</b>	<b>2%</b>	<b>26%</b>	<b>8%</b>	<b>14%</b>	<b>50%</b>	<b>1%</b>	<b>100%</b>

<sup>0</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix 1 The reported total HCBS Waiver participants reported by setting type is often different than the HCBS Waiver recipients in the expenditures calculation usually because states use of different data sources to compute the number of participants.

lived in a host home or with a foster family, 93,924 (14%) lived in a home they owned or leased, 340,720 (50%) lived in the home of a family member, and 8,566 lived in some other type of setting (See [Table 3.1](#)). Altogether, 43 states reported residential setting types for all HCBS Waiver recipients with IDD.

Only 10 states provided HCBS Waiver-funded LTSS to people with IDD in a state-operated setting. Those states included Colorado, Connecticut, Massachusetts, Minnesota, Mississippi, Missouri, New York, Oregon, Rhode Island, and Washington.

All states provided HCBS Waiver-funded LTSS to people with IDD in nonstate group homes, host home/foster family, own home, and/or family home settings. The proportion of HCBS Waiver recipients who lived in nonstate group homes ranged from a high of 83% in Delaware to 0% in Louisiana. Other states serving more than 60% of HCBS Waiver recipients in a nonstate group home included Alabama (61%) and Montana (65%).

The proportion of HCBS Waiver recipients with IDD who lived in a host home or foster family setting ranged from a high of 57% in Vermont to 0% in Louisiana, Mississippi, Missouri, New Mexico, and South Dakota. Other New Hampshire and Texas also reported more than 30% of HCBS Waiver recipients with IDD living in host home or foster family settings.

The proportion of HCBS Waiver recipients with IDD who lived in a home they owned or leased ranged from 70% in Nevada to 0% in Delaware and New Jersey. Other states serving more than 40% of HCBS Waiver recipients in homes they owned or leased included Indiana (40%), North Dakota (42%), Tennessee (47%) and Washington (44%).

The proportion of HCBS Waiver recipients with IDD who lived in the home of a family member ranged from a high of 83% in Arizona and Louisiana to less than 1% in Delaware. States reporting that more than 60% of HCBS Waiver recipients with IDD lived in the home of a family member included California (67%), Hawaii (64%), Mississippi (74%), Oregon (60%), and West Virginia (67%).

Finally 13 states reported HCBS Waiver recipients living in a setting other than those listed but only Colorado (12%) and New Mexico (46%) reported serving more than 10% of recipients in other settings.

## Size of State and Nonstate ICF/IID Certified Facilities

The Intermediate Care Facilities for Individuals with Intellectual Disabilities program is a Medicaid state plan option. Each state can decide whether or not to offer the ICF/IID as a state plan option. For participating states the ICF/IID program is an entitlement program for eligible enrollees. However, unlike the HCBS Waiver program, people are not free to move unless there is an opening in another ICF/IID facility. In the HCBS Waiver program the money goes with the person if he or she moves or changes service providers, offering substantially more flexibility in where the person lives and in the mix of services the person receives. The number of ICF/IID facilities and residents has been declining since the introduction of the Medicaid Home and Community-based Waivers.

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*IN THE HCBS WAIVER PROGRAM THE MONEY GOES WITH THE PERSON IF HE OR SHE MOVES OR CHANGES SERVICE PROVIDERS, OFFERING SUBSTANTIALLY MORE FLEXIBILITY IN WHERE THE PERSON LIVES AND IN THE MIX OF SERVICES THE PERSON RECEIVES.*

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As [Table 3.2](#) shows, there were an estimated 6,544 ICF/IID facilities in operation on June 30, 2012. Of those facilities, 339 (5%) were state-operated and 6,205 (95%) were operated by a nonstate entity.

Overall, an estimated 4,040 (61%) of the ICF/IID certified settings served 6 or fewer people, 2,107 (28%) served 7-15 people and 590 (8%) served 15 or more people with IDD.

Historically, ICF/IID settings with 16 or more people are classified as institutional settings, those with fewer than 16 people are classified by Medicaid as community ICF/IID settings by Medicaid. Under the 2014 Medicaid Home and Community Based Waiver rule all ICF/IID certified settings are considered institutions. The size of ICF/IID settings differed for those that were state-operated versus those that were nonstate-operated. Of the state-operated ICF/IID facilities, 21% served 6 or fewer people with IDD, 28% served 7 to 15 people with IDD and 52% served

**Table 3.2** Number of ICF/IID Certified Facilities by State and Size on June 30, 2012

State	State Settings				Nonstate Settings				All Settings			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
N States	51	51	51	51	47	47	48	49	49	49	49	47
AL	0	0	0 *	0	2	2	0	4	2	2	0	4
AK	0	0	0	0	0	0	0	0	0	0	0	0
AZ	1	3	1 *	5	0	0	1	1	1	3	2	6
AR	0	0	5	5	0	31	4	35	0	31	9	40
CA	0	0	5	5	1,226	0	10	1,236	1,226	0	15	1,241
CO	11	17	2	30	4	0	0	4	15	17	2	34
CT	0	0	6	6	63	4	0	67	63	4	6	73
DE	0	0	1	1	0	0	1	1	0	0	2	2
DC	0	0	0	0	72	0	0	72	72	0	0	72
FL	0	0	2	2	35	5	49	89	35	5	51	91
GA	0	0	2 *	2	0	0	0	0	0	0	2	2
HI	0	0	0	0	17	1	0	18	17	1	0	18
ID	0	0	1	1 <sup>e</sup>	DNF	DNF	0	67 <sup>e</sup>	0	0	1	68
IL	0	0	8	8	42	211	34	287	42	211	42	295
IN	0	0	0 *	0	220	319	3	542	220	319	3	542
IA	0	0	2	2	70	45	21	136	70	45	23	138
KS	0	0	2	2	DNF	DNF	0	28	DNF	DNF	2	DNF
KY	0 <sup>e</sup>	3 <sup>e</sup>	2 <sup>e</sup>	5 <sup>e</sup>	0	0	2 <sup>e</sup>	2 <sup>e</sup>	0	3	4	7
LA	0	1	4	5	494	14	8	516	494	15	12	521
ME	0	0	0	0	2	11	4	17	2	11	4	17
MD	0	1	2	3	0	0	0	0	0	1	2	3
MA	0	1	5	6	0	0	0	0	0	0	0	6
MI	0	0	0	0	0	0	0	0	0	0	0	DNF
MN	15	0	0	15	134	46	15	195	149	46	15	210
MS	1 <sup>e</sup>	60 <sup>e</sup>	6 *	67	0	0	7	7	1	60	13	74
MO	0	0	6	6	0	6	1	7	0	6	7	13
MT	0	0	1	1	0	0	0	0	0	0	1	1
NE	0	1	3	4	6	1	2	9	6	2	5	13
NV	0	0	1	1	6	1	1	8	6	1	2	9
NH	0	0	0	0	0	0	1	1	0	0	1	1
NJ	0	0	7	7	0	0	DNF	DNF	0	0	DNF	DNF
NM	1 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	1 <sup>ed</sup>	24 <sup>ed</sup>	14 <sup>ed</sup>	0 <sup>ed</sup>	38 <sup>ed</sup>	25	14	0	39
NY	8	7	46	61	83	416	31	530	91	423	77	591
NC	2	0	4 <sup>e</sup>	6 <sup>e</sup>	275	34 <sup>ed</sup>	13 <sup>e</sup>	322 <sup>e</sup>	277	34	17	328
ND	0	0	1	1	28	36	1	65	28	36	2	66
OH	0	0	10	10	106	233	81	420	106	233	91	430
OK	0	0	2	2	24	41	20	85	24	41	22	87
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	5	5	DNF	DNF	DNF	179	DNF	DNF	DNF	184
RI	4 <sup>e</sup>	0	0	4	0	0	1	1	4	0	1	5
SC	0	0	5	5	0	70	0	70	0	70	5	75
SD	0	0	1	1	0	0	1	1	0	0	2	2
TN	25	0	2	27	62	49	3	114	87	49	5	141
TX	2	0	13	15	784	49	9	842	786	49	22	857
UT	0	0	1	1	0	2	13	15	0	2	14	16
VT	0	0	0	0	1	0	0	1	1	0	0	1
VA	0	0	5	5	16	18	2	36	16	18	7	41
WA	0	0	3 *	3	7	1	0	8	7	1	3	11
WV	0	0	0 <sup>e</sup>	0	DNF	DNF	DNF	DNF	0	0	0	DNF
WI	0	0	2	2	0	4	6	10	0	4	8	12
WY	0	0	1	1	0	0	0	0	0	0	1	1
Reported Total	70	94	175	339	3,803	1,664	345	6,086	3,873	1,757	503	6,388
Estimated Total	70	94	175	339	3,970	2,013	415	6,205	4,040	2,107	590	6,544
								% of all ICF/IID	61%	28%	8%	100%

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish \* See state notes in Appendix

16 or more people with IDD. On the other hand, the majority (64%) of nonstate ICF/IID settings served 6 or fewer people, 32% served 7 to 15 people, and only 7% served 16 or more people.

States varied considerably both in the total number of people living in ICF/IID settings and in the size of those settings. Two states reported having no ICF/IID facilities located in the state (Alaska and Oregon) and 14 reported having fewer than seven ICF/IID settings. Alaska reported sending 17 people with IDD to live in an ICF/IID in another state. However, 12 states had 100 or more ICF/IID facilities.

States with the most ICF/IID settings on June 30, 2012 were California (1,241), Indiana (542), Louisiana (521), New York (591), and Texas (857). After 35 years of deinstitutionalization, in 15 states ICF/IID facilities with 16 or more residents housed 25% or more of all ICF/IID residents. States with the highest proportion of ICF/IID settings with 16 or more residents included Delaware (2 facilities, 100%), Florida (51, 56%), Georgia (2, 100%), Hawaii (2, 100%), Kentucky (4, 57%), Maryland (2, 67%), Missouri (7, 54%), Montana (1, 100%), New Hampshire (1, 100%), South Dakota (2, 100%), Utah (14, 88%), Wisconsin (8, 67%), and Wyoming (1, 100%). In eight states between 80% and 100% of all ICF/IID facilities had six or fewer residents (California, Connecticut, the District of Columbia, Hawaii, Louisiana, North Carolina, Texas, and Vermont).

Five states reported that all ICF/IID facilities were state-operated (Georgia, Maryland, Massachusetts, Montana and Wyoming). Conversely, all ICF/IID facilities were nonstate-operated in seven states (Alabama, the District of Columbia, Hawaii, Indiana, Maine, New Hampshire, and Vermont). Only 3 states operated ten or more ICF/IID settings serving 6 or fewer people (Colorado, 11; Minnesota, 15; and Tennessee, 25).

## People with IDD Living in ICF/IID Certified Facilities

An estimated 85,384 people with IDD lived in an ICF/IID certified facility on June 30, 2012 (See [Table 3.3](#)). Of those people 27,440 (32%) lived in state-operated facilities and 57,944 (68%) lived in nonstate facilities. Early in the deinstitutionalization process, states reduced the census in state-operated settings by moving people to large nonstate ICF/IID facilities. To continue to reduce the number of individuals served in ICF/IIDs, both state-operated and nonstate-operated ICF/IID settings will have to be downsized or closed.

An estimated total of 21,891 people (26%) lived in ICF/IID settings serving 6 or fewer people, 18,459 (22%) lived in ICF/IID settings with 7 to 15 people, and 45,034 (53%) lived in settings with 16 or more people. While only 32% of all people living in an ICF/



**Table 3.3** Persons with IDD Living in ICF/IID Certified Facilities by State and Size on June 30, 2012

State	Residents in State ICF/IID				Residents in Nonstate ICF/IID				Residents in All ICF/IID			
	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	47	47	49
AL	0	0	0	0	7	34	0	41	7	34	0	41
AK	0	0	0	0	0	0	0	0	0	0	0	0
AZ	6	25	82	113	0	0	35	35	6	25	117	148
AR	0	0	951	951	0	311	205	516	0	311	1,156	1,467
CA	0	0	1,682	1,682	6,279	0	765	7,044	6,279	0	2,447	8,726
CO	61	100	161	322	21	0	0	21	82	100	0	343
CT	0	0	612	612	333	39	0	372	333	39	612	984
DE	0	0	66	66	0	0	0	0	0	0	0	66
DC	0	0	0	0	363	0	0	363	363	0	0	363
FL	0	0	781	781	204	58	1,743	2,005	204	58	2,524	2,786
GA	0	0	300	300	0	0	0	0	0	0	300	300
HI	0	0	0	0	72	7	0	79	72	7	0	79
ID	0	0	47	47	DNF	DNF	0	438	DNF	DNF	47	485
IL	0	0	1,928	1,928	198	3,083	3,135	6,416	198	3,083	5,063	8,344
IN	0	0	0	0	1,102	2,447	290	3,839	1,102	2,447	290	3,839
IA	0	0	444	444	257	424	877	1,558	257	424	1,321	2,002
KS	0	0	334	334	DNF	DNF	0	175	DNF	DNF	334	509
KY	0	6 <sup>e</sup>	143 <sup>e</sup>	149	0	0	136 <sup>e</sup>	136 <sup>e</sup>	0	6	279	285
LA	0	9	839	848	3,035	172	549	3,756	3,035	181	1,388	4,604
ME	0	0	0	0	11	116	62	189	11	116	62	189
MD	0	0 <sup>e</sup>	54	54	0	0	0	0	0	0	54	54
MA	0	14	580	594	0	0	0	0	0	0	0	594
MI	0	0	0	0	0	0	0	0	0	0	0	0
MN	89	0	0	89	738	490	402	1,630	827	490	402	1,719
MS	6 <sup>e</sup>	586 <sup>e</sup>	1,441 <sup>e</sup>	2,033	0	0	732	732	6	586	0	2,765
MO	0	0	510	510	0	50	30	80	0	50	540	590
MT	0	0	55	55	0	0	0	0	0	0	55	55
NE	0	8	136	144	36	9	244	289	36	17	380	433
NV	0	0	48	48	32	6	18	56	32	6	66	104
NH	0	0	0	0	0	0	25	25	0	0	25	25
NJ	0	0	2,434	2,434	0	0	719	719	0	0	3,153	3,153
NM	4 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	4	110 <sup>ed</sup>	120 <sup>ed</sup>	0 <sup>ed</sup>	230 <sup>ed</sup>	114	120	0	234
NY	35	54	1,633	1,722	444	4,153	969	5,566	479	4,207	2,602	7,288
NC	0	0	1,424	1,424	1,500 <sup>e</sup>	392 <sup>e</sup>	614 <sup>e</sup>	2,506 <sup>e</sup>	1,500	392	2,038	3,930
ND	0	0	94	94	158	277	30	465	158	277	124	559
OH	0	0	1,134	1,134	550	2,028	3,214	5,792	550	2,028	4,348	6,926
OK	0	0	235	235	123	417	774	1,314	0	0	0	1,549
OR	0	0	0	0	0	0	0	0	0	0	0	0
PA	0	0	1,106	1,106	DNF	DNF	DNF	2,313	DNF	DNF	DNF	3,419
RI	21	0	0	21	0	0	21	21	21	0	21	42
SC	0	0	745	745	0	568	0	568	0	568	745	1,313
SD	0	0	140	140	0	0	59	59	0	0	199	199
TN	97	0	183	280	268	392	168	828	365	392	351	1,108
TX	10	0	3,787	3,797	4,541	555	574	5,670	4,551	555	4,361	9,467
UT	0	0	207	207	0	28	566	594	0	28	773	801
VT	0	0	0	0	6	0	0	6	6	0	0	6
VA	0	0	948	948	84	178	116	378	84	178	1,064	1,326
WA	0	0	576	576	39	14	0	53	39	14	576	629
WV	0	0	0 <sup>*e</sup>	0	DNF	DNF	DNF	562 <sup>e*</sup>	DNF	DNF	DNF	562
WI	0	0	390	390	0	28	477 <sup>e</sup>	505 <sup>e</sup>	0	28	867	895
WY	0	0	79	79	0	0	0	0	0	0	79	79
Reported Total	329	802	26,309	27,440	20,511	16,396	17,549	57,944	20,717	16,767	38,763	85,384
Estimated US Total	329	802	26,309	27,440	21,562	17,657	18,725	57,944	21,891	18,459	45,034	85,384

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix

IID live in a state-operated setting of any size, 61% of all people living in ICF/IIDs with 16 or more residents live in state operated settings. Overall, ICF/IID settings with 16 or more residents had a population of 76 people on June 30, 2012. Large state operated ICF/IIDs served 157 people each on average compared to 45 people each for nonstate ICF/IID settings.

*UNDER THE NEW HCBS RULES, BOTH PAST AND NEWLY CONVERTED FACILITIES WILL LIKELY REQUIRE SUBSTANTIAL OPERATIONAL AND PHYSICAL MODIFICATION (INCLUDING REDUCTIONS IN SIZE) TO QUALIFY FOR USE AS AN HCBS WAIVER FUNDED SETTING.*

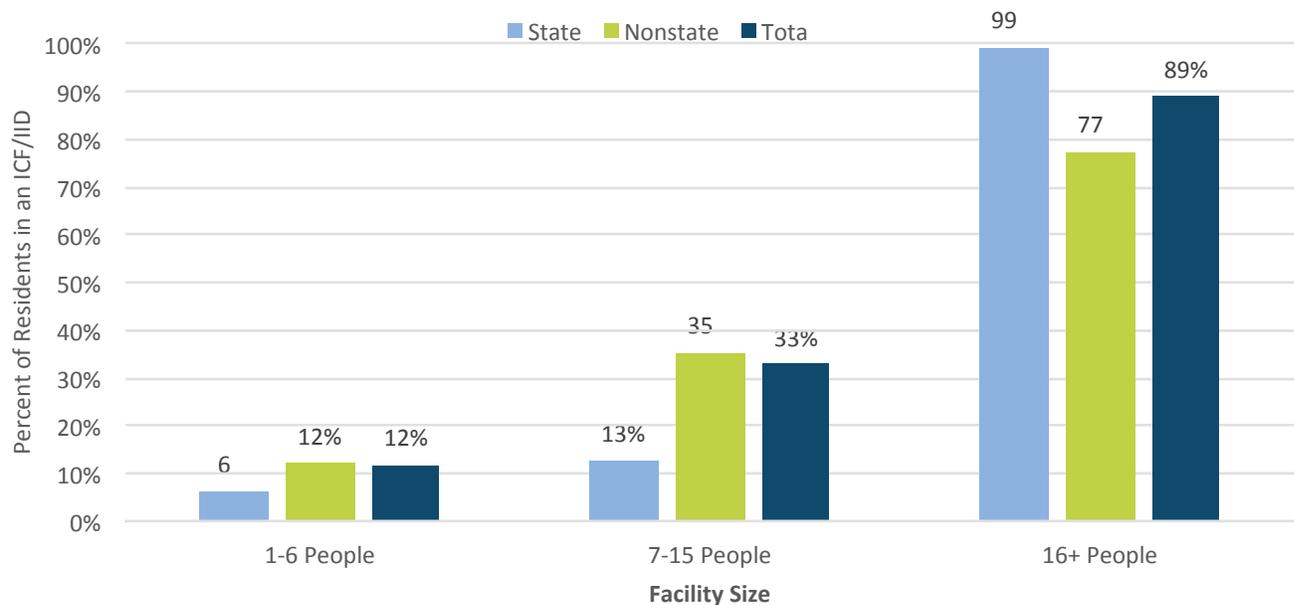
The number of people living in ICF/IID facilities ranged from 0% in Alaska, Michigan and Oregon to more than 8,000 in California (8,726), Illinois (8,344), and Texas (9,457). Among states with ICF/IID facilities, the proportion of ICF/IID residents who lived in facilities with 16 or more residents ranged from 0% in Alabama, Colorado, Delaware, the District of Columbia, Hawaii, Massachusetts, Mississippi, New

Mexico, Oklahoma and Vermont to 100% in Georgia, Maryland, Montana, New Hampshire, New Jersey, South Dakota, and Wyoming.

In the past, CMS has allowed states to convert residential settings from ICF/IID funding to HCBS Waiver funding without changing the facility. Under the new HCBS rules, both past and newly converted facilities will likely require substantial operational and physical modification (including reductions in size) to qualify for use as an HCBS Waiver funded setting. Former ICF/IID settings will likely be subject to the heightened scrutiny provisions of the rule which will require significant state attestation and evidence as to their community characteristics.

The proportion of people with IDD living in non-family settings who live ICF/IID facilities varies by both setting size and type of operation (See [Figure 3.1](#)). Overall, 12% of people in non-family settings with 6 or fewer residents lived in an ICF/IID compared with 33% in settings with 7 to 15 residents and 89% in settings with 16 or more residents. An estimated 77% of people with IDD living in nonstate settings of 16 or more people lived in an ICF/IID compared with 99% of people in state operated facilities of 16 or more residents. Only 13% of people living in state settings

**Figure 3.1** ICF/IID Residents as a Proportion of All Residents in State and Nonstate Congregate Settings by Size on June 30, 2012



**Table 3.4** Utilization Rates per 100,000 of State Population for ICF/IID, HCBS Waiver Recipients and All Non-Family Medicaid and Non-Medicaid Funded Settings by State on June 30, 2012

State	State Population (100,000)**	ICF/IID Residents				HCBS Total	HCBS and ICF/IID Total	Residential Service Recipients Not Living in Family Home (Medicaid and Non-Medicaid)					
		1-6	7-15	16+	Total			1-6	7-15	16+	Total		
<b>N States</b>		<b>47</b>	<b>47</b>	<b>49</b>	<b>48</b>	<b>51</b>	<b>51</b>	<b>48</b>	<b>51</b>	<b>39</b>	<b>40</b>	<b>43</b>	<b>51</b>
AL	48.2	0.1	0.7	0.0	0.9	116.2	117.1	60.8	16.9	0.0	77.7		
AK	7.3	0.0	0.0	0.0	0.0	232.8	232.8	153.0	0.0	0.0	153.0		
AZ	65.5	0.1	0.4	1.8	2.3	375.6	377.9	66.4	0.4	2.2	68.9		
AR	29.5	0.0	10.5	39.2	49.7	136.9	186.6	46.3	29.4	51.0	126.7		
CA	380.4	16.5	0.0	6.4	22.9	257.3	280.2	138.2	3.0	8.9	150.2		
CO	51.9	1.6	1.9	0.0	6.6	157.0	163.7	105.1	4.0	5.7	114.8		
CT	35.9	9.3	1.1	17.0	27.4	240.6	268.0	163.9	9.6	17.0	190.6		
DE	9.2	0.0	0.0	0.0	7.2	93.2	100.4	99.1	2.5	7.2	108.8		
DC	6.3	57.4	0.0	0.0	57.4	233.9	291.3	217.9	0.0	0.0	217.9		
FL	193.2	1.1	0.3	13.1	14.4	151.9	166.4	DNF	DNF	DNF	127.9		
GA	99.2	0.0	0.0	3.0	3.0	117.1	120.2	DNF	DNF	DNF	48.6		
HI	13.9	5.2	0.5	0.0	5.7	182.7	188.4	73.2	0.5	0.0	73.7		
ID	16.0	DNF	DNF	2.9	30.4	184.3	214.7	DNF	DNF	8.8	210.8		
IL	128.8	1.5	23.9	39.3	64.8	142.6	207.4	DNF	63.7	40.6	160.1		
IN	65.4	16.9	37.4	4.4	58.7	195.6	254.3	107.1	37.4	4.4	148.9		
IA	30.7	8.4	13.8	43.0	65.1	369.5	434.6	DNF	29.9	46.5	152.5		
KS	28.9	DNF	DNF	11.6	DNF	286.7	DNF	DNF	DNF	11.6	206.9		
KY	43.8	0.0	0.1	6.4	6.5	252.2	258.7	79.8	0.1	6.4	86.3		
LA	46.0	66.0	3.9	30.2	100.0	216.4	316.4	119.6	3.9	30.2	153.7		
ME	13.3	0.8	8.7	4.7	14.2	308.5	322.8	256.8	8.7	8.8	274.3		
MD	58.8	0.0	0.0	0.9	0.9	212.2	213.2	129.8	4.0	0.9	134.7		
MA	66.5	0.0	0.0	0.0	8.9	180.4	189.3	DNF	DNF	8.7	190.1		
MI <sup>1</sup>	98.8	0.0	0.0	0.0	0.0	403.1	403.1	DNF	DNF	DNF	214.1		
MN	53.8	15.4	9.1	7.5	32.0	352.5	384.5	DNF	DNF	DNF	279.5		
MS	29.8	0.2	19.6	0.0	92.6	61.3	154.0	11.0	21.8	72.8	106.2		
MO	60.2	0.0	0.8	9.0	9.8	183.3	193.1	93.5	18.4	10.3	122.2		
MT	10.1	0.0	0.0	5.5	5.5	265.4	270.9	144.6	41.3	5.5	191.3		
NE	18.6	1.9	0.9	20.5	23.3	244.2	267.5	186.4	6.5	20.5	213.4		
NV	27.6	1.2	0.2	2.4	3.8	59.9	63.6	59.8	0.2	5.5	65.6		
NH	13.2	0.0	0.0	1.9	1.9	342.2	344.1	128.3	1.4	1.9	131.8		
NJ	88.6	0.0	0.0	35.6	35.6	127.4	163.0	83.4	16.2	36.5	136.1		
NM	20.9	5.5	5.8	0.0	11.2	197.3	208.5	160.2	5.8	0.0	166.0		
NY	195.7	2.4	21.5	13.3	37.2	393.7	430.9	135.2	96.2	13.4	244.8		
NC	97.5	15.4	4.0	20.9	40.3	131.3	171.6	63.7	DNF	DNF	90.1		
ND	7.0	22.6	39.6	17.7	79.9	580.2	660.1	198.2	74.3	17.7	290.3		
OH	115.4	4.8	17.6	37.7	60.0	293.0	353.0	163.3	23.0	37.8	224.0		
OK	38.1	0.0	0.0	0.0	40.6	136.9	177.5	74.1	15.0	26.4	115.6		
OR	39.0	0.0	0.0	0.0	0.0	381.2	381.2	169.3	5.6	0.7	175.6		
PA	127.6	DNF	DNF	DNF	DNF	234.8	DNF	DNF	DNF	DNF	209.0		
RI	10.5	2.0	0.0	2.0	4.0	315.7	319.7	187.6	15.8	5.1	208.5		
SC	47.2	0.0	12.0	15.8	27.8	177.7	205.5	68.0	18.8	15.8	102.6		
SD	8.3	0.0	0.0	23.9	23.9	385.8	409.7	205.4	70.2	23.9	299.5		
TN	64.6	5.7	6.1	5.4	17.2	119.0	136.1	74.0	11.4	5.4	90.8		
TX	260.6	17.5	2.1	16.7	36.3	112.0	148.4	94.0	2.1	16.7	112.9		
UT	28.6	0.0	1.0	27.1	28.1	151.3	179.3	87.9	5.7	27.1	120.7		
VT	6.3	1.0	0.0	0.0	1.0	423.2	424.1	269.2	0.0	0.0	269.2		
VA	81.9	1.0	2.2	13.0	16.2	119.2	135.4	55.9	7.3	38.7	101.8		
WA	69.0	0.6	0.2	8.4	9.1	172.5	181.6	DNF	DNF	DNF	141.7		
WV	18.6	DNF	DNF	DNF	DNF	239.7	DNF	DNF	DNF	DNF	108.6		
WI	57.3	0.0	0.5	15.1	15.6	408.6	424.2	205.1	0.5	15.1	222.9		
WY	5.8	0.0	0.0	13.7	13.7	373.0	386.7	228.1	15.8	13.7	257.6		
<b>Estimated US Total</b>	<b>3,139.1</b>	<b>7.0</b>	<b>5.9</b>	<b>14.3</b>	<b>27.2</b>	<b>219.3</b>	<b>246.5</b>	<b>103.4</b>	<b>15.8</b>	<b>15.5</b>	<b>151.0</b>		

<sup>o</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish \* See state notes in Appendix 1 These columns exclude people living in family homes, nursing homes or psychiatric facilities.

with 7 to 15 residents and 6% of people living in state settings with 1 to 6 residents lived in an ICF/IID. By comparison, 35% of all people with IDD living in nonstate settings with 7 to 15 residents lived in an ICF/IID and 12% of people with IDD living in nonstate settings with 6 or fewer residents lived in an ICF/IID.

## State Utilization Rates for ICF/IID and HCBS Waiver-funded Services

Table 3.4 compares the number of people with IDD living in ICF/IID or HCBS Waiver-funded settings to the state and US total populations. Nationally, an average of 27.2 people with IDD lived in ICF/IID facilities per 100,000 of the population, and 218.3 people with IDD received HCBS Waiver-funded LTSS per 100,000 of the population.

An estimated 103.4 per 100,000 lived in ICF/IID or non-family HCBS Waiver funded settings with 6 or fewer residents, 15.8 per 100,000 lived in facilities with 7 to 15 residents, and 15.5 per 100,000 lived in facilities with 16 or more residents.

The number of people with IDD living in ICF/IID settings ranged from 0 per 100,000 in Oregon to 100 per 100,000 in Louisiana. States serving more than 50 people per 100,000 of the population in ICF/IID facilities included the District of Columbia (57.4 people per 100,000), Illinois (64.8), Indiana (58.7), Iowa (65.1), Louisiana (100.0), Mississippi (92.6), North Dakota (79.9) and Ohio (60.0).

The number of HCBS Waiver recipients with IDD per 100,000 of the population ranged from 27.8 per 100,000 in Wyoming to 580.2 in North Dakota. Other states with high utilization rates included Michigan (403.1 per 100,000), New York (393.7), South Dakota (385.8) and Vermont (423.2). Along with Wyoming, states with the lowest utilization of non-family HCBS Waiver-funded LTSS for people with IDD were Delaware (93.2), Mississippi (61.3), Nevada (59.9), and Texas (112.0).

Combined utilization rates for Medicaid ICF/IID or HCBS Waiver-funded LTSS per 100,000 of the population ranged from 39.2 in Wyoming to 660.1 in North Dakota. In addition to Wyoming, states with the lowest utilization rates for these programs were Alabama (117.1 people per 100,000), Delaware (100.4) and Nevada (63.6). In addition to North Dakota, states with the highest utilization rates for these programs were Iowa (434.5), New York (430.9), and Vermont (434.1).

Finally, the total number of people with IDD per 100,000 of the population served under the auspices of state IDD agencies or directors in settings other than the home of a family member ranged from 26.1 in Wyoming to 299.5 in South Dakota. Other states with utilization rates of less than 100 per 100,000 of the population included Alabama (77.7), Arizona (68.9), Georgia (48.6), Hawaii (73.7), Kentucky (86.3), Nevada (65.6), North Carolina (90.1) and Tennessee (90.8). Other states with utilization rates of more than 250 per 100,000 included Maine (274.3), Minnesota (279.5), North Dakota (290.3), and Vermont (269.2).





**SECTION FOUR**

**Medicaid HCBS Waiver  
and ICF/IID Expenditures for  
People with IDD**

**FY 2012**



## SECTION 4: MEDICAID HCBS WAIVER AND ICF/IID EXPENDITURES FOR PEOPLE WITH IDD IN FY 2012

**Section 4 includes the total** FY 2012 state and federal Medicaid expenditures for ICF/IID and HCBS Waiver-funded LTSS. Data sources for this section include the RISP/FISP survey of state IDD directors, the US Bureau of the Census, and the CMS website. Expenditures for Idaho, Michigan, Ohio, South Carolina, and Wyoming were from the report *Medicaid expenditures for long-term services and supports in FFY 2012* (Eiken et al., 2014). Five states reported expenditures and recipients for their HCBS 1915(c) IDD Waiver but did not report expenditures or recipients for other HCBS Waivers (Idaho, Mississippi, Ohio, South Carolina and Wyoming). For those states the HCBS Waiver Expenditures per recipient is based only people supported on 1915(c) Waivers.

### HCBS Waiver Expenditures in FY 2012

[Table 4.1](#) shows total annual expenditures for people with IDD receiving HCBS Waiver-funded LTSS in FY 2012. It also shows the federal cost share percentage for Medicaid for each state. Total HCBS Waiver expenditures for people with IDD in FY 2012 were \$29.5 billion dollars. The Federal government paid \$16.6 billion of the cost for HCBS Waiver supports (an average cost share of 59.6% per state).

Estimated annual expenditures per participant in HCBS Waiver-funded LTSS were \$45,219 for the United States. Annual per participant HCBS Waiver expenditures ranged from \$11,188 in Michigan to \$110,326 in Delaware. In addition to Delaware, the states with the highest per participant costs included Alaska (\$78,988), Connecticut (\$83,454), the District of Columbia (\$99,524), and Tennessee (\$78,659). Besides Michigan, the states with the lowest per participant costs were Arizona (\$26,030), California (\$21,534), Idaho (\$21,936), and Mississippi (\$24,163).

Caution is required when interpreting these results. The type and amount of service available to HCBS Waiver recipients varied by state. Section 1 showed that expenditures are higher for adults than for children, and higher for people living in a setting other than the home of a family member than for people living with a family member. State waivers are often targeted to specific disability types, specific age groups, and in some cases, specific types of living

arrangements. States that differ on those variables would have different costs overall but may be more similar if compared to programs with the same characteristics in other states.

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*STATE WAIVERS ARE OFTEN TARGETED TO SPECIFIC DISABILITY TYPES, SPECIFIC AGE GROUPS, AND IN SOME CASES, SPECIFIC TYPES OF LIVING ARRANGEMENTS. STATES THAT DIFFER ON THOSE VARIABLES MAY HAVE DIFFERENT COSTS OVERALL BUT MAY BE MORE SIMILAR IF COMPARED TO PROGRAMS WITH THE SAME CHARACTERISTICS IN OTHER STATES.*

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The last column on [Table 4.1](#) indexes the total HCBS Waiver expenditures for people with IDD to the state population (in 100,000s). Annual HCBS Waiver expenditures per 100,000 of the population averaged \$94 in FY 2012. Cost per 100,000 ranged from \$15 in Mississippi to \$279 in New York. HCBS Waiver services expenditures per 100,000 state residents were the highest in Maine (\$219), Minnesota (\$226), Vermont (\$226), the District of Columbia (\$233) and New York (\$279). HCBS Waiver services expenditures per 100,000 state residents were the lowest in Mississippi (\$15), Nevada (\$29), Idaho (\$40), and Texas (\$41).

### ICF/IID Expenditures on FY 2012

[Table 4.2](#) shows expenditures in FY 2012 for ICF/IID services. Overall expenditures for ICF/IID services were \$12.3 billion in FY 2012. The federal expenditures for the Medicaid ICF/IID program was \$6.9 billion.

The proportion of Federal Medicaid ICF/IID expenditures received per state ranged from a high of 23.3% in New York (which served 8.5% of all ICF/IID residents) to a low of 0.01% in Alabama (with 0.05% of ICF/IID recipients) and in Vermont (with 0.01% of ICF/IID residents).

**Table 4.1** HCBS Waiver Expenditures for People with IDD by State for Fiscal Year 2012

	Total HCBS Expenditures for People with IDD (\$)	Federal Cost Share (%)	Total Federal HCBS Payments(\$)	State % of Federal HCBS Payments	June 30, 2012 HCBS Recipients	HCBS Expenditures per Recipient	*State Population (100,000)	Annual HCBS Expenditure per State Resident (\$)
N States	51	51	51	51	51	51	51	51
AL	288,701,202	68.6	198,106,765	1.2%	5,604	51,517	48.2	59.87
AK	134,516,256	50.0	67,258,128	0.4%	1,703	78,988	7.3	183.90
AZ	640,785,297	67.3	431,248,505	2.6%	24,617	26,030	65.5	97.78
AR	173,134,527 <sup>e</sup>	70.7	122,423,424	0.7%	4,037	42,887	29.5	58.71
CA	2,107,489,165	50.0	1,053,744,583	6.3%	97,868	21,534	380.4	55.40
CO	331,009,675	50.0	165,504,838	1.0%	8,147	40,630	51.9	63.81
CT	720,877,844	50.0	360,438,922	2.2%	8,638	83,454	35.9	200.78
DE	94,328,870	54.2	51,097,949	0.3%	855	110,326	9.2	102.86
DC	147,196,144	70.0	103,037,301	0.6%	1,479	99,524	6.3	232.79
FL	879,855,035	56.0	493,070,762	3.0%	29,353	29,975	193.2	45.55
GA	407,211,908	66.2	269,411,399	1.6%	11,621	35,041	99.2	41.05
HI	102,909,919	50.5	51,948,927	0.3%	2,544	40,452	13.9	73.91
ID	64,424,617 <sup>T</sup>	70.2	45,245,409	0.3%	2,660	21,936 <sup>1</sup>	16.0	40.37
IL	591,460,042 <sup>e</sup>	50.0	295,730,021	1.8%	18,355	32,223	128.8	45.94
IN	489,970,561	67.0	328,084,288	2.0%	12,786	38,321	65.4	74.95
IA	387,579,845	60.7	235,299,724	1.4%	11,359	34,121	30.7	126.08
KS	330,269,359 <sup>e</sup>	56.9	187,956,292	1.1%	8,274	39,917	28.9	114.44
KY	406,429,143 <sup>e</sup>	71.2	289,296,264	1.7%	11,046	36,794	43.8	92.78
LA	407,247,885 <sup>e</sup>	61.1	248,787,733	1.5%	9,957	40,901	46.0	88.50
ME	291,071,088 <sup>e</sup>	63.3	184,160,678	1.1%	4,101	70,976	13.3	218.98
MD	686,893,892	50.0	343,446,946	2.1%	12,489	55,000	58.8	116.73
MA	841,480,869 <sup>T</sup>	50.0	420,740,435	2.5%	11,987	70,199	66.5	126.61
MI	445,712,073 <sup>T</sup>	66.1	294,793,965	1.8%	39,838	11,188	98.8	45.10
MN	1,215,080,921	50.0	607,540,461	3.7%	18,963	64,076	53.8	225.89
MS	43,976,251	74.2	32,621,583	0.2%	1,831	24,163 <sup>1</sup>	29.8	14.73
MO	533,966,837	63.5	338,801,958	2.0%	11,041	48,362	60.2	88.67
MT	90,871,419	66.1	60,075,095	0.4%	2,668	34,060	10.1	90.41
NE	239,920,704	56.6	135,891,087	0.8%	4,531	52,951	18.6	129.30
NV	78,766,702	56.2	44,266,887	0.3%	1,652	47,680	27.6	28.55
NH	192,024,701	50.0	96,012,351	0.6%	4,519	42,493	13.2	145.39
NJ	737,870,549 <sup>e</sup>	50.0	368,935,275	2.2%	11,297	65,316	88.6	83.24
NM	285,948,508 <sup>ed</sup>	69.4	198,333,885	1.2%	4,115	69,489	20.9	137.11
NY	5,468,224,696	50.0	2,734,112,348	16.4%	77,047	70,973	195.7	279.42
NC	619,805,304	65.3	404,608,902	2.4%	12,800	48,422	97.5	63.56
ND	129,617,461	55.4	71,808,073	0.4%	4,059	31,933	7.0	185.27
OH	1,240,862,952	64.2	796,013,584	4.8%	30,872	39,359 <sup>1</sup>	115.4	107.49
OK	273,951,817	63.9	175,000,421	1.1%	5,223	52,451	38.1	71.81
OR	597,868,202	62.9	376,118,886	2.3%	14,865	40,220	39.0	153.32
PA	1,816,306,161	55.1	1,000,239,803	6.0%	29,963	60,618	127.6	142.30
RI	203,663,206	52.1	106,149,263	0.6%	3,316	61,418	10.5	193.91
SC	291,243,055	70.2	204,569,122	1.2%	8,394	36,260 <sup>1</sup>	47.2	61.66
SD	101,739,037	59.1	60,158,293	0.4%	3,215	31,645	8.3	122.08
TN	604,098,205	66.4	400,879,569	2.4%	7,680	78,659	64.6	93.57
TX	1,058,827,386	58.2	616,449,304	3.7%	29,193	36,270	260.6	40.63
UT	155,514,728	71.0	110,399,905	0.7%	4,319	36,007	28.6	54.47
VT	141,617,128	57.6	81,543,142	0.5%	2,649	53,461	6.3	226.22
VA	602,412,138	50.0	301,206,069	1.8%	9,754	61,761	81.9	73.59
WA	550,895,554	50.0	275,447,777	1.7%	11,898	46,302	69.0	79.87
WV	303,861,581	72.6	220,664,280	1.3%	4,447	68,330	18.6	163.77
WI	855,374,008	60.5	517,757,887	3.1%	23,396	36,561	57.3	149.37
WY	98,412,406	50.0	49,206,203	0.3%	2,150	45,812 <sup>1</sup>	5.8	170.73
Est US Total	29,503,276,833	59.6	16,625,644,665	100.0%	688,410	44,160	3,139	93.99

<sup>o</sup> 2011 data <sup>e</sup> Estimate DNF Did not furnish \* See state notes in Appendix 1 Recipient and cost estimates based only on recipients and expenditures for HCBS 1915 (c) Waivers only (excludes people with IDD on other HCBS Waivers). <sup>T</sup> Data Source: Eiken et al (2014).

Nationally annual ICF/IID expenditures for FY 2012 per average daily participant were \$142,118. The highest average annual per person expenditures were in Kentucky (\$409,030), Montana (\$272,485), New York (\$444,122), and Wyoming (\$357,238). The lowest average annual per person expenditures were in Alabama (\$7,693), Georgia (\$13,799), Idaho (\$35,989), and Virginia (\$47,424).

Annual ICF/IID expenditures per 100,000 state residents averaged \$39.17 and ranged from a low of \$0.16 in Alaska which did not have an in-state ICF/IID, to a high of \$165.52 in New York.

Discussion: CMS approves eligibility criteria and the bundle of services for ICF/IID recipients. The cost variance across states is attributable to factors such as average wage paid to direct support professionals, the pace of downsizing or closure of facilities, the size of the facility relative to the number of people living in it, and possibly differential utilization of ICF/IID services for people with IDD with specialized support needs although we did not specifically test these hypotheses. With regard to the facility size, per person costs rise for facilities that are downsizing as the number of recipients declines while fixed expenditures (e.g., capital costs) remain constant. For that reason we report costs for both year-end residents and for average daily residents. States with large changes in populations have the largest differences between these two cost measures.

## Total Medicaid ICF/IID and HCBS Waiver Expenditures and Recipients

Table 4.3 shows total Medicaid LTSS expenditures for ICF/IID and HCBS Waiver programs for FY 2012. A total of 781,190 people with IDD were receiving LTSS through the ICF/IID or the HCBS Waiver programs on June 30, 2012. Combined annual expenditures totaled \$41.8 billion.

Overall, 89% of all ICF/IID plus HCBS Waiver participants with IDD received supports through the HCBS Waiver program while 11% received ICF/IID services. Overall, 71% of ICF/IID plus HCBS Waiver expenditures were for people receiving HCBS Waiver-funded services compared to 29% for people receiving ICF/IID services.

States that spent 95% or more of their combined ICF/IID and HCBS Waiver dollars on people with IDD



in HCBS Waiver-funded services included Alabama, Alaska, Arizona, Georgia, Maryland, Massachusetts, Michigan, New Hampshire, Oregon, Rhode Island, and Vermont. States serving 95% or more of the combined ICF/IID and HCBS Waiver recipients through the HCBS Waiver program were: Alabama,

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*THE COST VARIANCE ACROSS STATES IS LIKELY ATTRIBUTABLE TO SEVERAL FACTORS SUCH AS AVERAGE WAGE PAID TO DIRECT SUPPORT PROFESSIONALS, THE PACE OF DOWNSIZING OR CLOSURE OF FACILITIES, THE SIZE OF THE FACILITY RELATIVE TO THE NUMBER OF PEOPLE LIVING IN IT, AND POSSIBLY DIFFERENTIAL UTILIZATION OF ICF/IID SERVICES FOR PEOPLE WITH IDD WITH SPECIALIZED SUPPORT NEEDS.*

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Alaska, Arizona, Colorado, Georgia, Hawaii, Kentucky, Maine, Maryland, Massachusetts, Michigan, Missouri, Montana, New Hampshire, Oregon, Rhode Island, Vermont, Washington, and Wisconsin.

States with the highest proportion of service recipients in the ICF/IID program were Arkansas (27%), Illinois (31%), Louisiana (32%), Mississippi (60%), and Texas (25%). States spending the highest proportion of Medicaid ICF/IID plus Medicaid HCBS Waiver dollars on ICF/IID settings were Illinois (54%),

Table 4.2 ICF/IID Expenditures by State for Fiscal Year 2012<sup>1</sup>

State	ICF/IID Expenditures (\$)	Federal Cost Share (%)	Total Federal ICF/IID Payments (\$)	State % of Federal ICF/IID Expenditures	End of Year ICF/IID Residents	ICF/IID Expenditures per End of Year Residents (\$)	Average Daily Residents in ICFs/ IID	ICF/IID Expenditures per Average Daily Resident (\$)	State Population (100,000)	Annual Expenditure per State Resident (\$)
<b>N States</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>50</b>
AL	788,514	68.6	541,078	0.01	41	19,232	103	7,693	48.2	0.16
AK	3,050,708 <sup>*</sup>	50.0	1,525,354	0.02	17 <sup>*</sup>	N/A	17	89,727	7.3	4.17
AZ	32,592,983	67.3	21,935,078 <sup>1</sup>	0.32	148	220,223	163	199,957	65.5	4.97
AR	156,756,080 <sup>ed</sup>	70.7	110,842,224	1.60	1,467	106,855	1,468	106,818	29.5	53.15
CA	721,911,000	50.0	360,955,500	5.21	8,726	82,731	8,817	81,882	380.4	18.98
CO	39,533,350	50.0	19,766,675	0.29	343	115,258	260	152,051	51.9	7.62
CT	253,474,748	50.0	126,737,374	1.83	984	257,596	1,002	253,095	35.9	70.60
DE	17,461,859	54.2	9,459,089	0.14	66	264,574	66	264,574	9.2	19.04
DC	62,873,942	70.0	44,011,759	0.63	363	173,206	368	170,853	6.3	99.43
FL	326,570,783	56.0	183,010,267	2.64	2,786	117,219	2,856	114,346	193.2	16.91
GA	5,857,535	66.2	3,875,345	0.06	300	19,525	425	13,799	99.2	0.59
HI	7,714,574	50.5	3,894,317	0.06	79	97,653	83	92,947	13.9	5.54
ID	18,228,499	70.2	12,801,875	0.18	485	37,585	507	35,989	16.0	11.42
IL	688,114,511 <sup>e</sup>	50.0	344,057,256	4.96	8,344	82,468	8,402	81,899	128.8	53.44
IN	299,156,720	67.0	200,315,340	2.89	3,839	77,926	3,863	77,452	65.4	DNF
IA	301,738,929	60.7	183,185,704	2.64	2,002	150,719	2,025	149,044	30.7	98.15
KS	64,166,475	56.9	36,517,141	0.53	509	126,064	500	128,461	28.9	22.23
KY	130,480,686 <sup>e*</sup>	71.2	92,876,152	1.34	285	457,827	319	409,030	43.8	29.79
LA	461,013,123	61.1	281,632,917	4.06	4,604	100,133	4,708	97,921	46.0	100.18
ME	42,530,939 <sup>e</sup>	63.3	26,909,325	0.39	189	225,031	167	254,676	13.3	32.00
MD	11,138,099	50.0	5,569,050	0.08	54	206,261	103	108,137	58.8	1.89
MA	12,760,699	50.0	6,380,350	0.09	594	21,483	594	21,483	66.5	1.92
MI	N/A	66.1	N/A	N/A	0	N/A	0	N/A	98.8	N/A
MN	150,266,603	50.0	75,133,302	1.08	1,719	87,415	1,747	86,014	53.8	27.94
MS	270,287,227 <sup>e</sup>	74.2	200,499,065	2.89	2,765	97,753	2,713	99,627	29.8	90.55
MO	108,468,422	63.5	68,823,214	0.99	590	183,845	625	173,549	60.2	18.01
MT	14,714,204	66.1	9,727,560	0.14	55	267,531	54	272,485	10.1	14.64
NE	56,290,851	56.6	31,883,138	0.46	433	130,002	436	129,256	18.6	30.34

**Table 4.2** ICF/IID Expenditures by State for Fiscal Year 2012<sup>1</sup>

State	ICF/IID Expenditures (\$)	Federal Cost Share (%)	Total Federal ICF/IID Payments (\$)	State % of Federal ICF/IID Expenditures	End of Year ICF/IID Residents	ICF/IID Expenditures per End of Year Residents (\$)	Average Daily Residents in ICFs/ IID	ICF/IID Expenditures per Average Daily Resident (\$)	State Population (100,000)	Annual Expenditure per State Resident (\$)
NV	17,845,318 <sup>†</sup>	56.2	10,029,069	0.14	104	171,590	104	172,419	27.6	6.47
NH	3,154,211	50.0	1,577,106	0.02	25	126,168	25	126,168	13.2	2.39
NJ	672,344,202 <sup>e</sup>	50.0	336,172,101	4.85	3,153	213,240	3,204	209,845	88.6	75.85
NM	25,023,182	69.4	17,356,079	0.25	234	106,937	234	106,937	20.9	12.00
NY	3,239,298,018 <sup>†</sup>	50.0	1,619,649,009	23.36	7,288	444,470	7,360	440,122	195.7	165.52
NC	528,713,999 <sup>e</sup>	65.3	345,144,499	4.98	3,930	134,533	3,772	140,187	97.5	54.22
ND	92,568,160	55.4	51,282,761	0.74	559	165,596	568	163,116	7.0	132.31
OH	779,570,672	64.2	500,094,586	7.21	6,926	112,557	7,026	110,963	115.4	67.53
OK	122,248,746 <sup>e*</sup>	63.9	78,092,499	1.13	1,549	78,921	1,549	78,921	38.1	32.05
OR	N/A	62.9	N/A	N/A	0	N/A	0	N/A	39.0	N/A
PA	591,089,239	55.1	325,512,844	4.69	3,419	172,884	3,493	169,221	127.6	46.31
RI	4,038,624	52.1	2,104,931	0.03	42	96,158	42	97,316	10.5	3.85
SC	150,913,668	70.2	106,001,760	1.53	1,313	114,938	1,336	112,959	47.2	31.95
SD	29,974,187	59.1	17,723,737	0.26	199	150,624	202	148,755	8.3	35.97
TN	222,616,064	66.4	147,728,020	2.13	1,108	200,917	1,374	162,020	64.6	34.48
TX	1,029,396,453	58.2	599,314,615	8.64	9,467	108,735	9,547	107,830	260.6	39.50
UT	77,677,900	71.0	55,143,541	0.80	801	96,976	793	98,016	28.6	27.20
VT	1,266,784	57.6	729,414 <sup>1</sup>	0.01	6	211,131	6	211,131	6.3	2.02
VA	65,374,232	50.0	32,687,116	0.47	1,326	49,302	1,379	47,424	81.9	7.99
WA	134,366,232	50.0	67,183,116	0.97	629	213,619	660	203,740	69.0	19.48
WV	65,463,501	72.6	47,539,594	0.69	562	116,483	562	116,483	18.6	35.28
WI	157,750,772 <sup>e</sup>	60.5	95,486,542	1.38	895	176,258	832	189,604	57.3	27.55
WY	28,757,686	50.0	14,378,843	0.21	79	364,021	81	357,238	5.8	49.89
<b>Est US Total</b>	<b>12,297,393,913</b>	<b>59.4</b>	<b>6,933,797,228</b>	<b>100.0</b>	<b>85,401</b>	<b>143,996</b>	<b>86,530</b>	<b>142,118</b>	<b>3,139.1</b>	<b>39.17</b>

<sup>†</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix. <sup>1</sup>The number of recipients in this table is the the number for whom the state reported expenditures. <sup>2</sup> Source: <http://aspe.hhs.gov/health/fmap12.shtml>



Louisiana (53%), Mississippi (85%), New Jersey (48%), and Texas (49%).

## Medicaid Benefit Ratios

Table 4.4 shows state Medicaid benefit ratios which are computed as differences between the proportion of all Medicaid ICF/IID and HCBS Waiver expenditures received by the state for its citizens with IDD and the proportion of all federal income taxes paid by the state to the federal government. A state Medicaid benefit ratio of 1.00 would indicate that the state's share of Federal Medicaid ICF/IID plus HCBS Waiver expenditures is equal to the state's share of all federal income taxes paid. A ratio higher than 1 indicates the state received a higher proportion of federal Medicaid ICF/IID plus HCBS Waiver expenditures than the proportion it paid in federal income taxes. A ratio of less than 1 indicates that the state received a lower proportion of total Federal Medicaid ICF/IID plus HCBS Waiver expenditures than the proportion it paid of total federal income taxes.

States that get proportionally more federal assistance in Medicaid ICF/IID and HCBS Waiver expenditures than proportion of federal income taxes paid by the state included Maine (with a benefit ratio of 3.4), Mississippi (2.5), New Mexico (2.5), North Dakota (2.4) and West Virginia (4.0). States that get much less federal assistance in Medicaid ICF/IID and HCBS Waiver expenditures than would be predicted by the state's total income taxes paid include Colorado (0.5), Delaware (0.4), Georgia (0.5), Michigan (0.5) and Nevada (0.4).

## Average Daily Expenditures for State-operated LTSS Services

Table 4.5 shows average daily expenditures per person for state-operated LTSS for people with IDD by setting size and service type (ICF/IID, HCBS Waiver-funded settings, other IDD settings, and psychiatric facilities). States that provided services but who could not furnish the average daily cost per person for a specific size or type of setting are indicated as DNF (did not furnish).

Average daily per diems were reported for state-operated ICF/IID settings with 6 or fewer residents

**Table 4.3** ICF/IID Residents and HCBS Waiver Recipients and Expenditures by State on June 30, 2012

State N	Total ICF/IID + HCBS		% of Recipients		% of Expenditures	
	Recipients	Expenditures (\$)	HCBS	ICF/IID	HCBS	ICF/IID
States <sup>1</sup>	51	51	51	51	51	51
AL	5,645	289,489,716	99.3	0.7	99.7	0.3
AK	1,703	137,566,964	100.0	0.0	97.8	2.2
AZ	24,824	673,378,280	99.4	0.6	95.2	4.8
AR	5,504	329,890,607	73.3	26.7	52.5	47.5
CA	106,594	2,829,400,165	91.8	8.2	74.5	25.5
CO	8,760	370,543,025	96.1	3.9	89.3	10.7
CT	10,246	974,352,592	90.4	9.6	74.0	26.0
DE	936	111,790,729	92.9	7.1	84.4	15.6
DC	1,842	210,070,086	80.3	19.7	70.1	29.9
FL	32,139	1,206,425,818	91.3	8.7	72.9	27.1
GA	11,921	413,069,443	97.5	2.5	98.6	1.4
HI	2,623	110,624,493	97.0	3.0	93.0	7.0
ID	3,145	82,653,116	85.8	14.2	77.9	22.1
IL	26,699	1,279,574,553	68.7	31.3	46.2	53.8
IN	16,625	789,127,281	76.9	23.1	62.1	37.9
IA	13,429	689,318,774	85.1	14.9	56.2	43.8
KS	8,783	394,435,834	94.2	5.8	83.7	16.3
KY	11,331	536,909,829	97.5	2.5	75.7	24.3
LA	14,561	868,261,008	68.4	31.6	46.9	53.1
ME	4,290	333,602,027	95.6	4.4	87.3	12.7
MD	12,543	698,031,991	99.6	0.4	98.4	1.6
MA	13,752	854,241,568	95.7	4.3	98.5	1.5
MI	39,838	445,712,073	100.0	0.0	100.0	0.0
MN	21,014	1,365,347,524	91.8	8.2	89.0	11.0
MS	4,596	314,263,478	39.8	60.2	14.0	86.0
MO	11,842	642,435,259	95.0	5.0	83.1	16.9
MT	2,723	105,585,623	98.0	2.0	86.1	13.9
NE	4,964	296,211,555	91.3	8.7	81.0	19.0
NV	1,756	96,612,020	94.1	5.9	81.5	18.5
NH	4,544	195,178,912	99.4	0.6	98.4	1.6
NJ	14,496	1,410,214,751	78.2	21.8	52.3	47.7
NM	4,405	310,971,690	94.7	5.3	92.0	8.0
NY	91,664	8,707,522,714	92.0	8.0	62.8	37.2
NC	16,730	1,148,519,303	76.5	23.5	54.0	46.0
ND	4,618	222,185,621	87.9	12.1	58.3	41.7
OH	37,798	2,020,433,624	83.0	17.0	61.4	38.6
OK	6,772	396,200,563	77.1	22.9	69.1	30.9
OR	14,973	597,868,202	100.0	0.0	100.0	0.0
PA	33,382	2,407,395,400	89.8	10.2	75.4	24.6
RI	3,570	207,701,830	98.8	1.2	98.1	1.9
SC	9,707	442,156,723	86.5	13.5	65.9	34.1
SD	3,414	131,713,224	94.2	5.8	77.2	22.8
TN	8,788	826,714,269	87.4	12.6	73.1	26.9
TX	38,660	2,088,223,839	75.5	24.5	50.7	49.3
UT	5,120	233,192,628	84.4	15.6	66.7	33.3
VT	2,655	142,883,912	99.8	0.2	99.1	0.9
VA	11,080	667,786,370	88.0	12.0	90.2	9.8
WA	12,657	685,261,786	95.0	5.0	80.4	19.6
WV	5,009	369,325,082	88.8	11.2	82.3	17.7
WI	24,291	1,013,124,780	96.3	3.7	84.4	15.6
WY	2,229	127,170,092	96.5	3.5	77.4	22.6
Est US Total	781,190	41,800,670,746	88.9	11.1	70.6	29.4

<sup>a</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix

<sup>1</sup> Michigan had no ICF/IID recipients and an unknown number of HCBS recipients. This table includes estimates for non-reporting states.

**Table 4.4** Combined Federal ICF/IID and HCBS Waiver Expenditures and State Benefit Ratios by State for FY 2012

State	Federal Cost Share (%)	Federal ICF/IID Expenditures	Federal HCBS Waiver Expenditures	% of Federal ICF/IID + HCBS Expenditures	Federal Income Tax (Billions \$) <sup>1</sup>	% Federal Income Tax Paid	State Medicaid Benefit Ratio
<b>N States</b>		<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>	<b>51</b>
AL	68.6	541,078	198,106,765	0.84	19.222	0.91	0.9
AK	50.0	1,525,354	67,258,128	0.29	4.584	0.22	1.3
AZ	67.3	21,935,078	431,248,505	1.92	29.813	1.41	1.4
AR	70.7	110,842,224	122,423,424	0.99	19.553	0.93	1.1
CA	50.0	360,955,500	1,053,744,583	6.00	241.301	11.42	0.5
CO	50.0	19,766,675	165,504,838	0.79	35.433	1.68	0.5
CT	50.0	126,737,374	360,438,922	2.07	40.118	1.90	1.1
DE	54.2	9,459,089	51,097,949	0.26	13.247	0.63	0.4
DC	70.0	44,011,759	103,037,301	0.62	19.134	0.91	0.7
FL	56.0	183,010,267	493,070,762	2.87	109.627	5.19	0.6
GA	66.2	3,875,345	269,411,399	1.16	51.917	2.46	0.5
HI	50.5	3,894,317	51,948,927	0.24	5.611	0.27	0.9
ID	70.2	12,801,875	45,245,409	0.25	6.004	0.28	0.9
IL	50.0	344,057,256	295,730,021	2.72	100.881	4.77	0.6
IN	67.0	200,315,340	328,084,288	2.24	40.389	1.91	1.2
IA	60.7	183,185,704	235,299,724	1.78	16.314	0.77	2.3
KS	56.9	36,517,141	187,956,292	0.95	17.167	0.81	1.2
KY	71.2	92,876,152	289,296,264	1.62	22.350	1.06	1.5
LA	61.1	281,632,917	248,787,733	2.25	33.967	1.61	1.4
ME	63.3	26,909,325	184,160,678	0.90	5.590	0.26	3.4
MD	50.0	5,569,050	343,446,946	1.48	45.660	2.16	0.7
MA	50.0	6,380,350	420,740,435	1.81	70.216	3.32	0.5
MI	66.1	0	294,793,965	1.25	51.902	2.46	0.5
MN	50.0	75,133,302	607,540,461	2.90	60.641	2.87	1.0
MS	74.2	200,499,065	32,621,583	0.99	8.407	0.40	2.5
MO	63.5	68,823,214	338,801,958	1.73	40.433	1.91	0.9
MT	66.1	9,727,560	60,075,095	0.30	3.979	0.19	1.6
NE	56.6	31,883,138	135,891,087	0.71	12.899	0.61	1.2
NV	56.2	10,029,069	44,266,887	0.23	12.138	0.57	0.4
NH	50.0	1,577,106	96,012,351	0.41	8.221	0.39	1.1
NJ	50.0	336,172,101	368,935,275	2.99	93.468	4.42	0.7
NM	69.4	17,356,079	198,333,885	0.92	7.752	0.37	2.5
NY	50.0	1,619,649,009	2,734,112,348	18.48	178.287	8.43	2.2
NC	65.3	345,144,499	404,608,902	3.18	51.530	2.44	1.3
ND	55.4	51,282,761	71,808,073	0.52	4.595	0.22	2.4
OH	64.2	500,094,586	796,013,584	5.50	99.581	4.71	1.2
OK	63.9	78,092,499	175,000,421	1.07	18.442	0.87	1.2
OR	62.9	0	376,118,886	1.60	20.788	0.98	1.6
PA	55.1	325,512,844	1,000,239,803	5.63	91.352	4.32	1.3
RI	52.1	2,104,931	106,149,263	0.46	8.180	0.39	1.2
SC	70.2	106,001,760	204,569,122	1.32	16.386	0.78	1.7
SD	59.1	17,723,737	60,158,293	0.33	4.368	0.21	1.6
TN	66.4	147,728,020	400,879,569	2.33	40.872	1.93	1.2
TX	58.2	599,314,615	616,449,304	5.16	160.087	7.57	0.7
UT	71.0	55,143,541	110,399,905	0.70	12.619	0.60	1.2
VT	57.6	729,414	81,543,142	0.35	3.107	0.15	2.4
VA	50.0	32,687,116	301,206,069	1.42	53.214	2.52	0.6
WA	50.0	67,183,116	275,447,777	1.45	46.929	2.22	0.7
WV	72.6	47,539,594	220,664,280	1.14	6.001	0.28	4.0
WI	60.5	95,486,542	517,757,887	2.60	34.959	1.65	1.6
WY	50.0	14,378,843	49,206,203	0.27	3.325	0.16	1.7
<b>Estimated US Total</b>	100.0	6,933,797,228	16,625,644,665	100.00	2,113.690	100.0	1.00

<sup>1</sup>Source: [http://www.usgovernmentrevenue.com/federal\\_revenue\\_by\\_state.php](http://www.usgovernmentrevenue.com/federal_revenue_by_state.php) <sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in the Appendix

**Table 4.5** Average per Resident Daily Expenditures in State IDD Settings in FY 2012 by State, Size and Funding Authority

State	ICF/IID			HCBS Waiver			IDD Other	Psychiatric
	1 to 6	7 to 15	16+	1 to 6	7 to 15	16+		
<b>N States</b>	<b>8</b>	<b>7</b>	<b>36</b>	<b>13</b>	<b>4</b>	<b>3</b>	<b>5</b>	<b>9</b>
AL	N/A	N/A	1,532	N/A	N/A	N/A	N/A	N/A <sup>ei</sup>
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	430	418	429	393	N/A	308	N/A	N/A
AR	N/A	N/A	363	N/A	N/A	N/A	N/A	N/A
CA	N/A	N/A	910	N/A	N/A	N/A	N/A	N/A
CO	627	627	627	488	488	488	N/A	N/A
CT	N/A	N/A	1,448	813	813	N/A	N/A	N/A
DE	N/A	N/A	1,022	291	N/A	N/A	N/A	DNF
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	N/A	N/A	334	N/A	N/A	N/A	333	DNF
GA	N/A	N/A	284	N/A	N/A	N/A	N/A	N/A
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	N/A	N/A	707	N/A	N/A	N/A	N/A	N/A
IL	N/A	N/A	679	N/A	N/A	N/A	N/A	N/A
IN	N/A	N/A	604	N/A	N/A	N/A	N/A	595
IA	N/A	N/A	794	255	N/A	N/A	N/A	N/A
KS	N/A	N/A <sup>e</sup>	DNF <sup>e</sup>	N/A	N/A	N/A	N/A	N/A
KY	N/A	645	958	N/A	N/A	N/A	N/A	N/A
LA	N/A	673	550	N/A	N/A	N/A	N/A	660
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	DNF
MD	N/A	DNF	556	N/A	N/A	N/A	N/A	N/A
MA	N/A	DNF	DNF	DNF	DNF	N/A	N/A	N/A
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	271	N/A	N/A	369	N/A	N/A	N/A	N/A
MS	309 <sup>e</sup>	276 <sup>e</sup>	270	115 <sup>e</sup>	N/A	N/A	115 <sup>e</sup>	N/A
MO	N/A	N/A	498	281	N/A	N/A	N/A	637
MT	N/A	N/A	741	N/A	N/A	N/A	N/A	N/A
NE	N/A	700	842	N/A	N/A	N/A	N/A	N/A
NV	N/A	N/A	550	N/A	N/A	N/A	N/A	N/A
NH	N/A	N/A	N/A	N/A	N/A	N/A	551	N/A
NJ	N/A	N/A	760	DNF	DNF	N/A	N/A	DNF
NM	793 <sup>ed</sup>	N/A	N/A	681 <sup>ed</sup>	N/A	N/A	N/A	N/A
NY	773	656	DNF	605	1,082	N/A	N/A	N/A
NC	N/A	N/A	569	N/A	N/A	N/A	441	1,062
ND	N/A	N/A	681	N/A	N/A	N/A	N/A	N/A
OH	N/A	N/A	476	N/A	N/A	N/A	N/A	N/A
OK	N/A	N/A	547	N/A	N/A	N/A	N/A	N/A
OR	N/A	N/A	N/A	1,248	N/A	N/A	N/A	N/A
PA	N/A	N/A	737	N/A	N/A	N/A	N/A	551
RI	DNF	N/A	N/A	440	440	440	N/A	N/A
SC	N/A	N/A	347	N/A	N/A	N/A	N/A	N/A
SD	N/A	N/A	445	N/A	N/A	N/A	N/A	469
TN	1,011	N/A	993	N/A	N/A	N/A	N/A	697
TX	592	N/A	507	N/A	N/A	N/A	N/A	N/A
UT	N/A	N/A	430	N/A	N/A	N/A	N/A	N/A
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	N/A	N/A	645	N/A	N/A	N/A	N/A	613
WA	N/A	N/A	567	374	N/A	N/A	516	DNF
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	N/A	N/A	854	N/A	N/A	N/A	N/A	N/A
WY	N/A	N/A	718	N/A	N/A	N/A	N/A	741
<b>Est. US Average</b>	<b>\$610</b>	<b>\$577</b>	<b>\$650</b>	<b>\$496</b>	<b>\$689</b>	<b>\$412</b>	<b>\$391</b>	<b>\$669</b>

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>ed</sup> See state notes in the Appendix. Note: The estimated US averages are unweighted.

in 8 states, for ICF/IID settings with 7 to 15 residents in 7 states, and for ICF/IID settings with 16 or more residents in 36 states. Average per diem rates for ICF/IID settings with 6 or fewer people were \$610, for settings with 7 to 15 people were \$577, and for settings with 16 or more people were \$650.

Average daily per person expenditures were reported for state-operated HCBS Waiver funded settings of 1 to 6 people in 13 states, for settings with 7 to 15 people in 4 states, and for settings of 16 or more people for 3 states. Rates for state-operated HCBS Waiver funded settings were \$496 for settings with 1 to 6 people; \$689 for settings with 7 to 15 people, and \$412 for settings with 16 or more residents.

The average per diem in state-operated IDD settings not funded by either the ICF/IID or the HCBS Waiver was \$391 across five reporting states. Finally, the average per diem for a person with IDD living in a state-operated psychiatric facility was \$669 across nine reporting states.

Highest reported average per person daily costs were for state-operated ICF/IID settings with 6 or fewer residents in Tennessee (\$1,011), for settings with 7 to 15 residents in Nebraska (\$700), for settings of 16 or more residents in Alabama (\$1,532). Highest reported average per person daily costs were for state-operated HCBS funded settings of 1 to 6 people in Oregon (\$1,248), for settings of 7 to 15 people in New York (\$1,082), and for people with IDD living in state-operated psychiatric facilities in North Carolina (\$1,062).





**SECTION FIVE**

**Trends in Long-Term  
Supports and Services  
for People with IDD**

**FY 2012**



## SECTION 5: TRENDS IN LONG-TERM SUPPORTS AND SERVICES FOR PEOPLE WITH IDD

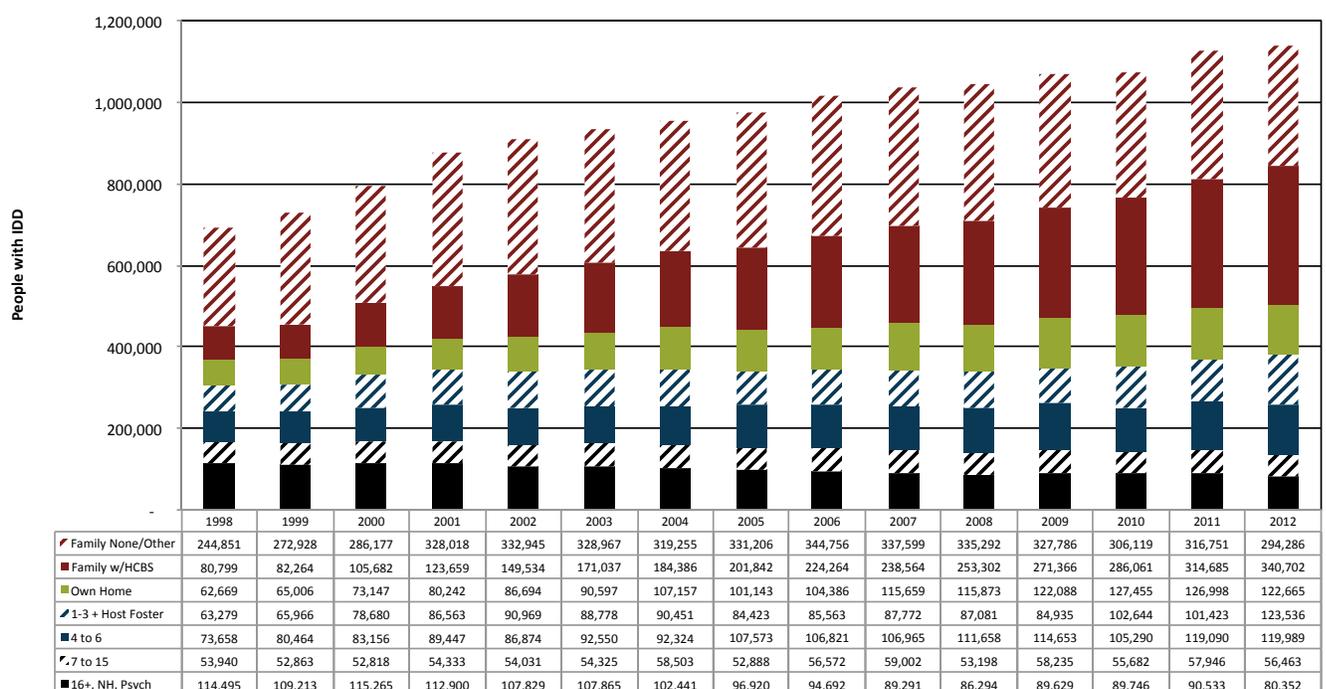
Sections 1 through 4 of this report provided state-by-state descriptions of LTSS for people with IDD in FY 2012. Section 5 focuses on trends over time for the United States as a whole.

### Changes in Size and Type of LTSS Settings for People with IDD

**Overall Change.** Figure 5.1 shows changes in the number of people with IDD known to or receiving LTSS under the auspices of a state IDD agency by setting type and size between 1998 and 2012. Overall, the number of people with IDD known to or receiving residential services under the auspices of a state IDD agency increased from 693,691 in 1998 to 1,138,121 in 2012 (an average increase of 31,745 people per year). The rate of change varied across time. Between 1998 and 2001 the average annual growth was 8.1% compared with 2.8% for 2002 through 2005, 2.3% between 2006 and 2009, and 2.1% between 2010 and 2012.

**Change in Type and Size of Setting.** The number of people with IDD living a home they own or rent nearly doubled from 62,669 in 1989 to 122,664 in 2012. The number of people living in the home of a family member also nearly doubled, increasing from 325,650 in 1998 to 634,988 in 2012. The number of people living in a host home, foster home or group setting shared by three or fewer people with IDD increased from 63,279 to 123,536. The number of people with IDD living in group settings with 4 to 6 residents increased from 73,658 to 119,989. The number of people with IDD in settings with 7 to 15 residents increased from 53,940 in 1998 to 56,463 in 2012. However, between 1998 and 2012 the overall number of people in LTSS with 16 or more residents declined from 114,495 to 80,352. The number of people in IDD facilities with 16 or more residents decreased from 89,348 to 51,149 but the number in state-operated psychiatric settings increased from 1,003 to 1,139; and the number in nursing facilities increased from 24,144 to 28,064.

**Figure 5.1** Size and Type of Residence for People with IDD on the Caseloads of State IDD Agencies by Year 1998 to 2012 (US Estimated Totals)



# 2012

**Change in Funding Source.** The number of HCBS Waiver recipients with IDD increased from 240,321 in 1998 to 680,610 in 2012, while the total number of people with IDD living in an ICF/IID declined from 124,248 to 86,000. The number of people with

funding mechanism not managed by the state IDD agency (e.g., a Medicaid State Plan service), who received state funded services only, who had not requested LTSS, or who had requested LTSS but were waiting to receive those services (an estimated 61,373 people in 1998 and 110,039 people in 2012).

*THE NUMBER OF PEOPLE WITH IDD KNOWN TO OR RECEIVING LTSS UNDER THE AUSPICES OF STATE IDD AGENCIES WHO DID NOT LIVE IN A PSYCHIATRIC FACILITY, NURSING HOME, OR ICF/IID AND WHO DID NOT RECEIVE HCBS WAIVER-FUNDED HOME AND COMMUNITY-BASED SUPPORTS GREW FROM 303,975 TO 342,181.*

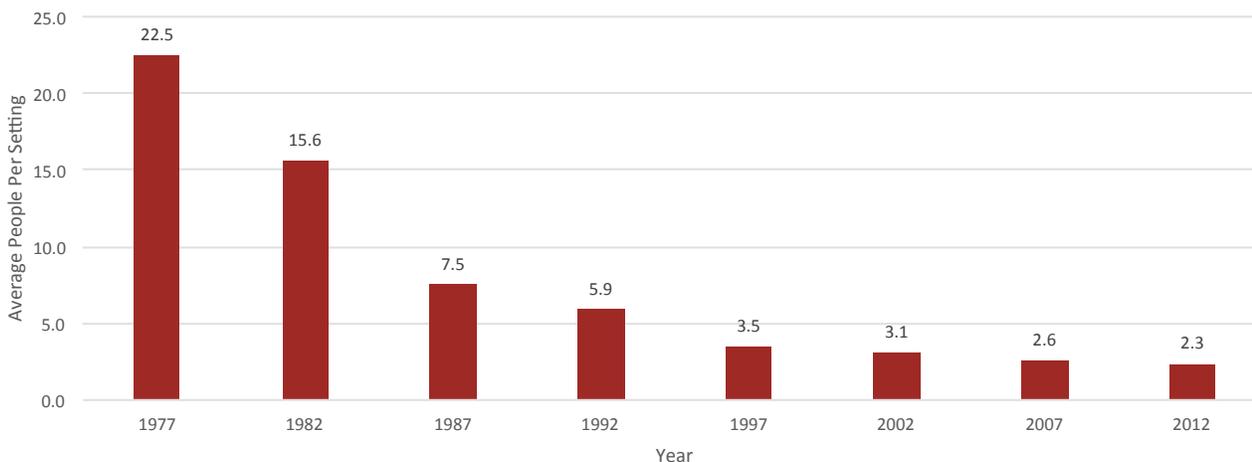
IDD estimated to be living in the home of a family member and receiving HCBS Waiver-funded supports increased 422% from 80,799 people in 1998 to 340,702 people in 2012.

The number of people with IDD known to or receiving LTSS under the auspices of state IDD agencies who did not live in a psychiatric facility, nursing home, or ICF/IID and who did not receive HCBS Waiver-funded home and community-based supports grew from 303,975 to 342,181. This includes people who received services through a

**Changes in the average number of people sharing a home.** The average size of non-family residential service settings for people with IDD declined from 22.5 people per setting in 1977, to 7.5 in 1987, 5.9 people in 1992, 3.1 in 2002, and 2.3 in 2012.

**Changes in the number of state and nonstate-operated residential IDD facilities by setting size.** Between 1977 and 2012, the total number of non-family settings in which people with IDD received LTSS increased from 11,008 to 201,378 (See [Table 5.1](#)). In 1977, 4% of all residential settings were state-operated compared to 1% in 2012. The proportion of non-family settings with 16 or more residents dropped from 15% in 1977 to 1% in 1997 and remained at 1% in 2002, 2007 and 2012. The proportion of settings shared by 7 to 15 people with IDD was 22% in 1977, 15% in 1987, 7% in 1997, 4% in 2007 and 3% in 2012. The proportion of settings shared by six or fewer people with IDD increased from 63% in 1977 to 80% in 1987, 92% in 1997, 95% in 2007, and 97% in 2012.

**Figure 5.2** Average Number of People with IDD per Residential Setting on June 30 of Selected Years 1977 to 2012



**Table 5.1** State and Nonstate Residential Settings by Setting Size for Persons with IDD on June 30 of 1977, 1982, 1987, 1992, 1997, 2002, 2007 and 2012

Year	Number of Residential Settings											
	Nonstate				State				Total			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
1977	6,855	2,310	1,378	10,543	43	95	327	465	6,898	2,405	1,705	11,008
1982	10,073	3,181	1,370	14,624	182	426	349	957	10,255	3,607	1,719	15,581
1987	26,475	4,713	1,370	32,558	189	443	287	919	26,664	5,156	1,657	33,477
1992	41,444	5,158	1,320	47,922	382	852	323	1,557	41,826	6,010	1,643	49,479
1997	87,917	5,578	1,040	94,535	1,047	702	246	1,995	88,964	6,280	1,286	96,530
2002	116,189	5,880	1,026	123,095	1,634	713	233	2,580	117,823	6,593	1,259	125,675
2007	158,365	6,092	784	165,241	1,683	733	217	2,633	160,048	6,825	1,001	167,874

**Table 5.2** Persons with IDD in State and Nonstate Residential Settings Other than the Home of a Family Member on June 30th of 1977, 1982, 1987, 1992, 1997, 2002, 2007 and 2012

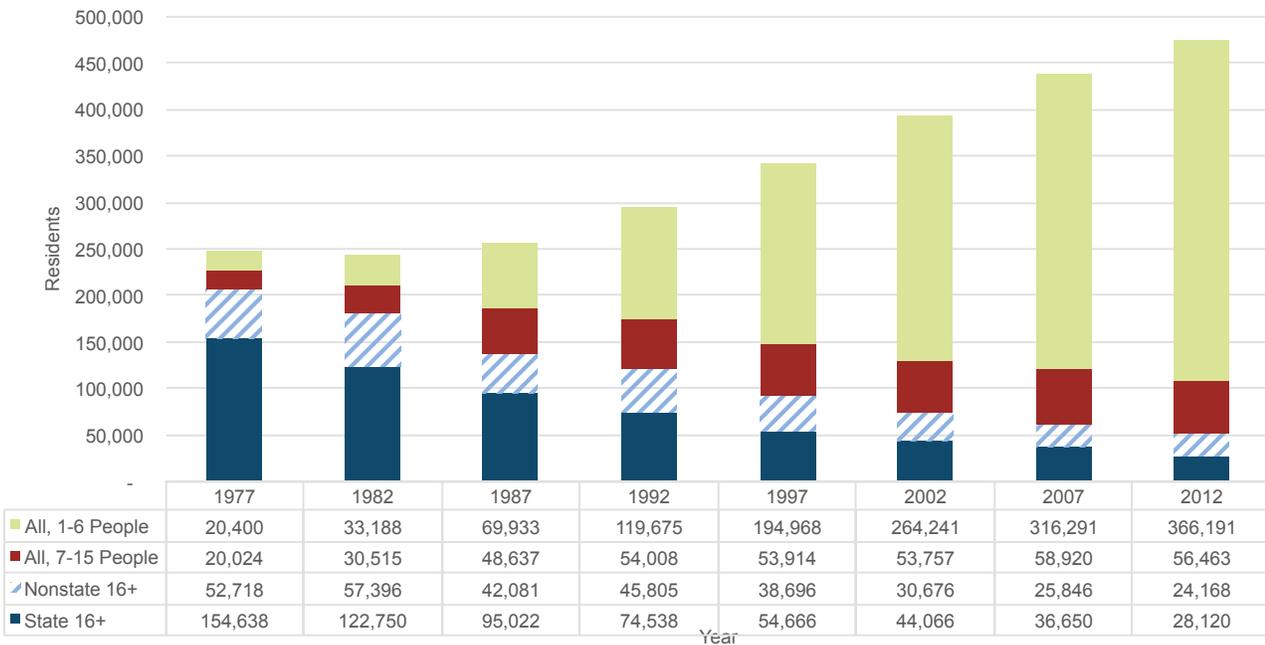
Year	Number of People with IDD											
	Nonstate Settings				State Settings				Total			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
1977	20,184	19,074	52,718	91,976	216	950	154,638	155,804	20,400	20,024	207,356	247,780
1982	32,335	28,810	57,396	118,541	853	1,705	122,750	125,308	33,188	30,515	180,146	243,849
1987	68,631	45,223	42,081	155,935	1,302	3,414	95,022	99,738	69,933	48,637	137,103	255,673
1992	118,304	46,023	45,805	210,132	1,371	7,985	74,538	83,894	119,675	54,008	120,343	294,026
1997	190,715	46,988	38,696	276,399	4,253	6,926	54,666	65,845	194,968	53,914	93,362	342,244
2002	258,709	46,728	30,676	336,113	5,532	7,029	44,066	56,627	264,241	53,757	74,742	392,740
2007	310,874	51,842	25,846	388,562	5,417	7,078	36,650	49,145	316,291	58,920	62,496	437,707
2012	360,805	50,069	24,168	435,042	5,386	6,394	28,120	39,900	366,191	56,463	52,288	474,942

**Discussion:** The RISP project has monitored the dramatic changes in the size of non-family residential settings for people with IDD since 1977. Until 1996 the project only monitored three size categories (1 to 6 people, 7 to 15 people, and 16 or more people) of LTSS settings. In the 1996 report a size category separating settings with 1 to 3 people from settings with 4 to 6 people was added as it became clear that most of the growth in LTSS for people with IDD was occurring in settings with 3 or fewer people. By 2001, another dramatic milestone was reached as the number of people getting Medicaid funded LTSS while living in the home of a family member first exceeded the number of Medicaid LTSS recipients in each of the other setting types. This report, with the investment of resources from the FISP project examines differences in service utilization by the age of the person with IDD. The FY 2013 RISP survey asks states to describe funding categories in more detail to better capture the many flavors of Medicaid

HCBS Waiver funding streams. In subsequent years with the continued investment of the FISP project, the project will continue to adapt its data collection and reporting processes to capture shifts in Medicaid LTSS for people with IDD. Annual surveys of DD agencies will continue to be supplemented with secondary analyses of data sources such as the National Health Interview Survey and the National Core Indicators suite of surveys to build a richer picture long-term supports and services needed by and received by people with IDD and their families.

**Change in the number of people with IDD in state and nonstate-operated residential IDD facilities by setting size.** Between 1977 and 2012 the total number of people with IDD living in a setting other than the home of a family member increased from 246,780 to 474,941 (See [Table 5.2](#)). In 1977, 91,976 (37%) of people who lived in a setting other than the home of a family member lived in a nonstate

**Figure 5.3** Persons with IDD in State and Nonstate Residential Settings on June 30 of 1977, 1982, 1987, 1992, 2002, 2007 and 2012 (US Estimated Totals)



setting. By 2012, this proportion had increased to 92%. The proportion of all people who lived in settings shared by 16 or more people with IDD declined from 84% in 1977 to 11% in 2012.

Figure 5.3 shows changes in the number of people with IDD living in non-family settings with 1 to 6, 7 to 15 or 16 or more people. The number of people in state-operated settings with 16 or more residents dropped from 52,718 in 1977 to only 28,120 in 2012.

entity. This proportion increased to 46%. If these proportions continue to shift the number of people with IDD living in nonstate-operated facilities of 16 or more people will exceed the number living in state-operated facilities of 16 or more people in the very near future. This has substantial implications for how states approach deinstitutionalization as the changes will have to occur increasingly in cooperation with nonstate entities. The figure also provides a dramatic portrayal of the growth in the number of people living in settings with 1 to 6 residents (a number that jumped from 20,400 in 1977 to 366,190 in 2012).

*BETWEEN 1988 AND 1992 TOTAL MEDICAID EXPENDITURES MORE THAN DOUBLED FROM \$30.5 BILLION TO \$64.0 BILLION WHILE TOTAL MEDICAID EXPENDITURES FOR LTSS FOR PEOPLE WITH IDD INCREASED FROM \$3.7 BILLION TO \$5.78 BILLION.*

### Changes in Expenditures for Medicaid HCBS Waiver-funded and ICF/IID LTSS

#### ICF/IID and HCBS Utilization for Persons with IDD as a Proportion of All Medicaid Expenditures.

The number of people in nonstate settings with 16 or more residents also declined. In 1977, only 25% of people with IDD living in settings with 16 or more people lived in settings operated by a nonstate

The Medicaid program serves many different populations only one of which is people with IDD. Table 5.3 summarizes changes for selected years between 1980 and 2012 in the proportion of all Medicaid expenditures allocated specifically to support the LTSS needs of people with IDD. Total Medicaid expenditures for FY 2012 were \$410

**Table 5.3** Federal Medicaid Expenditures for ICF/IID and HCBS Waiver Programs for Persons with IDD as a Proportion of All Federal Medicaid Expenditures Selected Years 1980 to 2012

Year	Total Medicaid Expenditures (Billions)	Total ICF/IID and HCBS Expenditures for Persons with IDD (Billions)	Total ICF/IID and HCBS Programs for Persons with IDD as a Proportion of All Medicaid Expenditures
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	\$334.20	\$34.27	10.3%
2010	\$383.50	\$39.16	10.2%
2012	\$410.00	\$41.81	10.2%

Data source: [http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CFORReport/Downloads/2012\\_CMS\\_Financial\\_Report.pdf](http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CFORReport/Downloads/2012_CMS_Financial_Report.pdf)

billion. Total expenditures for people with IDD in ICF/IID settings or receiving support through an HCBS Waiver were \$41.81 billion (10.2% of total Medicaid expenditures).

*BETWEEN 1993 AND 2012 THERE WERE TREMENDOUS VARIATIONS ACROSS STATES IN HOW THE MEDICAID ICF/IID AND HCBS WAIVER FUNDING STREAMS WERE USED TO PROVIDE LTSS FOR PEOPLE WITH IDD.*

In 1980, total Medicaid expenditures were \$14.6 billion, total ICF/IID expenditures were \$1.74 billion and the proportion of Medicaid expenditures for LTSS for people with IDD was 11.9%. By 1988, after the HCBS Waiver program had been established, total Medicaid expenditures were \$30.5 billion and combined ICF/IID and HCBS Waiver program expenditures for people with IDD were \$3.7 billion. The proportion of Medicaid expenditures for people with LTSS for people with IDD was 12%.

Between 1988 and 1992 total Medicaid expenditures more than doubled from \$30.5 billion to \$64.0 billion while total Medicaid expenditures for LTSS for people with IDD increased from \$3.7 billion to \$5.78 billion. However, the proportion of total Medicaid expenditures spent on LTSS for people with IDD declined from 12.0% to 9.0%. It has remained below 10.3% since 1992.

Medicaid LTSS expenditures for ICF/IID and HCBS Waiver-funded services for people with IDD rose at a rate similar to the change in total Medicaid expenditures between 2006 and 2012. Total Medicaid expenditures were 37% higher in 2012, than in 2006 while total Medicaid expenditures for people with IDD in ICF/IID or HCBS Waiver-funded LTSS were 35% higher in 2012 than in 2006.

### Comparison of Medicaid Costs and Utilization in 1993 and 2012

In 1993, total Medicaid expenditures for ICF/IID services were \$9.18 billion, almost five times the expenditures for HCBS Waiver-funded LTSS for people with IDD (\$2.18 billion; See [Table 5.4](#)). The number of ICF/IID recipients was 147,729 (63% of the combined recipients) compared to 86,604 HCBS Waiver recipients.

Between 1993 and 2012 the number of people in ICF/IID settings decreased from 147,729 to 86,000 but total Medicaid ICF/IID expenditures increased from \$9.2 billion to \$12.3 billion. By contrast the number of people with IDD receiving Medicaid-funded LTSS through an HCBS Waiver increased from 86,604 to 688,410 and total expenditures for HCBS Waiver-funded services increased from \$2.2 billion to \$29.5 billion. Overall ICF/IID expenditures increased 34% but the number of participants declined 42%. Overall HCBS Waiver expenditures increased 1,253% while the number of participants increased 695%. Overall combined ICF/IID plus HCBS Waiver expenditures per recipient with IDD increased 11% from \$48,505 in 1993 to \$53,990 in 2012.

Table 5.4 Medicaid ICF/IID, HCBS Waiver and Annual Combined Per Person Expenditures in FY 1993 and FY 2012

State	1993					1993 Inflation Adjusted Combined per person	2012				
	ICF/IID Expenditures	ICF/IID Residents	HCBS Expenditures	HCBS Recipients	Combined Per Person Costs		ICF/IID Expenditures	ICF/IID Residents	HCBS Expenditures	HCBS Recipients	Combined Per Person Costs
N States	51	51	51	51	51	51	51	51	46	46	
AL	79,030,041	1,266	22,182,047	2,184	29,337	46,613	788,514	41	288,701,202	5,604	51,283
AK*	10,362,069	85	0	0	121,907	193,696	3,050,708	17	134,516,256	1,703	79,981
AZ	16,911,180	298	114,161,800	6,071	20,580	32,699	32,592,983	148	640,785,297	24,617	27,191
AR	89,553,111	1,724	10,391,122	453	45,909	72,945	156,756,080	1,467	173,134,527	4,037	59,937
CA	356,304,904	11,025	92,414,694	11,085	20,295	32,246	721,911,000	8,726	2,107,489,165	97,868	26,544
CO	50,704,123	737	63,448,347	2,407	36,308	57,690	39,533,350	343	331,009,675	8,147	43,645
CT	181,959,971	1,272	139,890,550	2,069	96,334	153,064	253,474,748	984	720,877,844	8,638	101,263
DE	26,574,433	370	9,667,487	290	54,912	87,250	17,461,859	66	94,328,870	855	121,380
DC	63,961,219	804	0	0	79,554	126,403	62,873,942	363	147,196,144	1,479	114,045
FL	192,151,682	3,207	38,671,466	6,009	25,046	39,795	326,570,783	2,786	879,855,035	29,353	37,538
GA	116,223,419	1,933	15,068,108	359	57,283	91,016	5,857,535	300	407,211,908	11,621	34,651
HI	6,155,659	117	8,620,253	450	26,060	41,406	7,714,574	79	102,909,919	2,544	42,175
ID	38,497,578	494	2,700,000	174	61,673	97,992	18,228,499	485	64,424,617 <sup>†</sup>	DNF	DNF
IL	531,667,554	12,160	34,477,962	2,850	37,718	59,930	688,114,511	8,344	591,460,042	18,355	47,926
IN	283,528,589	6,213	483,489	447	42,644	67,758	299,156,720	3,839	489,970,561	12,786	47,466
IA	160,959,092	1,890	2,477,295	170	79,338	126,060	301,738,929	2,002	387,579,845	11,592	51,592
KS	106,648,757	1,837	36,813,107	1,066	49,418	78,521	64,166,475	509	330,269,359	8,274	44,909
KY	69,885,596	1,053	24,505,668	855	49,471	78,605	130,480,686	285	406,429,143	11,046	47,384
LA	324,034,343	4,678	13,087,458	1,134	58,004	92,163	461,013,123	4,604	407,247,885	9,957	59,629
ME	59,821,344	630	23,606,982	509	73,247	116,382	42,530,939	189	291,071,088	4,101	77,763
MD	60,767,020	894	64,502,005	2,437	37,607	59,754	11,138,099	54	686,893,892	12,489	55,651
MA	315,569,399	3,520	74,222,387	3,288	57,255	90,972	12,760,699	594	841,480,869	11,987	67,899
MI	149,187,111	3,342	78,234,680	2,885	36,522	58,030	0	0	445,712,073 <sup>†</sup>	39,838	11,188
MN	288,650,678	5,072	107,234,621	3,408	46,685	74,177	150,266,603	1,719	1,215,080,921	18,963	66,016
MS	79,043,314	2,038	0	0	38,785	61,625	270,287,227	2,765	43,976,251 <sup>†</sup>	DNF	DNF
MO	113,792,154	1,709	75,838,414	2,622	43,784	69,569	108,468,422	590	533,966,837	11,041	55,235
MT	10,387,598	165	13,515,850	504	35,730	56,772	14,714,204	55	90,871,419	2,668	38,775
NE	34,216,508	721	24,169,388	991	34,104	54,188	56,290,851	433	239,920,704	4,531	59,672
NV	26,810,867	208	2,295,417	186	73,874	117,378	17,845,318	104	78,766,702	1,652	55,018
NH	5,364,387	74	53,026,255	1,032	52,794	83,885	3,154,211	25	192,024,701	4,519	42,953
NJ	286,201,207	3,892	113,719,749	4,191	49,477	78,614	672,344,202	3,153	737,870,549	11,297	97,593
NM	42,832,979	681	7,552,177	612	38,968	61,916	25,023,182	234	285,948,508	4,115	71,504
NY	1,927,559,462	21,850	163,595,442	3,398	82,825	131,600	3,239,298,018	7,288	5,468,224,696	77,047	103,249
NC	316,571,784	4,662	16,223,347	1,190	56,869	90,358	528,713,999	3,930	619,805,304	12,800	68,650
ND	37,077,368	618	20,585,690	1,362	29,123	46,273	92,568,160	559	129,617,461	4,059	48,113
OH	449,570,809	8,222	26,512,352	1,120	50,962	80,973	779,570,672	6,926	1,240,862,952 <sup>†</sup>	DNF	DNF
OK	132,075,921	2,415	43,728,032	1,287	47,489	75,455	122,248,746	1,549	273,951,817	5,223	58,506
OR	800,434,15	468	86,645,986	2,023	66,917	106,324	0	0	597,868,202	14,865	40,220
PA	500,105,694	6,768	169,500,650	3,795	63,392	100,723	591,089,239	3,419	1,816,306,161	29,963	72,117
RI	105,169,194	457	74,432,864	1,192	108,916	173,056	4,038,624	42	203,663,206	3,316	61,853
SC	165,306,409	3,232	14,702,477	586	47,147	74,912	150,913,668	1,313	291,243,055 <sup>†</sup>	DNF	DNF
SD	29,613,205	504	20,474,218	923	35,100	55,770	29,974,187	199	101,739,037	3,215	38,580
TN	117,122,556	2,328	10,133,905	587	43,656	69,365	222,616,064	1,108	604,098,205	7,680	94,073
TX	508,053,498	12,143	10,741,860	968	39,569	62,872	1,029,396,453	9,467	1,058,827,386	29,193	54,015
UT	45,245,234	938	29,537,055	1,476	30,979	49,222	77,677,900	801	155,514,728	4,319	45,545
VT	11,213,196	79	28,628,023	598	58,850	93,506	1,266,784	6	141,617,128	2,649	53,817
VA	148,246,524	2,669	12,350,227	537	50,093	79,592	65,374,232	1,326	602,412,138	9,754	60,270
WA	206,468,229	1,650	79,960,529	1,711	85,221	135,408	134,366,232	629	550,895,554	11,898	54,703
WV	14,607,955	640	38,188,818	637	41,344	65,692	65,463,501	562	303,861,581	4,447	73,732
WI	207,826,034	3,887	50,139,752	2,017	43,693	69,424	157,750,772	895	855,374,008	23,396	41,708
WY	6,224,937	90	17,308,645	459	42,866	68,110	28,757,686	79	98,412,406 <sup>†</sup>	DNF	DNF
Est. US Total	9,185,859,310	147,729	2,180,368,650	86,604	48,505	77,069	12,307,191,775	85,401	29,503,276,833	688,410	54,032

<sup>‡</sup>2011 data \* Estimate <sup>DNF</sup> Did not furnish \* See state notes in the Appendix <sup>†</sup>Data Source: Truven 2014 based on CMS 64

There continue to be tremendous variations across states in how the Medicaid ICF/IID and HCBS Waiver funding streams are used to provide LTSS for people with IDD. State changes in ICF/IID expenditures between 1993 and 2012 ranged from an increase of 362% (from \$17.3 million to \$98.2 million) in Wyoming to a decrease of 100% in Michigan and Oregon both of which discontinued their use of the ICF/IID program.

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*ALL OF THE REPORTING STATES INCREASED EXPENDITURES AND THE NUMBER PEOPLE WITH IDD RECEIVING LTSS FUNDED BY AN HCBS WAIVER. THE DEGREE OF CHANGE VARIED DRAMATICALLY.*

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State changes in the number of ICF/IID participants between 1993 and 2012 ranged from an increase of 36% in Mississippi (from 2,038 people to 2,765) to a decrease of 100% in Michigan and Oregon. Other than Mississippi, only Iowa increased the total number of people living in ICF/IID facilities during this period (increasing from 1,890 people to 2,002).

All of the reporting states increased expenditures and the number people with IDD receiving LTSS funded by an HCBS Waiver. The degree of change varied dramatically. HCBS expenditures increased more than 1,000 fold in Indiana (from \$483,000 to \$490 million) and by more than 100 fold in Iowa

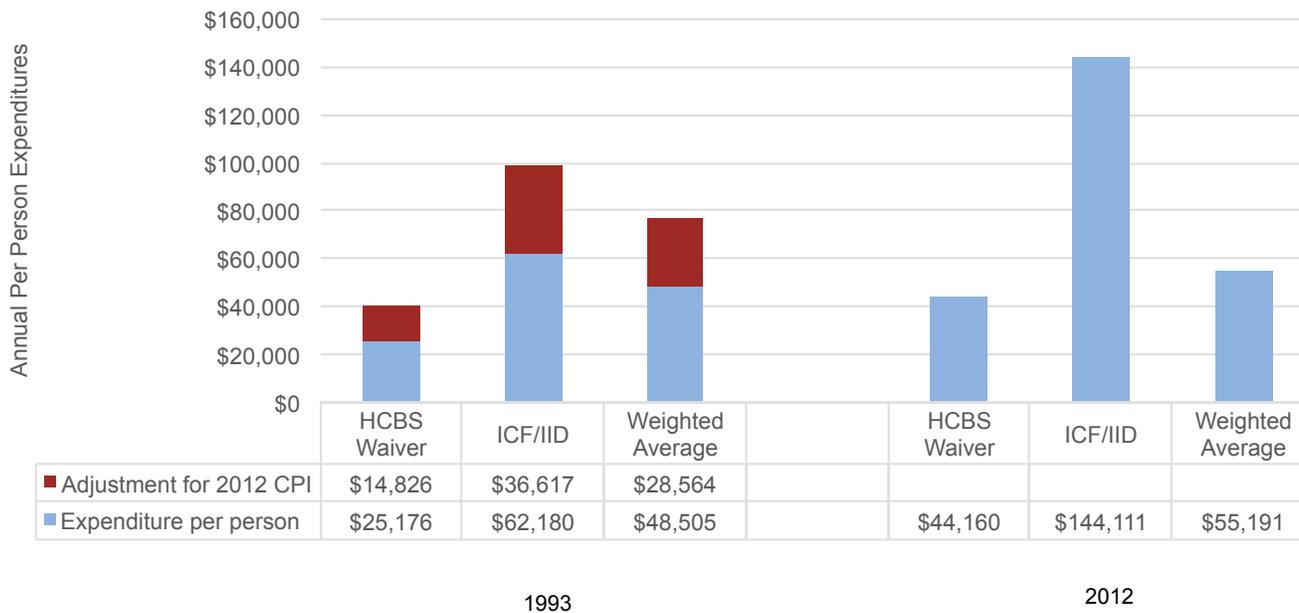
(from \$2.5 million to \$387 million). By contrast HCBS Waiver expenditures increased by only 170% in New Jersey and 174% in Rhode Island.

All of the states provided LTSS to more people with IDD using HCBS Waiver funding in 2012 than in 1993. Like the changes in expenditures, however, changes in the number recipients varied by state. The number of HCBS Waiver recipients in Iowa increased nearly 66 fold (from 170 in 1993 to 11,359 in 2012), and the number of recipients in Georgia increased 31 fold in Georgia (from 359 to 11,621). In contrast the number of HCBS Waiver recipients with IDD increased less than 2 fold in Alabama (157% increase), Delaware (195%), New Jersey (170%), Rhode Island (178%), and Utah (193%).

Changes in average combined expenditures varied by state both before and after the 1993 expenditures were adjusted to account for inflation. Per person annual Medicaid expenditures for people with IDD declined in 13 states with the biggest annual per person declines reported in Michigan (69%: 80% adjusted; declining from \$36,522 in 1993 to \$11,987 in 2012), Georgia (40%: 62% adj.), Oregon (40%: 62% adj.), Rhode Island (43%: 64% adj.), and Washington (36%: 60% adj.). The largest per person annual increases were in Delaware (increasing 121%: 39% adjusted; from \$54,912 in 1993 to \$121,380 in 2012), New Jersey (97%: 24% adj.), New Mexico (83%: 15% adj.), Tennessee (115%: 35% adj.), and West Virginia (78%: 12% adj.).

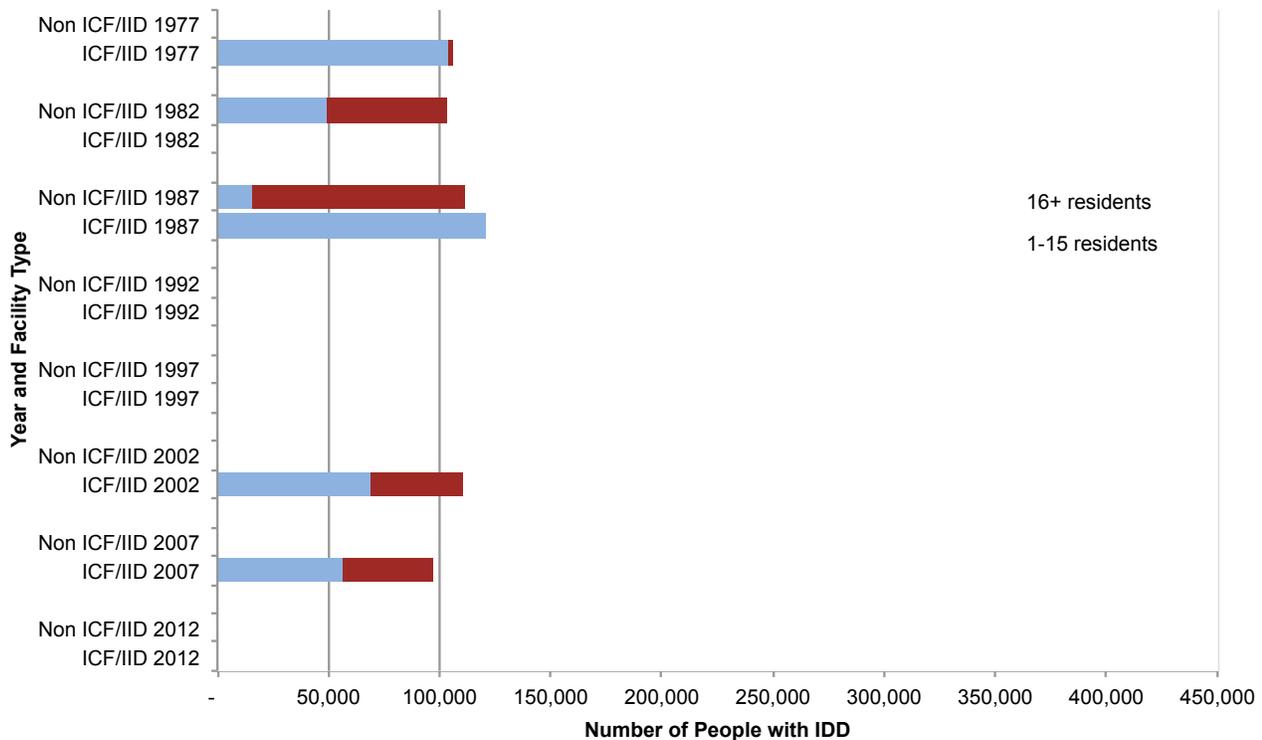


**Figure 5.4** US Estimated Average Annual Per Recipient Expenditures for Medicaid ICF/IID and HCBS Waiver Services, 1993 and 2012



Data Source [http://www.bls.gov/data/inflation\\_calculator.htm](http://www.bls.gov/data/inflation_calculator.htm)

**Figure 5.5** Estimated Number of People with IDD Living in ICF/IID and Non ICF/IID Settings (Excluding Family Home) by Facility Size Selected Years 1977 to 2012



To understand overall changes in expenditures and participants, changes at the state level must be considered. Some states increased their reliance on ICF/IID services while others decreased or discontinued use entirely shifting most or all LTSS for people with IDD to services funded by Medicaid HCBS Waiver programs.

Figure 5.4 summarizes changes in estimated average per person cost for HCBS versus ICF/IID services between 1993 and 2012 in absolute dollars as well as in inflation adjusted dollars. The annual cost per person with IDD receiving HCBS funded LTSS without an inflation adjustment nearly doubled from \$25,176 in 1993 to \$45,312 in 2012. The average annual expenditure per person for ICF/IID recipients increased from \$62,180 in 1993 to \$143,107 in 2012.

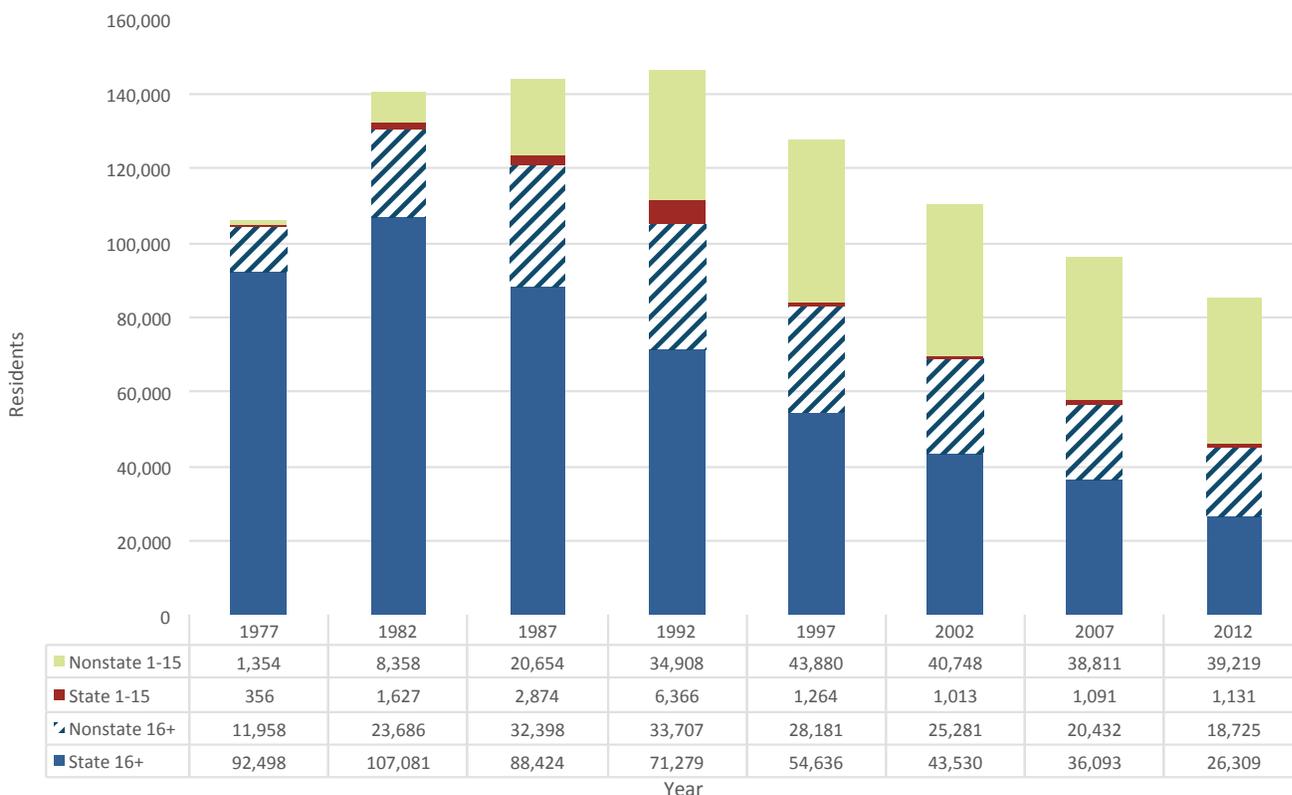
Once 1993 Medicaid expenditures are adjusted to account for inflation, average annual HCBS Waiver expenditures increased from \$40,002 to \$45,219 and ICF/IID expenditures increased from \$98,797 to \$144,111. However the combined weighted average inflation adjusted expenditures declined

from \$77,069 in 1993 to \$54,032 due primarily to a shift away from the more expensive ICF/IID service to reliance on home and community based long-term supports and services.

### Changes in Utilization of Residential Settings by Size and Type of Operation 1977 to 2012

Figure 5.5 compares the number of people living in large and small ICF/IID settings with the number of people living in large and small settings funded by other sources including the HCBS Waiver. In 1977, almost all ICF/IID facilities served 16 or more residents as did the majority of facilities funded by other funding sources. By 1982, however, more than one half of the people with IDD living in non-ICF/IID settings lived in settings with 15 or fewer people while the majority of people in ICF/IID settings continued to share living space with 16 or more people. By 1987 most non-ICF/IID settings served 15 or fewer people while ICF/IID settings continued to be primarily settings for 16 or more people. The number

**Figure 5.6** Estimated Number of People with IDD Living in State and Nonstate ICF/IID Settings by Facility Size on June 30 of Selected Years 1977 to 2012



of people with IDD living in non-ICF/IID settings with fewer than 16 people increased dramatically between 1992 and 2012 but it wasn't until 2012 that the majority of people living in ICF/IID settings lived with fewer than 16 people.

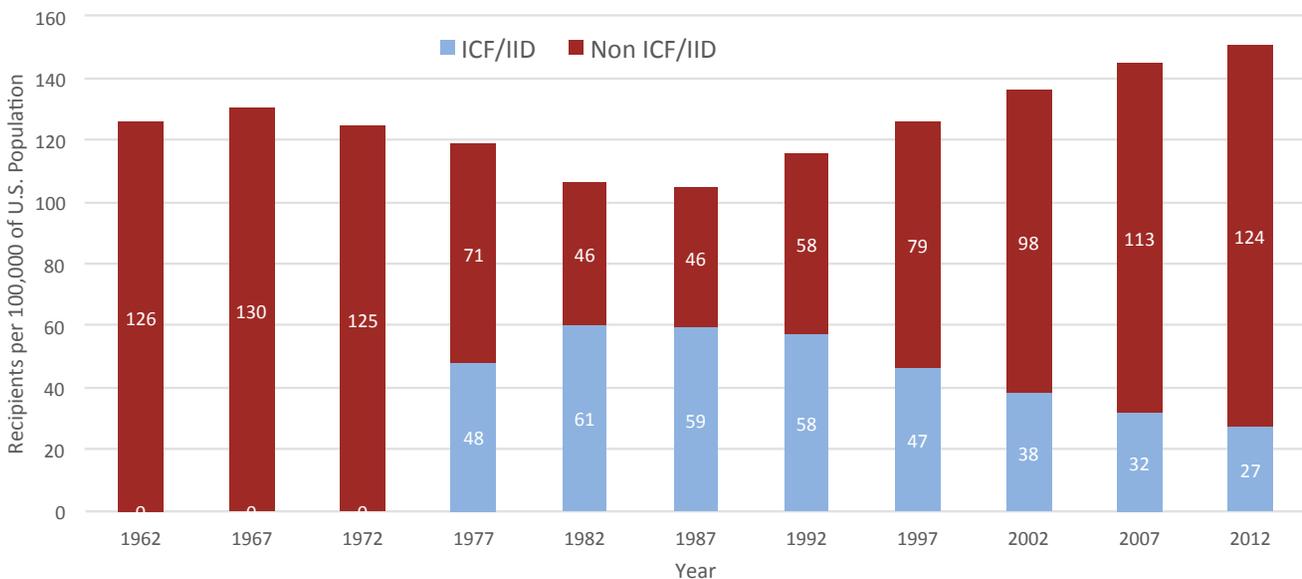
*TODAY MOST ICF/IID RESIDENTS LIVE IN NONSTATE SETTINGS WITH 15 OR FEWER RESIDENTS.*

Figure 5.6 compares changes in the size state and nonstate ICF/IID settings. In 1977, almost all of the people living in state-operated ICFs/IID lived with 16 or more people as did the majority of people living in nonstate settings. The total number of people living in state-operated ICF/IID with 16 or more people peaked in 1982 and then began to decline rapidly. The number of people living in nonstate ICF/IID facilities with 16 or more people did not peak until 1992 when 33,707 people with IDD lived in large nonstate ICF/IID settings. By 2012, only 18,725 people with IDD continued to live in nonstate ICF/IID settings with 16 or more residents.

The number of people with IDD living in state-operated ICF/IID settings of 15 or fewer people increased from 356 in 1977 to a peak of 6,366 on 1992. By 2012, only 1,131 people with IDD continued to live in state-operated ICF/IID settings with 15 or fewer residents. The number of people living in nonstate ICF/IID settings with 15 or fewer residents increased from 1,354 in 1977 to a peak of 43,880 in 1997. By 2007 there were more people with IDD living in nonstate ICF/IID settings of 15 or fewer people than were living in state-operated ICFs/IID with 16 or more residents. By 2012, nearly twice as many people with IDD lived in nonstate ICF/IID settings with 15 or fewer residents than in nonstate settings with 16 or more residents. Today most ICF/IID residents live in nonstate settings with 15 or fewer residents.

Figure 5.7 summarizes changes in utilization of ICF/IID and Non ICF/IID residential settings for people with IDD. The number of people with IID living in a setting other than the home of a family member was 125 per 100,000 in 1972 before the ICF/IID program began. Once the ICF/IID program began, states rapidly converted facilities serving people with IDD to receive federal financial assistance through the ICF/IID program. The utilization of the ICF/IID

**Figure 5.7** Estimated ICF/IID and Non-ICF/IID Residential Services Recipients per 100,000 of the US Population, 1962 to 2012



program peaked in 1982 at 61 residents with IDD per 100,000 of the population. The ICF/IID utilization rate remained steady from 1982 to 1992 but has since declined and was only 27 per 100,000 in 2012. The number of people with IDD living receiving LTSS in a non-ICF/IID setting other than the home of a family member nearly doubled from 58 per 100,000 in 1992 to 124 per 100,000 in 2012.

### Changes in the Number of HCBS Waiver-funded and ICF/IID LTSS Recipients by State

The following is a summary of annual state specific information about HCBS Waiver recipients, HCBS Waiver expenditures, ICF/IID expenditures and total Medicaid HCBS Waiver plus ICF/IID expenditures.

Tables [5.5a](#) - [5.5c](#) shows annual HCBS recipients by state from 1982 to 2012. In 1982, two states reported 1,381 HCBS Waiver recipients with IDD. In

1990, there were 39,838 HCBS Waiver recipients in 42 states. In 2001 the last state had an approved HCBS Waiver for people with IDD. By 2012 an estimated 688,410 people in all 50 States plus the District of Columbia received Medicaid HCBS Waiver-funded LTSS.

[Tables 5.6a](#) and [5.6b](#) summarize annual HCBS expenditures by state from 1987 to 2012. Total HCBS expenditures were \$293 million in 1987, \$9.6 billion in 2000, and \$29.4 billion in 2012.

[Table 5.7](#) shows the annual expenditures for Medicaid HCBS Waiver, ICF/IID and combined totals, by state, every other year from 1994 to 2012. Total Medicaid HCBS expenditures for people with IDD increased from \$2.9 billion in 1994 to \$429.5 billion in 2012. Total ICF/IID expenditures increased from \$9.2 billion in 1994 to \$12.3 billion in 2012. Combined expenditures more than tripled from 1994 to 2012 from \$12.2 billion to \$41.8 billion.



**Table 5.5a** HCBS Waiver Recipients by State on June 30 of Years 1982 through 1990

State	1982	1983	1984	1985	1986	1987	1988	1989	1990
AL	0	808	1,564	1,524	1,568	1,570	1,730	1,830	1,839
AK	0	0	0	0	0	0	0	0	0
AZ	0	0	0	0	0	0	0	0	0
AR	0	0	0	0	0	0	0	0	91
CA	0	433	619	2,500	2,962	3,027	2,493	3,355	3,628
CO	0	0	600	920	1,280	1,389	1,621	1,679	1,841
CT	0	0	0	0	0	0	644	1,127	1,555
DE	0	0	0	50	78	81	144	100	196
DC	0	0	0	0	0	0	0	0	0
FL	0	0	7,003	7,003	1,003	2,631	2,631	2,542	2,615
GA	0	0	0	0	0	0	0	25	160
HI	0	0	10	24	44	56	78	70	123
ID	0	0	18	51	25	55	201	270	346
IL	0	0	40	543	543	664	637	680	724
IN	0	0	0	0	0	0	0	0	0
IA	0	0	0	0	0	4	12	14	5
KS	0	0	23	186	173	135	185	314	361
KY	0	0	475	516	516	609	652	728	743
LA	0	2,006	2,046	2,087	0	0	0	0	0
ME	0	0	75	165	353	400	450	453	454
MD	0	0	28	356	464	685	716	813	858
MA	0	0	0	235	525	593	593	1,210	1,539
MI	0	0	0	0	2	3	580	1,292	1,658
MN	0	0	0	239	570	1,423	1,896	2,068	2,184
MS	0	0	0	0	0	0	0	0	0
MO	0	0	0	0	0	0	0	338	989
MT	21	44	69	78	192	210	286	274	276
NE	0	0	0	0	0	0	553	540	658
NV	0	34	80	90	108	129	117	136	133
NH	0	0	303	409	504	541	634	762	822
NJ	0	0	1,317	2,025	1,993	2,596	2,873	3,170	3,270
NM	0	0	0	53	244	220	134	135	160
NY	0	0	0	0	0	0	0	0	0
NC	0	0	17	120	331	328	405	553	731
ND	0	0	68	439	463	724	824	1,063	1,055
OH	0	0	56	62	86	100	134	240	245
OK	0	0	0	0	36	70	178	500	621
OR	1,360	1,886	1,992	973	572	832	968	1,218	1,282
PA	0	0	141	269	542	1,203	1,759	1,930	2,221
RI	0	0	11	25	117	136	250	449	277
SC	0	0	0	0	0	0	0	0	0
SD	0	382	457	523	498	596	610	683	721
TN	0	0	0	0	0	213	351	474	581
TX	0	0	0	0	70	70	412	417	485
UT	0	0	0	0	0	0	1,022	1,124	1,200
VT	0	11	74	116	234	196	248	280	323
VA	0	0	0	0	0	0	0	0	0
WA	0	0	844	998	905	886	946	1,084	1,250
WV	0	0	22	55	55	124	124	224	316
WI	0	0	20	56	124	190	598	913	1,302
WY	0	0	0	0	0	0	0	0	0
US Total	1,381	5,604	17,972	22,690	17,180	22,689	28,689	35,077	39,838
N States	2	8	27	31	32	35	38	40	42

**Table 5.5b** HCBS Waiver Recipients by State on June 30 of Years 1991 through 2000

State	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
AL	2,021	2,184	2,184	2,900	2,949	3,415	3,713	3,713	3,891	4,100
AK	0	0	0	32	127	190	353	424	466	665
AZ	3,794	4,832	6,071	6,773	7,117	7,727	8,508	9,248	10,180	11,259
AR	196	415	453	429	469	472	496	646	1,647	2,084
CA	3,360	3,360	11,085	13,266	19,101	29,133	37,478	33,202	30,386	28,233
CO	1,993	2,204	2,407	2,684	3,316	3,976	4,276	4,928	6,043	6,330
CT	1,655	1,693	2,069	2,361	2,542	2,999	3,371	3,380	4,493	5,076
DE	245	290	290	310	356	352	379	382	455	481
DC	0	0	0	0	0	0	0	0	0	67
FL	2,631	2,637	6,009	6,430	7,988	10,000	11,399	12,728	13,809	21,126
GA	353	359	359	556	848	1,619	2,332	2,400	2,847	2,468
HI	189	452	450	513	491	517	560	759	975	1,089
ID	165	225	174	333	362	415	434	441	509	801
IL	1,338	2,006	2,850	4,590	3,761	5,267	5,400	6,037	6,500	6,787
IN	0	0	447	529	594	816	1,067	1,405	1,554	2,081
IA	19	137	170	879	1,669	2,575	3,932	4,058	4,118	4,603
KS	497	555	1,066	1,339	1,613	3,146	3,872	4,891	5,120	5,442
KY	762	819	855	887	879	924	1,040	1,035	1,039	1,279
LA	56	939	1,134	1,543	1,926	2,100	2,048	2,407	2,973	3,629
ME	509	509	509	742	742	1,000	1,078	1,345	1,610	1,834
MD	1,082	1,972	2,437	2,787	2,898	3,306	3,392	3,353	3,660	4,959
MA	1,700	3,288	3,288	5,130	7,800	8,027	8,027	10,317	10,678	10,375
MI	2,122	2,741	2,885	3,367	3,842	5,207	6,199	5,708	8,024	8,287
MN	2,551	2,890	3,408	4,385	4,740	5,422	6,097	6,710	7,102	7,948
MS	0	0	0	0	0	65	231	413	550	850
MO	1,452	2,241	2,622	3,057	3,511	5,685	6,282	7,238	7,926	8,238
MT	355	444	504	546	646	807	891	931	929	1,206
NE	683	710	991	1,257	1,169	1,834	2,010	2,124	2,252	2,307
NV	135	136	186	172	278	361	374	392	800	795
NH	955	1,059	1,032	1,303	1,570	1,906	2,063	2,262	2,276	2,475
NJ	3,655	3,971	4,191	4,729	5,033	5,242	5,705	6,199	6,635	6,894
NM	160	334	612	402	1,243	1,553	1,603	1,617	1,765	2,104
NY	0	379	3,398	18,877	23,199	27,272	29,019	30,610	33,699	36,100
NC	780	939	1,190	1,318	1,818	3,098	3,726	3,986	4,974	5,364
ND	1,163	1,334	1,362	1,509	1,637	1,770	1,792	1,819	1,875	1,936
OH	246	397	1,120	2,399	2,593	2,593	2,646	3,968	5,325	5,624
OK	844	949	1,287	1,693	1,955	2,260	2,497	2,586	2,795	2,983
OR	2,177	1,458	2,023	2,136	2,500	2,523	2,586	3,704	5,500	5,824
PA	2,333	2,705	3,795	4,303	5,525	6,076	8,931	10,149	10,119	16,830
RI	793	993	1,192	1,333	1,304	1,914	2,178	2,296	2,393	2,471
SC	0	471	586	966	1,475	2,074	3,412	3,701	4,073	4,370
SD	788	852	923	1,004	1,157	1,295	1,457	1,619	1,971	1,991
TN	579	704	587	964	1,399	3,021	3,293	3,823	4,315	4,311
TX	973	968	968	1,564	2,728	3,658	4,753	5,666	6,058	6,406
UT	1,234	1,367	1,476	1,590	1,693	2,128	2,315	2,647	2,857	3,152
VT	485	413	598	722	913	1,107	1,372	1,485	1,540	1,684
VA	326	537	537	715	1,126	1,453	1,764	3,138	3,579	4,635
WA	1,736	1,918	1,711	3,068	3,361	4,666	6,643	7,125	8,165	8,984
WV	413	513	637	803	1,121	1,337	1,441	1,679	1,851	1,945
WI	1,643	1,812	2,017	2,315	3,382	5,063	6,558	7,273	8,375	9,547
WY	125	318	459	565	719	864	916	1,054	1,112	1,226
US Total	51,271	62,429	86,604	122,075	149,185	190,230	221,909	239,021	261,788	291,255
N States	45	48	48	49	49	50	50	50	50	50

**Table 5.5c HCBS Waiver Recipients by State on June 30 of 2001 through 2012**

State	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
AL	4,395	4,764	4,444	4,952	4,979	5,164	5,230	5,670	5,460	5,625	5,575	5,604
AK	844	884	931	973	1,003	1,008	1,011	1,061	1,248	1,343	1,486	1,703 <sup>e</sup>
AZ	12,317	13,471	14,494	15,659	16,724	17,845	19,066	20,154	21,811	22,755	23,692	24,617
AR	2,423	2,494	2,644	2,960	3,329	3,356	3,342	3,360	3,744	3,987	3,957	4,037
CA	29,044	44,205	53,775	57,533	61,587	69,782	73,024	75,867	80,862	85,294	92,076	97,868
CO	6,444	6,516	6,779	6,730	6,775	6,850	7,148	7,275	7,883	8,177	8,001	8,147
CT	5,508	5,972	5,825	6,356	6,583	7,232	7,692	7,905	8,519	8,640	8,741	8,638
DE	518	547	614	688	732	744	788	817	831	842	828	855
DC	224	225	226	466	609	890	1,090	1,203	1,338	1,446	1,442	1,479
FL	24,910	25,921	24,301	24,079	26,003	31,324	31,425	30,939	29,807	29,998	29,661	29,353
GA	4,051	8,190	8,902	8,484	8,475	8,617	9,194	11,296	11,433	11,631	11,797	11,621 <sup>†</sup>
HI	1,335	1,560	1,772	1,987	2,040	2,363	2,481	2,531	2,586	2,495	2,617	2,544
ID	1,031	1,139	1,302	1,501	1,702	1,813	2,015	2,233	2,484	2,933	2,933	2,660 <sup>ea</sup>
IL	6,787	6,787	9,785	9,727	10,457	12,409	12,800	14,496	15,302	16,954	18,108	18,355 <sup>e†</sup>
IN	2,646	3,802	7,983	9,307	9,285	9,431	9,976	10,247	10,961	11,246	12,283	12,786
IA	5,503	6,228	7,229	8,002	10,933	11,823	12,751	13,205	13,983	14,174	14,300	11,359
KS	5,835	6,239	6,340	6,457	6,771	6,869	7,195	7,373	7,749	7,749	8,060	8,274
KY	1,542	1,807	2,033	2,432	2,654	2,768	3,033	3,231	5,073	5,495	8,998	11,046 <sup>e†</sup>
LA	4,008	4,232	4,809	5,199	5,324	5,484	6,915	6,834	7,616	8,232	8,797	9,957 <sup>e</sup>
ME	2,052	2,440	2,458	2,549	2,604	2,666	2,781	2,867	4,212	4,288	4,156	4,101 <sup>e</sup>
MD	6,013	6,768	7,593	8,753	9,438	9,971	10,294	10,831	11,162	11,202	11,805	12,489
MA	11,196	11,315	11,764	11,388	11,126	11,460	11,962	11,381	11,861	11,861	DNF	11,987
MI	8,550	8,550	8,688	8,256	8,601	8,283	8,089	7,987	8,535	8,593	39,838	39,838 <sup>ed</sup>
MN	14,470	14,735	14,754	14,599	14,468	14,291	14,593	14,563	14,832	15,353	21,938	18,963 <sup>†</sup>
MS	1,720	1,673	1,908	2,030	1,940	1,838	1,978	1,975	1,974	1,888	1,809	1,831 <sup>ea</sup>
MO	8,419	8,143	7,861	8,219	8,268	8,183	8,396	8,729	8,766	9,105	10,215	11,041
MT	1,235	1,452	1,685	1,917	2,023	2,058	2,242	2,268	2,273	2,330	2,720	2,668
NE	2,398	2,419	2,769	2,983	2,908	3,238	3,304	3,589	3,728	4,000	4,229	4,531
NV	1,090	1,083	1,040	1,294	1,326	1,373	1,372	1,591	1,567	1,628	1,656	1,652
NH	2,750	2,779	2,835	3,053	3,154	3,254	3,339	3,580	4,108	4,052	4,467	4,519 <sup>†</sup>
NJ	6,978	7,486	8,122	8,455	9,075	9,611	9,923	10,048	10,081	10,083	10,315	11,297 <sup>e</sup>
NM	2,426	2,794	3,073	3,286	3,571	3,685	3,711	3,777	3,885	3,981	4,115	4,115 <sup>ed</sup>
NY	40,165	48,165	48,921	51,427	51,486	54,251	56,401	58,560	62,195	66,179	69,136	77,047
NC	6,141	6,013	5,692	6,011	6,753	7,831	9,309	9,700	10,333	11,094	12,838	12,800
ND	1,990	2,011	2,187	2,668	3,077	3,297	3,535	3,657	3,805	3,856	3,897	4,059
OH	5,661	7,858	10,093	10,424	11,736	14,370	16,362	18,106	24,312	26,735	29,227	30,872 <sup>†a</sup>
OK	3,605	4,100	4,253	4,220	4,418	5,043	5,308	5,548	5,248	5,157	5,286	5,223 <sup>†</sup>
OR	7,225	8,017	7,214	8,280	8,863	9,416	10,287	10,879	10,884	12,495	13,228	14,865
PA	19,513	24,969	25,550	25,474	24,896	25,643	26,558	29,357	30,393	32,224	32,824	29,963
RI	2,567	2,674	2,790	2,834	2,991	3,073	3,126	3,217	3,275	3,275	3,275	3,316
SC	4,346	4,410	4,471	5,041	4,774	4,895	5,186	5,652	5,768	7,719	7,670	8,394 <sup>†a</sup>
SD	2,168	2,295	2,359	2,413	2,467	2,522	2,609	2,733	2,901	3,018	3,294	3,215
TN	4,537	4,340	4,430	4,516	4,836	6,962	7,244	7,467	7,548	7,580	7,624	7,680
TX	7,304	7,873	8,471	11,247	12,317	13,999	16,301	18,409	19,795	22,247	24,935	29,193
UT	3,370	3,589	3,661	3,757	3,832	3,986	4,003	4,062	4,214	4,287	4,361	4,319
VT	1,796	1,844	1,896	1,957	2,003	2,102	2,200	2,270	2,372	2,460	2,539	2,649
VA	5,043	5,491	5,737	5,892	6,759	6,991	7,523	8,106	8,662	8,866	9,198	9,754
WA	9,413	9,900	10,165	9,625	9,461	9,475	9,317	9,205	10,831	11,341	11,644	11,898
WV	2,396	2,796	3,139	3,596	3,648	3,736	3,852	3,891	4,334	4,412	4,425	4,447 <sup>†</sup>
WI	10,686	9,474	10,615	11,163	12,987	13,938	12,504	17,268	17,424	19,617	19,617	23,396
WY	1,354	1,507	1,522	1,576	1,837	2,032	2,079	2,082	2,099	2,128	2,152	2,150 <sup>†a</sup>
Est. US Total	327,942	373,946	401,904	422,395	443,608	479,245	501,864	529,052	562,067	592,070	647,785	688,410
N States	51	51	51	51	51	51	51	51	51	51	51	51

<sup>a</sup> Includes only people receiving HCBS Waiver Services through a 1915(c) Waiver for people with IDD <sup>d</sup> 2011 data <sup>e</sup> Estimate DNF Did not furnish

\* See state notes in Appendix

**Table 5.6a** HCBS Waiver Expenditures in Thousands (\$) per Year by State for Fiscal Years 1998 to 2000

State	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
AL	\$6,422	\$8,187	\$9,431	\$10,504	\$12,400	\$12,400	\$22,182	\$30,500	\$38,000	\$45,690	\$72,327	\$77,000	\$77,810	\$96,422
AK	0	0	0	0	0	0	0	667	2,964	7,071	17,669	19,234	23,071	30,619
AZ	0	0	0	0	80,100	98,716	114,162	109,358	164,161	189,921	203,898	211,971	252,771	287,562
AR	0	0	0	425	1,803	11,250	10,391	14,057	10,472	13,238	12,063	16,815	25,213	34,048
CA	42,500	38,458	47,933	50,497	54,049	54,049	92,415	133,839	254,508	314,614	355,246	436,829	461,810	478,275
CO	18,016	31,399	34,872	38,720	52,714	60,192	63,488	77,602	107,034	125,499	133,283	148,628	176,383	191,257
CT	0	5,418	26,677	59,180	61,575	83,575	139,891	135,134	152,291	103,750	222,364	230,358	294,791	344,991
DE	851	1,766	3,392	3,585	4,705	5,105	9,668	9,074	12,353	22,911	16,279	17,679	18,452	27,433
DC	0	0	0	0	0	0	0	0	0	0	0	0	0	277
FL	11,636	13,905	18,900	17,766	18,000	20,246	38,675	67,760	99,540	113,853	131,805	108,525	122,002	251,835
GA	0	0	500	1,939	5,065	10,250	15,068	17,300	17,300	56,394	63,127	83,000	98,200	92,058
HI	542	645	1,188	1,915	3,052	4,385	8,620	12,000	13,406	11,982	11,721	17,100	19,700	23,000
ID	0	727	1,068	1,648	2,148	1,188	2,700	2,035	2,245	7,815	9,997	9,077	10,804	16,279
IL	11,732	13,357	14,500	19,100	16,900	79,600	34,478	57,554	51,957	58,435	116,000	151,000	149,300	140,200
IN	0	0	0	0	0	0	484	4,016	16,863	23,461	33,301	34,324	73,134	73,046
IA	0	42	54	42	54	774	2,477	4,025	16,702	32,213	48,272	51,737	74,235	88,573
KS	638	845	760	4,373	11,670	13,737	36,813	32,032	40,720	71,569	93,519	120,931	156,893	169,351
KY	12,012	13,201	13,500	13,818	16,257	19,821	24,506	25,165	27,820	25,722	29,430	40,640	42,192	60,432
LA	0	0	0	0	204	1,785	13,086	25,000	37,958	42,365	44,291	57,033	74,549	95,375
ME	6,545	7,752	11,681	12,316	12,500	13,250	23,607	23,738	15,291	15,600	60,067	69,044	93,074	108,341
MD	25,265	23,662	34,347	34,347	42,979	72,327	64,502	119,237	125,131	130,702	140,673	154,174	169,663	181,153
MA	3,820	15,800	26,200	43,780	57,029	90,000	74,222	204,300	231,500	248,400	280,000	377,347	408,875	423,922
MI	80	22,353	34,813	41,500	58,635	81,039	78,235	90,300	182,400	163,000	162,809	237,666	310,751	424,430
MN	13,383	24,371	46,944	55,185	79,344	95,381	107,235	127,711	137,928	215,225	260,223	311,248	355,968	408,224
MS	0	0	0	0	0	0	0	0	0	26	631	1,526	2,641	4,422
MO	0	0	9,085	13,818	28,373	65,792	75,838	80,548	80,122	137,228	155,018	168,970	186,561	198,882
MT	4,132	4,301	4,724	5,236	7,693	10,827	13,516	15,564	17,105	20,400	22,500	26,300	27,315	33,562
NE	0	5,897	11,086	1,339	19,569	25,522	24,169	32,271	22,277	45,063	58,901	67,148	77,807	84,258
NV	1,542	1,688	1,665	1,588	2,236	2,400	2,295	2,060	3,180	4,640	4,877	8,353	9,182	12,245
NH	13,129	18,981	25,506	31,565	39,200	44,400	53,026	64,005	70,390	80,460	89,427	97,407	102,434	99,743
NJ	27,221	36,092	70,152	77,103	91,503	108,601	113,720	130,064	141,104	154,968	180,066	199,366	284,536	296,254
NM	1,044	2,101	2,384	2,400	3,191	8,829	7,552	10,179	43,591	71,840	46,295	91,603	100,117	109,600
NY	0	0	0	0	0	34,496	163,595	403,371	403,957	728,614	1,114,423	1,343,414	1,561,068	1,694,410
NC	3,130	4,489	5,677	6,826	12,831	13,833	16,223	19,846	30,504	56,651	106,199	134,167	136,043	182,952
ND	6,543	6,111	11,755	13,361	16,336	18,975	20,586	23,270	26,589	28,925	30,176	33,850	37,634	41,962
OH	661	1,961	3,016	4,071	4,091	12,824	26,512	49,740	92,920	91,365	90,058	108,500	179,812	178,003
OK	516	1,325	3,506	5,499	11,818	39,375	73,728	57,849	73,677	104,988	93,593	119,328	134,251	147,633
OR	8,783	15,231	22,794	34,838	40,983	58,604	86,646	78,200	86,714	99,134	105,178	127,803	161,500	232,255
PA	35,640	70,645	81,969	107,984	120,100	133,681	169,501	247,511	294,264	340,699	415,400	446,454	532,018	677,863
RI	5,627	5,211	9,417	14,337	14,337	14,367	74,433	58,725	67,466	80,600	107,962	125,266	97,627	145,629
SC	0	0	0	0	0	4,961	14,703	18,000	22,700	32,600	51,300	70,200	92,203	111,100
SD	6,381	7,581	9,101	10,388	13,334	16,257	20,474	22,527	27,577	33,903	38,739	40,462	47,367	49,960
TN	1,824	5,832	6,412	7,909	11,390	14,431	10,134	16,031	23,777	71,431	72,739	96,593	135,111	159,937
TX	1,750	4,176	6,994	12,139	14,368	39,755	10,742	47,384	72,624	82,983	159,896	210,371	261,474	269,268
UT	0	6,416	7,809	13,309	20,000	23,000	29,537	31,114	35,170	40,827	50,794	58,316	65,768	74,302
VT	4,786	5,304	7,046	8,954	10,255	14,154	28,628	33,140	39,888	45,138	47,980	51,558	54,438	60,014
VA	0	0	0	0	264	15,975	12,350	26,130	31,217	50,479	67,430	88,557	113,355	144,548
WA	13,503	16,974	13,748	18,465	30,254	39,974	79,961	77,223	102,643	97,772	105,006	115,511	128,863	183,835
WV	863	1,818	2,850	7,197	10,040	13,200	38,189	19,923	29,410	36,075	43,660	57,751	66,636	87,636
WI	3,424	9,410	14,837	18,567	30,132	39,078	50,140	60,559	87,519	103,000	155,238	193,666	237,380	273,006
WY	0	0	0	0	846	12,508	17,309	23,987	26,695	29,158	33,428	38,222	40,983	44,144
US Total	293,939	453,433	658,291	827,530	1,144,323	1,654,857	2,180,369	2,971,625	3,711,624	4,714,394	5,965,273	7,133,409	8,363,766	9,644,522

Table 5.6b HCBS Waiver Expenditures in Thousands (\$) per Year by State for Fiscal Years 2000 to 2012

State	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Net Change 2002/2012
AL	\$98,005	\$120,395	\$148,745	\$188,908	\$219,627	\$249,095	\$253,259	\$267,363	\$272,231	\$272,842	\$283,512	\$288,701	\$190,696
AK	53,140	51,866	57,619	60,388	63,010	66,882	70,955	76,806	79,894	100,945	106,418	134,516	81,376
AZ	322,608	386,529	332,106	368,786	399,132	476,764	556,450	619,467	584,647	606,011	633,000	640,785	318,177
AR	43,009	53,077	55,976	62,676	75,597	83,131	91,380	97,105	129,052	139,744	160,404	173,135	130,125
CA	532,304	853,788	928,760	1,070,153	1,185,664	1,338,182	1,532,880	1,709,007	1,844,385	1,939,601	1,968,798	2,107,489	1,575,186
CO	217,914	205,028	237,440	243,392	237,868	253,093	268,080	311,355	326,926	336,292	328,105	331,010	113,096
CT	350,105	386,547	393,811	410,686	421,313	420,464	454,125	475,540	540,053	643,615	672,406	720,878	370,773
DE	32,132	34,181	45,424	48,205	53,848	68,914	75,090	83,576	89,294	89,162	91,007	94,329 <sup>e</sup>	62,197
DC	970	1,648	3,507	5,120	9,082	17,533	19,678	54,470	123,350	139,209	182,755	147,196	146,226
FL	403,110	496,921	551,082	635,135	664,000	761,392	908,572	945,063	870,806	933,666	959,141	879,855	476,745
GA	149,447	286,390	227,612	218,217	220,234	254,585	263,542	381,690	330,423	352,542	354,051	407,212 <sup>*</sup>	257,765
HI	27,227	34,728	43,996	64,200	71,969	85,000	97,000	104,462	107,166	100,020	101,065	102,910	75,683
ID	23,181	27,804	36,036	44,700	50,531	52,367	60,937	68,119	75,006	99,214	99,214	64,425 <sup>T</sup>	DNF
IL	140,200	140,200	285,368	324,900	359,100	401,424	416,200	461,700	493,700	525,600	569,178	591,460 <sup>e*</sup>	451,260
IN	107,431	198,630	267,608	395,771	378,413	393,536	402,597	443,950	497,510	509,458	480,744	489,971	382,540
IA	106,034	127,081	142,647	171,691	221,483	255,981	275,728	303,613	323,671	343,543	355,752	387,580	281,546
KS	176,570	189,358	194,212	206,000	217,398	229,623	247,334	274,844	280,702	280,702	319,851	330,269 <sup>e*</sup>	153,699
KY	76,424	91,756	92,623	121,822	156,788	172,623	163,060	233,130	247,721	266,304	340,297	406,429 <sup>e*</sup>	330,005
LA	121,145	129,015	157,448	210,067	242,183	244,332	258,220	322,452	385,861	398,179	399,348	407,248 <sup>e</sup>	286,102
ME	124,372	136,461	175,000	181,000	195,171	221,118	230,661	248,957	306,724	307,266	314,041	291,071 <sup>e</sup>	166,699
MD	200,725	251,357	297,237	312,912	371,693	449,636	495,386	517,578	539,178	588,228	707,167	686,894	486,169
MA	454,625	483,391	540,114	564,726	619,925	671,087	703,361	583,548	667,080	667,080	DNF	841,481 <sup>T</sup>	DNF
MI	538,109	538,109	420,690	370,729	330,689	345,619	316,274	381,731	382,926	420,834	431,254	445,712 <sup>T</sup>	DNF
MN	508,066	699,687	796,838	812,254	848,406	649,093	889,902	925,199	981,249	998,021	1,128,249	1,215,081	707,015
MS	10,414	20,699	28,348	30,200	36,500	35,459	39,461	38,013	43,011	35,624	35,092	43,976 <sup>T</sup>	DNF
MO	219,299	235,897	230,181	238,437	259,444	310,567	379,435	392,751	427,475	463,120	469,528	533,967 <sup>*</sup>	314,668
MT	36,886	42,005	59,851	55,109	57,897	62,987	68,412	78,281	81,879	98,904	89,185	90,871	53,985
NE	89,063	108,402	109,030	113,749	118,703	126,926	140,172	147,500	165,166	205,291	221,687	239,921	150,858
NV	20,047	24,367	27,432	33,976	42,935	51,479	61,585	65,416	71,990	72,474	72,743	78,767	58,720
NH	113,414	117,922	118,533	122,893	127,314	134,639	143,209	155,729	165,838	174,853	186,462	192,025	78,610
NJ	360,838	402,988	363,752	380,018	399,258	438,810	496,612	505,880	545,803	558,107	668,774	737,871 <sup>e</sup>	377,033
NM	132,070	157,256	183,000	197,237	222,738	243,699	247,597	267,982	277,843	294,460	285,949	285,949 <sup>ed</sup>	153,879
NY	1,701,780	2,125,806	2,120,120	2,517,127	3,159,344	3,187,877	3,449,069	3,825,877	4,338,249	4,766,909	5,261,374	5,468,225	3,766,444
NC	217,112	254,337	259,000	265,354	266,945	289,467	377,747	457,750	472,188	608,295	1,193,913	619,805	402,693
ND	44,856	47,531	49,235	53,907	57,489	64,630	71,823	77,570	85,486	97,697	113,644	129,617	84,761
OH	195,089	245,009	392,420	436,393	476,750	600,704	660,978	813,796	1,074,780	1,095,712	1,179,689	1,240,862 <sup>*</sup>	DNF
OK	177,065	222,356	205,537	216,911	211,694	228,941	253,401	267,878	273,415	280,202	271,849	273,952	96,887
OR	292,334	361,705	285,540	314,616	332,591	365,420	385,762	438,538	438,571	515,170	572,729	597,868	305,534
PA	789,399	977,487	1,044,794	1,075,806	1,040,866	1,103,171	1,199,739	1,224,628	1,339,183	1,636,580	1,827,305	1,816,306	1,026,907
RI	149,671	160,859	196,071	215,616	215,544	230,814	245,521	251,289	243,023	243,023	243,023	203,663	53,992
SC	132,300	142,500	146,580	150,253	157,040	170,000	185,700	213,200	220,500	226,600	230,571	291,243 <sup>T</sup>	DNF
SD	53,865	58,935	62,745	66,861	73,085	76,614	81,945	86,922	90,794	96,253	101,292	101,739	47,874
TN	201,249	205,314	277,188	285,820	356,432	461,903	525,964	553,899	569,200	574,382	583,159	604,098	402,849
TX	305,890	321,671	346,975	377,677	420,360	471,551	566,475	698,358	774,482	912,609	1,006,941	1,058,827	752,938
UT	82,351	88,991	94,610	98,482	102,906	104,433	113,867	126,595	140,448	148,513	151,270	155,515	73,163
VT	68,534	74,856	77,823	85,190	92,172	102,246	109,071	121,271	128,447	132,938	137,908	141,617	73,083
VA	174,354	198,911	228,194	231,967	291,600	333,987	394,326	443,733	498,673	539,806	562,873	602,412	428,058
WA	203,064	214,490	236,272	246,127	347,278	299,402	315,624	352,551	387,987	419,823	430,591	550,896	347,831
WV	97,574	120,218	141,396	143,431	173,426	167,342	203,371	222,657	263,676	245,100	249,295	303,862	206,287
WI	300,058	312,785	344,729	376,713	429,490	471,332	439,299	629,474	696,768	694,836	694,836	855,374	555,316
WY	46,598	56,957	61,658	67,461	75,442	79,225	87,041	93,970	96,558	90,361	95,692	98,412 <sup>T*</sup>	DNF
US Est. Total	10,922,985	13,224,202	14,122,912	15,489,768	17,158,367	18,375,098	20,293,874	22,442,230	24,390,989	26,285,720	27,923,133	29,503,277	18,580,292

**Table 5.7** HCBS Waiver and ICF/IID Expenditures in Thousands Selected Years 1994 to 2012

State	Program	1994	1996	1998	2000	2002	2004	2006	2008	2010	2011	2012
AL	HCBS	30,500	45,690	77,000	96,422	120,396	188,908	249,095	267,363	272,842	283,512	288,701
	ICF/IID	79,259	68,011	56,664	63,946	60,309	36,699	25,886	36,180	34,859	38,284	789
	Total	109,759	113,701	133,664	160,368	180,704	225,607	274,981	303,542	307,701	321,795	289,490
AK	HCBS	667	7,071	19,234	30,619	51,866	60,388	66,882	76,806	100,945	106,418	126,197
	ICF/IID	11,589	6,891	268	0	0	0	0	0	1,644	1,758	3,051
	Total	12,256	13,962	19,502	30,619	51,866	60,388	66,882	76,806	102,589	108,176	129,248
AZ	HCBS	109,358	189,921	211,971	287,562	327,357	368,786	476,764	619,467	606,011	633,000	640,785
	ICF/IID	16,911	17,792	16,190	12,457	14,165	17,320	20,418	15,371	DNF	35,959	32,593
	Total	126,269	207,712	228,160	300,019	341,522	386,106	497,182	634,838	DNF	668,959	673,378
AR	HCBS	14,057	13,238	16,815	34,048	53,077	62,676	83,131	97,105	139,744	160,404	173,135
	ICF/IID	94,187	105,335	109,175	121,240	119,491	113,000	134,528	147,860	158,996	153,643	156,756
	Total	108,244	118,573	125,990	155,288	172,568	175,676	217,659	244,965	298,740	314,047	329,891
CA	HCBS	133,839	314,614	436,829	478,275	853,788	1,070,153	1,338,182	1,709,007	1,939,601	1,968,798	2,107,489
	ICF/IID	365,970	471,049	391,152	387,213	420,000	698,896	706,596	610,506	560,646	867,094	721,911
	Total	499,810	785,663	827,981	865,489	1,273,788	1,769,049	2,044,778	2,319,513	2,500,247	2,835,892	2,829,400
CO	HCBS	77,602	125,499	148,628	191,257	205,028	243,392	253,093	311,355	336,292	328,105	331,010
	ICF/IID	38,873	24,165	22,252	17,986	19,202	20,545	46,063	22,289	28,496	37,519	39,533
	Total	116,475	149,664	170,880	209,243	224,231	263,937	299,156	333,644	364,788	365,625	370,543
CT	HCBS	135,134	103,750	230,358	344,991	386,547	410,686	420,464	475,540	643,615	672,406	720,878
	ICF/IID	179,704	180,936	204,211	230,625	238,700	254,583	288,307	236,998	292,219	249,929	253,475
	Total	314,838	284,686	434,569	575,616	625,247	665,269	708,771	712,538	935,833	922,335	974,353
DE	HCBS	9,074	22,911	17,679	27,433	34,181	48,205	68,914	83,576	89,162	91,007	94,329
	ICF/IID	27,270	30,886	32,558	32,545	31,219	28,454	22,751	29,834	30,734	28,555	17,462
	Total	36,344	53,797	50,237	59,978	65,401	76,659	91,664	113,410	119,896	119,562	111,791
DC	HCBS	0	0	0	277	1,648	5,120	17,533	54,470	139,209	182,755	147,196
	ICF/IID	64,030	60,969	69,176	70,280	79,480	80,809	79,031	82,084	69,360	87,823	62,874
	Total	64,030	60,969	69,176	70,557	81,128	85,928	96,564	136,553	208,569	270,579	210,070
FL	HCBS	67,760	113,853	108,525	251,835	496,921	635,135	761,392	945,063	933,666	959,141	804,259
	ICF/IID	212,267	226,118	255,994	281,143	310,393	309,107	314,473	338,700	333,718	330,575	326,571
	Total	280,027	339,971	364,519	532,978	807,315	944,243	1,075,864	1,283,763	1,267,384	1,289,716	1,130,830
GA	HCBS	17,300	56,394	83,000	92,058	223,566	218,217	254,585	381,690	352,542	354,051	401,354
	ICF/IID	119,694	125,848	106,845	110,219	110,659	146,179	111,654	103,532	91,957	41,805	5,858
	Total	136,994	182,242	189,845	202,277	334,226	364,395	366,239	485,222	444,499	395,856	407,212
HI	HCBS	12,000	11,982	17,100	23,000	34,728	64,200	85,000	104,462	100,020	101,065	102,910
	ICF/IID	10,541	11,238	10,027	7,976	8,589	7,466	7,707	9,027	9,014	5,992	7,715
	Total	22,541	23,219	27,127	30,976	43,317	71,666	92,707	113,490	109,034	107,057	110,624
ID	HCBS	2,035	7,815	9,077	16,279	27,804	44,700	52,367	68,119	99,214	99,214	33,843
	ICF/IID	40,364	40,572	46,796	53,211	55,251	53,544	56,856	62,010	66,258	40,794	18,228
	Total	42,399	48,387	55,873	69,490	83,055	98,244	109,223	130,129	165,472	140,008	52,071
IL	HCBS	57,554	58,435	151,000	140,200	236,978	324,900	401,424	461,700	525,600	569,178	591,460
	ICF/IID	489,075	591,719	610,073	649,195	695,913	759,064	714,281	659,781	636,142	699,422	688,115
	Total	546,628	650,154	761,073	789,395	932,892	1,083,964	1,115,705	1,121,481	1,161,742	1,268,600	1,279,575
IN	HCBS	4,016	23,461	34,324	73,046	198,630	395,771	393,536	443,950	509,458	480,744	330,269
	ICF/IID	309,133	308,113	300,946	258,455	343,223	346,162	580,565	304,805	313,997	408,575	64,166 <sup>d</sup>
	Total	313,150	331,574	335,270	331,501	541,853	741,933	974,101	748,755	823,455	889,320	394,436



Table 5.7 HCBS Waiver and ICF/IID Expenditures in Thousands Selected Years 1994 to 2012

State	Program	1994	1996	1998	2000	2002	2004	2006	2008	2010	2011	2012
IA	HCBS	4,025	32,213	51,737	88,573	127,081	171,691	255,981	303,613	343,543	355,752	366,606
	ICF/IID	161,161	178,844	177,480	191,252	208,168	225,591	264,363	288,093	286,661	308,565	301,739
	Total	165,187	211,056	229,217	279,825	335,249	208,389	520,345	591,706	630,203	664,317	668,345
KS	HCBS	32,032	71,569	120,931	169,351	189,358	206,000	229,623	274,844	280,702	319,851	330,269
	ICF/IID	105,436	98,690	84,831	66,924	65,928	68,847	65,014	63,193	61,911	60,331	64,166
	Total	137,468	170,259	205,762	236,275	255,286	274,847	294,638	338,037	342,614	380,183	394,436
KY	HCBS	25,165	25,722	40,640	60,432	91,756	121,822	172,623	226,531	145,523	340,297	393,442
	ICF/IID	71,529	58,065	79,355	83,524	97,888	106,756	128,759	111,178	145,523	137,785	130,481
	Total	96,694	83,787	119,995	143,956	189,644	228,578	301,381	337,709	411,827	478,082	523,923
LA	HCBS	25,000	42,365	57,033	95,375	129,015	210,067	244,332	322,452	398,179	399,348	404,249
	ICF/IID	299,879	312,380	323,915	347,439	359,385	419,202	426,076	480,842	472,347	431,138	461,013
	Total	324,879	354,745	380,948	442,813	488,400	629,269	670,407	803,294	870,526	830,486	865,262
ME	HCBS	23,738	15,600	69,044	108,341	155,500	181,000	221,118	248,957	307,266	314,041	270,956
	ICF/IID	54,807	49,476	38,824	35,306	50,370	60,794	71,845	65,103	60,512	24,991	42,531
	Total	78,545	65,076	107,868	143,647	205,870	241,794	292,963	314,060	367,779	339,033	313,487
MD	HCBS	119,237	130,702	154,174	181,153	251,357	312,912	449,636	517,578	588,228	707,167	677,765
	ICF/IID	59,589	63,594	55,636	58,820	54,063	60,160	61,676	55,148	24,984	29,185	11,138
	Total	178,825	194,296	209,810	239,973	305,420	373,072	511,313	572,726	613,212	736,351	688,903
MA	HCBS	204,300	248,400	377,347	423,922	483,391	564,726	671,087	583,548	667,080	DNF	597,478
	ICF/IID	295,029	276,185	252,869	210,037	198,049	228,173	165,698	234,838	417,064	142,825	0
	Total	499,329	524,585	630,216	633,959	681,440	792,899	836,785	818,386	1,084,144	DNF	597,478
MI	HCBS	90,300	163,000	237,666	330,194	393,285	370,729	345,619	381,731	420,834	431,254	242,100
	ICF/IID	157,234	192,726	242,896	27,884	26,913	19,101	35,285	16,728	0	29,670	150,914
	Total	247,534	355,726	480,562	358,077	420,198	389,830	380,904	398,459	420,834	460,924	393,014
MN	HCBS	127,711	215,225	311,248	408,224	699,687	812,254	649,093	925,199	998,021	1,128,249	1,033,090
	ICF/IID	245,807	183,855	223,835	208,714	207,900	180,916	171,025	178,358	169,111	139,737	150,267
	Total	373,518	399,080	535,083	616,938	907,587	993,170	820,118	1,103,557	1,167,132	1,267,987	1,183,356
MS	HCBS	0	26	1,526	4,422	20,699	30,200	35,459	38,013	35,624	35,092	39,889
	ICF/IID	84,961	101,925	131,471	158,201	178,043	186,535	233,922	285,878	269,536	245,446	270,287
	Total	84,961	101,951	132,997	162,623	198,742	216,735	269,381	323,891	305,160	280,538	310,176
MO	HCBS	80,548	137,228	168,970	198,882	235,897	238,437	310,567	392,751	463,120	469,528	533,967
	ICF/IID	144,139	156,510	110,152	164,292	213,814	263,379	237,512	129,145	133,888	112,714	108,468
	Total	224,686	293,738	279,122	363,174	449,711	501,816	548,079	521,896	597,007	582,241	642,435
MT	HCBS	15,564	20,400	26,300	33,562	42,005	55,109	62,987	78,281	DNF	89,185	90,871
	ICF/IID	14,222	14,747	12,132	17,425	14,061	19,299	12,745	13,044	12,659	9,748	14,714
	Total	29,786	35,147	38,432	50,987	56,066	74,408	75,731	91,325	111,564	98,932	105,586
NE	HCBS	32,271	45,063	67,148	82,541	108,402	129,734	126,926	147,500	205,291	221,687	239,921
	ICF/IID	34,234	36,498	42,976	48,862	47,953	60,807	60,368	68,218	34,313	21,019	56,291
	Total	66,506	81,561	110,124	131,403	156,355	190,541	187,294	215,718	239,604	242,706	296,212
NV	HCBS	2,060	4,640	8,353	12,245	24,367	33,976	51,479	65,416	72,474	72,743	78,767
	ICF/IID	20,335	23,737	25,449	28,496	30,468	26,019	26,728	18,994	18,473	16,600	17,845
	Total	22,395	28,377	33,802	40,741	54,836	59,995	78,207	84,410	90,948	89,343	96,612
NH	HCBS	64,005	80,460	97,407	99,743	117,922	122,893	131,770	155,729	174,853	186,462	187,262
	ICF/IID	5,980	3,291	1,502	1,660	1,953	2,290	2,484	3,005	3,106	3,076	3,154
	Total	69,985	83,751	98,910	101,403	119,874	125,183	134,254	158,735	177,959	189,538	190,416

**Table 5.7** HCBS Waiver and ICF/IID Expenditures in Thousands Selected Years 1994 to 2012

State	Program	1994	1996	1998	2000	2002	2004	2006	2008	2010	2011	2012
NJ	HCBS	130,064	154,968	199,366	296,254	402,988	380,018	438,810	505,880	558,107	668,774	737,871
	ICF/IID	357,321	359,085	347,216	380,580	462,969	512,838	644,231	633,121	619,411	493,788	672,344
	Total	487,385	514,053	546,582	676,834	865,957	892,856	1,083,041	1,139,001	1,177,518	1,162,562	1,410,215
NM	HCBS	10,179	71,840	91,603	109,600	157,256	197,237	243,699	267,982	294,460	285,949	273,679
	ICF/IID	38,311	31,853	16,316	27,815	18,993	22,941	21,730	23,172	24,695	25,184	25,023
	Total	48,490	103,693	107,919	137,415	176,249	220,178	265,429	291,154	319,155	311,132	298,702
NY	HCBS	403,371	728,614	1,343,414	1,694,410	2,125,806	2,517,127	3,187,877	3,825,877	4,766,909	5,261,374	5,465,599
	ICF/IID	2,011,018	2,112,557	2,047,529	2,129,387	2,201,916	2,575,882	2,893,576	2,675,003	3,373,069	3,226,551	3,239,298
	Total	2,414,389	2,841,171	3,390,944	3,823,797	4,327,723	5,093,010	6,081,453	6,500,880	8,139,978	8,487,924	8,704,897
NC	HCBS	19,846	56,651	134,167	182,952	254,337	265,354	289,467	457,750	608,295	1,193,913	564,510
	ICF/IID	331,538	347,958	380,157	396,863	416,423	431,968	442,437	461,931	491,450	494,128	528,714
	Total	351,384	404,609	514,324	579,815	670,759	697,323	731,904	919,681	1,099,745	1,688,041	1,093,224
ND	HCBS	23,270	28,925	33,850	41,962	47,531	53,907	64,630	77,570	97,697	113,644	129,617
	ICF/IID	38,747	41,528	44,306	49,981	53,137	54,839	62,936	70,722	90,198	87,465	92,568
	Total	62,017	70,453	78,156	91,942	100,668	108,746	127,566	148,293	187,895	201,109	222,186
OH	HCBS	49,740	91,365	108,500	178,003	245,009	436,393	600,704	813,796	1,095,712	1,179,689	1,232,259
	ICF/IID	453,033	473,812	534,896	558,612	926,944	961,446	741,765	691,975	763,030	730,639	779,571
	Total	502,772	565,177	643,396	736,615	1,171,954	1,397,840	1,342,469	1,505,771	1,858,742	1,910,327	2,011,830
OK	HCBS	57,849	104,988	119,328	147,633	222,356	216,911	228,941	267,878	280,202	271,849	273,952
	ICF/IID	91,298	92,345	106,414	103,178	108,822	120,545	125,061	126,917	123,592	100,901	122,249
	Total	149,146	197,334	225,742	250,811	331,178	337,456	354,002	394,795	403,793	372,750	396,201
OR	HCBS	78,200	99,134	127,803	232,255	283,161	314,616	365,420	438,538	515,170	572,729	597,478
	ICF/IID	78,885	77,571	76,396	24,520	9,895	13,281	11,282	12,241	2,193	58	N/A
	Total	157,085	176,705	204,199	256,775	293,056	327,897	377,691	450,778	517,363	572,787	597,478
PA	HCBS	247,511	340,699	446,454	677,863	977,487	1,075,806	1,103,171	1,224,628	1,636,580	1,827,305	1,734,035
	ICF/IID	501,094	554,621	554,601	496,919	497,867	501,748	555,408	578,711	598,966	618,977	591,089
	Total	748,605	895,319	1,001,055	1,174,782	1,475,354	1,577,553	1,658,579	1,803,339	2,235,547	2,446,282	2,325,125
RI	HCBS	58,725	80,600	125,266	145,629	160,860	215,616	230,814	251,289	243,023	243,023	203,663
	ICF/IID	42,165	34,011	5,893	6,292	7,244	7,686	7,813	8,738	11,462	11,180	4,039
	Total	100,890	114,611	131,159	151,921	168,104	223,302	238,627	260,026	254,485	254,203	207,702
SC	HCBS	18,000	32,600	70,200	111,100	142,500	150,253	170,000	213,200	226,600	230,571	242,100
	ICF/IID	172,312	184,919	172,453	171,932	174,843	174,884	161,279	154,256	140,570	134,373	150,914
	Total	190,312	217,519	242,653	283,032	317,343	325,137	331,279	367,456	367,170	364,944	393,014
SD	HCBS	22,527	33,903	40,462	49,960	58,935	66,861	76,614	86,922	96,253	101,292	101,739
	ICF/IID	31,815	28,309	20,469	17,999	18,448	18,794	20,785	22,367	24,524	19,435	29,974
	Total	54,342	62,212	60,931	67,960	77,383	85,655	97,400	109,288	120,777	120,727	131,713
TN	HCBS	16,031	71,431	96,593	159,937	205,314	285,820	461,903	553,899	574,382	583,159	604,098
	ICF/IID	135,560	201,503	243,620	234,719	253,863	227,494	262,019	241,019	225,406	168,197	222,616
	Total	151,591	272,934	340,213	394,656	459,176	513,314	723,922	794,918	799,787	751,356	826,714
TX	HCBS	47,384	82,983	210,371	269,268	321,671	377,677	471,551	698,358	912,609	1,006,941	819,495
	ICF/IID	552,769	580,188	646,618	728,987	771,326	826,576	817,811	890,443	974,081	1,036,957	1,029,396
	Total	600,153	663,170	856,989	998,255	1,092,996	1,204,254	1,289,362	1,588,801	1,886,691	2,043,898	1,848,892
UT	HCBS	31,114	40,827	58,316	74,302	88,991	98,482	104,433	126,595	148,513	151,270	155,515
	ICF/IID	38,095	46,128	43,955	53,199	54,883	53,977	60,702	69,803	57,404	63,840	77,678
	Total	69,209	86,955	102,271	127,501	143,874	152,459	165,136	196,398	205,917	215,110	233,193

**Table 5.7** HCBS Waiver and ICF/IID Expenditures in Thousands Selected Years 1994 to 2012

State	Program	1994	1996	1998	2000	2002	2004	2006	2008	2010	2011	2012
<b>VT</b>	HCBS	33,140	45,138	51,558	60,014	74,856	85,190	102,246	121,271	132,938	137,908	141,617
	ICF/IID	5,525	3,091	1,567	1,661	1,631	829	959	979	DNF	1,211	1,267
	Total	38,665	48,229	53,124	61,676	76,487	86,019	103,205	122,250	DNF	139,119	142,884
<b>VA</b>	HCBS	26,130	50,479	88,557	144,548	198,911	231,967	333,987	443,733	539,806	562,873	602,412
	ICF/IID	153,544	153,656	160,217	183,140	211,838	201,974	237,899	273,333	270,359	249,414	65,374
	Total	179,673	204,135	248,774	327,688	410,749	433,941	571,886	717,065	810,165	812,288	667,786
<b>WA</b>	HCBS	77,223	97,772	115,511	183,835	214,491	246,127	299,402	352,551	419,823	430,591	550,896
	ICF/IID	166,588	121,523	127,047	133,127	129,321	124,232	125,984	150,435	141,461	129,193	134,366
	Total	243,811	219,295	242,559	316,962	343,812	370,359	425,387	502,985	561,283	559,784	685,262
<b>WV</b>	HCBS	19,923	36,075	57,751	87,636	120,218	143,431	167,342	222,657	245,100	249,295	303,862
	ICF/IID	14,288	53,704	48,656	47,088	47,513	54,249	55,756	60,129	62,595	62,612	65,464
	Total	34,212	89,780	106,406	134,724	167,731	197,679	223,099	282,786	307,695	311,907	369,325
<b>WI</b>	HCBS	60,559	103,000	193,666	273,006	297,751	376,713	471,332	504,235	694,836	694,836	855,374
	ICF/IID	188,316	204,565	202,486	254,700	226,317	226,961	170,089	128,508	145,075	158,172	157,751
	Total	248,875	307,565	396,152	527,706	524,067	603,675	641,421	632,743	839,911	853,008	1,013,125
<b>WY</b>	HCBS	23,987	29,158	38,222	44,144	56,957	67,461	79,225	93,970	90,361	95,692	98,497
	ICF/IID	6,829	10,484	16,630	16,054	11,662	16,908	18,296	18,312	18,503	20,303	28,758
	Total	30,816	39,641	54,852	60,198	68,619	84,369	97,521	112,282	108,865	115,994	127,254
<b>US</b>	HCBS	2,971,625	4,714,394	7,133,409	9,663,901	12,979,622	15,505,754	18,372,229	22,310,393	26,285,720	27,923,133	29,503,277
	ICF/IID	9,222,257	9,733,573	9,833,092	9,902,143	10,867,404	11,929,750	12,511,425	11,962,854	12,871,190	12,573,135	12,307,192
	Total	12,193,883	14,447,967	16,966,501	19,566,043	23,847,026	27,435,504	30,883,653	34,273,247	39,156,910	40,496,267	41,810,469

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish \* See state notes in the Appendix



## SECTION SIX

# Status and Changes in State Operated LTSS Settings for People with IDD

**FY 2012**



## SECTION 6: STATUS AND CHANGES IN STATE-OPERATED LTSS SETTINGS FOR PEOPLE WITH IDD

**Section 6 includes three parts** describing state-operated long-term services and supports for people with IDD. The first part describes state-operated residential settings and residents by size, funding source and state. Facilities serving 16 or more people with IDD are described in further detail. Data for this section was provided by State IDD Directors. The second part lists each large state facility by state and describes the resident population at the beginning and end of the year, movement in and out of the facility and average cost per person. Data for this section came from a combination of individual facility surveys and reports from state IDD directors. The final part describes national longitudinal trends in the utilization of large state-operated IDD residences from 1950 through 2012 based on historic data maintained by the RISP project.

### Size and Funding Source for State-operated IDD Facilities

**Number of Settings.** An estimated 2,399 state-operated IDD settings were open on June 30, 2012 (see [Table 6.1](#)). Five states (Alabama, Hawaii, Michigan, Vermont and West Virginia) and the District of Columbia reported having no state-operated facilities as of June 2012. Of the remaining states, 14 had 1 or 2 state-operated facilities; 13 had 3 to 10 facilities; 10 had 11 to 50 facilities; 3 had 51 to 100 facilities, and 5 had 101 or more facilities. Nearly half (1,063, 47%) of all state-operated IDD facilities were located in New York. Other states with more than 100 facilities were Connecticut (312), Mississippi (215), Minnesota (104) and Massachusetts (total not furnished but more than 200).

**Setting Size.** An estimated 632 state-operated IDD settings had 3 or fewer residents, 895 had 4 to 6 residents, 685 had 7 to 15 residents and 178 had 16 or more residents. Size information was not available for 9 facilities. Twelve states (Alabama, Alaska, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Vermont, and West Virginia) and the District of Columbia report no IDD facilities with 16 or more residents. Alaska reported 17 people with IDD living in ICF-IID facilities in other states. Of the remaining states, 13 operated homes with 1 to 3 residents, 18 operated group homes with 4 to 6 residents, 12 operated facilities with 7 to 15

residents and 38 operated facilities with 16 or more residents. Of the 38 states operating IDD facilities with 16 or more residents, 20 had 1 or 2 facilities, 16 had 3 to 10 facilities, and 2 had 11 or more facilities (New York with 14 and Texas with 13 IDD facilities with 16 or more residents)

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*OF THE ESTIMATED 2,399 STATE-OPERATED IDD FACILITIES IN OPERATION ON JUNE 30, 2012, 339 WERE ICF/IID CERTIFIED, 2,051 WERE HCBS WAIVER-FUNDED, AND NINE WERE FUNDED BY ANOTHER SOURCE.*

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**Funding Source.** The RISP FY 2012 survey asked states to report the number of state-operated IDD facilities using three different funding mechanisms (ICF/IID, HCBS Waiver, and Other). Of the estimated 2,399 state-operated IDD facilities in operation on June 30, 2012, 339 were ICF/IID certified, 2,051 were HCBS Waiver-funded, and nine were funded by another source.

**Settings with 3 or Fewer Residents.** Of the estimated 632 state-operated HCBS Waiver-funded settings serving 1 to 3 people, 248 (39%) were located in Connecticut. Other states with 10 or more HCBS Waiver-funded facilities with 1 to 3 people included Mississippi (87), New York (71), Missouri (64), Rhode Island (36), Washington (19) and New Mexico (17).

**Group Homes with 4 to 6 Residents.** Of the 895 state-operated settings with 4 to 6 residents, 70 were ICF/IID and 825 were HCBS Waiver-funded. States with more than 10 ICF/IID certified group homes with 4 to 6 residents included Tennessee (25), Minnesota (15), and Colorado (11). The remaining ICF/IID facilities with 4 to 6 residents were located in Arizona, Mississippi, Texas, Rhode Island, New York, New Mexico, and North Carolina. Of the state-operated HCBS Waiver-funded group homes with 4 to 6 residents, 409 (50%) were located in New York. Other states with 25 or more state-operated HCBS Waiver-funded group homes with 4 to 6 residents included Minnesota (83), Connecticut (40), Mississippi (35), and Rhode Island (25).

**Table 6.1** Number of State Operated IDD Settings by Size and Funding Authority on June 30, 2012

State	1-3 Residents		4-6 Residents		1-6 Residents		7-15 Residents		ID/DD Facilities and Units (16+)		IDD Not ICF or HCBS	Total Settings
	HCBS	ICF/IID	HCBS	ICF/IID	HCBS	ICF/IID	HCBS	ICF/IID	HCBS			
<b>N States</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>	
AL	0	0	0	0	0	0	0	0*	0	0	0	
AK	0	0	0	0	0	0	0	0	0	0	0	
AZ	5	1	5	1	10	3	0	1*	1*	0	16	
AR	0	0	0	0	0	0	0	5	0	0	5	
CA	0	0	0	0	0	0	0	5	0	0	5	
CO	0	11	5	11	5	17	16	2 <sup>ed</sup>	0*	0	51	
CT	248 <sup>†</sup>	0	40	0	288	0	18	6	0	0	312	
DE	3	0	2	0	5	0	0	1	0	0	6	
DC	0	0	0	0	0	0	0	0	0	0	0	
FL	0	0	0	0	0	0	0	2	0	1	3	
GA	0	0	0	0	0	0	0	2*	0	0	2	
HI	0	0	0	0	0	0	0	0	0	0	0	
ID	0	0	0	0	0	0	0	1	0	0	1	
IL	0	0	0	0	0	0	0	8	0	0	8	
IN	0	0	0	0	0	0	0	0*	0	0	0	
IA	6	0	14	0	20	0	0	2	0	0	22	
KS	0	0	0	0	0	0	0	2	0	0	2	
KY	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	0 <sup>e</sup>	3 <sup>e</sup>	0 <sup>e</sup>	2 <sup>e</sup>	0 <sup>e</sup>	0	5	
LA	0	0	0	0	0	1	0	4	0	0	5	
ME	0	0	0	0	0	0	0	0	0	0	0	
MD	0	0	0	0	0	1	0	2	0	0	3	
MA	DNF	0	DNF	0	DNF	1	DNF	5	0	0	DNF	
MI	0	0	0	0	0	0	0	0	0	0	0	
MN	6	15	83	15	89	0	0	0	0	0	104	
MS	87	1 <sup>e</sup>	35	1 <sup>e</sup>	122	60 <sup>e</sup>	21	6*	0	5 <sup>e</sup>	215	
MO	64	0	9	0	73	0	0	6	0	0	79	
MT	0	0	0	0	0	0	0	1	0	0	1	
NE	0	0	0	0	0	1	0	3	0	0	4	
NV	0	0	0	0	0	0	0	1	0	0	1	
NH	0	0	0	0	0	0	0	0	0	1	1	
NJ	2	0	7	0	9	0	13	7	0	0	29	
NM	17 <sup>ed</sup>	1 <sup>ed</sup>	5 <sup>ed</sup>	1 <sup>ed</sup>	22 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>e</sup>	23	
NY	71	8	409	8	480	7	522	46	0	0	1,063	
NC	0	2	0	2	0	0	0	4	0	1	7	
ND	0	0	0	0	0	0	0	1	0	0	1	
OH	0	0	0	0	0	0	0	10	0	0	10	
OK	0	0	0	0	0	0	0	2	0	0	2	
OR	0	0	23	0	23	0	0	0	0	0	23	
PA	0	0	0	0	0	0	0	5	0	0	5	
RI	36	4 <sup>e</sup>	25	4 <sup>e</sup>	61	0	1	0	2	0	68	
SC	0	0	0	0	0	0	0	5	0	0	5	
SD	0	0	0	0	0	0	0	1	0	0	1	
TN	0	25	0	25	0	0	0	2	0	0	27	
TX	0	2	0	2	0	0	0	13	0	0	15	
UT	0	0	0	0	0	0	0	1	0	0	1	
VT	0	0	0	0	0	0	0	0	0	0	0	
VA	0	0	0	0	0	0	0	5	0	0	5	
WA	19	0	19	0	38	0	0	3*	0	1	42	
WV	0	0	0	0	0	0	0	0	0	0	0	
WI	0	0	0	0	0	0	0	2	0	0	2	
WY	0	0	0	0	0	0	0	1	0	0	1	
<b>US Total</b>	<b>564</b>	<b>70</b>	<b>681</b>	<b>70</b>	<b>1,245</b>	<b>94</b>	<b>591</b>	<b>175</b>	<b>3</b>	<b>9</b>	<b>2,187</b>	
<b>Estimated US Total</b>	<b>632</b>	<b>70</b>	<b>825</b>	<b>70</b>	<b>1,457</b>	<b>94</b>	<b>591</b>	<b>175</b>	<b>3</b>	<b>9</b>	<b>2,399</b>	

<sup>†</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in Appendix

**Facilities with 7 to 15 Residents.** Of the 685 state-operated facilities serving 7 to 15 people, 591 (86%) were funded by an HCBS Waiver and 94 (14%) were funded as ICF/IID. New York operated 522 (88%) of the 591 state-operated HCBS Waiver-funded facilities with 7 to 15 residents. Mississippi operated 21 facilities, Connecticut operated 18, and Colorado operated 16. Of the state-operated ICF/IID facilities with 7 to 15 residents 60 (66%) were located in Mississippi. Colorado operated 17 of those facilities, New York operated 7 and Kentucky operated 3. Louisiana, Maryland, Massachusetts, and Nebraska each had 1.

**Facilities with 16 or More Residents.** All but 3 of the 178 facilities with 16 or more residents were certified as ICF/IID. Rhode Island had two HCBS Waiver-funded facilities with 16 or more residents and Arizona had 1. States with the most state-operated ICF/IID facilities serving 16 or more people were New York (46), Texas (13), Ohio (10), Illinois (8), and New Jersey (7).

**Other-Funded Residences.** Five states reported having state-operated residences for people with IDD that were neither ICF/IID nor HCBS Waiver-funded including Mississippi (5 residences), Florida (1), New Hampshire (1), North Carolina (1), and Washington (1).

## People with IDD in State-operated Residences

**Number of People in State-Operated IDD Facilities by State.** On June 30, 2012, an estimated 38,761 people with IDD lived in state-operated IDD facilities in 42 states (See Table 6.2). Nearly half (45%) of those people lived in New York (9,051 people; 23% of the total), Texas (3,797; 10%), New Jersey (2,480; 6%) or Mississippi (2,262; 6%). The number of people living in state-operated IDD facilities was less than 100 in 9 states, between 100 and 499 in 13 states, between 500 and 999 in 9 states, between 1,000 and 1,999 in 7 states, and 2,000 or more in four states.

**Funding Source.** Of 38,761 people with IDD living in a state-operated residence, 10,843 (28%) lived in a residence funded by an HCBS Waiver, 27,440 (71%) lived in an ICF/IID, and 478 (1%) lived in a facility funded by another source. Twenty-four states reported that all of the people in state-operated IDD facilities lived in an ICF/IID; Oregon reported that all people in state-operated settings had HCBS Waiver funding and New Hampshire reported all people in a state-operated IDD facility lived in a setting that was neither an ICF/IID nor HCBS Waiver-funded. Finally, 25 states operated IDD facilities funded by a combination of ICF/IID, HCBS Waiver, and other sources.



**Table 6.2** People with IDD Living in State Residential Settings by Size and Funding Authority on June 30, 2012

State	Size and Funding Source									Other Funding Source	Total
	1-3 People		4-6 People		1-6 People		7-15 People		16+ People		
	HCBS	ICF/ IID	HCBS	ICF/ IID	HCBS	ICF/ IID	HCBS	ICF/ IID	HCBS		
<b>N States</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>	<b>51</b>	<b>50</b>
AL	0	0	0	0	0	0	0	0*	0	0	
AK	0	0	0	0	0	0	0	0	0	0	0
AZ	16	6	17	6	33	25	0	82	26	0	
AR	0	0	0	0	0	0	0	951	0	0	951
CA	0	0	0	0	0	0	0	1,682	0	0	
CO	0	61	28	61	28	100	107	161	135*	0	592
CT	262	0	220	0	482	0	142	612	0	0	
DE	7	0	8	0	15	0	0	66	0	0 <sup>e</sup>	81
DC	0	0	0	0	0	0	0	0	0	0	
FL	0	0	0	0	0	0	0	781	0	118	899
GA	0	0	0	0	0	0	0	300	0	0	
HI	0	0	0	0	0	0	0	0	0	0	0
ID	0	0	0	0	0	0	0	47	0	0	
IL	0	0	0	0	0	0	0	1,928	0	0	1,928
IN	0	0	0	0	0	0	0	0	0	0	
IA	18	0	50	0	68	0	0	444	0	0	512
KY	0	0	0	0	0	0	0	334 <sup>e*</sup>	0	0	
LA	0	0	0	0	0	9	0	839	0	0	149
ME	0	0	0	0	0	0	0	0	0	0	0
MD	0	0	0	0	0	0 <sup>e</sup>	0	54	0	0	
MA	DNF	0	DNF	0	923	14	248	580	0	0	1,765
MI	0	0	0	0	0	0	0	0	0	0	
MN	15	89	317	89	332	0	0	0	0	0	421
MS	106 <sup>e</sup>	6 <sup>e</sup>	106 <sup>e</sup>	6 <sup>e</sup>	212 <sup>e</sup>	586 <sup>e</sup>	0	1,441	0	17 <sup>e</sup>	
MO	175	0	36	0	211	0	0	510	0	0	721
MT	0	0	0	0	0	0	0	55	0	0	
NE	0	0	0	0	0	8	0	136	0	0	144
NV	0	0	0	0	0	0	0	48	0	0	
NH	0	0	0	0	0	0	0	0	0	4	4
NJ	4 <sup>e</sup>	0	42 <sup>e</sup>	0	46 <sup>e</sup>	0	0	2,434	0	0	
NM	36 <sup>ed</sup>	4 <sup>ed</sup>	20 <sup>ed</sup>	4 <sup>ed</sup>	56 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>ed</sup>	0 <sup>e</sup>	60
NY	186	35	2,062	35	2,248	54	5,081	1,633	0	0	
NC	0	0	0	0	0	0	0	1,424	0	82	1,506
ND	0	0	0	0	0	0	0	94	0	0	
OH	0	0	0	0	0	0	0	1,134	0	0	1,134
OK	0	0	0	0	0	0	0	235	0	0	
OR	0	0	108	0	108	0	0	0	0	0	108
PA	0	0	0	0	0	0	0	1,106	0	0	
RI	36	21	129	21	165	0	14	0	33	0	233
SC	0	0	0	0	0	0	0	745	0	0	
SD	0	0	0	0	0	0	0	140	0	0	140
TN	0	97	0	97	0	0	0	183	0	0	
TX	0	10	0	10	0	0	0	3,787	0	0	3,797
UT	0	0	0	0	0	0	0	207	0	0	
VT	0	0	0	0	0	0	0	0	0	0	0
VA	0	0	0	0	0	0	0	948	0	0	
WA	54	0	76	0	130	0	0	576	0	257	963
WV	0	0	0	0	0	0	0	0	0	0	
WI	0	0	0	0	0	0	0	390	0	0	390
WY	0	0	0	0	0	0	0	79	0	0	
<b>Reported Total</b>	<b>915</b>	<b>329</b>	<b>3,219</b>	<b>329</b>	<b>5,057</b>	<b>802</b>	<b>5,592</b>	<b>26,309</b>	<b>194</b>	<b>478</b>	<b>38,761</b>
<b>US Estimated Total</b>	<b>1,119</b>	<b>329</b>	<b>3,938</b>	<b>329</b>	<b>5,057</b>	<b>802</b>	<b>5,592</b>	<b>26,309</b>	<b>194</b>	<b>478</b>	<b>38,761</b>

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish \* See state notes in the Appendix

In six states, more than half of the people with IDD in state-operated residences lived in an HCBS Waiver-funded setting (New Mexico, 93%; Rhode Island, 91%; New York, 81%; Minnesota, 79%; Massachusetts, 66%; and Connecticut, 50%). The other 19 states using multiple funding sources reported that the majority of people with IDD lived in an ICF/IID.

States serving people with IDD in settings that were neither ICF/IID certified nor HCBS Waiver-funded included: Washington (257 people), Florida (118), North Carolina (82), Mississippi (17), and New Hampshire (4).

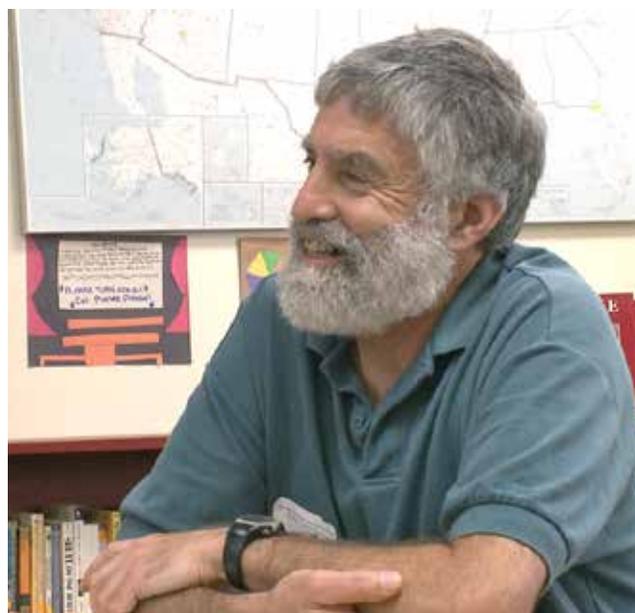
**Setting Size.** Of the 38,761 people with IDD living in a state-operated IDD residence 1,119 (3%) lived with three or fewer people with IDD, 4,267 (9%) lived with 4 to 6 people, 6,394 (16%) lived in a facility with 7 to 15 residents, and 26,503 (68%) lived in a facility with 16 or more residents (478 people with IDD lived in a facility whose size was not reported). Among states with state-operated IDD settings, the number of people living in group homes with 6 or fewer residents ranged from 10 in Texas to 2,283 in New York. The number living in facilities with 7 to 15 residents ranged from 6 in Kentucky to 5,135 in New York. Finally, the number living in facilities with 16 or more residents ranged from 33 in Rhode Island to 3,787 in Texas.

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*OF THE 38,761 PEOPLE WITH IDD LIVING IN A STATE-OPERATED IDD RESIDENCE 1,119 (3%) LIVED WITH THREE OR FEWER PEOPLE WITH IDD, 4,267 (9%) LIVED WITH 4 TO 6 PEOPLE, 6,394 (16%) LIVED IN A FACILITY WITH 7 TO 15 RESIDENTS, AND 26,503 (68%) LIVED IN A FACILITY WITH 16 OR MORE RESIDENTS*

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In New Mexico, 36 people (60%) in state-operated IDD settings lived in a home with 3 or fewer other people and 24 (40%) lived in a group home with 4 to 6 people. The majority of people in state-operated residences lived in group homes of 4 to 6 people in Oregon (100%), Minnesota (96%), Rhode Island (64%), and Massachusetts (52%). In New York, 57% of people with IDD in state-operated facilities lived with 7 to 15 people. In 14 states between 50% and 99% of people with IDD in a state-operated facility lived with 16 or more residents and in 22 states 100% of those in a state-operated facility lived with 16 or more people.



**People per 100,000 of the Population Living in State-operated IDD Facilities with 16 or More Residents, Nursing Homes or Psychiatric Facilities.** Indexing the population of state-operated IDD residences by the U.S. general population permits a better picture of the relative use of these settings across states. On June 30, 2012, 38,761 people with IDD lived in a state ICF/IID or HCBS Waiver-funded setting with 16 or more people, 1,139 people lived in a state psychiatric facility and 28,064 lived in a nursing home (See [Tables 1.1](#) and [6.2](#)). Indexed to the general population that was 8.4 per 100,000 of the general population living in a state-operated IDD facility with 16 or more people, 7.7 per 100,000 in nonstate IDD facilities with 16 or more people, 0.4 per 100,000 in psychiatric facilities, and 8.9 per 100,000 in nursing homes (See [Table 6.3](#)). Overall utilization was 25.4 people with IDD per 100,000 across these facility types.

There were tremendous state variations in the utilization of large state facilities to provide LTSS to people with IDD. The District of Columbia had the lowest overall utilization rate (0.9 per 100,000), followed by Alaska (1.4), Arizona (3.3), Hawaii (3.8) and Minnesota (4.1). States with the highest overall utilization of large state settings were Mississippi (77.5 per 100,000), Arkansas (71.2), Iowa (67.2), North Carolina (57.4), and Ohio (54.8). People with IDD in Mississippi, Arkansas, and Iowa were roughly 48 times more likely to live in a large state facility than people in the District of Columbia, or Alaska.

**Table 6.3** Persons with IDD Living in State or Nonstate IDD Facilities with 16 or More People, Psychiatric Facilities or Nursing Homes per 100,000 of the General Population on June 30, 2012

State	2012 State Population (100,000)	State IDD Facility 16+	Nonstate Facility 16+	Psychiatric Facilities	Nursing Homes	Total 16+
AL	48.2	0.0	0.0	0.0	17.7	17.7
AK	7.3	0.0	0.0	0.0	1.4	1.4
AZ	65.5	1.6	0.5	0.0	1.1	3.3
AR	29.5	32.2	18.8	0.0	20.2	71.2
CA	380.4	4.4	4.5	0.0	3.0	12.0
CO	51.9	5.7	0.0	0.0	1.8	7.5
CT	35.9	17.0	0.0	0.0	10.5	27.5
DE	9.2	7.2	0.0	0.3	3.2	10.7
DC	6.3	0.0	0.0	0.0	0.9	0.9
FL	193.2	4.0	DNF	0.1	1.6	5.8
GA	99.2	3.0	DNF	0.0	11.0	14.1
HI	13.9	0.0	0.0	0.0	3.8	3.8
ID	16.0	2.9	5.9	0.0	3.1	11.9
IL	128.8	15.0	25.6	0.0	8.5	49.1
IN	65.4	0.0	4.4	1.6	23.8	29.8
IA	30.7	14.4	32.1	0.0	20.6	67.2
KS	28.9	11.6	0.0	0.0	9.1	20.7
KY	43.8	3.3	3.1	0.0	6.2	12.6
LA	46.0	18.2	11.9	0.3	11.1	41.6
ME	13.3	0.0	8.8	0.2	3.7	12.7
MD	58.8	0.9	0.0	0.0	4.1	5.0
MA	66.5	8.7	0.0	0.0	5.5	14.2
MI	98.8	0.0	DNF	0.0	6.2	6.2
MN	53.8	0.0	DNF	0.0	4.1	4.1
MS	29.8	48.3	24.5	0.0	4.7	77.5
MO	60.2	8.5	1.9	6.2	17.4	33.9
MT	10.1	5.5	0.0	0.0	8.0	13.4
NE	18.6	7.3	13.1	0.0	16.5	37.0
NV	27.6	1.7	3.8	0.0	2.9	8.4
NH	13.2	0.0	1.9	0.0	6.4	8.3
NJ	88.6	27.5	9.1	0.7	11.8	49.0
NM	20.9	0.0	0.0	0.0	5.2	5.2
NY	195.7	8.3	5.1	0.0	9.7	23.1
NC	97.5	14.6	DNF	0.9	41.9	57.4
ND	7.0	13.4	4.3	0.0	14.3	32.0
OH	115.4	9.8	28.0	0.0	17.0	54.8
OK	38.1	6.2	20.3	0.0	8.3	34.7
OR	39.0	0.0	0.7	0.0	5.0	5.7
PA	127.6	8.7	DNF	0.6	12.1	21.4
RI	10.5	3.1	2.0	0.0	4.2	9.3
SC	47.2	15.8	0.0	0.0	4.4	20.1
SD	8.3	16.8	7.1	3.7	16.1	43.7
TN	64.6	2.8	2.6	0.2	6.5	12.1
TX	260.6	14.5	2.2	0.0	7.4	24.2
UT	28.6	7.2	19.8	0.0	5.8	32.9
VT	6.3	0.0	0.0	0.0	5.1	5.1
VA	81.9	11.6	27.1	3.8	11.4	53.9
WA	69.0	8.4	DNF	0.3	4.3	12.9
WV	18.6	0.0	DNF	0.0	17.7	17.7
WI	57.3	6.8	8.3	0.0	0.6	15.7
WY	5.8	13.7	0.0	1.4	4.3	19.4
<b>Est US Total</b>	3,139.1	8.4	7.7	0.4	8.9	25.4

°2011 data °Estimate DNF Did not furnish \* See state notes in the Appendix

States varied not just in their overall utilization of large facilities, but also in the type of large facility people with IDD were most likely to live. The highest utilization rates for large state facilities were in Mississippi (48.3), Arkansas (32.2), and New Jersey

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*STATES VARIED NOT JUST IN THEIR OVERALL UTILIZATION OF LARGE FACILITIES, BUT ALSO IN THE TYPE OF LARGE FACILITY PEOPLE WITH IDD WERE MOST LIKELY TO LIVE.*

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(27.5). Highest utilization rates for large nonstate IDD facilities were in Iowa (32.1), Ohio (28.0), Virginia (27.1) Illinois (25.6), Mississippi (24.5), and Oklahoma (20.3). None of the states had a utilization rate exceeding 7 per 100,000 for psychiatric facilities. Finally, highest utilization rates of nursing home use for people with IDD were in North Carolina (41.9 per 100,000), Indiana (23.8), Iowa (20.6) and Arkansas (20.2).

### **Movement of Residents in Large State IDD Facilities in FY 2012**

The population of large state facilities is not static. Many people are admitted, discharged or die each year (See [Table 6.4](#)). The average daily resident population is a statistic that takes movement in and

out of the facility into account. The estimated US average daily population in state residential facilities with 16 or more residents was 29,251 in FY 2012.

**Admissions.** During FY 2012, an estimated 1,141 people with IDD were admitted to large state IDD facilities. This was equal to 4% of the year's average daily population of those facilities. Nine states with open facilities reported no admissions to their large state facilities (Alabama, Arizona, Connecticut, Georgia, Indiana, Missouri, Rhode Island, Tennessee, and Wisconsin) while 4 states reported admissions equaling or exceeding 20% of the year's average daily population (Kentucky, Maryland, Montana, and South Dakota).

**Discharges.** During FY 2012, an estimated 2,436 people with IDD were discharged from large state facilities (8% of the average daily population). Of the 38 states operating large state facilities, five states discharged more than 30% of their average daily residents including two states that discharged more than 50% of their average daily population (Alabama, 178%; and Montana, 54%).

**Deaths.** During FY 2012, an estimated 747 people with IDD (3% of the average daily population) died while residing in large state facilities compared with 699 deaths (3%) in FY 2011. Nine states with large state facilities reported no deaths during the year (Alabama, Idaho, Indiana, Kansas, Maryland,



**Table 6.4** Movement of Persons with IDD In and Out of Large State IDD Facilities in Fiscal Year 2012 by State

State	Average Daily Population	Admissions		Discharges		Deaths		Residents		
		N	% of Population	N	% of Population	N	% of Population	7/1/2011	6/30/2012	% Change
<b>N Reporting States</b>	<b>51</b>	<b>49</b>	<b>37</b>	<b>49</b>	<b>37</b>	<b>50</b>	<b>37</b>	<b>50</b>	<b>51</b>	<b>40.0</b>
AL	69	0	0.0	123	178.3	0	0.0	123	0	-100.0
AK	0	0	N/A	0	N/A	0	N/A	0	0	N/A
AZ	109	0	0.0	0	0.0	3	2.8	111	108	-0.0
AR	1,017	114	11.2	116	11.4	13	1.3	966	951	-0.0
CA	1,787	67	3.7	226	12.6	50	2.8	1,892	1,682	-0.1
CO	299	29 <sup>e*</sup>	9.7	15 <sup>e*</sup>	5.0	4 <sup>e*</sup>	1.3	294 <sup>e*</sup>	296	0.0
CT	634	0	0.0	3	0.5	25	3.9	656	612	-0.1
DE	65	7 <sup>e</sup>	10.8	1 <sup>e</sup>	1.5	4 <sup>e</sup>	6.2	64 <sup>e</sup>	66	0.0
DC	0	0	N/A	0	N/A	0	N/A	0	0	N/A
FL	782	16	2.0	10	1.3	14	1.8	898	899	0.0
GA	400	0	0.0	177	44.3	9	2.3	477	300	-0.4
HI	0	0	N/A	0	N/A	0	N/A	0	0	N/A
ID	46	5	10.9	7	15.2	0	0.0	49	47	-0.0
IL	1,967	55	2.8	131	6.7	21	1.1	2,034	1,928	-0.1
IN	26	0	0.0	3	11.5	0	0.0	27	0	-1.0
IA	454	15	3.3	38	8.4	7	1.5	474	444	-0.1
KS	325	DNF	DNF	DNF	DNF	0	DNF	336	334	-0.0
KY	146	40 <sup>e</sup>	27.4	48 <sup>e</sup>	32.9	43 <sup>e</sup>	29.5	152 <sup>e</sup>	143	-0.1
LA	884	64	7.2	134	15.2	22	2.5	929	839	-0.1
ME	0	0	N/A	0	N/A	0	N/A	0	0	N/A
MD	54	20	37.0	18	33.3	0	0.0	52	54	0.0
MA	635	DNF	DNF	DNF	DNF	DNF	DNF	DNF <sup>e</sup>	580	DNF
MI	0	0	N/A	0	N/A	0	N/A	0	0	N/A
MN	0	0	N/A	0	N/A	0	N/A	0	0	N/A
MS	1,458	68 <sup>e</sup>	4.7	71	4.9	29 <sup>e</sup>	2.0	1,490 <sup>e</sup>	1,458	-0.0
MO	632	0	0.0	59	9.3	6	0.9	575	510	-0.1
MT	55	24	43.6	30	54.5	0	0.0	59	55	-0.1
NE	142	2	1.4	16	11.3	3	2.1	153	136	-0.1
NV	48	8	16.7	8	16.7	0	0.0	48	48	0.0
NH	0	0	N/A	0	N/A	0	N/A	4	4	0.0
NJ	2,511	22	0.9	104	4.1	71	2.8	2,587	2,434	-0.1
NM	0	0 <sup>ed</sup>	N/A	0 <sup>ed</sup>	N/A	0 <sup>ed</sup>	N/A	0 <sup>ed</sup>	0	N/A
NY	1,724	34	2.0	178	10.3	38	2.2	1,815	1,633	-0.1
NC	1,431	28	2.0	26	1.8	51	3.6	1,551	1,506	-0.0
ND	108	21	19.4	23	21.3	3	2.8	99	94	-0.1
OH	1,184	93	7.9	147	12.4	40	3.4	1,228	1,134	-0.1
OK	241	1	0.4	6	2.5	5	2.1	245	235	-0.0
OR	0	0	N/A	0	N/A	0	N/A	0	0	N/A
PA	1,123	10	0.9	5	0.4	56	5.0	1,157	1,106	-0.0
RI	33	0	N/A	0	N/A	6	N/A	34	33	-0.0
SC	751	52	6.9	48	6.4	21	2.8	763	745	-0.0
SD	139	33	23.7	32	23.0	0	0.0	139	140	0.0
TN	221	0	0.0	51	23.1	8	3.6	242	183	-0.2
TX	3,881	133	3.4	244	6.3	96	2.5	3,994	3,787	-0.1
UT	206	1	0.5	7	3.4	3	1.5	206	207	0.0
VT	0	0	N/A	0	N/A	0	N/A	0	0	N/A
VA	1,012	91	9.0	176	17.4	23	2.3	1,059	948	-0.1
WA	593	22	3.7	68 <sup>*</sup>	11.5	16	2.7	866 <sup>*</sup>	833	-0.0
WV	0	0	N/A	0	N/A	0	N/A	0	0	N/A
WI	393	0	0.0	2 <sup>e</sup>	0.5	6 <sup>e</sup>	1.5	398 <sup>e</sup>	390	-0.0
WY	80	2	2.5	2	2.5	3	3.8	82	79	-0.0
<b>Reported Total</b>	<b>27,665</b>	<b>1,077</b>	<b>3.9</b>	<b>2,353</b>	<b>8.5</b>	<b>699</b>	<b>2.5</b>	<b>28,328</b>	<b>26,981</b>	<b>-0.0</b>
<b>US Estimated Total</b>	<b>29,251</b>	<b>1,141</b>	<b>3.9</b>	<b>2,436</b>	<b>8.3</b>	<b>747</b>	<b>2.6</b>	<b>29,018</b>	<b>26,981</b>	<b>-0.1</b>

<sup>d</sup> 2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in the Appendix

Massachusetts, Montana, Nevada, and South Dakota). Three states reported that the number of deaths was equal to or greater than 5% of the average daily population (Delaware, 6%; Kentucky, 30%; and Pennsylvania, 5%).

**Overall Change.** The number of people in large state facilities decreased 7% between July 1, 2011 and June 30, 2012 from 29,018 to 26,981 in the 38 states that started the year with one or more facility. Two states closed their remaining large state IDD

*THE NUMBER OF PEOPLE IN LARGE STATE FACILITIES DECREASED 7% BETWEEN JULY 1, 2011 AND JUNE 30, 2012 FROM 29,018 TO 26,981 IN THE 38 STATES THAT STARTED THE YEAR WITH ONE OR MORE FACILITY.*

facilities (Alabama and Indiana). Thirty states reported overall reductions in the resident census of large state facilities including Georgia (with a reduction of 37%), and Tennessee (with a reduction of 24%). The resident census of large state facilities grew by two people in Colorado, Connecticut and Maryland and by one person each in Florida, South Dakota, and Utah.

## Facility Closures in FY 2012 and Projections through 2015

**Facility Closures July 1, 2011 through June 30, 2012.** Information about the closure of large state facilities comes from both the state IDD directors and from a survey of facilities. Of the 354 facilities operating between 1960 and 2012, 207 had closed, converted to non-IDD use, privatized, or downsized to 15 or fewer residents (See [Table 6.5](#)) by June 30, 2012. Thirteen states (Alabama, Alaska, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia) and the District of Columbia had no open large state facilities with 16 or more residents.

Between July 1, 2011 and June 30, 2012 one facility downsized to 15 or fewer residents with IDD (The Fernald Center, LA), two ICF/IIDD units closed (Central State Hospital, GA; and Logansport State Hospital, IN), and 5 facilities closed (Wm. D. Partlow Dev. Ctr.,

**Table 6.5** Number of Large State Residential Facilities Operating, Closed, and Projected to Close, FY 1960-2012

State	Operating Between 1960-2012	Closed FY 1960-2011	Closed, Converted or Downsized in FY 2012	Open June 30, 2012	Projected Closures through 2015
AL	5	4	1	0	0
AK	1	1	0	0	0
AZ	4	3	0	1	0
AR	6	2	0	4	0
CA	13	8	0	5	1
CO	3	1	0	2	0
CT	15	9	0	6	0
DE	1	0	0	1	0
DC	3	3	0	0	0
FL	10	5	0	5	0
GA	11	7	1	3	0
HI	2	2	0	0	0
ID	1	0	0	1	0
IL	17	9	0	8	0
IN	11	9	2	0	0
IA	2	0	0	2	0
KS	4	2	0	2	0
KY	5	2	0	3	0
LA	10	4	1	5	1
ME	3	3	0	0	0
MD	9	7	0	2	0
MA	11	5	2	4	2
MI	13	13	0	0	0
MN	9	9	0	0	0
MS	5	0	0	5	0
MO	16	11	0	5	2
MT	2	1	0	1	0
NE	1	0	0	1	0
NV	2	1	0	1	0
NH	2	2	0	0	0
NJ	11	4	0	7	2
NM	3	3	0	0	0
NY	28	18	1	9	1
NC	6	1	0	5	0
ND	2	1	0	1	0
OH	23	13	0	10	0
OK	4	2	0	2	2
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	1
TX	15	2	0	13	0
UT	1	0	0	1	0
VT	1	1	0	0	0
VA	8	3	0	5	2
WA	6	3	0	3	0
WV	4	4	0	0	0
WI	3	1	0	2	0
WY	1	0	0	1	0
<b>US Total</b>	<b>354</b>	<b>207</b>	<b>8</b>	<b>139</b>	<b>14</b>

<sup>a</sup>2011 data <sup>®</sup>Estimate <sup>DNF</sup>Did not furnish <sup>\*</sup> See state notes in the Appendix  
<sup>1</sup>These nine facilities are located on six campuses. [Table 6.1](#) reports on the six campuses.

AL; Evansville State Hospital, IN; Leesville Dev. Ctr., LA; Monson Dev. Ctr., MA; and Capital District DDSO, NY). See [Table 6.6a](#) for a complete list of closed downsized or converted facilities tracked by the RISP project.

**Proposed or Planned Closures.** Respondents reported the actual or planned closures of 19 facilities in nine states between July 1, 2012 and the end of 2015 with 5 additional closures projected between 2015 and 2020 (See [Table 6.6b](#)). California, Louisiana, and Tennessee each projected 1 facility closure. Massachusetts, Missouri, and Oklahoma projected 2 facility closures. New Jersey and New York each projected 3 facility closures. Virginia projected 4 closures by 2020. Three closures were projected for FY 2013, 5 for FY 2014, 6 for FY 2015, and 5 for later than June 2015.

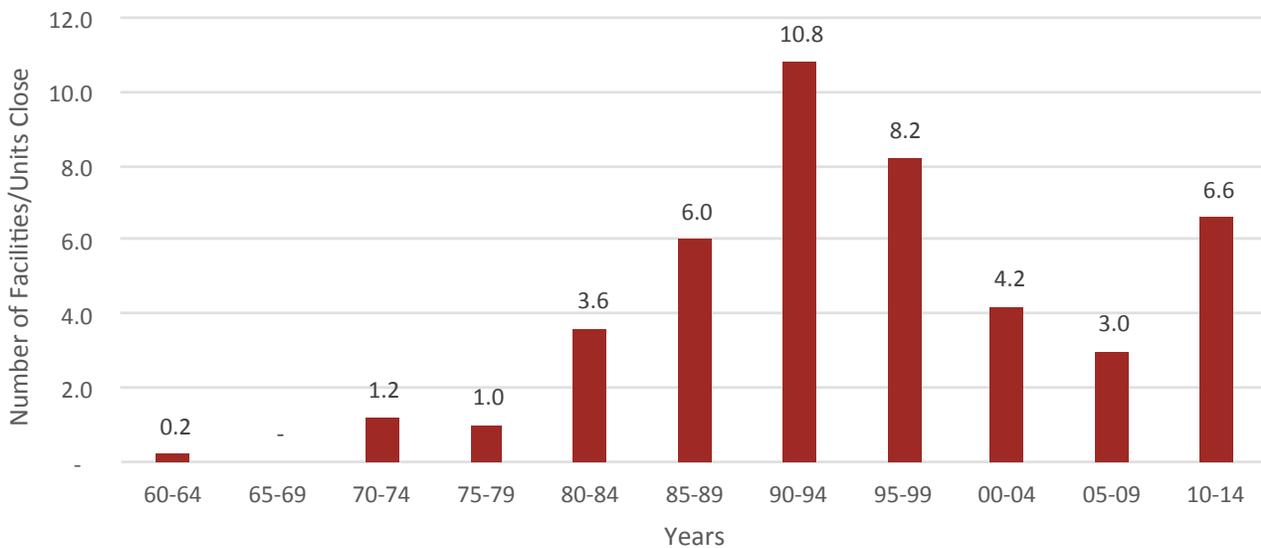
**Movement Patterns and Expenditures in State-operated IDD Facilities.** [Table 6.6b](#) identifies all open large state IDD facilities tracked by the RISP project as of June 30, 2012. It shows the year each facility opened, the projected closure year and month (if applicable), resident populations, average per cost per person per day, and a summary of admissions, readmissions discharges and deaths between July 1, 2011 and June 30, 2012. The total number of residents on June 30, 2012 was provided by 106 facilities, daily per person costs by 94 facilities and movement patterns by 91 facilities.

The total number of people with IDD in large state facilities on June 30, 2012 ranged from 575 in California's Sonoma Developmental Center to 26 in Connecticut's Meridian Center. Per day, per person, expenditures ranged from \$264 to \$1,058. Seventeen facilities reported per diems of less than \$400, 42 reported per diem expenditures between \$400 and \$599, 24 reported per diem expenditures between \$600 and \$799, and 12 reported expenditures of more than \$800 including 1 that reported per diem expenditures exceeding \$1000.

**Limitations.** Due to decisions made in previous decades of this project, the RISP project does not individually survey 39 large facilities in New York, one in Florida, two in Georgia, one in Massachusetts, one unit in Montana, and one facility in Rhode Island. In Missouri, what is reported as six facilities on [Table 3.5](#) is reported as nine facilities here (three of the facilities are operated by a single site).

Variations between [Table 6.5](#) and [Table 4.5](#) in average per resident expenditures are related to several factors. First, [Table 4.5](#) reports the aggregated weighted (by population) costs across ICF/IID and non-ICF/IID facilities for three size categories (1-6, 7-15 and 16 or more). Second, the aggregated data in [Table 4.5](#) are reported by state agencies whereas the data for [Table 4.5](#) are reported by facilities. Reported costs may reflect and reflect variations in accounting practices such as variations in the absorption of state

**Figure 6.1** Average Annual Closures, Conversions and Anticipated Closures of Large State IDD Facilities and Units, FY 1960-2014 in 5-year Intervals



**Table 6.6a** Year When Large State IDD Facilities or Units Closed; Converted to Non-IDD Use; were Privatized; or Were Downsized to Fewer than 15 People with IDD

		Opened	Closed, Converted, or Downsized
AK	Harborview Ctr. (Valdez)	1967	1997
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
AR	Alexander Human Dev. Ctr. (Alexander)	1968	2011
AZ	Arizona State Hospital (Phoenix)	1978	1994
AZ	Arizona Trng. Program (Tucson)	1970	1995
AZ	Arizona Trng. Program (Phoenix)	1973	1988
CA	Agnews Dev. Ctr. (San Jose)	1966	2009
CA	Camarillo Ctr. (Camarillo)	1968	1997
CA	DeWitt State Hospital (Auburn)	1946	1972
CA	Modesto State Hospital (Modesto)	1947	1962
CA	Napa State Hospital Forensic Unit (Napa)	1995	2000
CA	Patton State Hospital (Patton)	1963	1982
CA	Sierra Vista (Yuba City)	2000	2009
CA	Stockton Ctr. (Stockton)	1972	1996
CO	Pueblo State Regional Ctr. (Pueblo)	1935	1988
CT	Bridgeport Ctr. (Bridgeport)	1965	1981
CT	Clifford Street Group Home (Hartford)	1982	1995
CT	John Dempsey Ctr. (Putnam)	1964	1997
CT	Mansfield Trng. School (Mansfield)	1917	1993
CT	Martin House Group Home (Norwalk)	1971	2000
CT	Mystic Ctr. (Groton)	1979	2010
CT	New Haven Ctr. (New Haven)	1962	1994
CT	Seaside Ctr. (Waterford)	1961	1996
CT	Waterbury Ctr. (Cheshire)	1971	1989
DC	Bureau of Forest Haven (Laurel, MD)	1925	1990
DC	D.C. Village (Washington, DC)	1975	1994
DC	St. Elizabeth's Hospital (Washington, DC)	1987	1994
FL	Community of Landmark (Miami)	1966	2005
FL	Gulf Coast Ctr. (Fort Meyers)	1960	2010
FL	N.E. Florida State Hospital (MacClenny)	1981	2000
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) <sup>1</sup>	1842	2012
GA	Georgia Regional Hospital (Savannah)	2000	2005
GA	Northwest Regional Hospital (Rome)	1971	2011
GA	River's Crossing (Athens)		1996
GA	Rose Haven	1968	2000
GA	West Central Georgia Regional Hospital (Columbus)	2000	2004
HI	Kula Hospital (Kula)	1984	1994
HI	Waimano Trng. School and Hospital (Pearl City)	1921	1999
IL	Alton Mental Health & Dev. Ctr. (Alton)	1914	1994
IL	Bowen Ctr. (Harrisburg)	1966	1982
IL	Dixon Ctr. (Dixon)	1918	1987
IL	Elgin Mental Health & Dev. Ctr. (Elgin)	1872	1994
IL	Galesburg Ctr. (Galesburg)	1959	1985
IL	Howe Dev. Ctr. (Tinley Park)	1973	2010
IL	Lincoln Dev. Ctr. (Lincoln)	1866	2002
IL	Meyer Mental Health Ctr. (Decatur)	1967	1993
IL	Singer Mental Health & Dev. Ctr. (Rockford)	1966	2002
IN	Central State Hospital (Indianapolis)	1848	1995
IN	Evansville State Hospital (Evansville)	1890	2011
IN	Fort Wayne Dev. Ctr. (Fort Wayne)	1890	2007
IN	Logansport State Hospital (Logansport) <sup>1</sup>	1888	2012
IN	Muscatatuck Dev. Ctr. (Butlerville)	1920	2005
IN	New Castle Ctr. (New Castle)	1907	1998
IN	Norman Beatty Memorial Hospital (Westville)	1951	1979
IN	Northern Indiana Ctr. (South Bend)	1961	1998
IN	Richmond State Hospital (Richmond)	1890	2010
IN	Silvercrest State Hospital (New Albany)	1974	1995
KS	Norton State Hospital (Norton)	1963	1988
KS	Winfield State Hospital (Winfield)	1884	1998
KY	Frankfort State Hospital and School (Frankfort)	1860	1973
KY	Outwood ICF/IID (Dawson Springs) <sup>1</sup>	1962	1994
LA	Acadiana Region Supports and Services Center (Iota) <sup>1</sup>	1972	2011
LA	Bayou Region Supports and Services Center (Thibodaux)	1982	2010
LA	Columbia Dev. Ctr. (Columbia) <sup>1</sup>	1970	2009
LA	Leesville Dev. Ctr. (Leesville)	1964	2012

**Table 6.6a** Year When Large State IDD Facilities or Units Closed; Converted to Non-IDD Use; were Privatized; or Were Downsized to Fewer than 15 People with IDD

		Opened	Closed, Converted, or Downsized
LA	Metropolitan Development Center	1967	2007
LA	North Lake Supports and Services Center (Hammond) <sup>1</sup>		2012
LA	Northeast Supports and Services Center (Ruston)	1959	2010
MA	Belchertown State School (Belchertown)	1922	1992
MA	Berry Regional Ctr. (Hawthorne)	1967	1994
MA	Medfield State Hospital (Medfield)		1994
MA	Monson Dev. Ctr. (Palmer)	1898	2012
MA	Paul A. Dever Dev. Ctr. (Taunton)	1946	2001
MA	The Fernald Ctr. (Waltham) <sup>1</sup>	1848	2015
MA	Worcester State Hospital (Worcester)		1994
MD	Great Oaks Ctr. (Silver Springs)	1970	1996
MD	Henryton Ctr. (Henryton)	1962	1985
MD	Highland Health Facility (Baltimore)	1972	1989
MD	Joseph Brandenburg Ctr. (Cumberland)	1978	2011
MD	Rosewood Ctr. (Owings Mills)	1887	2009
MD	Victor Cullen Ctr. (Sabillasville)	1974	1992
MD	Walter P. Carter Ctr. (Baltimore)	1978	1990
ME	Aroostook Residential Ctr. (Presque Isle)	1972	1995
ME	Elizabeth Levinson Ctr. (Bangor)	1971	1998
ME	Pineland Ctr. (Pownal)	1908	1995
MI	Alpine Regional Ctr. for DD (Gaylord)	1960	1981
MI	Caro Regional Mental Health Ctr. (Caro)	1914	1997
MI	Coldwater Regional Ctr. for DD (Coldwater)	1935	1987
MI	Fort Custer State Home (Augusta)	1956	1972
MI	Hillcrest Regional Ctr. for DD (Howell)	1959	1982
MI	Macomb-Oakland Regional Ctr. for DD (Mt. Clemens)	1967	1989
MI	Mount Pleasant Ctr. (Mount Pleasant)	1937	2009
MI	Muskegon Regional Ctr. for DD (Muskegon)	1969	1992
MI	Newberry Regional Mental Health Ctr. (Newberry)	1895	1992
MI	Northville Residential Trng. Ctr. (Northville)	1972	1983
MI	Oakdale Regional Ctr. for DD (Lapeer)	1895	1992
MI	Plymouth Ctr. for Human Development (Northville)	1960	1984
MI	Southgate Regional Ctr. (Southgate)	1977	2002
MN	Brainerd Regional Human Services Ctr. (Brainerd)	1958	1999
MN	Cambridge Regional Human Services Center (Cambridge)	1925	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) <sup>1</sup>	1997	2011
MN	Moose Lake Regional Treatment Ctr. (Moose Lake)	1970	1994
MN	Owatonna State Hospital (Owatonna)	1945	1972
MN	Rochester State Hospital (Rochester)	1968	1982
MN	St. Peter Regional Treatment Ctr. (St. Peter)	1968	1996
MN	Willmar Regional Treatment Ctr. (Willmar)	1973	1996
MO	Albany Regional Ctr. (Albany)	1967	1989
MO	Hannibal Regional Ctr. (Hannibal)	1967	1991
MO	Joplin Regional Ctr. (Joplin)	1967	1992
MO	Kansas City Regional Ctr. (Kansas City)	1970	1993
MO	Kirksville Regional Ctr. (Kirksville)	1968	1988
MO	Marshall Regional Ctr. (Marshall)	1975	1982
MO	Midtown Habilitation Ctr. (St. Louis)		2004
MO	Poplar Bluff Regional Ctr. (Poplar Bluff)	1968	1992
MO	Rolla Regional Ctr. (Rolla)	1968	1984
MO	Sikeston Regional Ctr. (Sikeston)	1969	1992
MO	Springfield Regional Ctr. (Springfield)	1967	1990
MT	Eastmont Human Services Ctr. (Glendive)	1969	2003
NC	Broughton Ctr. (Morganton)	1883	1994
ND	San Haven State Hospital (Dunseith)	1973	1987
NH	Laconia State School and Trng. Ctr. (Laconia)	1903	1991
NH	New Hampshire Hospital, Brown Building (Concord)	1842	1990
NJ	Ctr. at Ancora (Hammonton)		1992
NJ	E.R. Johnstone Trng. & Research Ctr. (Bordentown)	1955	1992
NJ	Edison Habilitation Ctr. (Princeton)	1975	1988
NJ	North Princeton Ctr. (Princeton)	1975	1998
NM	Fort Stanton Hospital and Trng. Ctr. (Fort Stanton)	1964	1995
NM	Los Lunas Hospital and Trng. Ctr. (Los Lunas)	1929	1997
NM	Villa Solano-Hagerman Residential School (Roswell)	1964	1982
NV	Sierra Regional Ctr. (Sparks)	1977	2008
NY	Bronx DDSO (Bronx)	1971	1992
NY	Capital District DDSO (Schenectady)	1973	2012
NY	Central New York DDSO (Syracuse)	1851	1998
NY	Craig DDSO (Soynea)	1935	1988
NY	Gouverneur (New York)	1962	1978

**Table 6.6a** Year When Large State IDD Facilities or Units Closed; Converted to Non-IDD Use; were Privatized; or Were Downsized to Fewer than 15 People with IDD

		Opened	Closed, Converted, or Downsized
NY	Hudson Valley DDSO (Thiells)	1911	2000
NY	J.N. Adams (Perrysburg)	1960	1993
NY	Long Island DDSO (Commack)	1965	1993
NY	Long Island DDSO (Melville)	1965	1992
NY	Manhattan Ctr. (New York)	1972	1992
NY	Newark Ctr. (Newark)	1878	1991
NY	Rome Ctr. (Rome)	1894	1989
NY	Sampson State School (Willard)	1961	1971
NY	Staten Island DDSO (Staten Island)	1947	1988
NY	Valatie (Valatie)	1971	1974
NY	Westchester NY DDSO (Tarrytown)	1979	1988
NY	Western NY DDSO (West Seneca)	1962	2011
NY	Willowbrook State School (Staten Island)	1947	1988
NY	Wilton DDSO (Wilton)	1960	1995
OH	Apple Creek Dev. Ctr. (Apple Creek)	1931	2006
OH	Athens Mental Health & Dev. Ctr. (Athens)	1975	1994
OH	Broadview Ctr. (Broadview Hghts.)	1967	1992
OH	Cambridge Mental Health Ctr. (Cambridge)	1978	1990
OH	Central Ohio Psychiatric Hospital (Cleveland)	1978	1994
OH	Cleveland Ctr. (Cleveland)	1976	1988
OH	Dayton Ctr. (Dayton)	1979	1983
OH	Dayton Mental Health Ctr. (Dayton)	1978	1994
OH	Massillon State Hospital (Massillon)	1978	1994
OH	Orient Ctr. (Orient)	1898	1984
OH	Springview Developmental Ctr. (Springfield)	1975	2005
OH	Toledo Mental Health Ctr. (Toledo)	1978	1994
OH	Western Reserve Psychiatric Hab. Ctr. (Northfield)	1978	1990
OK	Hisson Memorial Ctr. (Sand Springs)	1964	1994
OK	Robert M. Greer Memorial Ctr. (Enid) <sup>1</sup>	1992	2000
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	Holidaysburg Mental Retardation Ctr. (Holidaysburg)	1974	1976
PA	Laurelton Ctr. (Laurelton)	1920	1998
PA	Marcy Ctr. (Pittsburgh)	1975	1982
PA	Mayview Mental Retardation Unit (Mayview)	1974	2001
PA	Pennhurst Ctr. (Pennhurst)	1908	1988
PA	Philadelphia Mental Retardation Unit (Philadelphia)	1983	1989
PA	Somerset Mental Retardation Unit (Somerset)	1974	1996
PA	Torrance Mental Retardation Unit (Torrance)	1974	1998
PA	Warren Mental Retardation Unit (Warren)	1975	1976
PA	Wernersville Mental Retardation Unit (Wernersville)	1974	1987
PA	Western Ctr. (Cannonsburg)	1962	2000
PA	Woodhaven Ctr. (Philadelphia)	1974	1995
RI	Dorothea Dix Unit (Cranston)	1982	1989
RI	Dr. Joseph H. Ladd Ctr. (N. Kingstown)	1908	1994
RI	Zambrano Memorial Hospital (Wallum Lake)	1967	1989
SD	Custer State Ctr. (Custer)	1964	1996
TN	Arlington Dev. Ctr. (Arlington)	1969	2010
TN	Harold Jordan Habilitation Ctr. (Nashville)	1979	2003
TN	Winston Ctr. (Bolivar)	1979	1998
TX	Ft. Worth State School (Ft. Worth)	1976	1996
TX	Travis State School (Austin)	1961	1996
VA	Eastern State Hospital (Williamsburg)		1990
VA	Southwestern State Hospital (Marion)	1887	1988
VA	Western State Hospital (Stanton)	1828	1990
VT	Brandon Trng. School (Brandon)	1915	1993
WA	Frances Haddon Morgan Ctr. (Bremerton)	1972	2011
WA	Interlake School (Medical Lake)	1967	1994
WI	Northern Wisconsin Ctr. (Chippewa Falls) <sup>1</sup>	1897	2005
WV	Colin Anderson Ctr. (St. Mary's)	1932	1998
WV	Greenbrier Ctr. (Lewisburg)	1974	1994
WV	Spencer State Hospital (Spencer)	1893	1989
WV	Weston State Hospital (Weston)	1985	1988

<sup>1</sup> These facilities have been downsized to 15 or fewer people with IDD, converted to non-IDD use, or privatized so though they have not closed, they no longer meet the criteria of a large, state IDD facility.

Table 6.6b State Operated IDD Facilities Open on June 30, 2012<sup>1</sup> and Movement Patterns and Expenditures in FY 2012

State	Large State IDD Facilities or Units Operating On June 30, 2012	Year Opened	Projected Closure Date	Residents With IDD June 2012	All Residents June 2012	Average Daily with IDD FY 2012	Residents With IDD June 2011	% Change 2011 - 2012	Average per Diem Expenditure (\$)	Admissions/Readmissions	Discharges	Deaths
AR	Arkadelphia Human Dev. Ctr. (Arkadelphia)	1968		126	126	126	128	-1.56	299	7	6	3
AR	Booneville HDC (Booneville)	1972		134	134	138.6	143	-6.29	296	10	18	1
AR	Conway HDC (Conway)	1959		483	483	483	481	0.42	392	17	6	9
AR	Jonesboro HDC (Jonesboro)	1970		109	109	108	106	2.83	291.05	28	30	1
AR	Southeast Arkansas HDC (Warren)	1978		96	96	95	101	-4.95	410	5	10	0
AZ	Arizona Trng. Program (Coolidge)	1952		107	107	109.5	111	-3.60	404.21	0	0	4
CA	Canyon Springs (Cathedral City)	2001		56	56	DNF	55	1.82	DNF	11	10	0
CA	Fairview Dev. Ctr. (Costa Mesa)	1959		373	373	DNF	397	-6.05	DNF	11	22	13
CA	Lanterman Dev. Ctr. (Pomona)	1927	2014	256	256	DNF	313	-18.21	DNF	0	42	8
CA	Porterville Dev. Ctr. (Porterville)	1953		467	467	DNF	545	-14.31	DNF	31	101	8
CA	Sonoma Dev. Ctr. (Eldridge)	1891		530	530	DNF	575	-7.83	DNF	5	28	22
CO	Grand Junction Regional Ctr. (Grand Junction)	1919		40	40	40	36	11.11	835.58	8	4	2
CO	Wheat Ridge Regional Ctr. (Wheatridge)	1912		129	129	125	121	6.61	572.8	21	11	2
CT	DMR Northwest Ctr. (Torrington)	1984		40	40	40	40	0.00	836	0	0	0
CT	Ella Grasso Ctr. (Stratford)	1981		38	38	39	39	-2.56	370	0	0	1
CT	Hartford Ctr. (Newington)	1965		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	Lower Fairfield County Ctr. (Norwalk)	1976		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	Meridan Ctr. (Wallingford)	1979		15	15	15	26	-42.31	836	0	10	1
CT	Southbury Trng. School (Southbury)	1940		401	401	415	429	-6.53	538	0	5	23
DE	Stockley Ctr. (Georgetown)	1921		66	66	66	64	3.13	1058.4	7	1	4
FL	Florida State Hospital (Chattahoochee), Unit 27	1976		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
FL	Mentally Retarded Defendant Program	1977		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
FL	Seguin Unit-Alachua Retarded Defendant Ctr. (Gainesville)	1989		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
FL	Sunland Ctr. (Marianna)	1961		333	333	331	332	0.30	305.8	11	6	4
FL	Tacachale Community of Excellence	1921		448	448	451	457	-1.97	364.8	5	4	10
GA	East Central Regional Hospital (Gracewood)	1921		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
GA	Georgia Regional Hospital of Atlanta (Decatur)	1968		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
GA	Southwestern State Hospital (Thomasville)	1967		75	75	75	83	-9.64	531.83	0	6	2
IA	Glenwood Resource Ctr. (Glenwood)	1876		263	263	271	279	-5.73	778.11	5	16	5
IA	Woodward Resource Ctr. (Woodward)	1917		181	181	186	194	-6.70	878.7	7	18	2
ID	Idaho State School and Hospital (Nampa)	1918		47	48	46	49	-4.08	707.47	5	7	0
IL	Choate Dev. Ctr. (Anna)	1873		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	Fox Dev. Ctr. (Dwight)	1965		113	113	114	117	-3.42	632	8	8	4
IL	Jacksonville Dev. Ctr. (Jacksonville)	1851		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	Kiley Dev. Ctr. (Waukegan)	1975		209	209	214	218	-4.13	6	6	15	0
IL	Ludeman Dev. Ctr. (Park Forest)	1972		398	406	409.4	410	-2.93	632	1	8	5
IL	Mabley Dev. Ctr. (Dixon)	1987		91	91	91.6	95	-4.21	671	0	4	0
IL	Murray Dev. Ctr. (Centralia)	1964		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
IL	Shapiro Dev. Ctr. (Kankakee)	1879		545	545	556	563	-3.20	331.07	17	29	6
IN	Madison State Hospital (Madison)	1910		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KS	Kansas Neurological Institute (Topeka)	1960		150	150	150	153	-1.96	498	3	1	5
KS	Parsons State Hospital (Parsons)	1952		175	175	178	186	-5.91	395	14	22	3
KY	Central State Hospital ICF/IID (Louisville)	1873		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
KY	Oakwood ICF/IID (Somerset)	1972		134	DNF	DNF	164	DNF	DNF	DNF	DNF	DNF
KY	Hazelwood Ctr. (Louisville)	1971		117	117	123	125	-6.40	786.47	2	5	3
LA	Louisiana Special Education Center (Alexandria)	1952		69	69	72	74	-6.76	DNF	2	5	2
LA	Northwest Louisiana Dev. Ctr. (Bossier City)	1973	Sept 2012	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
LA	Pinecrest Supports and Services Center (Pineville)	1918		412	412	421	432	-4.63	802.51	45	56	9
MA	Glavin Regional Ctr. (Shrewsbury)	1974	2013	28	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MA	Hogan Regional Ctr. (Hawthorne)	1967		155	155	155	DNF	DNF	534.16	22	15	8
MA	Templeton Dev. Ctr. (Baldwinsville)		2014	59	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MA	Wrentham Dev. Ctr. (Wrentham)	1907		323	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MD	Holly Ctr. (Salisbury)	1975		80	80	78.43	86	-6.98	470	1	4	3
MD	Potomac Ctr. (Hagerstown)	1978		55	54	53.93	54	1.85	555.1	19	18	0
MO	Bellefontaine Habilitation Ctr. (St. Louis)	1924		138	138	140	142	-2.82	352.48	0	4	0
MO	Higginsville Habilitation Ctr. (Higginsville)	1956		53	53	57	63	-15.87	423.37	0	9	1
MO	Marshall Habilitation Ctr. (Marshall)	1901		DNF	92	100	DNF	DNF	514	1	11	1
MO	Nevada Habilitation Ctr. (Nevada)	1973		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	Northwest Habilitation Ctr. (St. Louis)*			DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	South County Habilitation Ctr.		Oct 2012	55	55	55	55	0.00	625.02	1	0	1
MO	Southeast Missouri Residential Services (Poplar Bluff)	1992		37	37	37	40	-7.50	400	0	2	1
MO	Southeast Missouri Residential Services (Sikeston)	1992		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	St. Charles Habilitation Ctr. (St. Louis)*			49	49	57	34	44.12	554.41	24	8	1
MS	Boswell Regional Ctr. (Sanatorium)	1976		139	139	138	140	-0.71	298.06	19	19	1
MS	Ellisville State School (Ellisville)	1920		429	428	437	444	-3.38	307.23	6	6	15
MS	Hudspeth Regional Ctr. (Whitfield)	1974		278	278	281	281	-1.07	270	12	11	4
MS	North Mississippi Regional Ctr. (Oxford)	1973		280	284	277	280	0.00	263.83	17	8	9
MS	South Mississippi Regional Ctr. (Long Beach)	1978		160	160	159	160	0.00	325	6	4	2
MT	Montana Developmental Ctr. (Boulder)	1905		48	48	52	53	-9.43	689	30	35	0
NC	Black Mountain Ctr. (Black Mountain)	1982		82	146	83	84	-2.38	441	8	4	6
NC	Caswell Ctr. (Kinston)	1914		373	374	377	389	-4.11	638.36	6	3	19
NC	J. Iverson Riddle Dev.Ctr. (Morganton)	1963		314	314	312	319	-1.57	494.36	5	4	6
NC	Murdoch Ctr. (Butner)	1957		475	481	479	481	-1.25	556.36	16	16	6
NC	O'Berry Ctr. (Goldsboro)	1957		262	262	263	278	-5.76	586.36	5	7	14

**Table 6.6b** State Operated IDD Facilities Open on June 30, 2012<sup>1</sup> and Movement Patterns and Expenditures in FY 2012

State	Large State IDD Facilities or Units Operating On June 30, 2012	Year Opened	Projected Closure Date	Residents With IDD June 2012	All Residents June 2012	Average Daily with IDD FY 2012	Residents With IDD June 2011	% Change 2011 - 2012	Average per Diem Expenditure (\$)	Admissions/Readmissions	Discharges	Deaths
ND	North Dakota Developmental Ctr. (Grafton)	1904		94	94	95	99	-5.05	670.9	21	23	3
NE	Beatrice State Dev. Ctr. (Beatrice)	1875		136	136	142	153	-11.11	797	2	16	3
NJ	Green Brook Regional Ctr. (Green Brook)	1981		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ	Hunterdon Dev. Ctr. (Clinton)	1969		520	520	516	534	-2.62	647	1	2	12
NJ	New Lisbon Dev. Ctr. (New Lisbon)	1914		398	398	407	415	-4.10	750.7	19	33	8
NJ	North Jersey Dev. Ctr. (Totowa)	1928	2014	359	362	370	383	-6.27	687	6	21	9
NJ	Vineland Dev. Ctr. (Vineland)	1888	July 2013	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ	Woodbine Dev. Ctr. (Woodbine)	1921		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NJ	Woodbridge Ctr. (Woodbridge)	1965	Jan 2015		336	330	DNF	DNF	738	0	2	5
NV	Desert Regional Ctr. (Las Vegas)	1975		48	48	48	48	0.00	550	8	8	0
NY	Bernard M. Fineson Dev. Ctr. (Hillside; Howard Park)	1970	Mar 2017	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	Brooklyn DDSO (Brooklyn)	1972	Dec 2015	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	Broome DDSO (Binghamton)	1970	2016	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	Finger Lakes DDSO (Rochester)	1969		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	Staten Island DDSO (Staten Island)	1987		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	Sunmount DDSO (Tupper Lake)	1965		169	167	178	186	-9.14	971	27	44	0
NY	Taconic DDSO (Wassaic)	1930		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NY	Valley Ridge	2000		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	Cambridge Dev. Ctr. (Cambridge)	1965		93	93	93	96	-3.13	438.2	7	8	2
OH	Columbus Dev. Ctr. (Columbus)	1857		96	96	99	103	-6.80	601.47	0	5	2
OH	Gallipolis Dev. Ctr. (Gallipolis)	1893		168	168	173	184	-8.70	434.85	4	10	10
OH	Montgomery Dev. Ctr. (Huber Heights)	1981		93	93	93	99	-6.06	515	8	10	4
OH	Mount Vernon Dev. Ctr. (Mount Vernon)	1948		132	132	140	153	-13.73	457.1	4	20	5
OH	Northwest Ohio Dev. Ctr. (Toledo)	1977		125	125	127	128	-2.34	557.47	10	11	2
OH	Southwest Ohio Dev. Ctr. (Batavia)	1981		110	108	112	116	-5.17	457.48	15	19	2
OH	Tiffin Dev. Ctr. (Tiffin)	1975		120	119	125	128	-6.25	495.43	9	11	6
OH	Warrensville Dev. Ctr. (Warrensville)	1975		95	96	101	106	-10.38	DNF	9	14	6
OH	Youngstown Ctr. (Mineral Ridge)	1980		120	104	102	108	11.11	452.88	5	9	2
OK	Northern Oklahoma Resource Ctr. (Enid)	1909	June 2014	111	111	114.8	117	-5.13	545	1	5	2
OK	Southern Oklahoma Resource Ctr. (Pauls Valley)	1952	Apr 2014	110	124	126.1	128	-14.06	546.25	1	2	3
PA	Ebensburg Ctr. (Ebensburg)	1957		267	267	263	274	-2.55	7022	1	3	5
PA	Hamburg Ctr. (Hamburg)	1960		113	113	113	120	-5.83	782	2	0	9
PA	Polk Ctr. (Polk)	1897		277	277	277	292	-5.14	630.93	1	1	15
PA	Selinsgrove Ctr. (Selinsgrove)	1929		293	291	299	310	-5.48	647	2	1	18
PA	White Haven Ctr. (White Haven)	1956		156	156	157	161	-3.11	803.85	4	0	9
SC	Coastal Ctr. (Ladson)	1968		171	171	170	167	2.40	351	24	15	5
SC	Midlands Ctr. (Columbia)	1956		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Pee Dee Regional Ctr. (Florence)	1971		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Thad E. Saleeby Ctr. (Hartsville)			DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SC	Whitten Ctr. (Clinton)	1920		218	225	223	232	-6.03	320	3	11	6
SD	South Dakota Dev. Ctr. (Redfield)	1902		140	140	139.09	139	0.72	442.63	33	32	0
TN	Clover Bottom Dev. Ctr. (Nashville)	1923	Dec 2013	42	42	DNF	48	-12.50	DNF	0	4	2
TN	Greene Valley Dev. Ctr. (Greeneville)	1960		140	141	175.99	194	-27.84	854	0	46	8
TX	Abilene State School (Abilene)	1957		418	407	431	447	-6.49	656	3	20	12
TX	Austin State School (Austin)	1917		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TX	Brenham State School (Brenham)	1974		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TX	Corpus Christi State School (Corpus Christi)	1970		256	256	262	272	-5.88	466.24	9	12	10
TX	Denton State School (Denton)	1960		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TX	El Paso State Ctr. (El Paso)	1973		126	126	128	131	-3.82	575.04	5	6	4
TX	Lubbock State School (Lubbock)	1969		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TX	Lufkin State School (Lufkin)	1962		363	363	358	385	-5.71	582.57	6	22	6
TX	Mexia State School (Mexia)	1946		272	274	284	297	-8.42	461.22	29	50	4
TX	Richmond State School (Richmond)	1968		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
TX	Rio Grande State Ctr. (Harlingen)	1973		70	70	68	71	-1.41	526.93	11	8	1
TX	San Angelo State School (Carlsbad)	1969		227	232	232	240	-5.42	DNF	24	34	3
TX	San Antonio State School (San Antonio)	1978		277	277	271	278	-0.36	559.99	10	5	6
UT	Utah State Dev. Ctr. (American Fork)	1931		207	207	207	206	0.49	430	10	8	3
VA	Central Virginia Trng. Ctr. (Lynchburg)	1911	2020	259	335	273	287	-9.76	683	1	25	4
VA	Northern Virginia Trng. Ctr. (Fairfax)	1973	2014	153	153	154	156	-1.92	696	1	3	1
VA	Southeastern Virginia Trng. Ctr. (Chesapeake)	1975		104	104	114	123	-15.45	590.03	0	16	3
VA	Southside Virginia Trng. Ctr. (Petersburg)	1939	2014	197	197	220	242	-18.60	828	4	46	3
VA	Southwestern Virginia Trng. Ctr. (Hillsville)	1976	2018	173	169	173	181	-4.42	434.34	10	14	4
WA	Fircrest (Seattle)	1959		215	215	200	203	5.91	547	17	2	3
WA	Lakeland Village School (Medical Lake)	1915		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
WA	Rainier School (Buckley)	1939		341	349	342	344	-0.87	535.29	6	0	9
WA	Yakima Valley School (Selah)	1958		80	80	80	80	0.00	548.62	DNF	DNF	DNF
WI	Central Wisconsin Ctr. (Madison)	1959		231	245	232	238	-2.94	858	0	3	4
WI	Southern Wisconsin Ctr. (Union Grove)	1919		151	153	153	155	-2.58	958	0	2	2
WY	Wyoming Life Resource Ctr. (Lander)	1912		79	93	80.167	82	-3.66	717.92	2	0	5

<sup>DNF</sup> Did not furnish <sup>1</sup> This table does not list 39 large state facilities in New York, 1 in Florida, 2 in Georgia, 1 in Massachusetts or 1 in Rhode Island.



administrative expenditures into the reported rates, and exclusion of costs of some off-campus services in the individual facility rates.

### Trends in the Utilization of Large State IDD Facilities 1950 - 2012

This section describes national and state-by-state trends in the utilization of large state IDD facilities.

#### Trends in Closures of Large State IDD Facilities.

Figure 6.1 summarizes the average annual facility closures and anticipated closures in five year intervals between 1960 and 2014. The peak of the deinstitutionalization period for large state IDD facilities was 1990 through 1994. During that time an average of 10.8 facilities closed each year. Closures slowed to 8.2 per year from 1995 to 1999, 4.2 per year from 2000 to 2004, and 3.0 per year from 2005 and 2009. The pattern shifted in 2010. There were 8 closures in 2010, 9 in 2011, 8 in 2012 and 8 projected for 2013 or 2014. The average number of closures or projected closures for 2010 through 2014 was 6.6 per year (higher than all five year periods since 1960 except 1990 to 1994 and 1995 to 1999).

#### Downsizing of Large State Psychiatric Facilities.

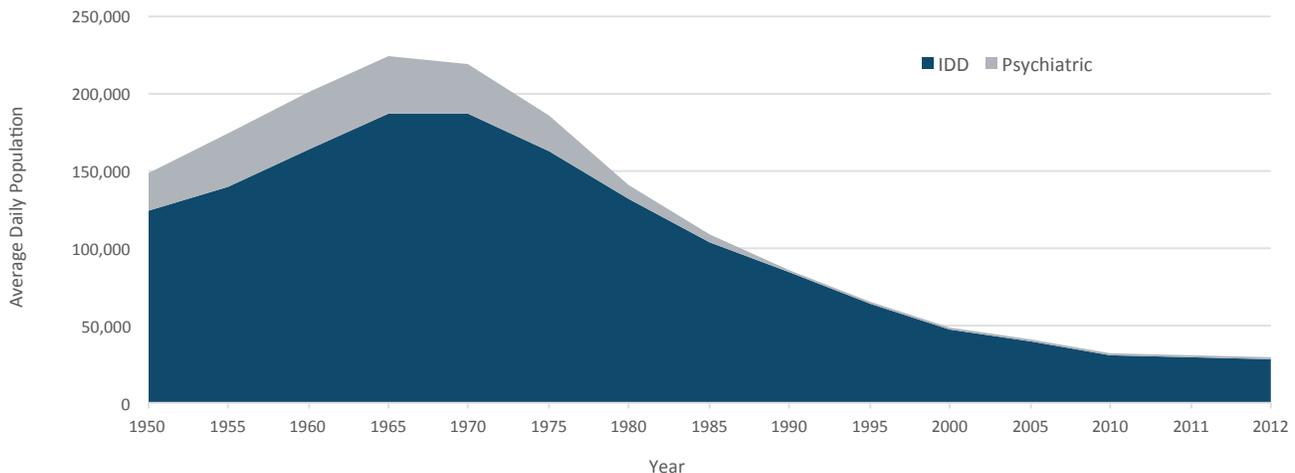
The average daily population is the sum of the number of people living in a facility on each day of the year divided by the total number of days. Table 6.7 and Figure 6.2 show changes in number of people with IDD in living in large state IDD and psychiatric facilities between 1950 and 2012.

**Table 6.7** Average Daily Population of Persons with IDD in State IDD Facilities Serving 16 or More People and State Psychiatric Facilities 1950-2012

Year	IDD	Psychiatric	Total	% in Psychiatric
1950	124,304	23,905	148,209	16%
1955	138,831	34,999	173,830	20%
1960	163,730	37,641	201,371	19%
1965	187,305	36,285	223,590	16%
1970	186,743	31,884	218,627	15%
1975	162,654	22,881	185,535	12%
1980	131,345	9,405	140,750	7%
1985	103,629	4,536	108,165	4%
1990	84,239	1,487	85,726	2%
1995	63,762	1,381	65,143	2%
2000	47,872	488	48,360	1%
2001	46,236	565	46,801	1%
2002	44,598	267	44,865	1%
2003	43,289	386	43,675	1%
2004	42,120	394	42,514	1%
2005	40,076	396	40,472	1%
2006	38,810	361	39,171	1%
2007	37,172	782	37,954	2%
2008	35,651	300	35,951	1%
2009	33,682	417	34,099	1%
2010	30,602	873	31,475	3%
2011	29,809	864	30,673	3%
2012	28,146	1,075	29,221	4%

<sup>1</sup> States that did not furnish information about 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).

**Figure 6.2** Average Daily Population with IDD in Large State IDD and Psychiatric Facilities 1950 to 2012



Although the populations of state psychiatric facilities began to decline in 1956, the number of persons with a primary diagnosis of ID in state psychiatric facilities continued to increase until 1961. In 1961, nearly 42,000 persons with a primary diagnosis ID (20% of the 209,114 persons with IDD in large state facilities) lived in state psychiatric facilities. By 1967, the number of persons with IDD in state psychiatric facilities had decreased to 33,850.

Medicaid legislation in the late 1960s and early 1970s allowed states to obtain federal cost-sharing of institutional services to persons with IDD in ICF/IIDs and in nursing homes, but excluded residents of facilities for “mental diseases” from participation in Medicaid, except for children and elderly residents. Distinct units for persons with IDD within psychiatric facilities could be ICF/IID certified. States responded by repurposing large state residential facilities to serve persons with IDD, and some created independent IDD units on the grounds of what were historically state psychiatric facilities.

Between 1970 and 1995 the number of people with IDD living in state psychiatric facilities was reduced from 31,884 to 1,381 people. Between 2000 and 2011 the number of people with IDD state psychiatric facilities was less than one thousand people but increased to 1,075 in 2012.

**Downsizing of Large State IDD Facilities.** The total number of people with IDD in large state IDD facilities peaked in 1967 at 194,650 people but had declined to 131,345 by 1980, 84,239 in 1990, 47,872 in 2000, and 30,602 in 2010. Between 2010 and 2012 the average daily population of those settings declined by another 10% to 27,610. Between 1967 and 2012, the number of people with IDD in large state IDD facilities declined by a total of 85.5%.

**Utilization of Large State IDD and Psychiatric Facilities.** The average number of people with IDD per 100,000 of the total U.S. population who lived in large state IDD and psychiatric facilities peaked in 1965 at 115.8 per 100,000 (See Table 6.8). The combined number declined to 107.2 per 100,000 in 1970, 34.5 per 100,000 in 1990, 17.2 per 100,000 in 2000, and 8.7 per 100,000 in 2012. The number of people with IDD per 100,000 in large IDD state facilities declined from 96.8 in 1965 to 8.3 in 2012. The number in large state psychiatric facilities declined from 21.2 in 1955 to 0.4 in 2012.

**Table 6.8** Average Daily Number of Persons with IDD in Large State IDD and Psychiatric Facilities per 100,000 of the General Population, 1950-2012

Year	US			Total
	Population (100,000)	IDD	Psychiatric <sup>1</sup>	
1950	1,518.68	81.9	15.8	97.6
1955	1,650.69	84.1	21.2	105.3
1960	1,799.79	91.0	20.9	111.9
1965	1,935.26	96.8	19.0	115.8
1970	2,039.84	91.6	15.6	107.2
1975	2,113.57	82.2	14.3	96.5
1980	2,272.36	57.8	4.1	61.9
1985	2,361.58	47.1	2.2	49.3
1988	2,444.99	37.3	0.8	38.1
1989	2,482.43	35.7	0.7	36.4
1990	2,487.09	33.9	0.6	34.5
1991	2,521.77	31.8	0.6	32.5
1992	2,540.02	29.6	0.6	30.2
1993	2,559.50	27.9	0.7	28.6
1994	2,579.04	26.2	0.6	26.9
1995	2,634.37	24.2	0.5	24.7
1996	2,659.99	22.5	0.4	22.9
1997	2,711.21	20.7	0.3	21.0
1998	2,708.09	19.4	0.4	19.7
1999	2,726.91	18.4	0.4	18.7
2000	2,746.34	17.0	0.2	17.2
2001	2,769.03	16.2	0.2	16.4
2002	2,791.72	15.5	0.1	15.6
2003	2,814.41	15.4	0.1	15.5
2004	2,936.55	14.3	0.1	14.5
2005	2,964.10	13.7	0.1	13.8
2006	2,993.98	13.0	0.1	13.1
2007	3,016.21	12.3	0.3	12.6
2008	3,040.60	11.5	0.3	11.8
2009	3,070.07	10.7	0.2	10.9
2010	3,087.46	10.1	0.3	10.4
2011	3,115.93	9.3	0.3	9.6
2012	3,139.14	8.4	0.4	8.8

<sup>1</sup> States that did not furnish information about 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).

**Changes in the Average Daily Populations of Large State IDD Facilities by State.** Between 1980 and 2012 the average daily populations of large state IDD facilities declined by 79% (See Table 6.9). Eleven states had reductions of 100% (Alaska, the District of Columbia, Hawaii, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Vermont, and West Virginia).

**Table 6.9** Average Daily Population of Persons with IDD Living in Large State IDD Facilities and Percentage Changes, By State Between 1980-2012

State	Average Daily Population								% change	
	1980	1985	1990	1995	2000	2005	2010	2012	1980-2012	2010-2012
AL	1,651	1,422	1,305	985	642	212	178	69	96	61
AK	86 <sup>e</sup>	76	58	33	0	0	0	0	100	N/A
AZ	672	538	360 <sup>e</sup>	183	166	138	119	109	84	8
AR	1,550	1,254	1,260	1,262	1,229	1,079	1,067	1,017	34	5
CA	8,812	7,524	6,768	5,494	3,879	3,307	2,149	1,787	80	17
CO	1,353	1,125	466 <sup>e</sup>	241	129	110	0	299 <sup>e</sup>	78	N/A
CT	2,944	2,905	1,799	1,316	992	847	705	634 <sup>e</sup>	78	10
DE	518	433	345	308	256	123	71	65 <sup>e</sup>	87	8
DC	775	351	309 <sup>e</sup>	0	0	0	0	0	100	N/A
FL	3,750	2,268	1,992	1,502	1,508	1,341	963 <sup>1</sup>	782	79	19
GA	2,535	2,097	2,069	1,979	1,510	1,202	802	400	84	50
HI	432	354	162	83	0	0	0	0	100	N/A
ID	379	317	210	139	110	94	68	46	88	32
IL	6,067	4,763	4,493	3,775	3,237	2,833	2,183	1,967	68	10
IN	2,592	2,248	1,940 <sup>e</sup>	1,389	854	456	205	26	99	87
IA	1,225	1,227	986	719	674	646	525	454	63	14
KS	1,327	1,309	1,017 <sup>e</sup>	756	379	360	340	325	76	4
KY	907	671	709	679 <sup>e</sup>	628	489	170	146 <sup>e</sup>	84	14
LA	3,171	3,375	2,622	2,167	1,749	1,571	1,144	884	72	23
ME	460	340	283	150	0	0	0	0	100	N/A
MD	2,527	1,925	1,289	817	548	380	138	54 <sup>+</sup>	98	61
MA	4,531	3,580	3,000	2,110	1,306	1,089	759 <sup>2</sup>	635 <sup>e*</sup>	86	16
MI	4,888 <sup>e</sup>	2,191	1,137 <sup>e</sup>	392	271	173	0	0	100	N/A
MN	2,692	2,065	1,392	610	42	29	25	0	100	100
MS	1,660	1,828	1,498	1,439	1,383	1,359	1,324	1,458 <sup>e</sup>	12	-10
MO	2,257	1,856	1,860 <sup>e</sup>	1,492	1,286	1,152	671	632	72	6
MT	316	258	235	163	131	84	52 <sup>3</sup>	55 <sup>e</sup>	83	-6
NE	707	488	466	414	401	372	182	142	80	22
NV	148	172	170	160	157	93	47	48	68	-2
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	2,511	65	7
NM	500	471	350	221	0	0	0	0 <sup>ed</sup>	100	N/A
NY	15,140	13,932	7,694	4,552	2,466	2,233	2,019	1,724	89	15
NC	3,102	2,947	2,654	2,288	1,939	1,736	1,515	1,431	54	6
ND	1,056	763	232	156	144	140	120	108	90	10
OH	5,045	3,198	2,665 <sup>e</sup>	2,150	1,996	1,728	1,376	1,184	77	14
OK	1,818	1,505	935	618	391	368	270	241	87	11
OR	1,724	1,488	838	462	62	43	22	0	100	100
PA	7,290	5,980	3,986	3,460	2,127	1,452	1,189	1,123	85	6
RI	681	415	201	0	0	0	0	33	95	N/A
SC	3,043	2,893 <sup>e</sup>	2,286	1,788	1,129	953	786	751	75	4
SD	678	557	391	345	196	172	149	139	79	7
TN	2,074	2,107	1,932	1,669	948	680	416	221	89	47
TX	10,320	9,638	7,320 <sup>e</sup>	5,459	5,431	4,977	4,337	3,881	62	11
UT	778	706	462	357	240	230	215	206	74	4
VT	331	200	180	0	0	0	0	0	100	N/A
VA	3,575	3,069	2,650	2,249	1,625	1,524	1,197	1,012	72	15
WA	2,231	1,844	1,758	1,320	1,143	973	914	593 <sup>+</sup>	73	35
WV	563	498	304 <sup>e</sup>	94	0	0	0	0	100	N/A
WI	2,151	2,058 <sup>e</sup>	1,678 <sup>e</sup>	1,341	900	590	448	393	82	12
WY	473	413	367	151	113	98	83	80	83	4
<b>Reported Total</b>	<b>131,345</b>	<b>109,614</b>	<b>84,239</b>	<b>63,762</b>	<b>47,872</b>	<b>40,532</b>	<b>31,654</b>	<b>27,665</b>	<b>79</b>	<b>13</b>

<sup>d</sup>2011 data <sup>e</sup> Estimate <sup>DNF</sup> Did not furnish <sup>\*</sup> See state notes in the Appendix

Between 2010 and 2012, the average daily population of large state IDD facilities declined by an average of 13%. Four states reduced their total more than 50% including Alabama (61% decrease), Georgia (50%), Indiana (87%), and Maryland (61%). On the other hand, three states reported increases in the average daily population of large state IDD facilities between 2010 and 2012 (Mississippi, 10% increase, Montana 6%, and Nevada 2%).

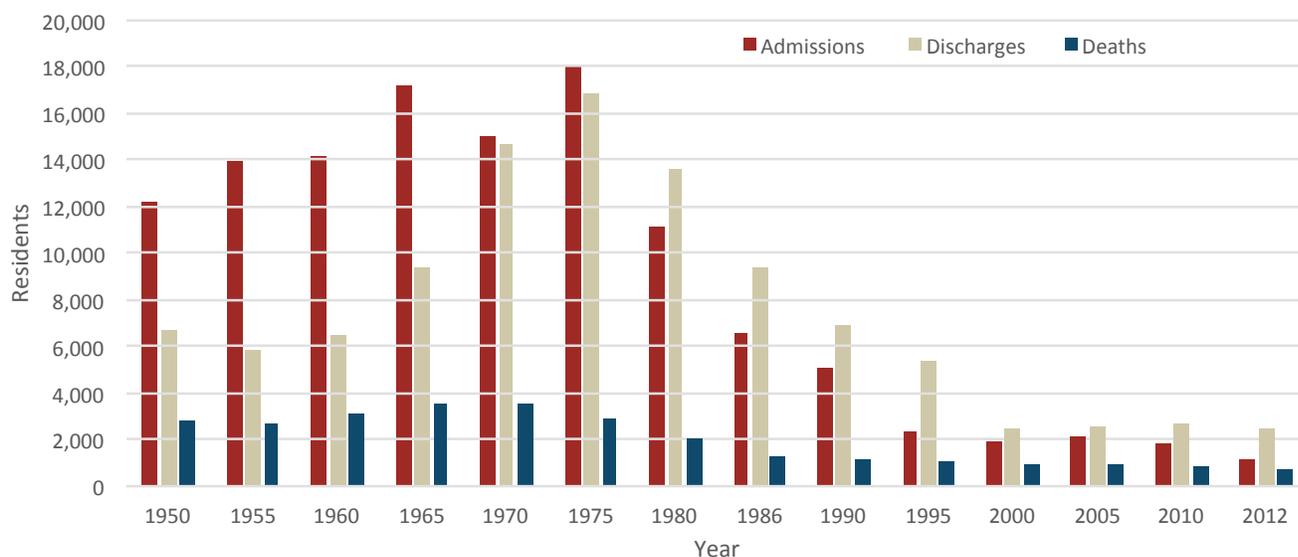
**Movement In and Out of Large State IDD Facilities between 1950 and 2012.** [Table 6.10](#) and [Figure 6.3](#) show annual movement patterns for large state IDD facilities at the national level. Average daily populations of large state IDD facilities were 124,304 in 1950, 187,305 in 1965, 84,732 in 1990, 47,872 in 2000 and 27,665 in 2012.

**Admissions.** Between 1950 and 1967, populations of large state IDD facilities grew as admissions substantially outnumbered discharges and deaths. The number of admissions to large state IDD residential facilities peaked in 1975 when 18,075 people were admitted. Between 1980 and 1999, the number of admissions dropped from 11,141 per year to 2,317 per year. The number of annual admissions continued to drop more slowly from 1,936 in FY 2000 to 1,077 in FY 2012.

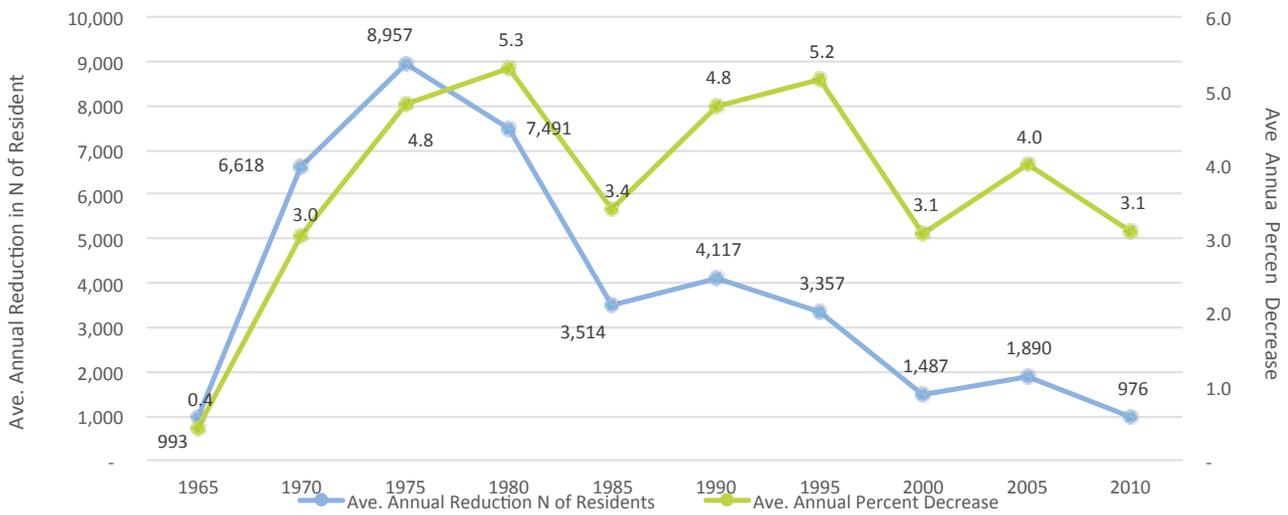
**Discharges.** The total number of people discharged from large state facilities in FY 2012, 2,353 is down slightly from 2,871 reported for FY 2011. Between 2005 and 2012, the average number of people discharged was 1,846 per year, with 3,111 discharged in FY 2009. The proportion of the average daily population discharged in FY 2012 was 9%.

**Deaths.** Overall, 699 people with IDD died while living in a large state IDD facility in FY 2012. The number of deaths per year since 1998 had been between 800 and 950, but in 2012 the number of deaths decreased significantly. FY 2012 deaths constituted 22.9% of all deaths plus discharges from large state facilities, a decrease from 26.1% in 2005. The proportion of all those who died has remained relatively steady at between 21% and 27% since 1999. Between 1965 and 1969 the average annual reduction in the number of people in large state IDD facilities was 993 (0.4%) per year (See [Figure 6.4](#)). Between 1975 and 1979 the average annual reduction was 8,957 (4.8%) coinciding with passage of PL 94-142. The average annual decreased fluctuated peaked between 1980 and 1984 at 5.3% and again between 1995 and 1999 at 5.2%. Between 2010 and 2012 the average change in the number of people with IDD in large state facilities was a reduction of 976 people per year (3.1%).

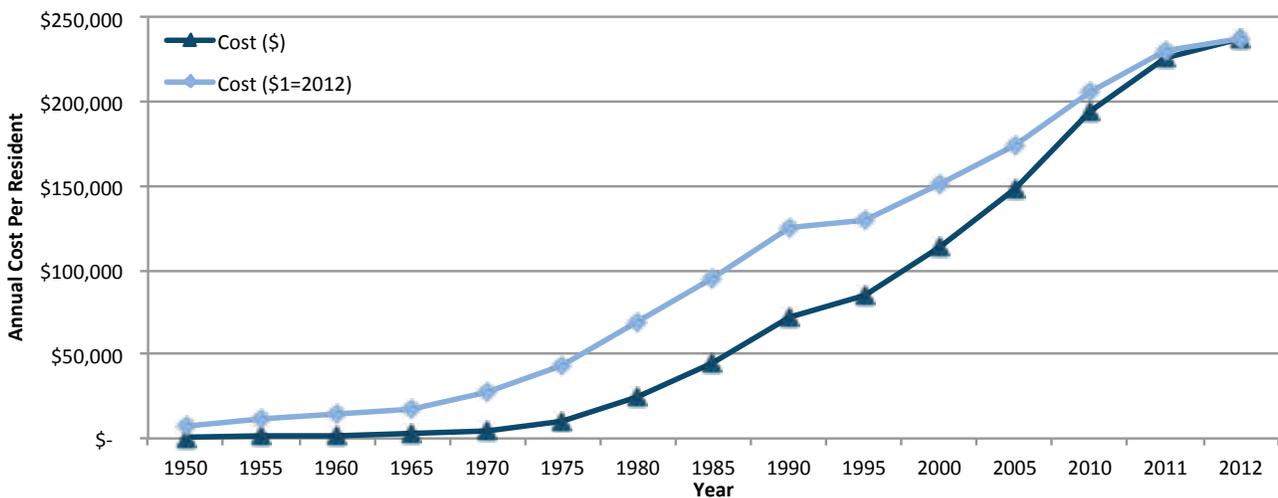
**Figure 6.3** Movement Patterns in Large State IDD Facilities, Selected Years 1950-2012



**Figure 6.4** Average Annual Numeric and Percentage Decrease in the Number of People with IDD in Large Public IDD and Psychiatric Facilities 1965 to 2012



**Figure 6.5** Average Annual Per Resident Expenditures in Large State IDD Residential Facilities, 1950-2012



### Annual per Resident Expenditures for Large State IDD Facilities

Average per resident daily expenditures in large state facilities in FY 2012 ranged from a low of \$270 in Mississippi to a high of \$1,448 in Connecticut (See Table 6.11). In addition to Mississippi four other states paid less than \$400 per day per person in FY 2012 (Arkansas, \$363; Florida, \$334; Georgia, \$284; and South Carolina, \$347). Seven states in addition to Nebraska paid more than \$800 per person per day in FY 2011 (California, \$910; Connecticut, \$1,448,

Delaware, \$1,022; Kentucky, \$958; Nebraska, \$842; Tennessee, \$993; and Wisconsin, \$854). Similar variations across states in per day per person costs were noted for state facilities with 7 to 15 residents (ranging from \$276 in Mississippi to \$813 in Connecticut), and for state group homes with 6 or fewer residents (ranging from \$115 in Mississippi to \$1,248 in Oregon). Rhode Island and Tennessee reported expenditures for people living in settings of 1-6 people that were higher than for people living in settings with 16 or more people.

**Longitudinal trends of large state facility expenditures.** The annual per person expenditures for large state facilities have increased dramatically since 1950, when it was \$746 (See Table 6.11 and Figure 6.4). Annual per resident expenditures in 2012 dollars increased from \$7,107 in 1950 to \$27,427 in 1970. By 1990 costs had increased to \$125,881 per person per year. Those costs increased to \$205,526 by FY 2010. Between FYs 2011 and 2012 the average annual expenditure per resident of large state IDD facilities increased by \$2,489 (1.1%) in 2012 dollars (from \$230,785 to \$233,274). When adjusted to control for changes in the Consumer Price Index, average annual expenditures per person in 2012 (\$237,149 per year) were 32.8 times higher than in 1950.

The introduction of the ICF/IID program significantly contributed to rapidly increasing large state facility costs. For example, in 1970, one year before enactment of the ICF/IID program, the average annual per resident real dollar (\$1=2012) expenditure in large state IDD facilities was about \$27,427. By 1977, more than 70% of all large state facilities were certified as ICF/IID and average annual

real dollar costs had more than doubled to \$61,144 a 122% increase in 7 years (or an increase of 17.4% per year). The upward pressure on expenditures

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*THE ANNUAL PER PERSON EXPENDITURES FOR LARGE STATE FACILITIES HAVE INCREASED DRAMATICALLY SINCE 1950, WHEN IT WAS \$746.*

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from creation of the ICF/IID program continued but at a slower pace as the remaining state facility units were certified. Between 1977 and 1999, large state facilities' real dollar expenditures grew by 242.3% to \$148,197 (an average increase of 11% per year). Court decisions and settlement agreements also drove increases in large state facility expenditures with their requirements for upgrading staffing levels, adding programs, improving physical environments, and, often, reducing resident populations. In addition, fixed costs (e.g. grounds, utilities, food service, laundry, physical plant and so forth) were shared by fewer and fewer residents.



**Table 6.10** Movement Patterns in Large State IDD Residential Facilities 1950-2012

Year	Average Daily Population	Annual State Facility		
		Admissions	Discharges	Deaths
1950	124,304	12,197	6,672	2,761
1955	138,831	13,906	5,845	2,698
1960	163,730	14,182	6,451	3,133
1965	187,305	17,225	9,358	3,585
1970	186,743	14,979	14,702	3,496
1975	168,214	18,075	16,807	2,913
1980	128,058	11,141	13,622	2,019
1986	100,190	6,535	9,399	1,322
1990	84,732	5,034	6,877	1,207
1991	80,269	3,654	5,541	1,077
1992	75,151	4,349	6,316	1,075
1993	71,477	2,947	5,536	1,167
1994	67,673	2,243	5,490	995
1995	63,697	2,338	5,337	1,068
1996	59,936	2,537	4,652	996
1997	56,161	2,467	4,495	777
1998	52,469	2,414	4,761	908
1999	50,094	2,317	3,305	927
2000	47,872	1,936	2,425	915
2001	46,236	1,927	2,433	897
2002	44,598	2,149	2,785	803
2003	43,289	2,117	2,679	873
2004	42,120	2,215	2,534	887
2005	40,076	2,106	2,561	909
2006	38,810	1,994	2,559	886
2007	37,172	2,128	2,637	821
2008	35,651	2,056	2,879	918
2009	33,682	1,981	3,111	870
2010	30,602	1,833	2,690	820
2011	29,809	1,593	2,690	810
2012	27,665	1,141	2,436	747

**Table 6.11** Average Annual per Resident Expenditures for Care in Large State IDD Residential Facilities Selected Years 1950-2012

Year	Cost (\$)	Cost (\$1=2012)
1950	746	7,107
1955	1,286	11,017
1960	1,868	14,489
1965	2,361	17,209
1970	4,635	27,427
1975	10,155	43,337
1980	24,944	69,502
1985	44,271	94,464
1990	71,660	125,881
1991	75,051	126,514
1992	76,946	125,918
1993	81,453	129,420
1994	82,256	127,432
1995	85,760	129,199
1996	92,345	135,130
1997	98,561	140,991
1998	104,098	104,098
1999	107,536	148,197
2000	113,863	151,813
2001	121,406	159,481
2002	125,746	160,481
2003	131,123	163,614
2004	138,996	168,939
2005	148,811	174,942
2006	167,247	190,471
2007	176,226	195,139
2008	188,318	200,818
2009	196,710	210,516
2010	195,197	205,526
2011	226,106	230,785
2012	237,149	237,149

Source: <http://www.usinflationcalculator.com/>



## SECTION SEVEN

# Characteristics of People with IDD and Staff in Large Public Residential Facilities

**FY 2012**



## SECTION 7: CHARACTERISTICS OF PEOPLE WITH IDD AND STAFF IN LARGE STATE-OPERATED IDD FACILITIES

**This section shares results** from the FY 2012 bi-annual long-form survey of administrators of large state IDD facilities. The section is divided into three parts. The first part focuses on overall national characteristics of people living in large state IDD facilities. The second part examines state-by-state differences in characteristics of residents for FY 2012. The final part examines services offered and staffing patterns and outcomes in large state IDD facilities. While there is considerable overlap between data in this section and data in previous parts of the report, they are not identical because different data sources were used. In cases where the same data are listed in both sections, please use Sections 1 through 6 for your source.

### Resident Characteristics on June 30, 1977, 1987, 1998, 2008, and 2012

Table 7.1 shows age, diagnostic and functional characteristics of people living in large state facilities in 2012 and provides comparisons going back to 1977. A total of 86 large state facilities (serving 65% of the estimated 26,503 total residents) provided data for the FY 2012 report. Blank spaces indicate that a data element was not included on the survey for that year.

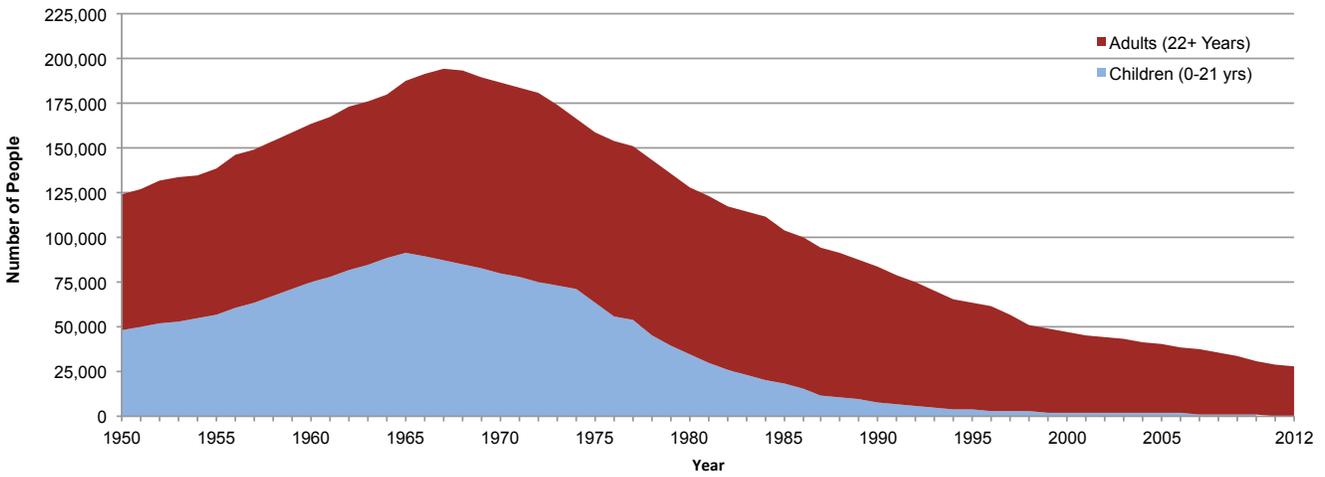
**Gender.** In FY 2012, an estimated 63% of people with IDD living in large state facilities were male. This is higher than in 1977 through 1998 but similar to the proportion in 2008.

**Table 7.1** Characteristics of Residents of Large State IDD Facilities on June 30 of Selected Years Between 1977 and 2012 in Percent

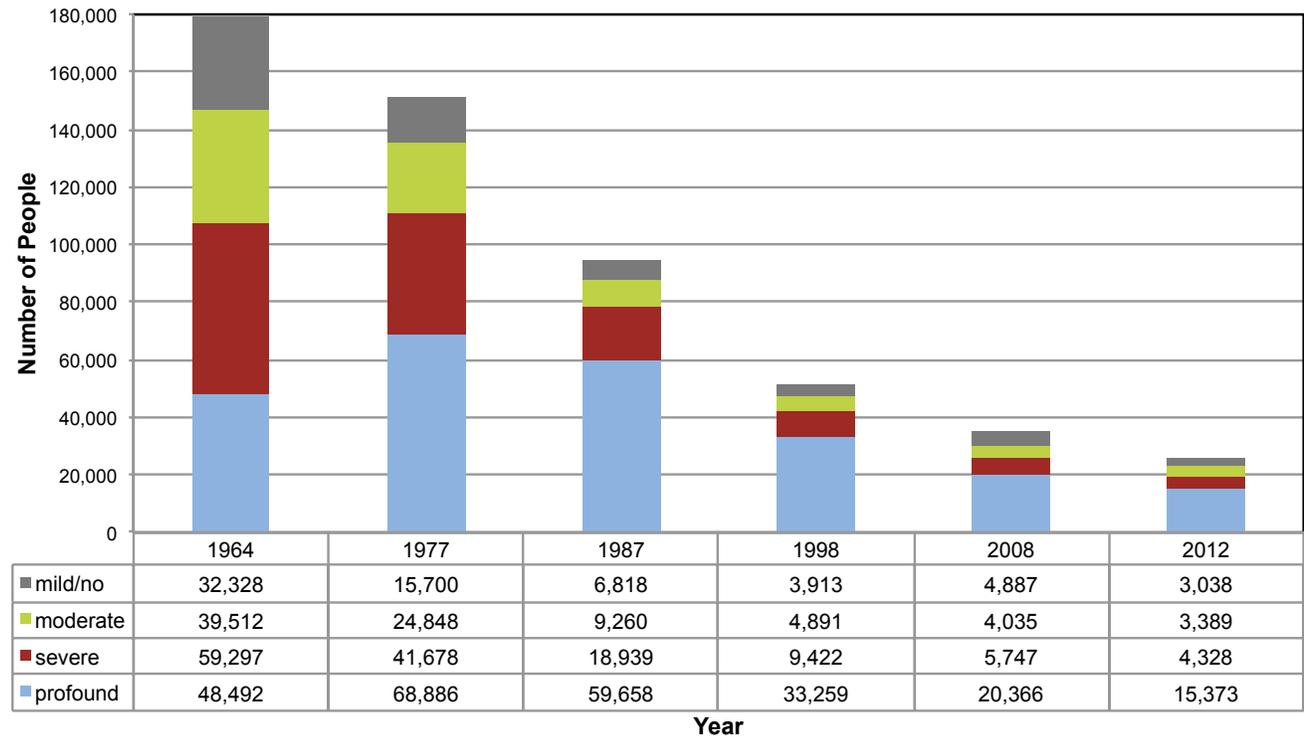
Characteristic (%)		June 30 of the Year				
		1977	1987	1998	2008	2012
<b>Estimated total residents</b>		151,112	94,695	51,485	35,035	26,503
<b>Gender</b>	<b>Male</b>	57%	57%	60%	63%	63%
<b>Age</b>	0-21 Years	36	13	5	5	4
	22-39 Years	41	54	38	23	19
	40-62 Years	19	27	49	61	59
	63+ Years	4	6	8	12	17
	Unknown					2
<b>Level of Intellectual Disability</b>	Mild/No ID	10	7	8	14	11
	Moderate	16	10	10	12	13
	Severe	28	20	18	16	16
	Profound	46	63	65	58	58
	Unknown					1
<b>Other Conditions</b>	Alzheimer's Disease					3
	Autism Spectrum Disorder					17
	Cerebral Palsy	19	21	24	23	19
	Behavior Disorder	25	41	44	52	52
	Psychiatric Disorder			34	52	54
<b>Needs assistance or supervision with</b>	Walking	23	30	39	39	43
	Eating	21	38	56	51	60
	Dressing	56	61	70	53	65
	Toileting	34	47	60	57	56
<b>Cannot...</b>	Express needs verbally	44	55	60	58	57
	Understand verbal requests				34	31

Percentages for 2012 based on between 73 and 86 long form reporting facilities.

**Figure 7.1** Average Daily Adult and Child Populations of Large State IDD facilities, 1950-2012



**Figure 7.2** Level of Intellectual Disability of Residents of Large State IDD Facilities on June 30 of Selected Years, 1964-2012



**Age.** In FY 2012, 4% of all residents of large state IDD facilities were 21 years old or younger, 19% were 22 to 39 years, 59% were 40 to 62 years, 16% were 63 years old or older and 2% did not have a reported age. As the number of people living in large state facilities declined from 151,112 in 1977 to 26,503 in 2012 the number of people in each age category also declined. The proportion of residents who were

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*REDUCTIONS IN THE TOTAL NUMBER OF LARGE STATE FACILITY RESIDENTS CLOSELY MIRRORED REDUCTIONS IN THE NUMBER OF RESIDENTS WHO WERE BIRTH TO 21 YEARS OLD*

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21 years or younger declined from 36% in 1977, and 13% in 1987 to 4% in 2012. The proportion of residents who were ages 22 to 39 years decreased from a high of 54% in 1987 to 19% in 2012. By comparison, the proportion 40 to 62 years old increased from 19% in 1977 to 61% in 2008 and 59% in 2012. Finally, the proportion who were 63 years or older increased from 4% in 1977 to 12% in 2008, and to 17% in 2012.

Reductions in the total number of large state facility residents closely mirrored reductions in the number of residents who were birth to 21 years old (See [Figure 7.1](#)). In 1950, 48,354 of the 124,304 large state facility residents were 21 years or younger (39%). By 1965, the number had increased to 91,592 (49% of all residents). Following passage of PL 94-142 in 1975, the population of children and youth in large state facilities declined to 54,098 (36%) in 1977, 12,026 (13%) in 1987, 2,471 (5%) in 1998, 1,274 (4%) in 2008, and 623 (2%) in 2012.

**Level of ID.** On June 30, 2012, 58% of all people with ID in large state facilities had profound ID, 16% had severe ID, 13% had moderate ID and 11% had mild or no ID (level of IDD was unknown for 1%).

Between 1964 and 1977 the total number of residents the number of people with mild, moderate or severe ID declined from 131,137 to 82,226 (See [Figure 7.2](#); and Scheerenberger, 1965). However the number of people with profound ID increased from 48,492 1964 to 68,886 in 1977.

The number of people in large state facilities at each level of ID continued to decline between 1998

and 2012, but while the proportion of residents with profound ID declined from 65% in 1998 to 58% in 2012 and the proportion with severe ID declined from 18% to 16%, the proportion with moderate ID increased from 10% to 13% and the proportion with mild ID increased from 8% to 11%.

**Other Conditions.** In 2012, 3% of residents of large state facilities had a diagnosis of Alzheimer's disease, 17% had Autism Spectrum Disorder (ASD) and 19% had Cerebral Palsy (CP). The proportion of residents described as having a behavior disorder requiring staff attention was 52% and the proportion with a disorder requiring psychiatric attention was 54%.

The proportion reported residents in large state facilities with CP was 19% in both 1977 and 2012 and remained below 25% throughout this period. The proportion of residents with a behavior disorder requiring staff attention increased from 25% in 1977 to 52% in 2012 and the proportion with a condition requiring psychiatric attention increased from 34% in 1998 to 54% in 2012. However, the number of residents with each of these diagnoses was smaller in 2012 than in previous years. No historical comparisons were available for Alzheimer's Disorder and ASD which were added to the survey in 2012.



**Types of Supports Needed.** On June 30, 2012, the proportion of residents in large state facilities who needed assistance or supervision was 43% for walking, 57% for using the toilet; 60% for eating; and 65% for dressing. An estimated 57% did not use spoken words to communicate and 31% could not understand simple verbal requests.

*OVERALL THE PEOPLE LIVING IN LARGE STATE FACILITIES IN 2012 WERE OLDER, MORE LIKELY TO HAVE A BEHAVIOR DISORDER OR PSYCHIATRIC DISORDER REQUIRING SUPPORT, AND MORE LIKELY TO NEED SUPPORT WITH WALKING AND EATING THAN IN PREVIOUS YEARS.*

The proportion of residents needing assistance walking increased from 23% in 1977 to 43% in 2012. The proportion needing assistance with eating increased from 21% in 1977 to 56% in 1998, and to 60% in 2012. The proportion needing assistance with toileting was lowest in 1977 (34%), highest in 1998 (60%), and declined slightly in 2012 to 56%. The proportion needing assistance dressing rose from 56% in 1977 to 70% in 1998 but dropped to 65% in 2012. The proportion who could not express what they wanted verbally increased from 44% in 1977 to 57% in 2012. Finally the proportion who could not

understand simple verbal requests decreased from 34% in 198 to 31% in 2012.

**Discussion.** Overall the people living in large state facilities in 2012 were older, more likely to have a behavior disorder or psychiatric disorder requiring support, and more likely to need support with walking and eating than in previous years. However, while the proportion with profound ID in 2012 was higher than in 1977, it was the same in 2008. Large state facilities continue to serve people with all levels of intellectual disability. Although the census has declined overall, the proportion of large state IDD facility residents with mild or moderate ID remained at 24% in 2012. The total number of people with all levels of needs and characteristics living in large state facilities continues to decline as the number of states operating large facilities declines. As Figure 6.1 showed, the number of facility closures is increasing again after slowing down between 2000 and 2009. This will create a second surge in the need for assistance to states who are still have a long way to go in the downsizing and closure process to help them build community infrastructures to support people with a wide range of characteristics needs. States continue to close all of their large state IDD facilities which suggests that whatever the challenges of people who continue to live in those settings very likely have an analogue (a person with very similar characteristics) living in a community setting both within each state and across states.

**Table 7.2** Level of Intellectual Disability of Current, New, Readmitted and Discharged Residents of Large State Facilities on June 30, 2012

Level Intellectual Disability	Resident Status FY 2012				
		June 30	New	Readmitted	Discharged
Mild or None	N	1,961	284	48	355
	%	[11.5%]	[50.0%]	[34.3%]	[33.1%]
Moderate	N	2,188	151	32	235
	%	[12.8%]	[26.6%]	[22.9%]	[21.9%]
Severe	N	2,794	62	19	157
	%	[16.3%]	[10.9%]	[13.6%]	[14.6%]
Profound	N	9,924	64	29	303
	%	[58.0%]	[11.3%]	[20.7%]	[28.3%]
IDD Level Unknown	N	242	7	12	22
	%	[1.4%]	[1.2%]	[8.6%]	[2.1%]
Total	N	17,109	568	140	1,072
	%	[100.0%]	[100.0%]	[100.0%]	[100.0%]
<b>Estimated US Total</b>		<b>26,503</b>	<b>1,077</b>		<b>2,353</b>

Note: New admissions, readmissions and discharges are based on 85 (long form) reporting facilities.

## Movement Into and Out of Large State IDD Facilities in Selected Years 1985 to 2012

Eight-five facilities reported data on an estimated 68% of all new admissions, 67% of readmissions and 46% of discharges for 2012. In 2012, an estimated 2,338 people were discharged compared with an estimated 1,048 new admissions and readmissions (34% more were discharged than were admitted). Overall, 14 of 85 reporting facilities (16%) reported no new admissions, 40 (47%) reported no readmissions, and 5 (6%) reported no discharges.

### Level of Intellectual Disability

Table 7.2 and Figure 7.3 show level of intellectual disability of current, newly admitted, readmitted and discharged residents of large state facilities. Compared to current residents, people who were newly admitted, readmitted or discharged during FY 2012 were much more likely to have mild ID (12% of current residents compared with 50% of new admissions, 34% of readmissions, and 33% of discharges) or moderate ID (13% of end of the year residents, but 27% of new admissions, 23% of readmissions and 22% of discharges). In fact, 73% of all people admitted or readmitted had mild or moderate ID compared to 53% of those discharged.

There were smaller differences in the proportion of people with severe ID (16% of year end residents compared with 11% of new admissions, 14% of

readmissions, and 15% of discharges). An opposite pattern was noted for people with profound ID. At the end of the year, 58% of current residents had profound ID compared with 11% of new admissions, 21% of readmissions, and 28% of discharges.

**Admissions and Readmissions.** Of the 708 people who were admitted or readmitted to the reporting facilities during FY 2012, 47% (332 people) had mild ID; 33% (235) had moderate ID, 13% (303) had severe ID; and only 3% had profound ID.

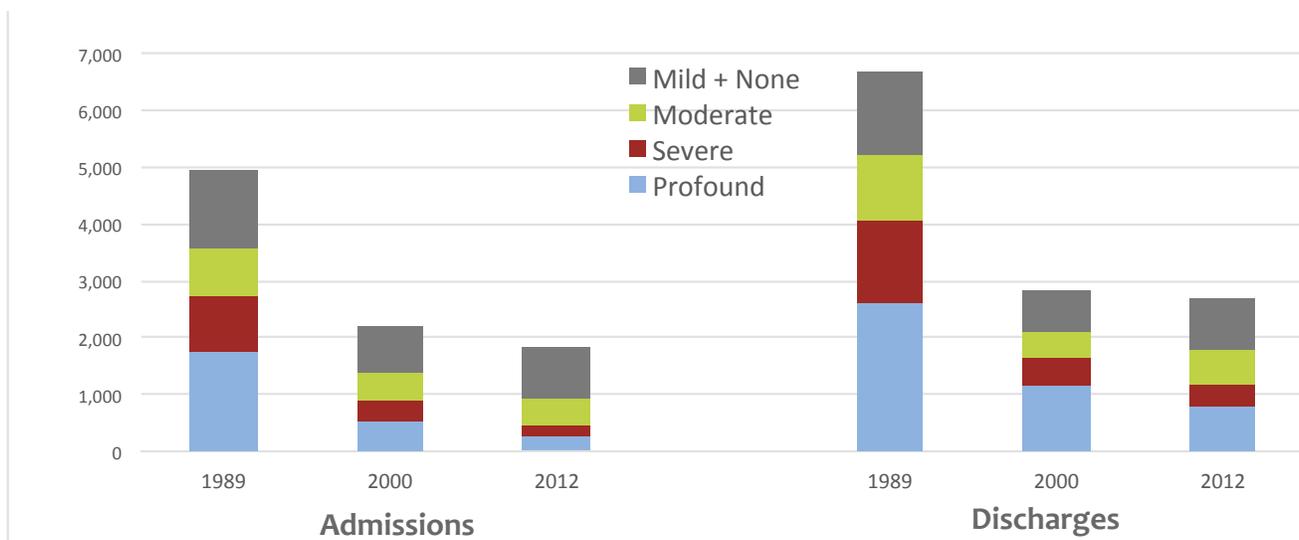
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*WHILE THE PROPORTIONS OF RESIDENTS WITH SOME CHARACTERISTICS HAS INCREASED, THE TOTAL NUMBER OF PEOPLE WITH ALL LEVELS OF NEEDS AND CHARACTERISTICS LIVING IN LARGE STATE FACILITIES CONTINUES TO DECLINE AS THE NUMBER OF STATES OPERATING LARGE FACILITIES DECLINES.*

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Newly admitted residents in FY 2012 were more likely to have mild ID and less likely to have profound ID than the June 30, 2012 large state facility population. Persons with mild ID made up 50% of new admissions compared with 12% of the general large state facility population. People with profound ID made up only 11% of new admissions but 58% of the large state facility population. The proportion of

**Figure 7.3** Estimated Admissions and Discharges by Level of Intellectual Disability in Fiscal Years 1989, 2000, 2012





people newly admitted to large state facilities with profound ID declined dramatically from 35% in 1989, 25% 1998, 13% in 2008, and 11% in 2012.

**Discussion.** Changes in admission and readmission patterns suggest that large state facilities in 2012 are serving a different population and possibly a different policy purpose than facilities in the distant or the near past. Facilities in 2012 likely need staff members providing direct support who have different characteristics, skills and training needs than staff who were hired during previous eras. These facilities may struggle to support people with very disparate needs within a single campus environment. For example, the average facility in 2012 with a current population that is 75% or more people with severe or profound ID may find it challenging to find ways to also serve typical incoming residents 80% of whom have mild or moderate ID and behavioral or psychiatric needs.

**Discharges.** Of the 1,072 people discharged from reporting facilities in 2012, 33% had mild or no ID, 22% had moderate ID, 15% had severe ID, 28% had profound ID, and level of ID was not known for 2%.

People who were discharged were more likely to have mild or moderate ID and less likely to have profound ID than the resident population as a whole. The proportion of current residents with mild or no ID was 12% compared with 22% of those who were discharged. The proportion current residents with

moderate ID was 13% compared with 22% of those who were discharged. The proportion of leavers with severe ID was similar to the proportion of year end residents with severe ID (15% versus 16%). Finally, the proportion of leavers with profound ID was only half of the proportion of year end residents with profound ID (28% versus 58%).

There were more people discharged than were admitted or readmitted at all levels of ID. Amongst people with mild or no ID, 6% more people were discharged than entered facilities in 2012 (355 vs 332). Amongst people with moderate ID, 22% more were discharged (235 vs 183). Amongst people with severe ID, 48% more were discharged (157 vs 76). Finally, amongst people with profound ID, 69% more were discharged (303 vs 93). The net effect of these trends was that facilities are serving an increasing proportion of people with mild or moderate ID and a decreasing proportion of people with severe or profound ID.

**Change in Admissions or Readmissions.** Between 1989 and 2012 resident movement of all types decreased. The total number of people admitted or readmitted to a large state facility declined from 4,964 in 1989 to 1,833 in 2012 (See [Figure 7.3](#)). The pattern varied by level of ID. The combined number of people admitted or readmitted who had profound ID was 1,739 in 1989, 518 in 2000, and 247 in 2012. The number with severe ID declined from 1,006 in 1989, to 369 in 2000 and 215 in 2012. The

number of admissions or readmissions of people with moderate ID declined from 857 in 1989 to 488 in 2000 but remained at 487 in 2012. Similarly the number of admissions or readmissions for people with mild ID declined from 1,362 in 1989 to 815 in 2000, but increased to 883 in 2012.

**Change in Discharges.** The total number of people with ID discharged from large state facilities declined from 6,698 during FY 1989, to 2,690 in 2012. The number of discharges for people with profound ID declined from 2,613 in 1989 to 776 in 2012. The number of discharges for people with severe ID declined from 1,453 in 1989 to 402 in 2012. By comparison, the number of people with moderate ID who were discharged from large state facilities declined from 1,165 in 1989 to 440 in 2000 but then increased to 602 in 2012. Similarly the number of people with mild or no ID who were discharged declined from 1,467 in 1989 to 751 in 2000 but then increased to 909 in 2012.

### Age

On June 30, 2012, of the estimated 26,503 people living in large state facilities, 287 (2%) were 18 years or younger; 336 (2%) were 19 to 21 years; 3,208

(19%) were 22 to 39; 6,287 (38%) were 40 to 54; 3,800 (23%) were 55 to 62; and 2,827 (17%; See [Table 7.3](#)) were 63 years or older. Compared to current residents, people who were newly admitted, readmitted or discharged were more likely to be 21 years old or younger (4% of current residents compared with 35% of people newly admitted, 14% of people readmitted, and 11% of people discharged). They were also more likely to be 22 to 39 years (19% of current residents compared with 44% of new admissions, 50% of readmissions, and 35% of discharged). Conversely they were less likely to be 40 years or older (77% of current residents versus 21% of new admissions, 37% of readmissions, and 53% of discharges).

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*THE ESTIMATED TOTAL NUMBER OF CHILDREN AND YOUTH READMITTED TO LARGE STATE FACILITIES DECREASED FROM 292 IN 1989, TO 195 IN 1998, 52 IN 2008, AND 17 IN 2012 AS TOTAL READMISSIONS DECLINED OVERALL.*

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**Table 7.3** Age Group of Current, New, Readmitted and Discharged Residents of Large State Facilities on June 30, 2012

Age Group	Resident Status			
	Current	New	Readmitted	Discharged
0-14 years	86 [0.5%]	39 [6.9%]	0 [0.0%]	12 [1.1%]
15-18 years	201 [1.2%]	72 [12.7%]	6 [4.3%]	57 [5.3%]
19-21 years	336 [2.0%]	86 [15.1%]	11 [7.9%]	57 [5.3%]
22-39 years	3,208 [18.8%]	247 [43.5%]	64 [46.0%]	374 [34.6%]
40-54 years	6287 [36.7%]	73 [12.9%]	25 [18.0%]	288 [26.6%]
55-62 years	3800 [22.2%]	32 [5.6%]	11 [7.9%]	156 [14.4%]
63+ years	2827 [16.5%]	16 [2.8%]	11 [7.9%]	118 [10.9%]
Age Unknown	364 [2.1%]	3 [0.5%]	11 [7.9%]	19 [1.8%]
<b>Reported Total</b>	<b>17,109</b> [100.0%]	<b>568</b> [100.0%]	<b>139</b> [100.0%]	<b>1,081</b> [100.0%]
<b>Estimated US Total</b>	<b>26,503</b>		<b>1,077</b>	<b>2,353</b>

Note: New admissions, readmissions and discharges are based on 85 (long form) reporting facilities.

**New Admissions.** Of the 565 newly admitted residents whose age was known, 7% were 0-14 years, 13% were 15 to 18, 15% were 19 to 21, 44% were 22 to 39, 13% were 40 to 54, 6% were 55 to 62 and 3% were 63 or older. While the proportion of new admissions ages 0-21 years in 2012 (35%) is greater than in 1998 (32%), it is less than in 1989 (37%) and 2008 (43%). The proportion of newly admitted middle aged and older residents (40 years and older) in 2012 (21%) was slightly less than in 1989 (23%) and 1998 (23%).

**Readmissions.** Of the 128 readmitted residents whose age was known, none were 14 years or younger, 5% were 15 to 18 years, 9% were 19 to 21, 50% were 22 to 39, 20% were 40 to 54, 9% were 55 to 62 and 9% were 63 years or older.

The profile of people who were readmitted is similar to but a bit older to those who were newly admitted (e.g., 34% of readmissions were 40 years or older compared with 21% of new admissions). The estimated total number of children and youth readmitted to large state facilities decreased from 292 in 1989, to 195 in 1998, 52 in 2008, and 17 in 2012 as total readmissions declined overall.

People readmitted in 2012 were younger than the general large state facility population (e.g., 12% vs. 4% were 21 years or younger; 8% vs. 17% were 63 years or older). The proportion of children and youth (0-21 years) among readmissions (12%) was lower than in 1998 (31%), or 1989 (19%).

Readmissions have steadily declined as a proportion of total admissions (30% in 1989, 28% in 1998, 18% in 2008, 17% in 2010, and 13% in 2012) and in total numbers (1,299 in 1989, 627 in 1998, 266 in 2008, and 139 in 2012). This suggests that states have developed community residential supports that provide sufficient support to assist people who have left large state IDD facilities to remain in community settings.

**Discharges.** Of the 1,062 people who were discharged from large state facilities in FY 2012, 1% were 14 years or younger, 5% were 15 to 18 years, 5% were 19 to 21, 35% were 22 to 39, 14% were 40 to 54, 6% were 55 to 62, and 11% were 63 or older.

Children and youth 21 years or younger made up 4% of the general population, but 2% of persons discharged. People between the ages of 22 and 54 years made up 56% of the general large state facility population and 61% of discharges. People 55 and

older made up 39% of the general population, but only 25% of the people discharged.

### Former and Subsequent Place of Residence

Tables 7.4, 7.5 and 7.6 show the prior place of residence for newly admitted or readmitted large state facility residents, and subsequent place of residence for discharged residents from 1985 to 2012. For 2012, former and subsequent places of residence have been categorized individualized settings (including the home of a parent or relative; a foster family or host home; or semi-independent or independent supported living); state and nonstate IDD congregate settings; or non IDD congregate facilities (mental health, correctional, nursing, or boarding home).

### Previous Residence for Newly Admitted People.

In FY 2012, the most common types of previous residence for newly admitted residents were home of a family member (23%), mental health facility (14%), correctional facility (12%) or a group home with 15 or fewer residents (11%; See Table 7.4). In all, 31% of people who were newly admitted came from the home of a family member, a foster family or host home, or a semi-independent or independent supported living setting. Another 11% came from a

**Table 7.4** Previous Place of Residence of Persons Newly Admitted to Large State Facilities Selected Fiscal Years 1985 to 2012

Previous Place of Residence	Fiscal Years (%)							
	1985	1989	1994	1998	2002	2008	2010	2012
Home of parents or relative	39.2	28.5	19.1	20.9	18.5	21.1	15.2	23.5
Foster/host family home	3.5	5.2	2.9	2.3	2.6	3.3	1.9	2.3
Semi-ind./ Ind. supported living	1.0	1.3	2.1	1.9	2.7	4.0	2.5	5.9
Group home (1-6 res.)								5.9
Group home (7-15 res.)								5.2
Group home (15 or fewer res.)	5.6	8.4	14.1	14.4	16.4	21.7	12.0	
Group facility (16-63 res.)	3.5	4.0	3.1	3.8	3.0	3.6	11.4	
State facility (64+res.)	20.6	18.5	23.1	25.3	13.8	12.9	18.3	
Nonstate facility (64+ res.)	1.8	0.0	5.4	2.1	5.0	3.8	1.6	
State IDD residential facility (16+ res.)								11.7
Non-state IDD residential facility (16+ res.)								2.5
Mental health facility	13.6	16.3	15.9	12.0	16.4	13.3	16.0	14.4
Correctional facility	2.3	3.0	4.3	10.3	12.6	8.4	16.1	12.5
Nursing facility	1.6	2.7	2.1	1.7	1.4	1.8	0.9	2.1
Boarding homes/Board and care	0.5	1.7	0.6	0.5	0.4	0.1	0.3	0.0
Unknown/Other	6.7	10.4	7.3	5.9	6.7	6.0	3.9	14.1
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>101</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>

Note: Statistics for FY 2012 are based on 84 large state facilities reporting on 562 (67%) of the estimated 838 new admissions. In FY 2012 the group home 15 or fewer people category was divided into homes with 1 to 6 people or 1 to 15 people. Facilities with 16 or more residents were separated only by whether they were state operated or nonstate operated.

**Table 7.5** Previous Place of Residence of Persons Readmitted to Large State Facilities for Selected Fiscal Years 1985 to 2012

Previous Place of Residence	Fiscal Years (%)							
	1985	1989	1994	1998	2002	2006	2010	2012
Home of parents or relative	36.8	19.6	26.7	33.8	28.2	10.7	14.4	12.3
Semi-ind./ Ind. supported living	0.6	1.3	2.5	4.4	5.5	7.6	11.0	5.8
Foster home	7.1	9.3	5.4	5.9	6.5	0.8	1.7	0.0
Group home (1-6 res.)								15.9
Group home (7-15 res.)								12.3
Group home (15 or fewer res.)	19.7	22.9	30.1	31.3	27.3	40.9	32.0	
Group facility (16-63 res.)	4.1	2.4	5.1	2.5	2.8	4.2	3.3	
Nonstate facility (64+ res.)	2.5	2.9	1.8	0.8	1.4	0.8	2.2	
State facility (64+res.)	7.4	13.5	8.7	4.5	4.5	6.5	2.8	
State IDD residential facility (16+ res.)								3.6
Nonstate IDD residential facility (16+ res.)								4.3
Mental health facility	8.5	12.8	8.1	8.9	8.3	6.7	11.0	18.8
Nursing facility	2.0	3.1	1.8	2.7	3.6	5.6	1.7	7.2
Correctional facility	0.0	0.9	3.1	2.5	4.2	8.3	7.7	3.6
Boarding homes/Board and care	1.2	0.9	0.6	0.2	1.2	1.4	0.0	0.0
Unknown/Other	7.9	0.1	0.1	0.1	6.5	6.4	12.2	15.9
<b>Total</b>	<b>97.8</b>	<b>89.7</b>	<b>94.0</b>	<b>97.6</b>	<b>100.0</b>	<b>99.9</b>	<b>100.0</b>	<b>100.0</b>

Note: Statistics on previous placements for Readmissions in FY 2012 are based on the reports of 84 large state facilities reporting on 138 (65.8%) of 210 estimated readmissions. For FY 2012 the group home 15 or fewer people split into homes with 1 to 6 people or 1 to 15 people. Facilities with 16 or more residents were separated only by whether they were state operated or nonstate operated.

**Table 7.6** New Place of Residence of Persons Discharged From Large State Facilities Selected Fiscal Years 1985 to 2012

New Place of Residence	Fiscal Years (%)							
	1985	1989	1994	1998	2002	2006	2010	2012
Semi-independent/Supported living	1.4	1.9	4.6	9.2	7.0	7.5	10.8	11.6
Home of parents or relative	17.1	12.4	9.2	10.8	13.8	6.9	7.7	9.1
Foster/host family home	7.1	7.4	8.6	6.3	3.9	2.2	1.2	2.6
Group home (1-6 res.)								32.1
Group home (7-15 res.)								8.4
Group home (15 or fewer res.)	40.4	48.8	55.6	50.9	46.3	46.6	51.0	
Group facility (16-63 res.)	7.4	5.3	4.3	3.7	2.0	6.4	5.2	
State facility (64+ res.)	10.1	10.2	8.8	6.1	6.7	7.0	9.3	
Nonstate facility (64+ res.)	3.8	2.6	2.4	0.7	1.2	1.2	0.8	
Nonstate IDD residential facility (16+ res.)								9.8
State IDD residential facility (16+ res.)								6.9
Nursing facility	4.1	2.0	2.6	2.6	4.2	6.4	4.6	2.8
Correctional facility	0.2	1.3	0.4	0.0	2.5	1.9	1.7	1.3
Mental health facility	1.4	1.4	0.9	1.5	2.2	3.5	1.6	1.5
Boarding homes/Board and care	3.2	2.3	1.4	3.1	0.5	0.7	0.1	0.1
Unknown/Other	3.7	4.3	5.8	5.0	8.8	9.7	6.0	13.9
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>99</b>	<b>100</b>	<b>100</b>	<b>100</b>

Note: Statistics for FY 2012 are based on reports from 83 large state facilities serving 1,001 (43%) of the estimated 2,338 total discharges.

# 2012

group home with 1 to 6 residents (6%), or 7 to 15 residents (5%). Of the rest, 14% came from an IDD facility with 16 or more residents, 28% came from a non-IDD facility, and 14% came from unknown or other residential setting.

**Changes in Previous Residence of Newly Admitted Residents.** The proportion of newly admitted residents who came from a family, foster home or semi-independent living declined from 44% in 1985 to 24% in 1994 but increased to 32% in 2012 (See Figure 7.4). The proportion who had lived in a group facility with 15 or fewer people with IDD increased from 6% in 1985 to 22% in 2008, but declined to 11% in 2012. The proportion of newly admitted residents coming from a group facility with 16 or more residents changed very little between 1985 and 2012. There was a decrease in the proportion coming from an IDD group facility with 16 or more residents from 26% in 1985 to 14% in 2012. However, there was a notable increase in the proportion of new residents coming from a correctional facility (from 2% 1985 to 12% in 2012).

**Previous Residence of People Readmitted in FY 2012.** In FY 2012 the most common previous residence types of people who were readmitted

to a large state facility were mental health facilities (19%), group homes with 1 to 6 residents (16%), group homes with 7 to 15 residents (12%) and family homes (12%; See Table 7.5). The remaining people were readmitted from a nursing facility (7%), semi-independent or independent living (6%), a nonstate

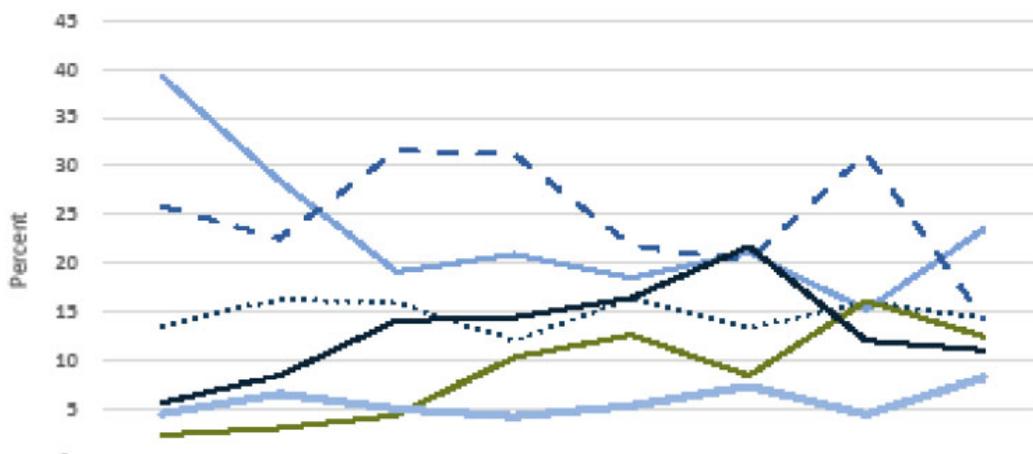
*THE PROPORTION OF NEWLY ADMITTED RESIDENTS WHO CAME FROM A FAMILY, FOSTER HOME OR SEMI-INDEPENDENT LIVING DECLINED FROM 44% IN 1985 TO 24% IN 1994 BUT INCREASED AGAIN TO 32% IN 2012.*

IDD facility with 16 or more residents (4%), a state IDD facility with 16 or more residents (4%), or a correctional facility (4%). The previous residence was something else or was unknown for 16% of readmitted residents.

**Change in Previous Residence for People Readmitted between FY 1985 and FY 2012.**

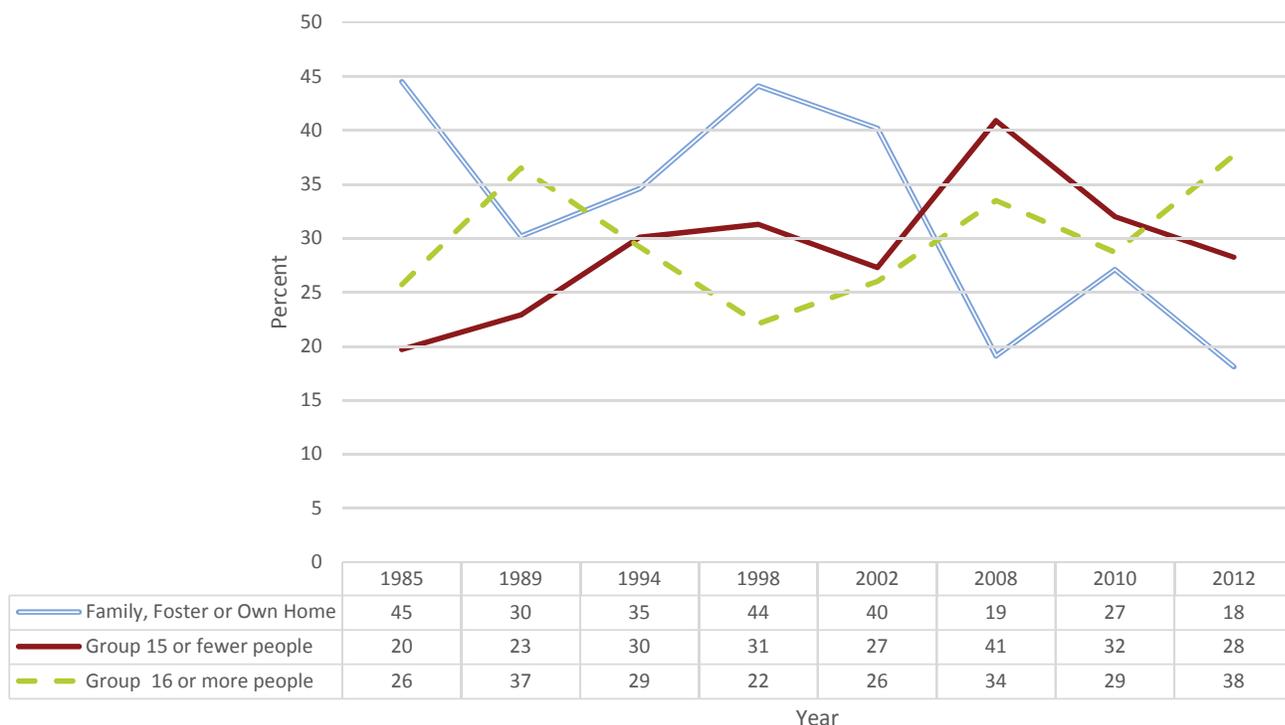
Between 1985 and 2012 the proportion of readmissions from family, foster or semi-independent living settings declined from 45% to

**Figure 7.4** Previous Place of Residence for People with IDD Newly Admitted to a Large State Facility Between 1985 and 2012



	1985	1989	1994	1998	2002	2008	2010	2012
Family Home	39	29	19	21	19	21	15	23
Mental Health	14	16	16	12	16	13	16	14
IDD 16 or more people	26	23	32	31	22	20	31	14
Correctional Facility	2	3	4	10	13	8	16	12
Group 15 or fewer people	6	8	14	14	16	22	12	11
Own Host. Foster Home	5	7	5	4	5	7	4	8

**Figure 7.5** Previous Place of Residence for People with IDD Readmitted to a Large State Facility FY 1985 to FY 2012



18% (See Figure 7.5). Readmissions from group settings with 15 or fewer residents increased overall from 20% in 1985 to 28% in 2012. Finally readmission from congregate facilities with 16 or more residents decreased from 26% in 1985 to 22% in 1998 before increasing to 38% in 2012.

A closer examination reveals that the biggest changes in individual setting types were for home of parents or relative (declining overall from 17% in 1985 to 12% in 2012), foster homes (declining from 7% in 1985 to 0% in 2012), nursing facilities (increasing from 2% in 1985 to 7% in 2012), and mental health facilities (increasing from 9% in 1985 to 19% in 2012),

**New Place of Residence for People Discharged from Large State Facilities.** In FY 2012, the most common places people with IDD moved after being discharged from a large state facility were group homes with 6 or fewer residents (32%), semi-independent or supported independent living (12%), private IDD facilities with 16 or more residents (10%) and the home of family member (9%; See Table 7.6). The remaining people who were discharged moved to a group home with 7 to 15 residents (8%), a state IDD facility with 16 or more residents (7%), a nursing

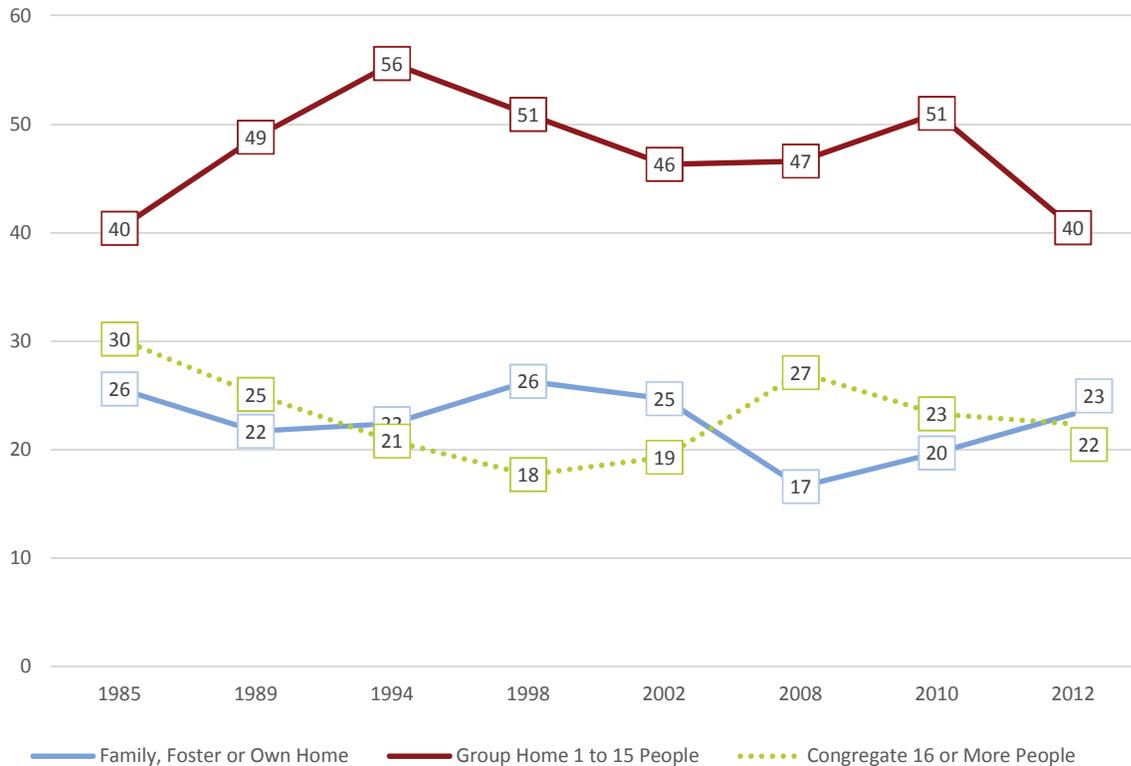
facility (3%), a foster family or host home (3%), mental health or correctional facilities (1% each), and other 14%.

**Change in the Type of New Residence for People Discharged.** The proportion of people discharged to live in a group facility with 15 or fewer residents was 40% in both 1985 and 2012 (See Figure 7.6). It spiked to 56% in 1994 and 51% in 2010. The proportion of people discharged from large state IDD facilities to another congregate setting with 16 or more residents declined overall from 30% in 1985 to 22% in 2012. Finally, the proportion who were discharged to a family home, foster home, host home, or supported independent setting declined from 26% in 1985 to 23% in 2012.

### Characteristics of People Living in Large State Facilities by State

This part of Section 7 provides state-by-state comparisons of characteristics of people living in large state facilities and compares current residents, new admissions, readmission, and discharges by state. It also provides state-by-state summaries of the utilization of large state facilities to provide on-site respite or short term stays, to support

**Figure 7.6** Subsequent Place of Residence for People Discharged from Large State Facilities FY 1985 to 2012



people with IDD who have been involved in the criminal justice system, and to provide services to people with IDD not living in the facility. State breakdowns are provided only for states in which the reporting facilities provided services for 60% or more of the estimated state total of large state facility residents. States with responses for less than that are listed as DNF on the tables even if a minority of facilities responded to the questions because of the decreasing likelihood that the information will be representative of the state as a whole as the response rate declines

**Gender.** Overall, 63% of large state facility residents were male (See [Table 7.7](#)). The proportion of residents who were male ranged from 46% in Kentucky to 81% in Idaho. Besides Kentucky, Arizona, Maryland, and Wyoming reported that 55% or fewer of residents were male. In addition to Idaho, Florida, Iowa, and South Dakota reported that more than 70% of residents were male.

**Age.** Overall, on June 30, 2012 4% of residents in reporting large state facilities were ages 21 or younger, 55% were 22 to 54 years and 39% were 55 years or older (See [Table 7.8](#)). Children and

youth ages birth to 18 years made up 24% of the U.S. population (US Bureau of the Census, 2014) but only 2% of the people in reporting large state facilities. States with the highest proportion of large state facility residents ages 21 or younger were South Dakota (26%) and Nevada (15%). Three states reported having no residents 21 years or younger (Arizona, Tennessee, and Wisconsin).

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*IN THREE STATES 90% OR MORE OF RESIDENTS WERE 40 YEARS OR OLDER (ARIZONA, 100%; CONNECTICUT, 94% AND PENNSYLVANIA, 96%).*

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In all but three reporting states (Idaho, Nevada, and South Dakota), the majority of large state facility residents were 40 years or older. In three states 90% or more of residents were 40 years or older (Arizona, 100%; Connecticut, 94% and Pennsylvania, 96%). States with the highest proportion of facility residents ages 63 and older were Arizona (50%), Connecticut (45%), Delaware (30%), and Pennsylvania (28%). Seven states reported that fewer than 10% of facility residents were 63 years or older (Nevada, 0%;

**Table 7.7** Gender Distribution of Residents of Large State Facilities by State on June 30, 2012

State	Gender (%)		N in Reporting Facilities
	Male	Female	
AL	N/A	N/A	N/A
AK	N/A	N/A	N/A
AZ	50	50	107
AR	63	37	948
CA	DNF	DNF	DNF
CO	DNF	DNF	DNF
CT	62	38	454
DE	56	44	66
DC	N/A	N/A	N/A
FL	70	30	781
GA	DNF	DNF	DNF
HI	N/A	N/A	N/A
ID	81	19	47
IL	66	34	1,356
IN	N/A	N/A	N/A
IA	73	27	444
KS	72	28	325
KY	46	54	117
LA	DNF	DNF	DNF
ME	N/A	N/A	N/A
MD	56	44	135
MA	DNF	DNF	DNF
MI	N/A	N/A	N/A
MN	N/A	N/A	N/A
MS	61	39	1,286
MO	DNF	DNF	DNF
MT	DNF	DNF	DNF
NE	60	40	136
NV	69	31	48
NH	N/A	N/A	N/A
NJ	DNF	DNF	DNF
NM	N/A	N/A	N/A
NY	DNF	DNF	169
NC	60	40	1,506
ND	68	32	94
OH	68	32	929
OK	DNF	DNF	DNF
OR	N/A	N/A	N/A
PA	57	43	993
RI	N/A	N/A	N/A
SC	DNF	DNF	DNF
SD	72	28	140
TN	49	51	182
TX	DNF	DNF	DNF
UT	60	40	207
VT	N/A	N/A	N/A
VA	59	41	886
WA	62	38	636
WV	N/A	N/A	N/A
WI	61	39	382
WY	56	44	79

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N = 86 facilities reported; Total N 17,090 was reported in gender item; used as denominator

Arizona and South Dakota, 4%; Idaho, 6%; Wisconsin, 7%; and Utah and Kansas, 8%).

**People admitted during FY 2012.** There were clear differences between states in the age of people who entered a large state facility in 2012. A total of 22 states reported the age of one or more people who were admitted or readmitted in 2012 (See [Table 7.9](#)). Seven of those states reported that the majority or plurality of admissions were of people younger than 22 years (Idaho, 60%; Iowa, 58%; Kansas, 53%; Utah, 50%; South Dakota, 48%; North Carolina, 40%; and North Dakota, 33%). All of the remaining states with one or more admission or readmission reported that the majority or a plurality of incoming residents were between 22 and 54 years old. Three states reported that 25% or more of the people admitted were ages 55 or older (Delaware, 43%; Illinois, 31%; and North Carolina, 25%).

*SEVEN STATES REPORTED THAT THE MAJORITY OR PLURALITY OF ADMISSIONS WERE OF PEOPLE YOUNGER THAN 22 YEARS (IDAHO, 60%; IOWA, 58%; KANSAS, 53%; UTAH, 50%; SOUTH DAKOTA, 48%; NORTH CAROLINA, 40%; AND NORTH DAKOTA, 33%). ALL OF THE REMAINING STATES WITH ONE OR MORE ADMISSION OR READMISSION REPORTED THAT THE MAJORITY OR A PLURALITY OF INCOMING RESIDENTS WERE BETWEEN 22 AND 54 YEARS OLD.*

**People Discharged during FY 2012.** Facilities in 32 states reported the age of one or more person who was discharged from a large state facility during FY 2012 (See [Table 7.10](#)). In all but three states the majority or a plurality of all the people discharged were between 22 and 54 years old (the largest proportion of discharges were people younger than 22 years in North Carolina, 47%; and the largest proportion of discharges were people 55 years or older in Pennsylvania, 60%; and Tennessee, 54%).

### Level of ID

**Current Residents.** Large state facilities in 25 states reported level of ID for 12,289 current residents of large state IDD facilities (See [Table 7.11](#)). Persons reported not to have ID have been combined with the “mild” ID group on this table. Respondents were allowed to categorize the level of ID as unknown.

**Table 7.8** Age of Current Residents in Reporting Large State Facilities by State on June 30, 2012

State	Age of Residents in Years (% of residents)								N in Responding Facilities
	0-14	15-18	19-21	22-39	40-54	55-62	63+	Unknown	
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	0	0	0	0	7	43	50	0	107
AR	2	2	5	31	36	20	4	0	948
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	0	0	0	5	19	30	45	0	454
DE	0	0	3	11	36	20	30	0	66
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	0	0	1	15	38	27	20	0	781
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	2	0	13	36	30	13	6	0	47
IL	0	0	0	17	47	20	16	0	1,361
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	1	2	4	25	35	19	14	0	444
KS	2	3	3	19	44	21	8	0	325
KY	0	0	1	10	45	30	12	2	117
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	0	0	3	18	44	20	16	0	135
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	2	3	4	33	35	12	11	0	1,286
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	0	0	1	13	39	31	17	0	136
NV	0	0	15	67	19	0	0	0	48
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	0	1	1	11	36	28	23	0	1,506
ND	2	4	2	23	30	21	17	0	94
OH	0	1	1	18	32	20	16	12	931
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	0	0	0	4	29	39	28	0	991
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	389
SD	6	9	10	49	20	1	4	0	140
TN	0	0	0	10	42	25	23	0	182
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	2,014
UT	0	1	3	23	40	26	8	0	207
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	0	0	1	14	43	24	17	0	886
WA	0	2	3	11	36	25	23	0	636
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	0	0	0	0	17	15	7	60	382
WY	0	0	1	25	53	0	20	0	79

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N = 86 facilities reported; N=17,109

**Table 7.9** Age of New and Readmitted Residents of Large State Facilities by State on June 30, 2012

State	Age of Residents in Years (%)								N in Responding Facilities
	0-14	15-18	19-21	22-39	40-54	55-62	63+	Unknown	
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	0	0	0	0	0	0	0	0	0
AR	12	6	13	49	15	3	1	0	67
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	0	0	0	0	0	0	0	0	0
DE	0	0	14	0	43	14	29	0	7
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	0	0	25	56	13	6	0	0	16
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	20	0	40	20	20	0	0	0	5
IL	0	0	16	31	22	6	25	0	32
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	17	8	33	42	0	0	0	0	12
KS	18	12	24	18	12	12	6	0	17
KY	0	0	0	0	100	0	0	0	2
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	0	0	10	45	35	10	0	0	20
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	3	5	5	55	13	10	7	2	60
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	0	0	0	100	0	0	0	0	2
NV	0	0	13	88	0	0	0	0	8
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	20	15	5	20	15	13	13	0	40
ND	14	10	10	14	10	0	0	43	21
OH	2	13	17	48	20	0	0	0	54
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	0	0	0	0	0	0	0	0	8
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	18	24	6	33	12	0	6	0	33
TN	0	0	0	0	0	0	0	0	0
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	0	20	30	40	10	0	0	0	10
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	0	6	19	44	19	6	6	0	16
WA	0	17	22	43	13	4	0	0	23
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	0	0	0	0	0	0	0	0	0
WY	0	0	0	100	0	0	0	0	2

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N = 85 facilities reported; AZ, CT, TN, WI had zero new or readmissions

**Table 7.10** Age of Residents Discharged from Large State Facilities in FY 2012 by State

State	Age of Residents in Years (%)								N in Responding Facilities
	0-14	15-18	19-21	22-39	40-54	55-62	63+	Unknown	
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	0	0	0	0	0	0	0	0	0
AR	1	4	6	53	21	9	6	0	70
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	0	0	0	19	38	13	0	31	16
DE	0	0	0	0	100	0	0	0	1
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	0	0	0	10	50	10	30	0	10
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	0	0	29	14	57	0	0	0	7
IL	0	0	4	25	40	16	15	0	73
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	0	12	15	41	12	12	9	0	34
KS	4	13	0	43	17	22	0	0	23
KY	0	0	0	60	40	0	0	0	5
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	0	0	5	32	27	32	5	0	22
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	0	6	2	52	12	14	14	0	50
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	0	0	6	38	19	19	19	0	16
NV	0	0	0	100	0	0	0	0	8
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	0	2	2	25	34	11	23	4	56
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	3	38	6	15	24	12	3	0	34
ND	4	13	9	9	30	0	0	35	23
OH	0	1	5	32	26	23	13	0	98
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	0	0	0	20	20	0	60	0	5
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	3	16	6	56	16	0	3	0	32
TN	0	0	0	10	36	36	18	0	50
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	0	0	25	50	25	0	0	0	8
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	0	1	2	31	37	15	14	0	104
WA	0	50	50	0	0	0	0	0	2
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	0	0	0	20	20	0	0	60	5
WY	0	0	0	0	0	0	0	0	0

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N = 85 facilities reported; AZ and WY had no discharges

In 2012, the proportion of large state facility residents with profound ID ranged from 8% in South Dakota to 90% in Kentucky. Six states reported that fewer than 50% of residents had profound ID including two states that reported fewer than 25% of residents had profound ID (Nevada and South Dakota).

The use of large state facilities to support people with no/mild or moderate ID varied dramatically across the states. Nationwide, 24% of residents were reported to have no/mild or moderate ID. In five states, persons with no/mild or moderate ID made up fewer than 10% of all residents (Delaware, 5%; Kentucky, 2%; Tennessee, 3%; Wisconsin, 3%; and Wyoming 9%). But in two other states more than 50% of residents had no/mild or moderate ID (Nevada, 56% and South Dakota, 87%).

**People admitted in FY 2012.** Facilities in 28 states reported on 456 people who were admitted or readmitted during 2012 (See Table 7.12). The proportion of total admissions with mild or no ID was

*THE USE OF LARGE STATE FACILITIES TO SUPPORT PEOPLE WITH NO/MILD OR MODERATE ID VARIED DRAMATICALLY ACROSS THE STATES.*

highest in Nebraska (100%) and Nevada (88%). The proportion of total admissions with moderate ID was highest in Virginia (63%), Iowa (50%) and Wyoming (50%). The proportion of total admissions with severe ID was highest in Idaho (40%) and Washington (30%). Finally the proportion of total admissions with profound ID was highest in Kentucky (100%) and Delaware (57%).

**People discharged in FY 2012.** Facilities in 32 states reported 687 people who were discharged in 2012 (See Table 7.13). States with the most reported discharges were Texas (167), Virginia (167) and Ohio (98). In the reporting facilities, 33% of people who were discharged had no or mild ID; 22% had moderate ID; 15% had severe ID; and 28% had profound ID.

The proportion of total discharges who had mild or no ID was highest in Maryland (64%) and South Dakota (59%). The proportion with moderate ID was highest in North Carolina (44%) and North Dakota (43%). The proportion with severe ID was

**Table 7.11** Level of Intellectual Disability of Current Residents of Large State Facilities by State on June 30, 2012

State	Level of Intellectual Disability (%)					N in Responding Facilities
	Mild	Moderate	Severe	Profound	Unknown	
AL	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A
AZ	7	16	34	44	0	107
AR	5	11	18	65	0	948
CA	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF
CT	9	13	24	54	0	454
DE	0	5	18	77	0	66
DC	N/A	N/A	N/A	N/A	N/A	N/A
FL	21	15	12	51	0	781
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A
ID	17	21	32	30	0	47
IL	7	18	20	56	0	1,360
IN	N/A	N/A	N/A	N/A	N/A	N/A
IA	19	18	16	47	0	444
KS	12	15	17	55	0	325
KY	0	2	7	90	2	117
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A
MD	12	7	20	61	0	135
MA	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A
MS	9	13	15	64	0	1,286
MO	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF
NE	15	15	16	53	1	136
NV	31	25	23	19	2	48
NH	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF
NC	4	10	16	70	0	1,506
ND	26	14	20	40	0	95
OH	5	19	17	41	18	931
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A
PA	4	7	15	73	0	991
RI	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF
SD	62	25	5	8	0	140
TN	1	2	7	90	0	182
TX	DNF	DNF	DNF	DNF	DNF	DNF
UT	12	6	11	70	2	207
VT	N/A	N/A	N/A	N/A	N/A	N/A
VA	3	9	18	69	1	886
WA	7	14	18	61	0	636
WV	N/A	N/A	N/A	N/A	N/A	N/A
WI	1	2	25	71	0	382
WY	5	4	14	77	0	79

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities

**Table 7.12** Level of Intellectual Disability of New or Readmitted Residents of Large State Facilities by State on June 30, 2012

State	Level of Intellectual Disability (%)					Total Admitted/Readmitted
	Mild or None	Moderate	Severe	Profound	Unknown	
AL	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A
AZ	0	0	0	0	0	0
AR	46	24	10	19	0	67
CA	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF
CT	0	0	0	0	0	0
DE	14	0	29	57	0	7
DC	N/A	N/A	N/A	N/A	N/A	N/A
FL	81	6	13	0	0	16
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A
ID	20	40	40	0	0	5
IL	12	33	18	36	0	33
IN	N/A	N/A	N/A	N/A	N/A	N/A
IA	42	50	8	0	0	12
KS	24	41	24	12	0	17
KY	0	0	0	100	0	2
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A
MD	60	35	5	0	0	20
MA	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A
MS	27	22	23	27	2	60
MO	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF
NE	100	0	0	0	0	2
NV	88	13	0	0	0	8
NH	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF
NC	25	40	20	15	0	40
ND	43	5	10	5	38	21
OH	46	31	9	6	7	54
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A
PA	50	38	0	13	0	8
RI	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF
SD	79	9	6	6	0	33
TN	0	0	0	0	0	0
TX	DNF	DNF	DNF	DNF	DNF	DNF
UT	70	30	0	0	0	10
VT	N/A	N/A	N/A	N/A	N/A	N/A
VA	13	63	25	0	0	16
WA	22	39	30	9	0	23
WV	N/A	N/A	N/A	N/A	N/A	N/A
WI	0	0	0	0	0	0
WY	0	50	0	50	0	2

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from large state facilities; N = 85 facilities reported; AZ, CT, TN and WI had no New or Readmissions

highest in Nevada (38%) and Washington (50%). Finally the proportion of discharges with profound ID was highest in Delaware, Kentucky and Wisconsin (all reported that 100% of the people who were discharged had profound ID).

### Select Secondary Conditions of People in Large State Facilities on June 30, 2012 by State

Table 7.14 presents the proportion of current residents in large state facilities who have intellectual or developmental disabilities and select secondary (co-occurring) conditions.

**Deaf.** Nationally, 7% of large state facility residents were reported to be functionally deaf (having little or no useful hearing). The range was 0% in South Dakota to 40% in Kentucky. Six states reported more than 10% of residents being functionally deaf.

**Blind.** Nationwide, 13% of large state facility residents were reported to be functionally blind in June 2012 (defined as having little or no useful vision). The range was from 0% in South Dakota to 47% in both Delaware and Kentucky. Eight states reported 15% or more residents to be functionally blind.

**Cerebral Palsy.** Nationwide, 19% of large state facility residents were reported to have cerebral palsy. The range was from 1% in Utah to 57% in Wisconsin. Eight states reported that fewer than 10% of residents had cerebral palsy while seven states reported that more than 30% of all residents did.

**Epilepsy.** Nationwide, 45% of large state facility residents were reported to have epilepsy. The range was from 26% in Utah to 75% in Tennessee. Two states reported that fewer than 30% of residents had epilepsy while four states reported that more than 60% did.

**Disorder Requiring Psychiatric Attention.** Facilities reported the number of residents who have psychiatric disorders defined as requiring psychiatric attention. Nationwide, 54% of large state facility residents were reported to need attention for psychiatric conditions. The range was from 12% in Kentucky to 99% in South Dakota. In three states, 80% or more of large state facility residents were reported to require psychiatric attention, while in five states, fewer than 40% were reported to require psychiatric attention.

### Behavior Disorder Requiring Staff Attention.

Facilities reported the number of residents with behavior disorders requiring special staff attention. Nationally, 52% of large state facility residents were reported to have behavior disorders. The range was from 23% in Nevada to 100% in South Dakota. In six states, 70% or more of large state facility residents were reported to have behavior disorders while in four states fewer than 30% of large state facility residents were reported to have behavioral disorders.

**Multiple Conditions.** A total of 61% of large state facility residents were reported to have two or more of the above conditions in addition to ID. The range was from 6% in Wisconsin to 100% in Idaho. In three states, more than 90% of all residents had two or more conditions, while in two states fewer than 40% did.

**Autism Spectrum Disorders.** Nationwide, 17% of large state facility residents were reported to have an autism spectrum disorder. The range was from 0.9% of residents in Kentucky to 63% in Connecticut. Five states reported fewer than 10% of residents had ASD, while eight states reported more than 20% of residents had ASD.

**Alzheimer's disease.** This is a new category in 2012. Nationwide, 3% of large state facility residents were reported to have Alzheimer's disease. This ranged from 0% in Idaho and Nevada to 34% in Connecticut. Twenty-one states reported fewer than 5% of residents had Alzheimer's disease, while only one state reported more than 10% of residents had Alzheimer's disease. The question did not differentiate between Alzheimer's and other forms of dementia.

### Medications for Mood, Anxiety, or Behavior.

Nationally, 52% of all residents of large state facilities received prescribed medications for mood, anxiety or behavior problems. This ranged from 0% in Nebraska to 99% in South Dakota. In five states more than 75% of all residents were prescribed these medications, while in one state fewer than 25% were.

### Discussion

The dramatic differences between states in characteristics of people being supported suggest that at least in some states, large state IDD facilities specialize in providing supports to people with

**Table 7.13** Level of Intellectual Disability of Discharged Residents of Large State Facilities by State on June 30, 2012

State	Level of Intellectual Disability (%)					Total Discharged
	Mild/None	Moderate	Severe	Profound	Unknown	
AL	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A
AZ	0	0	0	0	0	0
AR	37	27	20	16	0	70
CA	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF
CT	12	41	12	35	0	17
DE	0	0	0	100	0	1
DC	N/A	N/A	N/A	N/A	N/A	N/A
FL	57	21	14	7	0	14
GA	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A
ID	43	0	29	29	0	7
IL	14	17	22	47	0	59
IN	N/A	N/A	N/A	N/A	N/A	N/A
IA	50	29	12	9	0	34
KS	39	35	13	13	0	23
KY	0	0	0	100	0	5
LA	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A
MD	64	14	5	18	0	22
MA	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A
MS	22	20	14	38	6	50
MO	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF
NE	31	19	13	31	6	16
NV	38	13	38	0	13	8
NH	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF
NC	24	44	9	24	0	34
ND	43	43	0	13	0	23
OH	19	21	14	35	10	98
OK	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A
PA	20	20	0	60	0	5
RI	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF
SD	59	19	6	16	0	32
TN	8	4	18	70	0	50
TX	DNF	DNF	DNF	DNF	DNF	DNF
UT	50	25	0	0	25	8
VT	N/A	N/A	N/A	N/A	N/A	N/A
VA	5	38	17	39	0	104
WA	0	0	50	50	0	2
WV	N/A	N/A	N/A	N/A	N/A	N/A
WI	0	0	0	100	0	5
WY	0	0	0	0	0	0
US Total	52	34	23	44	3	687

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from large state facilities; N = 85 facilities reporting; AZ WY have no discharges

**Table 7.14** Proportion of Current Residents of Large State Facilities with Specific Conditions by State on June 30, 2012

State	Deaf (%)	Blind	Cerebral Palsy	Epilepsy	Psychiatric Disorder	Behavioral Disorder	Two or More Conditions	Autism Spectrum Disorder	Alzheimers	Receiving Medication for mood/behavior
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	14	26	46	59	39	47	84	6	7	39
AR	7	15	30	48	70	71	81	14	4	65
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	6	19	34	35	49	59	83	63	34	52
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
DE	14	47	2	55	47	27	95	14	2	29
FL	6	5	6	37	60	65	64	10	2	58
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	2	9	9	36	77	100	100	26	0	77
IL	5	8	8	41	45	71	51	17	0	45
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	3	10	4	30	81	30	31	30	2	77
KS	7	8	26	52	53	36	69	20	1	27
KY	40	47	34	69	12	34	62	1	1	12
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	13	24	34	54	51	64	59	11	3	51
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	5	13	20	38	38	41	51	18	2	33
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	5	10	2	40	57	60	51	7	4	0
NV	4	2	2	42	81	23	52	29	0	81
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	5	14	26	50	39	48	59	14	3	42
ND	9	13	21	27	76	80	71	27	3	80
OH	14	14	18	44	66	54	46	17	2	68
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	5	11	19	54	68	37	77	26	7	56
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	0	0	7	34	99	100	99	31	1	99
TN	3	16	47	75	31	25	59	7	2	31
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	6	7	1	26	68	68	68	8	1	68
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	11	18	22	55	48	53	60	13	2	51
WA	5	14	15	53	42	55	60	21	4	53
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	9	18	57	73	43	77	6	24	6	43
WY	1	9	11	61	49	57	46	15	5	54
US Total	7	13	19	45	54	52	61	17	3	52

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; Note: Reported by 76-86 long form facilities

certain characteristics. For example, some facilities specialize in supporting people with very significant medical support needs while others specialize in serving people involved in the criminal justice system. Similarly some may specialize in supporting youth and young adults while others serve people over 40 exclusively.

## Assistance Needs of People in Large State Facilities on June 30, 2012 by State

Table 7.15 describes specific functional limitations of residents of large state IDD facilities in 23. States varied dramatically in the proportion of residents who required functional assistance with various tasks. For example, Kentucky reported that all of the residents in its large state facilities needed assistance or help with transferring, walking, eating, toileting, and dressing. Tennessee also reported that 100% of residents required assistance with toileting and dressing while the rate was much lower in other states.

**Dressing.** Nationwide, 61% of large state facilities residents were reported to need assistance or supervision in dressing. The range was from 1% in South Dakota to 100% in Kentucky and Tennessee. In eight states fewer than 30% of residents need assistance to dress while in seven states more than 70% of residents required assistance to dress.

**Eating.** Nationwide, 60% of large state facility residents were reported to need assistance or supervision with eating. The range was from 2% in Nevada to 100% in Kentucky. In two states fewer than 30% of residents needed assistance or supervision with eating while in ten states, more than 70% of residents needed assistance or supervision with eating.

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*THE DRAMATIC DIFFERENCES BETWEEN STATES IN CHARACTERISTICS OF PEOPLE BEING SUPPORTED SUGGEST THAT AT LEAST IN SOME STATES, LARGE STATE IDD FACILITIES SPECIALIZE IN PROVIDING SUPPORTS TO PEOPLE WITH CERTAIN CHARACTERISTICS.*

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**Toileting.** Nationwide, 56% of large state facility residents were reported to need assistance or supervision with toileting. The range was from 11% in South Dakota to 100% in Kentucky. In seven states fewer than 30% of residents required assistance or supervision with toileting but in five states more than 70% needed such assistance.

**Communicating.** A total 57% of large state facility residents were reported to be unable to communicate their basic desires verbally, compared



**Table 7.15** Selected Functional Needs of Current Residents of Large State IDD Facilities by State on June 30, 2012

State	Needs Assistance/ Supervision with...					Cannot...	
	Transferring	Walking	Eating	Toileting	Dressing	Understand Simple Verbal Requests	Communicate Basic Desires Verbally
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	56	70	72	71	81	46	81
AR	44	28	70	55	67	34	54
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	67	65	70	56	82	62	64
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A
DE	DNF	DNF	DNF	DNF	DNF	DNF	DNF
FL	27	31	47	40	52	20	48
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	26	51	51	51	64	51	55
IL	24	23	41	32	49	24	61
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	49	60	94	78	81	1	43
KS	48	41	65	65	70	28	62
KY	100	100	100	100	100	26	91
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	52	56	64	59	60	54	67
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	38	43	53	64	73	28	41
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	51	52	60	63	68	15	57
NV	2	2	13	25	25	8	27
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	61	56	82	71	88	43	70
ND	40	40	40	40	40	40	40
OH	44	34	66	64	69	29	61
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	55	47	74	64	84	32	46
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	1	5	11	11	12	3	7
TN	86	86	87	100	100	35	86
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	43	43	45	54	43	54	72
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	41	62	77	76	79	49	66
WA	64	38	60	44	61	56	76
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	85	85	93	92	96	76	94
WY	67	62	87	92	80	25	71
US Total	45	43	60	56	65	31	57

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; Note: Reported by 77-83 long form facilities

to 58% in 2008. The range was from 1% in Iowa to 76% in Wisconsin. Fewer than 30% of all residents in two states were unable to communicate basic desires verbally, while more than 70% were unable to do so in six states.

**Transferring.** Nationally, 45% of large state facility residents required assistance or supervision to transfer from one position to another. The range was from 1% in South Dakota to 100% in Kentucky. Reported rates varied from less than 30% in five states to more than 70% of residents in Kentucky, Tennessee, and Wisconsin.

**Walking.** Nationwide, 43% of large state facility residents were reported to need assistance or supervision in walking. The range was from 2% in Nevada to 100% in Kentucky. Illinois and South Dakota also reported fewer than 30% required assistance for walking. Arizona, Tennessee and Wisconsin reported that more than 70% required assistance for walking.

**Understanding.** Nationwide, 31% of large state facility residents were reported not to be able to understand simple verbal requests. The range was from 1% in Iowa to 76% in Wisconsin. Fewer than 20% of residents were unable to understand simple verbal requests in four states, while more than half were unable to do so in six states.

## Types of Criminal Court Involvement for Residents as of June 30, 2012

Table 7.16 presents state-by-state data regarding residents in 83 large state facilities involved in the criminal justice system. States were included in the table if more than 60% of total residents were represented in the reporting facilities. The categories are not mutually exclusive, and some facilities reported residents who were involved in the criminal justice system for multiple reasons. Some states have reported having at least one large state IDD facility specializing in supporting people with severe behavior support needs including those involved with the criminal courts at their large state facilities.

**Behavior.** Nationwide, 5% of large state facility residents (756 people) were reported to be receiving services in a state residential facility because of behaviors that led to the involvement of the criminal justice system. The proportion of residents in the facility because of behavior ranged from 0% in seven

states (Arizona, Delaware, Kentucky, Nebraska, Tennessee, Virginia, and Wyoming) to 21% in Florida.

**Charged and Court Ordered to Facility for Competency Training.** Nationwide, 0.5% of large state facility residents (83 people) had been charged with a crime and had been court-ordered to the facility to complete competency training. Twenty states reported that none of their residents were in the facility to complete competency training. Four states reported less than 5% of their facility residents ordered to competency training (Illinois, 0.4%; Iowa, 0.6%; Maryland, 2%; Ohio, 0.2%). Idaho reported 100% of residents in this category.

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*BASED ON RESPONSES FROM REPORTING FACILITIES WE ESTIMATE THAT OF THE 26,503 LARGE STATE FACILITY RESIDENTS, 1,247 HAVE ENGAGED IN BEHAVIOR THAT LED TO INVOLVEMENT BY THE CRIMINAL JUSTICE SYSTEM, 144 HAVE BEEN CHARGED WITH A CRIME AND COURT ORDERED FOR COMPETENCY TRAINING, 1,338 HAD BEEN FOUND INCOMPETENT TO STAND TRIAL, 100 WERE UNDER PAROLE SUPERVISION, AND 446 WERE UNDER CRIMINAL COURT JURISDICTION FOR SOME OTHER REASON.*

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**Found Incompetent for Trial.** Nationwide, 5% of residents (791 people) in large state facilities had been found incompetent to stand trial. Proportions ranged from 0% in ten states to more than 5% in five states (Arizona, 12%; Delaware, 9%; Florida, 21%; North Carolina, 17%; Utah, 7%).

**Under Parole Supervision.** Nationwide, 0.4% of large state facility residents (58 people) were reported to be under parole supervision. Seventeen states reported having no residents on parole, and eight states reported between 0.1% and 1.4% of residents on parole with South Dakota reporting the largest proportion.

**Otherwise Under Criminal Court Jurisdiction.** Nationally, 1.7% of residents (260 people) living in large state IDD facilities were reported to be under jurisdiction of the criminal courts for another reason. Sixteen states reported having no residents involved in the criminal justice system for another reason; five

**Table 7.16** Number and Proportion of Large State IDD Facility Residents Involved in the Criminal Justice System by State on June 30, 2012

State	Residents with IDD in Reporting Facilities		Behavior Led to Criminal Justice Involvement		Charged and Court Ordered for Competency Training		Found Incompetent to Stand Trial		Under Parole Supervision		Other Criminal Court Jurisdiction	
	N		N	%	N	%	N	%	N	%	N	%
AL	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	107		0	-	0	-	0	-	0	-	0	-
AR	948		9	0.9	0	-	110	11.6	1	0.1	1	0.1
CA	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	454		20	4.4	0	-	0	-	1	0.2	0	-
DE	66		0	-	0	-	6	9.1	0	-	0	-
DC	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	781		165	21.1	0	-	165	21.1	0	-	101	12.9
GA	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	47		3	6.4	47	100.0	1	2.1	0	-	0	-
IL	1,356		9	0.7	5	0.4	0	-	1	0.1	1356	100.0
IN	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	444		13	2.9	1	0.6	3	1.7	0	-	0	-
KS	325		12	3.7	0	-	3	0.9	1	0.3	0	-
KY	117		0	-	0	-	0	-	0	-	0	-
LA	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	135		6	4.4	3	2.2	3	2.2	1	0.7	8	5.9
MA	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	1,286		4	0.3	0	-	2	0.2	0	-	0	-
MO	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	136		0	-	0	-	0	-	0	-	0	-
NV	48		2	4.2	0	-	2	4.2	0	-	1	2.1
NH	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	1,506		26	1.7	0	-	262	17.4	0	-	1	0.1
ND	94		4	4.3	0	-	2	2.1	0	-	0	-
OH	931		21	2.3	2	0.2	16	2.0	1	0.1	4	0.5
OK	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	716		10	1.4	0	-	7	1.0	1	0.1	1	0.1
RI	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	140		25	17.9	0	-	4	2.9	2	1.4	8	5.7
TN	182		0	-	0	-	0	-	0	-	0	-
TX	DNF		DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	207		15	7.2	0	-	14	6.8	0	-	0	-
VT	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	886		0	-	0	-	0	-	0	-	0	-
WA	295		1	0.3	0	-	0	-	0	-	0	-
WV	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	382		0	-	0	-	0	-	0	-	0	-
WY	79		0	-	0	-	0	-	0	-	0	-
Reported Total	16,065		756	4.7	83	0.5	791	5.0	58	0.4	260	1.7
Estimated US Total	26,503		1,247	4.7	144	0.5	1,338	5.0	100	0.4	446	1.7

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N = 79-83 long forms reporting

states reported between 0.1% and 5%. Florida, Illinois, Maryland, and South Dakota reported the largest proportion of residents in this category (13%, 100%, 6% and 6%, respectively).

Based on responses from reporting facilities we estimate that of the 26,503 large state facility residents, 1,247 have engaged in behavior that led to involvement by the criminal justice system, 144 have been charged with a crime and court ordered for competency training, 1,338 had been found incompetent to stand trial, 100 were under parole supervision, and 446 were under criminal court jurisdiction for some other reason.

The proportion of residents who were reported to have exhibited behavior that led to criminal justice system involvement was 4.7% in 2012 compared with 4.9% in 2010. The estimated proportion who had been charged and court ordered to the facility for competency training decreased from 1.2% in 2010 to an estimated 0.5% in 2012. The proportion of residents who had been found incompetent to stand trial increased from 3.1% in 2010 to 5.0% in 2012. The proportion reported to be under parole supervision increased from an estimated 0.2% in 2010 to 0.4% in 2012. Finally the proportion estimated to be under criminal court jurisdiction for some other reason declined from 1.9% in 2010 to 1.7% in 2012.

### Short-term Admissions to Large State Facilities

FY 2012 was the second year that the large state facility long-form survey asked about short-term admissions.

Table 7.17 shows, the number of people who had one or more short-term admissions in FY 2012 for on-campus respite services, short-term (90 days or less) evaluation (e.g., for behavior or medication adjustment), or for short-term (90 days or less) crisis housing. In Arizona for example, five facilities with 948 residents reported that 72 different people had a respite stay, 3 people had a short-term stay for evaluation, and 3 had a short-term stay for crisis housing in FY 2012. Facilities were asked to report the number of different people having one or more short-term stays, not the number of stays or the number of days those people lived on-campus.

Respondents in 15 states reported providing short term on-campus residential services to one or more

**Table 7.17** Admissions to Public Residential Facilities for Respite, Short-term Evaluation, and Short-term Crisis Housing in FY 2012

State	N Reporting*		Number of Different People with Short Term Stays For		
	Facilities	Residents	Respite	Evaluation	Crisis Housing
AL	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A
AZ	1	107	0	0	0
AR	5	948	72	3	3
CA	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF
CT	3	454	6	0	0
DE	1	66	5	1	0
DC	N/A	N/A	N/A	N/A	N/A
FL	2	781	0	0	0
GA	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A
ID	1	47	0	9	0
IL	5	1,356	0	10	0
IN	N/A	N/A	N/A	N/A	N/A
IA	2	444	7	2	0
KS	2	325	0	0	0
KY	1	117	0	0	0
LA	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A
MD	2	135	11	0	1
MA	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A
MS	5	1,286	33	29	0
MO	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF
NE	1	136	0	0	0
NV	1	48	0	0	0
NH	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF
NC	5	1,506	12	6	1
ND	1	94	0	7	0
OH	8	931	1	29	0
OK	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A
PA	4	993	0	1	0
RI	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF
SD	1	140	0	2	0
TN	2	182	0	0	0
TX	DNF	DNF	DNF	DNF	DNF
UT	1	207	0	0	0
VA	5	886	13	14	7
VT	N/A	N/A	N/A	N/A	N/A
WA <sup>1</sup>	3	636	306	16	0
WV	N/A	N/A	N/A	N/A	N/A
WI	2	382	0	197	0
WY	1	79	0	0	0
<b>Reported total</b>	<b>86</b>	<b>17,101</b>	<b>531</b>	<b>398</b>	<b>17</b>
<b>Estimated US Total</b>	<b>178</b>	<b>26,503</b>	<b>823</b>	<b>617</b>	<b>26</b>

<sup>1</sup> WA reported on 2 of its 3 facilities; N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities

people with IDD during FY 2012 while respondents in 8 states with large state facilities reported providing no services of this type (Arizona, Florida, Kansas, Kentucky, Nebraska, Nevada, Tennessee and Wyoming). For 12 states with large state facilities, too few facilities reported to be confident that their reports were representative of large state facilities in those states.

In FY 2012 large state facilities provided respite services to estimated 823 people, short-term evaluation stays to an estimated 617 people, and crisis housing stays to an estimated 26 people. Overall, respite services were provided during FY 2012 to 1 person for every 32 residents; short-term evaluation to one person for every 43 residents; and crisis housing to 1 person per 1,000 residents in the facilities on June 30, 2012.

The reporting states with high relative rates of on-site respite care per person in the facility included North Carolina with 1 person served in respite care for every 125.5 residents; Connecticut with 1 person served for every 76 residents; Virginia with 1 person

served for every 68 residents; and Iowa with 1 person served for every 63 residents.

The reporting states with the highest relative rates of short-term evaluation stays per person in the facility on June 30, 2012 included Arizona with 1 person receiving short-term on-campus evaluation services for every 316 residents; North Carolina with 1 person for every 251 residents; Iowa with 1 person for every 222 residents; Illinois with 1 person for every 136 residents and Delaware with 1 person receiving short-term on-campus evaluation stays for every 66 residents.

The reporting states with the highest relative use of on-campus short term crisis housing services were North Carolina with one person staying for crisis housing per 1,506 residents; Arizona with one person per 316 residents; Maryland with one person per 135 residents; and Virginia with one person per 127 residents. None of the other states provided crisis housing to more than 1 person per 100 people in residence on June 30, 2012.

**Table 7.18** Community Services Provided by Public Residential Facilities 2000 to 2012

Service Provided to Non-Residents	% Providing Services Directly to Persons with IDD in the Community							% Providing Training or Technical Assistance to Community Agencies						
	2000	2002	2004	2006	2008	2010	2012	2000	2002	2004	2006	2008	2010	2012
<b>Behavioral assessment and intervention</b>	51	48	40	53	51	52	33	54	44	33	47	44	39	26
<b>Dental services</b>	41	39	34	43	32	38	32	10	10	10	13	8	16	8
<b>Crisis support services</b>	44	41	30	40	42	37	26	35	35	26	36	35	27	19
<b>Respite</b>	56	50	38	17	46	38	23	9	8	8	15	4	10	4
<b>Vocational training</b>	25	31	26	9	29	24	21	20	16	9	8	17	11	10
<b>Assistive technology assessment and intervention</b>	33	29	30	39	35	21	20	38	34	22	31	32	25	18
<b>Family support/Home visitation by staff</b>	38	41	24	36	44	39	20	24	16	15	17	10	17	14
<b>Recreation</b>	24	25	16	48	29	27	20	17	16	10	8	9	13	6
<b>Diagnostic services</b>	36	30	26	32	33	21	19	20	21	15	17	24	18	8
<b>Speech services</b>	19	20	20	25	14	21	18	20	24	15	12	11	17	12
<b>Medical and/or nursing treatment</b>	22	25	18	25	22	16	17	20	20	15	19	22	13	12
<b>Consultant health services</b>	29	28	25	32	25	22	14	26	33	19	26	18	22	12
<b>Physical therapy</b>	20	18	15	13	18	19	12	17	20	14	9	11	18	12
<b>Other</b>	15	11	10	10	7	9	12	9	10	6	8	7	6	5
<b>Primary health care</b>	10	8	8	25	7	9	10	11	10	6	13	8	12	6
<b>Personal/Social Counseling</b>				19	24	21	10				13	9	15	5
<b>Self-help or developmental classes</b>	15	13	11	13	20	17	8	19	18	13	10	11	15	8
<b>Audiological assessment and intervention</b>	26	26	21	23	17	19	6	15	16	8	9	6	13	8
<b>Sex education</b>	9	11	8	24	9	9	4	15	9	10	15	7	10	2
<b>No services provided to people not living at the institution</b>	9	8	21	6	18	18	41	8	9	21	29	34	49	55
Average number of services provided	5.5	4.9	4.0	5.1	4.8	4.4	3.3	4.1	3.6	2.5	3.1	2.8	3.0	2.0

N = 84 long form facilities reporting; Sorted by 2012 Direct Services (largest to smallest)

## Community Services Provided by Large State Facilities

A total of 84 of 178 large state facilities reported providing an array of direct and indirect services to people with IDD who live in community settings (See [Table 7.18](#)). In 2012, the most frequently offered services provided directly to people with IDD who lived in the community were behavioral assessment and intervention (provided by 33% of reporting facilities), dental services (32%), crisis support services (26%), respite (23%), and vocational training (21%). The proportion of facilities reporting that they offered direct services to community residents increased between 2010 and 2012 for medical and/or nursing treatment services, primary health care, and other care. The proportion of facilities reporting that they offered direct services to community residents declined between 2010 and 2012 for the other listed services with the largest declines being for behavioral assessment and intervention services, (declining from 52% of reporting facilities in 2010 to 33% of reporting facilities in 2012), respite, family support and home visitation by staff, and crisis support services.

In 2012, reporting large state facilities offered an average of 3.3 services directly to community residents with IDD, but 41% of facilities reported not offering any of these services directly to individuals not living on the campus which is a 23% increase from 2010.

The reporting large state facilities also offered indirect services through training or technical assistance to community provider organizations on an array of topics. In 2012, facility staff offered training or technical assistance on 2.0 topics, but 55% of facilities reported not offering any of these services. The most common topics on which training or technical assistance was provided by large state facilities in 2012 were behavioral supports and intervention (offered by 26% of facilities), crisis supports and services (19%), and assistive technology assessment and intervention (18%). The proportion of facilities offering training or technical assistance decreased between 2010 and 2012 for all indirect services provided.

The most notable change between 2000 and 2012 is that the number of facilities reporting they did not offer any of the listed services to community dwelling people with IDD (increasing from 9% to 41% for



direct services, and from 8% to 55% for training or technical assistance).

## Staffing Patterns, Characteristics and Outcomes in Large State Residential Facilities in 2012

### Number of Full-Time Equivalent Staff Members in Various Positions

A total of 78 of 178 large state facilities reported the number of full-time equivalent staff members in each of several positions as of June 30, 2012 (See [Table 7.19](#)). The 2012 survey categories changed slightly from past years.

The facilities reported employing 4,457 full-time equivalent physicians and/or nurses (e.g., registered nurses, licensed practical nurses), 346 teachers or teacher's aides, 1,333 psychologists and/or qualified mental retardation professionals (QMRP), and 874 occupational, speech or physical therapists. They also employed 27,927 direct support professionals (aides and technicians) who directly provided care, treatment or training services to residents, 2,587 administrative or management employees and 10,102 support personnel including laundry, maintenance, dining, business office and similar positions.

**Table 7.19** Total Number of FTE Staff in Various Types of Positions in Large State Facilities By State on June 30, 2012

State	Facilities Reporting	Residents	Physicians/ Nurses	Teachers/ Aides	Psychologists/ Other QIDDP	OT/PT/ Speech	Direct Support Professionals	Administration/ Management	Support Personnel	Total
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	1	107	27	3	2	2	234	21	48	337
AR	5	948	191	29	31	16	1,256	92	730	2,344
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	2	439	116	3	15	18	1,091	28	147	1,418
DE	1	66	33	0	3	6	132	14	58	246
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	2	781	149	0	21	30	1,173	180	499	2,052
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	1	47	11	0	3	2	136	12	23	187
IL	4	1147	181	26	47	19	1471	112	313	2169
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	2	444	107	0	35	30	951	92	370	1,584
KS	2	325	80	6	30	4	587	44	175	925
KY	1	117	137	0	8	34	326	51	194	750
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	2	135	49	0	11	7	192	27	79	364
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	5	1286	241	122	175	85	1,737	188	677	3,225
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	1	136	52	0	9	15	371	42	93	582
NV	1	48	12	0	1	0	76	14	13	116
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	5	1506	455	103	109	137	3,051	277	1,343	5,475
ND	1	94	257	0	14	19	264	15	70	640
OH	7	836	173	0	21	14	1,197	182	272	1,859
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	4	993	285	0	8	39	1,954	245	543	3,074
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	1	140	15	4	8	4	195	8	167	400
TN	1	140	66	0	33	11	401	35	168	714
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	1	207	51	0	12	12	490	10	31	606
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	5	886	295	10	295	84	1,931	265	1,344	4,223
WA	3	636	198	0	57	17	1,044	60	188	1,564
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	2	382	143	4	26	33	597	99	251	1,154
WY	1	79	16	0	4	7	214	13	70.75	324
<b>Reported Total</b>	<b>78</b>	<b>15,634</b>	<b>4,457</b>	<b>346</b>	<b>1,333</b>	<b>874</b>	<b>27,927</b>	<b>2,587</b>	<b>10,102</b>	<b>47,625</b>
<b>Estimated Total</b>	<b>178</b>	<b>26,503</b>	<b>7,555</b>	<b>586</b>	<b>2,259</b>	<b>1,481</b>	<b>47,342</b>	<b>4,385</b>	<b>17,125</b>	<b>80,734</b>

N/A = Not applicable (state without large state facilities); QIDP = Qualified Intellectual Disability Professional; DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N = 78 long form facilities reporting; Data provided by facilities serving 59.0% of all residents in 2012; \* Direct support professionals include aides, teachers aides, technicians and direct support workers not covered on any of the licensed professional categories. Support personnel include those working with laundry, maintenance, dining, transportation, security, and business office employees.

States reporting the largest number of direct support professionals in aide/technician roles were North Carolina with 3,051; Pennsylvania with 1,954; Virginia with 1,931; and Mississippi with 1,737.

Based on the staff to resident ratios in the reporting facilities we estimate that the total number of physicians and nurses combined was 7,555 in 2012 compared with an estimated 464 physicians and 7,286 nurses in 2010. The estimated number of FTE teachers or teacher's aides was 586 in 2012 compared with 866 in 2010. The combined estimated number of FTE Psychologists or QIDP's

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*WHILE THE NUMBER OF PEOPLE LIVING IN LARGE STATE FACILITIES DECLINED FROM 31,101 IN 2010 TO 26,503 IN 2012 (A DECLINE OF 15%), THE ESTIMATED NUMBER OF FULL-TIME EQUIVALENT POSITIONS DECREASED FROM 90,399 TO 80,734 (A DECLINE OF 11%).*

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was 2,259 in 2012 compared with an estimate of 609 psychologists, and 1,946 QIDP's in 2010. The estimated combined compliment of occupational, physical and speech therapists was 1,481 in 2010 compared with an estimated 609 OT or PTs, and 381 speech therapists in 2010. Finally the estimated US total staff complement of direct support workers was 47,342 in 2012 compared with 49,759 in 2010.

The number of people living in large state facilities declined from 31,101 in 2010 to 26,503 in 2012 (a decline of 15%), while the estimated number of full-time equivalent positions decreased from 90,399 to 80,734 (a decline of 11%).

### **Percent of Full-Time Equivalent Staff in Various Positions**

Table 7.20 shows the proportion of staff in large state residential facilities in each of several different positions. Staff contingents were computed based on the number of full-time equivalent workers who would be employed if all of the employees worked 40 hours per week. A 0.5 FTE staff member works an average of 20 hours per week. Overall, the largest proportion of FTE staff members were direct support professionals (59%) and support personnel (21%) in FY 2012. Physicians/Nurses were 9% of the FTE staff contingent, and administrators and managers were 5%.

**Direct Support Professionals.** Nationally, 59% of large state facility staff worked in direct support professional (aides, technicians) roles. This proportion ranged from 41% in North Dakota to 81% in Utah. Four states reported having less than 50% of their FTE staff in aide or technician roles, 8 states had between 50% and 59%, and 13 had 60% or more of their staff contingent in those roles.

**Support Personnel.** Nationally, 21% of large state facility staff worked in support roles (e.g.,



**Table 7.20** Percent of FTE Staff in Various Types of Positions in Large State Facilities By State on June 30, 2012

State	Facilities Reporting	Residents	Physicians/ Nurses	Teachers/ Aides	Psychologists/ Other QIDP	OT/PT/Speech	Direct Support Professionals*	Administration/ Management	Support Personnel
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	1	107	8%	1%	1%	0%	69%	6%	14%
AR	5	948	8%	1%	1%	1%	54%	4%	31%
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	2	439	8%	0%	1%	1%	77%	2%	10%
DE	1	66	13%	0%	1%	2%	54%	6%	24%
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	2	781	7%	0%	1%	1%	57%	9%	24%
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	1	47	6%	0%	2%	1%	73%	6%	12%
IL	4	1,147	8%	1%	2%	1%	68%	5%	14%
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	2	444	7%	0%	2%	2%	60%	6%	23%
KS	2	325	9%	1%	3%	0%	63%	5%	19%
KY	1	117	18%	0%	1%	5%	43%	7%	26%
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	2	135	13%	0%	3%	2%	53%	7%	22%
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	5	1,286	7%	4%	5%	3%	54%	6%	21%
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	1	136	9%	0%	2%	3%	64%	7%	16%
NV	1	48	10%	0%	1%	0%	66%	12%	11%
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	5	1,506	8%	2%	2%	3%	56%	5%	25%
ND	1	94	40%	0%	2%	3%	41%	2%	11%
OH	7	836	9%	0%	1%	1%	64%	10%	15%
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	4	993	9%	0%	0%	1%	64%	8%	18%
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	1	140	4%	1%	2%	1%	49%	2%	42%
TN	1	140	9%	0%	5%	2%	56%	5%	24%
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	1	207	8%	0%	2%	2%	81%	2%	5%
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	5	886	7%	0%	7%	2%	46%	6%	32%
WA	3	636	13%	0%	4%	1%	67%	4%	12%
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	2	382	12%	0%	2%	3%	52%	9%	22%
WY	1	79	5%	0%	1%	2%	66%	4%	22%
<b>Reported Total</b>	<b>78</b>	<b>11,925</b>	<b>9%</b>	<b>1%</b>	<b>3%</b>	<b>2%</b>	<b>59%</b>	<b>5%</b>	<b>21%</b>

N/A = Not applicable (state without large state facilities); QIDP = Qualified Intellectual Disability Professional; DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; \*Percentages and total national FTE includes only facilities that providing complete FTE information (n=78)

maintenance, laundry, dietary). The proportion varied from a low of 5% in Utah to a high of 42% in South Dakota. One state reported employing fewer than 10% of all staff in support roles, while four states reported employing 25% or more staff in support roles.

**Physicians/Nurses.** Nationally, 9% of all large state facility staff worked in physician or nursing roles. The proportion working as physicians/nurses ranged from 5% in Wyoming to 40% in North Dakota. Seven states reported that more than 10% of their staff members were physicians/nurses, while one state reported that less than 5% were physicians/nurses.

**Administrative/Management.** Nationally, 5% of large state facility staff worked in administrative or management roles. The proportion ranged from 1.7% in Utah to 12% in Nevada. Nevada was the only state to report more than 10% of their staff worked in administrative or management roles while nine states reported that fewer than 5% were in administrative or management roles.

**Teachers and Teachers Aides.** Nationally, 0.7% of large state facility staff worked in teacher or teacher's aide roles. Fifteen states did not employ any teachers/teacher aides and ten additional states reported employing less than 5% of their staff in teacher/teacher aide roles. No states reported that more than 10% of all staff were in teacher or teacher

aide positions. Arizona, Tennessee and Wisconsin reported having no residents younger than 22 years old suggesting that the teacher title was given to staff in roles other than traditional Pre-K -12 education.

**Psychologists/Qualified Intellectual Disability Professional (QIDP).** Nationally, 2.8% of the staff members of large state facilities were employed as psychologists or qualified intellectual disability professionals. In Virginia, 7% of staff members were psychologists/qualified mental retardation

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*NATIONALLY, 9% OF ALL LARGE STATE FACILITY STAFF WORKED IN PHYSICIAN OR NURSING ROLES. THE PROPORTION WORKING AS PHYSICIANS/NURSES RANGED FROM 5% IN WYOMING TO 40% IN NORTH DAKOTA.*

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professionals as were 5% of staff members in Mississippi. Twelve states employed between 0.3% and 1.9% of their staff contingent as psychologists/qualified intellectual disability professionals. Finally, 11 states employed between 2% and 5% of their staff contingent in these positions.

**Occupational, Physical or Speech Therapy (OT/PT/ST).** Nationally, 1.8% of staff members in large state facilities were in an OT, PT, or ST role. One state (Nevada) did not report employing any staff in OT/PT/ST roles while Kentucky reported that 5% of their staff contingent worked in these roles. Fourteen states employed between 0.5% and 1.9% of their staff in OT, PT or ST roles. The remaining nine states employed between 2% and 3% of their staff in OT, PT or ST roles.

### **Ratio of Staff to Residents**

The average large state IDD facility employed 0.29 FTE physicians/nurses per resident, 1.79 FTE direct support professionals (aides and technicians) per resident and 3.05 FTE total employees per resident in 2012 (See [Table 7.21](#)). These ratios have been increasing steadily for many years. In 1989, the ratio of direct support professionals to residents was 0.96 (Braddock & Mitchell, 1992). The ratio increased from 1.27 in 2000, to 1.70 in 2010 and 1.79 in 2012.



**Table 7.21** Ratio of Staff to Residents in Large State Facilities by State on June 30, 2012

Number of Staff per Person Supported									
State	Physicians/ Nurses	Teachers/ Aides	Psychologists/ Other QI/DDP	OT/PT/Speech	Direct Support Professionals*	Administration/ Mgmt	Support Personnel	All Staff	
AL	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	0.25	0.03	0.02	0.01	2.19	0.20	0.45	3.15	
AR	0.20	0.03	0.03	0.02	1.32	0.10	0.77	2.47	
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	0.26	0.01	0.03	0.04	2.48	0.06	0.33	3.23	
DE	0.50	0.00	0.05	0.09	2.00	0.21	0.88	3.73	
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	0.19	0.00	0.03	0.04	1.50	0.23	0.64	2.63	
GA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	0.23	0.00	0.06	0.04	2.89	0.26	0.49	3.98	
IL	0.16	0.02	0.04	0.02	1.28	0.10	0.27	1.89	
IN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	0.24	0.00	0.08	0.07	2.14	0.21	0.83	3.57	
KS	0.25	0.02	0.09	0.01	1.81	0.14	0.54	2.85	
KY	1.17	0.00	0.07	0.29	2.79	0.44	1.66	6.41	
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	0.36	0.00	0.08	0.05	1.42	0.20	0.59	2.70	
MA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MS	0.19	0.09	0.14	0.07	1.35	0.15	0.53	2.51	
MO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NE	0.38	0.00	0.07	0.11	2.73	0.31	0.68	4.28	
NV	0.25	0.00	0.02	0.00	1.58	0.29	0.27	2.42	
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NC	0.30	0.07	0.07	0.09	2.03	0.18	0.89	3.64	
ND	2.74	0.00	0.15	0.20	2.81	0.16	0.74	6.81	
OH	0.21	0.00	0.03	0.02	1.43	0.22	0.32	2.22	
OK	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
PA	0.29	0.00	0.01	0.04	1.97	0.25	0.55	3.10	
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
SD	0.10	0.03	0.06	0.03	1.39	0.06	1.19	2.85	
TN	0.47	0.00	0.24	0.08	2.86	0.25	1.20	5.10	
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	0.25	0.00	0.06	0.06	2.37	0.05	0.15	2.93	
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	0.33	0.01	0.33	0.09	2.18	0.30	1.52	4.77	
WA	0.31	0.00	0.09	0.03	1.64	0.09	0.30	2.46	
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	0.37	0.01	0.07	0.09	1.56	0.26	0.66	3.02	
WY	0.20	0.00	0.04	0.09	2.71	0.16	0.90	4.10	
Reported Total	0.29	0.02	0.09	0.06	1.79	0.17	0.65	3.05	

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; \*Includes only facilities that providing complete FTE information (n=78)

**Table 7.22** Personnel Costs in Large Public Residential Facilities by State on June 30, 2012

State	Number of Facilities Reporting <sup>1</sup>	Total Operating and Personnel Budget (\$) <sup>2</sup>	Personnel Budget (including fringe) (\$)	% Personnel Costs
AL	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A
AZ	1	\$16,158,563	\$13,160,909	81%
AR	5	\$107,331,513	\$86,684,583	81%
CA	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF
CT	1	\$79,878,439	\$74,260,976	93%
DE	1	\$20,759,900	\$16,838,000	81%
DC	N/A	N/A	N/A	N/A
FL	2	\$96,534,756	\$76,880,590	80%
GA	DNF	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A
ID	1	\$12,373,100	\$10,139,800	82%
IL	4	\$142,261,235	\$128,003,839	90%
IN	N/A	N/A	N/A	N/A
IA	2	\$135,576,769	\$112,475,104	83%
KS	2	\$53,262,823	\$45,278,113	85%
KY	1	\$34,710,799	\$29,449,653	85%
LA	DNF	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A
MD	2	\$28,387,579	\$22,353,938	79%
MA	DNF	DNF	DNF	DNF
MI	N/A	N/A	N/A	N/A
MN	N/A	N/A	N/A	N/A
MS	5	\$177,278,039	\$133,140,700	75%
MO	DNF	DNF	DNF	DNF
MT	DNF	DNF	DNF	DNF
NE	1	\$50,033,471	\$35,172,100	70%
NV	1	\$9,794,785	\$6,387,557	65%
NH	N/A	N/A	N/A	N/A
NJ	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A
NY	DNF	DNF	DNF	DNF
NC	5	\$318,089,786	\$257,465,665	81%
ND	DNF	DNF	DNF	DNF
OH	7	\$142,032,869	\$121,085,628	85%
OK	DNF	DNF	DNF	DNF
OR	N/A	N/A	N/A	N/A
PA	4	\$242,068,364	\$202,365,378	84%
RI	N/A	N/A	N/A	N/A
SC	DNF	DNF	DNF	DNF
SD	1	\$22,656,042	\$17,488,745	77%
TN	2	\$76,850,014	\$51,538,594	67%
TX	DNF	DNF	DNF	DNF
UT	1	\$30,221,053	\$25,469,186	84%
VT	N/A	N/A	N/A	N/A
VA	5	\$237,841,303	\$184,350,977	78%
WA	3	\$119,848,093	\$99,269,646	83%
WV	N/A	N/A	N/A	N/A
WI	2	\$116,824,867	\$93,758,099	80%
WY	1	\$24,028,340	\$21,088,585	88%
<b>Reported Total</b>	<b>80</b>	<b>\$3,092,619,758</b>	<b>\$2,533,149,487</b>	<b>82%</b>
<b>Estimated Total</b>	<b>178</b>	<b>\$6,285,151,674</b>	<b>\$5,148,136,526</b>	<b>82%</b>

DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N/A = Not applicable (state without large state facilities); 1 Excludes facilities not reporting personnel budget; 2 Excludes remodeling and construction expenses; N = 80 long form facilities reporting

The ratio of physicians/nurses to residents ranged from 0.10 in South Dakota to 2.74 in North Dakota. Four states had physician/nurse to resident ratios of less than 0.20 while 10 states had ratios over 0.30.

The ratio of direct support professionals (aides and technicians) to residents ranged from 1.28 in Illinois to 2.89 in Idaho. Twelve states employed fewer than 1.9 FTE direct support professionals per resident while 14 states employed 2.0 FTE or more per resident. The total number of full time equivalents per person served ranged from 1.89 in Illinois to 6.81 in North Dakota. One state (Illinois) employed fewer than 2.0 FTE total staff per resident, while six states employed more than 4.0 FTE total staff per resident (Kentucky, Nebraska, North Dakota, Tennessee, Virginia and Wyoming).

### Personnel Costs in Large State Settings

A total of 80 large state facilities housing 61% of all large state facility residents with IDD reported both their total operating budget and their personnel budget for July 1, 2011 to June 30, 2012 (See [Table 7.22](#)). Capital expenses (e.g., remodeling, construction and repairs) were excluded from these analyses. The total budget for the 80 reporting facilities was \$3.092 billion in FY 2012. Of that, \$2.533 billion (or 82%) was spent on personnel costs (including fringe benefits); a smaller proportion than



states reported that more than 85% of their annual expenditures were for personnel costs including fringe benefits.

### Wages and Benefits

[Table 7.23](#), [Figure 7.7](#), and [Figure 7.8](#) show changes in wages and benefits for direct support professionals (aides/technicians; aka DSP) from 2000 to 2012. In 2012, starting wages for DSPs were \$11.99 (\$24,939 per year for a 40 hour a week employee), and average wages were \$14.67 (\$30,514 for a 40 hour a week employee). DSP starting wages remained stable and average wages decreased 1% between 2010 and 2012. Starting wages increased 25% and average wages increased 19% between 2002 and 2012.

In 2012, DSP wages varied widely across states. Starting wages ranged from \$7.62 per hour in Mississippi to \$17.33 per hour in Connecticut. Average wages ranged from \$9.12 per hour in Mississippi (\$18,970 for a full time employee) to \$22.33 per hour in Connecticut (\$46,446 per year a full-time employee). Starting wages were above \$15.00 per hour in three states (Connecticut, Illinois and Iowa). Average wages were below \$10.50 per hour in Florida, Georgia, and Mississippi. Average wages for were above \$20.00 in Connecticut and Iowa.

The U.S. Census Bureau 2012 poverty level for a family with two adults and two children was \$23,050 (\$11.08 per hour for one wage earner working full-time) (<http://www.aspe.hhs.gov/poverty>). A typical

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*THE TOTAL ESTIMATED OPERATING AND PERSONNEL BUDGETS FOR ALL 178 LARGE STATE RESIDENTIAL SETTINGS WAS ESTIMATED TO BE \$6.285 BILLION WITH AN ESTIMATED \$5.148 BILLION SPENT ON PERSONNEL COSTS. PERSONNEL COSTS ACCOUNTED FOR BETWEEN 65% OF ALL EXPENDITURES (NEVADA) TO 93% OF ALL EXPENDITURES (CONNECTICUT).*

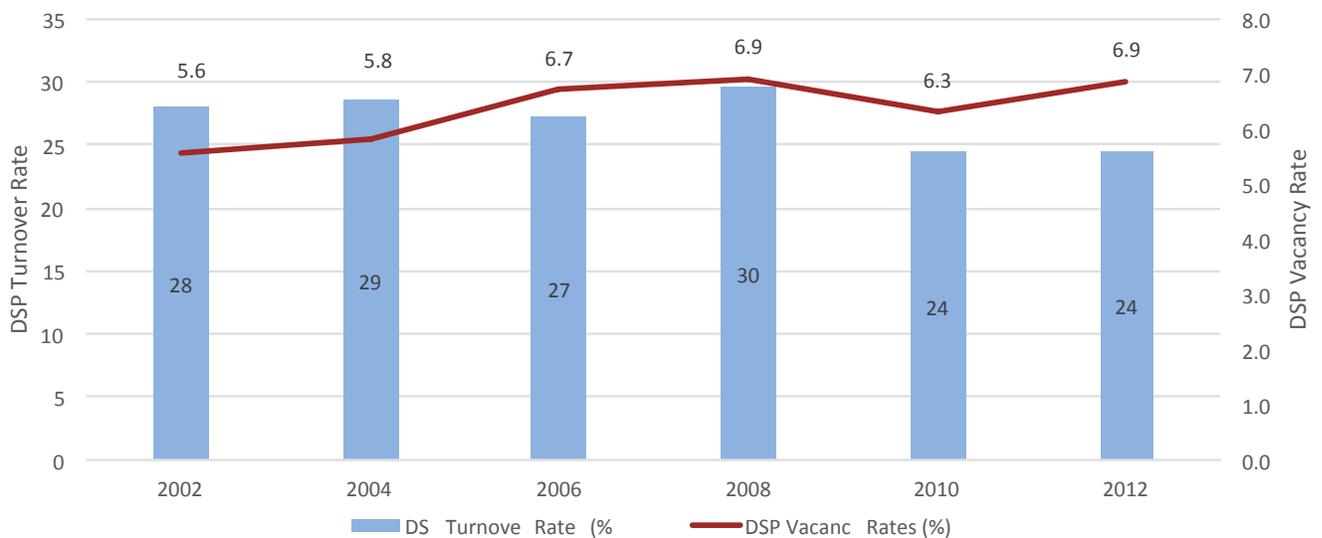
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in FY 2010 (84%). The total estimated operating and personnel budgets for all 178 large state residential settings was estimated to be \$6.285 billion with an estimated \$5.148 billion spent on personnel costs. Personnel costs accounted for between 65% of all expenditures (Nevada) to 93% of all expenditures (Connecticut). Three states reported personnel expenditures accounting for less than 75% of all costs (Nebraska, Nevada, and Tennessee). Five

**Figure 7.7** Change in Starting and Mean Wage for DSPs in Public Residential Facilities 2000 to 2012



**Figure 7.8** Changes in DSP Turnover and Vacancy Rates in Large Public Facilities 2002 to 2012



DSP in large state facilities working 40 hours a week earning an average wage earned less than this threshold in Florida, Georgia and Mississippi. An entry level DSP working full-time earned less than this level in five states.

The biggest increases in starting wage between 2010 and 2012 were in Maryland (14%), Illinois (13%), and Iowa (11%). Connecticut reported a decrease of 10%, and Arizona reported a decrease

of 6% in starting wages while five other states reported decreases of less than 5%. Average wage increased between 2010 and 2012 in all but 9 states (Connecticut, Florida, Kansas, Kentucky, Mississippi, Nevada, Ohio, Utah, and Washington). Virginia (32%) was the only state that reported an increase in average wage of more than 20% during this period. The number of hours direct support professionals in large state facilities had to work to be eligible for paid time off (e.g., sick, vacation, holiday) ranged from 4 to

Table 7.23 Wages and Benefits of Direct Support Staff on June 30 of FY 2000 to FY 2012

State	Mean Starting Wage (\$)							Mean Wage (\$)							Change 2002 to 2012 (%)		Hours for Paid Leave Eligibility
	2000	2002	2004	2006	2008	2010	2012	2000	2002	2004	2006	2008	2010	2012	Starting Wage	Average Wage	
AL	6.96	7.85	7.93	8.41	9.37	9.70	N/A	8.80	9.26	9.94	11.50	10.09	10.44	N/A	N/A	N/A	N/A
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AZ	8.29	8.50	9.00	10.42	10.22	10.42	10.22	11.29	11.16	10.00	11.06	11.90	11.70	DNF	20%	DNF	20
AR	7.71		7.65	7.79	7.84	9.59	9.07	9.60	10.12	9.48	10.00	9.67	11.03	11.93	DNF	18%	34
CA	14.45	16.48	17.01	22.09	DNF	20.87	DNF	18.99	24.15	20.05	22.81	DNF	24.53	DNF	DNF	DNF	DNF
CO	9.15	10.04	11.13	9.83	12.00	12.13	DNF	12.20	15.30	15.50	15.37	18.00	17.35	DNF	DNF	DNF	DNF
CT	14.86	15.90	DNF	17.61	18.96	19.34	17.33	19.18	22.42	DNF	23.88	24.96	24.35	22.33	19%	-0%	18
DE	9.52	DNF	12.62	12.51	12.80	DNF	12.77	11.75	DNF	15.24	15.55	14.92	DNF	14.78	DNF	DNF	38
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
FL	8.31	9.30	9.43	9.71	10.26	10.51	10.63	11.07	10.24	10.74	10.88	11.56	11.21	10.33	14%	1%	29
GA	8.44	7.87	7.98	8.32	9.11	8.22	DNF	10.50	10.16	8.80	9.65	13.94	DNF	10.17	DNF	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
ID	10.31	9.28	DNF	11.65	10.00	12.50	12.00	11.59	13.01	DNF	15.69	14.16	14.02	14.48	29%	11%	40
IL	8.87	10.39	11.24	12.02	12.95	13.60	15.35	12.43	14.34	16.52	15.37	17.33	18.70	19.63	48%	37%	25
IN	8.87	9.24	11.54	DNF	11.83	10.92	N/A	12.18	12.45	14.34	DNF	18.91	15.48	N/A	N/A	N/A	N/A
IA	11.56	14.12	14.83	13.56	14.37	14.59	16.19	13.83	18.46	20.25	18.75	19.47	19.83	21.32	15%	15%	30
KS	8.50	9.43	9.87	11.63	11.52	12.43	11.82	10.98	11.45	12.51	13.33	13.08	13.75	13.66	25%	19%	20
KY	8.63	8.86	8.76	10.73	DNF	12.29	12.33	9.52	11.71	12.21	11.89	12.30	16.95	12.81	39%	9%	38
LA	5.62	6.55	6.61	7.06	8.00	8.02	DNF	7.65	7.98	8.46	8.64	10.21	11.21	11.24	DNF	DNF	DNF
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MD	8.16	8.83	9.79	10.15	9.93	11.36	12.90	11.75	12.62	13.00	13.43	13.55	13.76	14.37	46%	14%	20
MA	10.26	10.92	10.94	11.96	12.81	12.81	DNF	12.04	13.58	13.07	14.65	16.75	19.67	DNF	DNF	DNF	DNF
MI	12.33	12.83	13.48	15.18	15.22	DNF	N/A	15.57	15.63	15.91	17.32	17.76	DNF	N/A	N/A	N/A	N/A
MN	11.54	13.73	13.73	14.00	15.22	15.22	N/A	15.51	15.68	16.61	16.97	19.07	27.30	N/A	N/A	N/A	N/A
MS	6.95	6.60	7.37	7.33	7.54	7.76	7.62	7.89	7.80	7.76	8.26	9.03	9.24	9.12	15%	17%	28
MO	7.23	7.51	7.88	8.75	9.52	9.73	DNF	8.31	8.88	9.28	9.92	10.43	10.65	DNF	DNF	DNF	DNF
MT	7.21	7.83	8.09	9.48	9.37	DNF	DNF	8.99	10.02	9.53	10.26	11.73	DNF	DNF	DNF	DNF	DNF
NE	8.59	8.94	9.52	DNF	11.13	10.83	11.97	9.63	10.25	10.51	DNF	12.45	12.54	12.95	34%	26%	20
NV	10.36	11.43	11.88	12.36	12.85	14.41	14.00	15.05	16.41	16.61	17.37	18.59	18.93	18.00	22%	10%	21

**Table 7.23** Wages and Benefits of Direct Support Staff on June 30 of FY 2000 to FY 2012

State	Mean Starting Wage (\$)							Mean Wage (\$)							Change 2002 to 2012 (%)		Hours for Paid Leave Eligibility
	2000	2002	2004	2006	2008	2010	2012	2000	2002	2004	2006	2008	2010	2012	Starting Wage	Average Wage	
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	9.58	10.32	11.07	11.59	12.53	13.27	DNF	13.25	12.35	13.77	15.51	16.03	17.95	DNF	DNF	DNF	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NY	10.12	10.99	11.61	12.48	14.60	DNF	DNF	13.25	16.97	14.59	15.82	20.20	DNF	DNF	DNF	DNF	DNF
NC	8.75	9.26	9.57	10.87	11.53	11.94	12.28	10.55	10.72	11.33	11.54	13.29	13.53	13.86	33%	29%	24
ND	7.36	DNF	7.70	8.01	9.24	10.02	10.49	8.65	DNF	9.34	9.76	11.30	12.44	13.92	DNF	DNF	4
OH	11.81	13.10	12.88	13.87	14.73	14.86	14.35	13.41	14.41	14.37	14.94	15.88	16.34	15.85	10%	10%	14
OK	6.83	8.02	8.03	8.45	8.77	10.21	DNF	8.34	DNF	9.69	10.30	10.79	11.98	DNF	DNF	DNF	DNF
OR	9.80	10.22	10.53	10.81	11.56	DNF	N/A	11.00	11.57	11.92	12.99	15.19	DNF	N/A	N/A	N/A	N/A
PA	10.12	10.31	10.75	11.63	11.40	12.54	12.61	14.11	14.99	18.66	15.59	15.73	17.61	18.18	22%	21%	39
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	6.80	8.04	8.10	8.58	8.72	9.63	DNF	7.88	9.04	10.03	9.78	10.13	10.88	DNF	DNF	DNF	DNF
SD	8.59	8.50	8.93	9.41	10.00	10.81	11.70	9.73	10.60	10.05	11.14	12.00	12.16	12.53	38%	18%	20
TN	8.24	9.12	9.85	10.88	10.93	11.02	11.46	8.57	10.09	10.92	12.65	14.20	12.50	13.00	26%	29%	38
TX	7.79	7.97	8.10	8.44	9.58	10.34	DNF	8.56	9.27	8.83	9.44	10.24	11.50	DNF	DNF	DNF	DNF
UT	7.72	8.94	9.03	9.26	10.19	10.70	10.70	8.54	10.00	9.56	9.44	12.59	12.27	12.00	20%	20%	40
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
VA	8.96	8.64	8.94	9.82	9.74	10.32	11.11	10.39	9.99	10.71	11.13	11.20	11.39	15.00	29%	50%	38
WA	10.46	11.24	12.25	11.48	12.36	11.97	13.00	14.52	14.42	14.91	14.44	15.01	16.60	16.50	16%	14%	20
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WI	11.47	10.07	10.52	11.95	13.61	12.03	12.84	14.32	12.52	12.34	14.42	17.43	DNF	16.50	28%	32%	30
WY	6.94	6.95	6.95	10.13	DNF	DNF	13.00	8.95	7.52	8.74	10.95	DNF	DNF	13.58	87%	81%	10
<b>Average</b>	<b>\$9.19</b>	<b>\$9.62</b>	<b>\$10.12</b>	<b>\$11.06</b>	<b>\$11.35</b>	<b>\$11.95</b>	<b>\$11.99</b>	<b>\$11.57</b>	<b>\$12.33</b>	<b>\$12.53</b>	<b>\$13.17</b>	<b>\$14.13</b>	<b>\$14.76</b>	<b>\$14.67</b>	<b>25%</b>	<b>19%</b>	<b>27</b>

DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N/A = Not applicable (state without large state facilities); N = 82 long form facilities reporting wages; N=74 long form facilities reporting hours paid leave

**Table 7.24** Direct Support Professional/Direct Care (DSP) Staff Turnover and Vacancy Rates in Large State Facilities by State on June 30, 2002, 2004, 2006, 2008, 2010 and 2012

State	DSP Turnover Rates (%)						DSP Vacancy Rates (%)					
	2002	2004	2006	2008	2010	2012	2002	2004	2006	2008	2010	2012
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AL	58.7	32.4	65.3	59.7	17.0	N/A	1.2	0.0	6.4	1.1	2.1	N/A
AR	37.1	45.5	56.7	47.0	47.9	23.9	6.6	5.6	9.1	11.2	8.4	7.9
AZ	67.0	40.3	40.4	24.2	38.8	34.2	8.2	0.0	0.0	4.2	8.5	9.3
CA	17.2	11.8	DNF	DNF	15.1	DNF	4.9	2.5	DNF	DNF	7.2	DNF
CO	28.7	5.3	20.7	23.8	23.4	DNF	4.6	12.9	11.0	2.3	2.3	DNF
CT	11.6	DNF	16.1	21.6	7.3	4.5	5.6	DNF	9.5	5.6	14.7	1.0
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
DE	DNF	14.0	12.9	8.9	DNF	6.1	DNF	21.3	4.7	1.3	DNF	0.0
FL	19.0	46.5	33.9	32.4	10.4	17.3	6.4	9.3	10.2	11.4	6.7	4.6
GA	25.1	33.4	20.5	100.9	DNF	DNF	18.8	11.8	12.3	18.4	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	12.7	9.6	13.9	13.5	17.8	12.3	4.9	0.8	DNF	1.7	4.3	4.6
ID	73.6	DNF	26.2	46.5	27.1	18.4	2.8	DNF	5.3	5.3	9.2	21.4
IL	16.9	11.3	19.1	18.3	1.2	15.3	5.2	5.8	3.6	2.1	0.0	6.0
IN	35.6	31.1	DNF	DNF	21.8	N/A	16.8	2.3	1.9	DNF	0.0	N/A
KS	11.3	13.6	15.4	9.2	13.3	21.0	9.0	4.4	4.4	6.5	9.2	3.7
KY	14.1	126.1	15.1	48.1	78.3	21.8	10.7	17.4	9.0	2.5	10.5	3.0
LA	63.9	53.7	60.0	59.3	47.0	DNF	3.0	5.6	17.7	12.4	12.6	DNF
MA	19.0	34.2	18.8	24.6	18.8	DNF	4.8	5.1	4.3	3.2	2.3	DNF
MD	15.2	19.0	18.7	33.2	15.2	26.7	7.9	4.9	6.6	8.2	6.3	4.3
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MI	16.8	22.6	13.1	10.3	N/A	N/A	2.5	8.2	0.0	1.5	N/A	N/A
MN	45.8	15.5	18.4	5.4	6.9	N/A	0.0	8.8	0.0	0.8	5.7	N/A
MO	15.3	26.8	23.7	20.0	16.2	17.2	7.6	3.2	7.8	5.7	3.6	3.4
MS	42.9	49.9	48.8	55.5	27.6	DNF	5.3	5.9	9.8	6.0	10.0	DNF
MT	30.2	34.3	18.8	24.4	DNF	DNF	2.6	13.6	1.8	1.6	DNF	DNF
NC	26.8	24.8	32.1	17.3	28.5	16.4	3.1	3.6	3.9	3.2	3.0	5.7
ND	DNF	16.6	23.8	19.5	16.6	15.8	DNF	3.7	7.1	9.8	6.2	10.8
NE	46.3	41.0	DNF	66.3	30.7	1.9	15.8	9.8	DNF	13.8	21.3	22.1
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	17.6	10.7	10.9	7.4	14.9	DNF	5.3	3.1	1.2	1.8	4.0	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NV	15.4	15.8	39.3	4.4	DNF	6.9	2.3	4.3	7.1	3.6	DNF	2.7
NY	13.9	9.8	19.3	7.8	DNF	DNF	3.8	9.8	4.9	DNF	DNF	DNF
OH	21.7	25.1	20.1	15.5	14.6	21.6	3.3	4.5	3.0	5.7	4.1	7.7
OK	DNF	41.8	33.7	38.1	53.3	DNF	DNF	11.9	14.4	22.9	8.3	DNF
OR	23.8	65.5	37.5	25.1	N/A	N/A	0.0	6.6	3.4	23.4	N/A	N/A
PA	8.5	9.8	7.7	7.4	10.9	9.3	4.7	2.4	2.1	2.0	4.1	2.6
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	14.6	16.1	26.6	24.3	31.6	DNF	4.8	6.3	8.0	8.7	1.8	DNF
SD	18.8	21.6	18.9	21.7	24.5	23.4	9.5	2.2	10.2	12.0	4.4	12.0
TN	26.3	24.9	10.7	35.4	7.4	60.0	4.1	2.4	25.5	5.2	3.2	5.7
TX	39.5	38.4	37.6	56.2	39.8	DNF	5.8	4.9	6.2	7.7	6.1	DNF
UT	35.1	37.7	31.6	46.9	21.0	39.6	2.4	2.3	0.7	1.1	2.7	1.3
VA	20.0	22.2	23.8	23.6	19.5	17.2	7.3	6.0	3.4	9.6	7.1	6.8
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WA	17.6	24.9	26.7	21.0	17.8	19.2	3.4	4.0	4.2	4.8	5.2	6.4
WI	33.6	32.4	29.8	21.4	14.3	17.0	6.5	10.1	11.9	12.5	5.8	6.8
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WY	36.8	43.9	DNF	DNF	DNF	22.0	4.3	14.9	7.0	DNF	DNF	7.4
<b>Average</b>	<b>28.0</b>	<b>28.5</b>	<b>27.3</b>	<b>29.6</b>	<b>24.4</b>	<b>24.5</b>	<b>5.6</b>	<b>5.8</b>	<b>6.7</b>	<b>6.9</b>	<b>6.3</b>	<b>6.9</b>

DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N/A = Not applicable (state without large state facilities); N = 78 and 80 facilities reporting turnover and vacancy rates, respectively.

40 hours per week in 2012. The national average was 27 hours per week. In 2012, the threshold for earning paid leave was between 11 and 20 hours per week in 9 states (down from 13 states in 2010).

### Turnover and Vacancy Rates

Several staffing outcomes were measured in the survey of large state facilities (See [Table 7.24](#) and [Figure 7.9](#)). In 2012, the average state facility reported direct support professional turnover rates of 33.2%, the highest rate reported during the past decade. DSP turnover rates in 2012 ranged from 2% in Nebraska to 228% in Utah. Three states (Tennessee, Utah and Virginia) reported 2012 turnover rates that exceeded 50%, compared with 2 states in 2010. DSP turnover rates in 2012 were less than 10% in five states: Connecticut (5%), Delaware (6%), Nebraska (2%), Nevada (7%), and Pennsylvania (9%). Between 2002 and 2012, 13 states reported declines in their turnover rates for direct support professionals, while 10 states reported increases.

While most states reported only small differences between 2002 and 2012, four states reported at least a 50% decline: Connecticut (from 12% in 2002 to 5% in 2012); Idaho (from 74% to 18%), and Nebraska (from 46% to 2%). Turnover rates increased by more than 50% in six states: Kansas (increasing from 11% to 21%), Kentucky (increasing from 14% to 22%), Maryland (increasing from 15% to 27%), Tennessee (increasing from 26% to 60%), Utah (increasing from 35% to 228%), and Virginia (increasing from 20% to 144.2%). Across states, the average DSP turnover rate increased from 28% in 2002 to 33.2% in 2012.

Vacancy rates for direct support professional positions increased from 6.3% in 2010 to 7.7% in 2012. Two states reported vacancy rates of less than 2%: Connecticut (1%) and Delaware (0%). Five states reported that more than 10% of their funded direct support positions were vacant: Idaho (21%), North Dakota (11%), Nebraska (22%), South Dakota (12%), and Virginia (22%). Between 2002 and 2012, vacancy rates declined more than 75% in only one state: Connecticut (82%); but more than doubled in 7 states: Idaho (673%), North Carolina (86%), Ohio (133%), Utah (187%), Virginia (201%), and Washington (90%).

### Administrator Workforce Concerns

Administrators were given a list of common workforce concerns and asked to mark up to three as the biggest concerns for their facility (See [Table 7.25](#)). Overall, the biggest concerns for administrators in 2012 were direct support professional turnover (52%); finding qualified direct support professionals (43%); morale problems (37%); and direct support wages and benefits (31%).

Between 2010 and 2012, the proportion of administrators reporting concerns about finding qualified workers, direct care staff wages/benefits, new hires quitting in the first six months, training and development, concerns about coworkers not getting along, and staff dissatisfaction with supervisors declined overall. Concerns about direct care staff turnover increased (from 45% to 52%) as did concern about morale (from 31% to 37%) and direct care staff motivation (from 21% to 29%).

**Table 7.25** Staffing Outcomes and Administrative Concerns by Year FY 2002 to FY 2012

Staffing Outcomes and Administrative Concerns	% Reporting Concerns						% Change 2002-2012
	2002	2004	2006	2008	2010	2012	
<b>Staffing Outcomes</b>							
Direct Support Staff Turnover Rate (%)	28%	29%	27%	30%	24%	24%	-13%
Direct Support Staff Vacancy Rate (%)	6%	6%	7%	7%	6%	7%	23%
<b>Administrative Concerns</b>							
Direct care staff turnover	54%	54%	60%	56%	45%	52%	-3%
Finding qualified direct care staff	61%	51%	57%	47%	44%	43%	-30%
Morale problems	19%	10%	24%	26%	31%	37%	96%
Direct care staff wages/benefits	25%	32%	37%	31%	43%	31%	26%
Direct care staff motivation	35%	36%	28%	21%	21%	29%	-17%
New hires quit during the first 6 months	31%	20%	26%	33%	22%	13%	-59%
Direct care staff training and development	37%	31%	22%	21%	16%	12%	-69%
Coworkers do not get along	6%	27%	7%	10%	17%	11%	75%
Direct care staff are dissatisfied with supervisors	6%	9%	5%	13%	9%	7%	17%
None of the above	6%	3%	4%	2%	1%	4%	-42%

Between 2002 and 2012, administrative concern increased for morale problems (from 19% to 37%), direct care staff wages/benefits (from 25% to 31%), coworkers not getting along (from 6% to 11%), and direct care staff being dissatisfied with supervisors (from 6% to 7%; See [Figure 7.9](#)). Administrative concern decreased for direct care staff turnover (from 54% to 52% of administrators), finding qualified direct support staff (decreasing from 61% to 43%), direct care staff motivation (from 35% to 29%), new hires quitting in the first six months (31% to 13%), and direct care staff training and development (from 37% to 12%). The proportion of administrators reporting none of the listed problems declined from 6% in 2002 to 4% in 2012.

### Regional Differences in Workforce Outcomes and Concerns

Using the U.S. Census Bureau areas, states were divided into four regions (Midwest, Northeast, South and West). Two staffing outcomes for large state facilities were compared across regions: direct support staff turnover rates, and direct support staff vacancy rates (See [Table 7.26](#)). Significant regional differences were not found for either outcome during FY 2012.

However, there were regional differences in the proportion of facility administrators reporting specific workforce concerns (See [Figure 7.10](#)). Administrators in the Northeast were least likely to report direct support turnover was a concern (7%) while most administrators in the South (74%) were concerned about this. There were also differences in the proportion of administrators who were concerned about morale problems (21% in the South, 40% in the West, 46% in the Midwest, and 64% in the Northeast). Coworker's inability to get along was a third concern expressed by the administrators. The South reported 3% compared to 8% in the Midwest, 20% in the West, and 20% in the Northeast. Lastly, administrators in the West were less likely to report concerns with direct care staff being dissatisfied with supervisor (0%) than the Northeast (29%). The South and Midwest were at 3% and 4%, respectively.

### Frontline Supervisor Staffing Outcomes

Frontline supervisors (FLS) are staff members whose primary job is to supervise direct support workers. On June 30, 2012, there were 3,102 frontline supervisors in 81 reporting facilities. The average number of direct support workers per frontline supervisor was 11.0 in 2012 compared with 11.8 in 2006.

**Figure 7.9** Percent of PRF Administrators Reporting Specific Personnel Challenges FY 2002 versus FY 2012

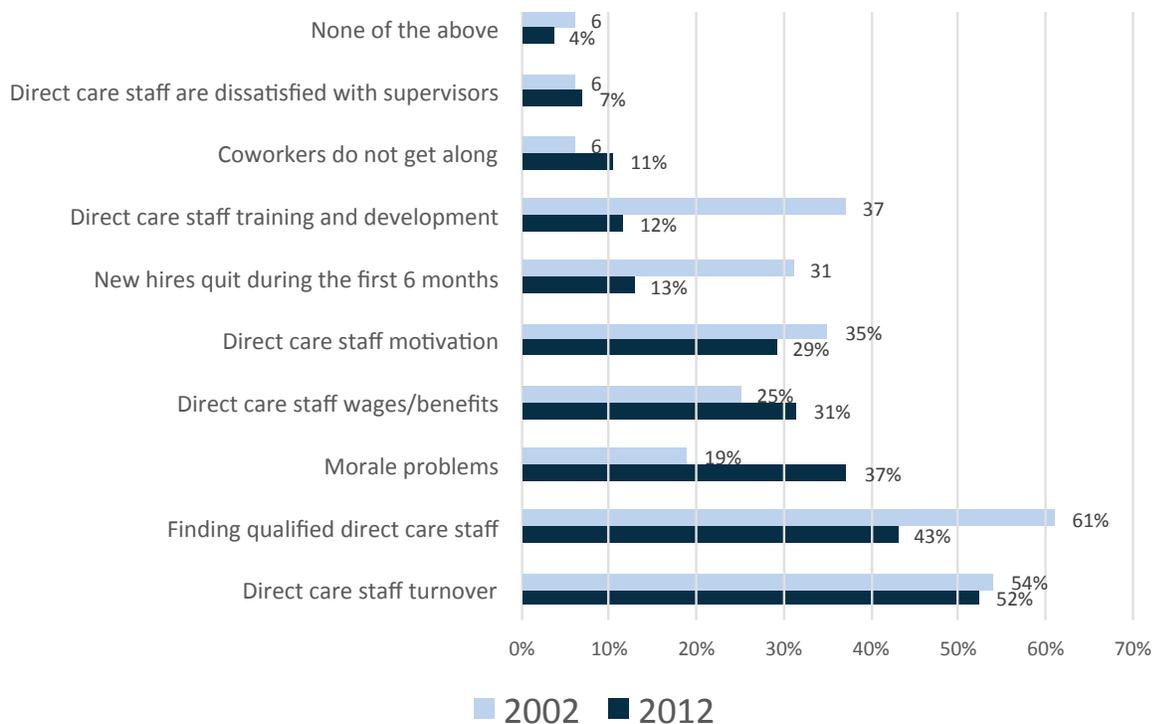
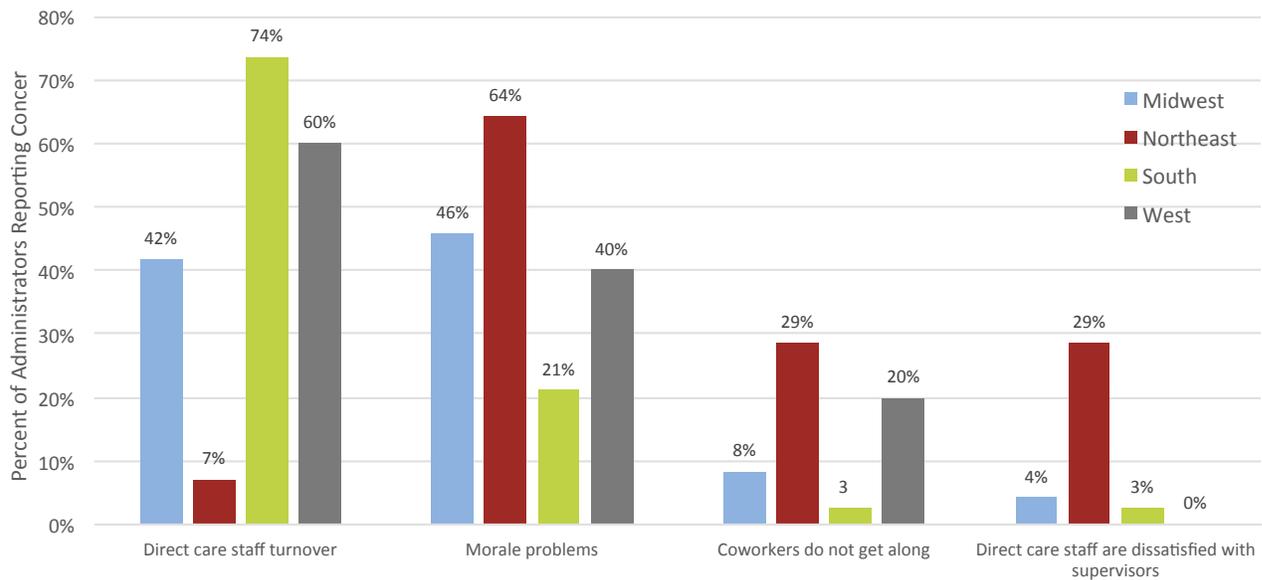


Table 7.27 summarizes vacancy and turnover rates for FLS positions. At the time of the 2012 survey, 6.6% of frontline supervisor positions were vacant. FLS vacancy rates ranged from 0% in 6 states to 17% in Connecticut.

In 2012, the overall turnover rate for frontline supervisors was 14%, higher than 2006, 2008 and

2010 (See Figure 7.11). Turnover rates for FLS ranged from 0% in three states (Delaware, Missouri, and Nevada) to 25% in Maryland. Nine states reported turnover rates for FLS of less than 10% while only Maryland (25%) reported a rate of 25% or higher. Overall, FLS turnover rates decreased between 2010 and 2012 in eight states but increased in fifteen states. FLS turnover rates more than doubled

**Figure 7.10** Regional Differences in Personnel Concerns Reported by Administrators of Large Public Facilities



**Table 7.26** Regional Differences in Staffing Outcomes and Concerns of Large State IDD Facility Administrators by Region FY 2012

Staffing Outcomes and Administrative Concerns	Region				National	F	Sig.
	Midwest	Northeast	South	West			
<b>Staffing Outcomes</b>							
Direct Support Staff Turnover Rate (%)	17.7 <sup>1,2</sup>	15.8 <sup>1</sup>	32.7 <sup>2</sup>	22.8 <sup>1,2</sup>	24.5	4.92	**
Direct Support Staff Vacancy Rate (%)	7.2	3.9	7.4	8.2	6.9	1.56	
<b>Administrative Concerns</b>							
Direct care staff turnover	42% <sup>1,2</sup>	7% <sup>1</sup>	74% <sup>2</sup>	60% <sup>2</sup>	52%	8.14	***
Finding qualified direct care staff	50%	21%	47%	40%	43%	1.15	
Morale problems	46% <sup>1,2</sup>	64% <sup>2</sup>	21% <sup>1</sup>	40% <sup>1,2</sup>	37%	3.37	*
Direct care staff wages/benefits	25%	7%	42%	40%	31%	2.29	
Direct care staff motivation	33%	29%	26%	30%	29%	0.11	
New hires quit during the first 6 months	13%	0%	16%	20%	13%	0.93	
Direct care staff training and development	8%	7%	13%	20%	12%	0.42	
Coworkers do not get along	8% <sup>1</sup>	29% <sup>1</sup>	3% <sup>1</sup>	20% <sup>1</sup>	11%	2.99	*
Direct care staff are dissatisfied with supervisors	4% <sup>1</sup>	29% <sup>2</sup>	3% <sup>1</sup>	0% <sup>1</sup>	7%	4.52	**
None of the above	4%	14%	0%	0%	4%	2.28	

Regions with different superscripts were statistically different at  $p < .05$  using Tukey B followup test; \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ ; N = facilities reported concerns; N=78 facilities reported DSP turnover; N=80 facilities reported DSP vacancy rate

**Table 7.27** Frontline Supervisor Vacancy and Turnover Rates in Large State Facilities by State FY 2002 - FY 2012

State	FLS Vacancy Rates (%)						FLS Annual Turnover (%)					
	2002	2004	2006	2008	2010	2012	2002	2004	2006	2008	2010	2012
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AL	12%	0%	8%	0%	0%	N/A	19%	10%	6%	8%	5%	N/A
AR	12%	4%	2%	10%	4%	8%	15%	67%	38%	10%	6%	9%
AZ	0%	5%	13%	6%	26%	15%	11%	26%	13%	17%	5%	12%
CA	20%	13%	10%	DNF	14%	DNF	13%	27%	0%	DNF	10%	DNF
CO	25%	0%	2%	0%	0%	DNF	12%	0%	12%	0%	32%	DNF
CT	0%	DNF	0%	4%	25%	17%	3%	DNF	0%	17%	4%	6%
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
DE	DNF	12%	0%	0%	DNF	0%	DNF	7%	4%	11%	DNF	0%
FL	8%	8%	9%	8%	6%	10%	7%	19%	12%	7%	6%	21%
GA	16%	14%	7%	6%	DNF	DNF	35%	13%	34%	0%	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	4%	2%	2%	7%	7%	13%	7%	5%	14%	29%	20%	13%
ID	0%	DNF	0%	12%	29%	0%	14%	DNF	3%	12%	29%	13%
IL	18%	17%	6%	11%	0%	12%	14%	7%	13%	9%	17%	12%
IN	8%	6%	DNF	7%	12%	N/A	9%	12%	DNF	7%	10%	N/A
KS	8%	2%	7%	11%	12%	6%	13%	7%	5%	9%	9%	11%
KY	13%	23%	11%	8%	9%	0%	9%	53%	18%	17%	18%	21%
LA	9%	7%	12%	5%	7%	DNF	20%	26%	6%	8%	10%	DNF
MA	5%	7%	4%	5%	4%	DNF	19%	21%	8%	7%	6%	DNF
MD	0%	13%	19%	17%	6%	8%	2%	30%	22%	17%	16%	25%
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MI	9%	7%	0%	0%	N/A	N/A	13%	14%	14%	4%	N/A	N/A
MN	0%	0%	0%	0%	14%	N/A	20%	17%	0%	0%	0%	N/A
MO	10%	15%	1%	9%	0%	3%	12%	24%	8%	12%	7%	0%
MS	7%	5%	9%	7%	5%	DNF	17%	17%	18%	23%	7%	DNF
MT	2%	0%	4%	0%	DNF	DNF	30%	0%	14%	7%	DNF	DNF
NC	4%	2%	6%	1%	5%	7%	16%	15%	14%	12%	14%	8%
ND	DNF	3%	0%	9%	8%	3%	DNF	10%	11%	10%	13%	6%
NE	15%	5%	DNF	22%	12%	DNF	3%	19%	DNF	26%	8%	DNF
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	3%	2%	3%	5%	8%	DNF	7%	4%	7%	5%	6%	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NV	0%	8%	6%	0%	0%	0%	9%	4%	31%	25%	25%	0%
NY	4%	14%	3%	0%	DNF	DNF	12%	6%	18%	0%	DNF	DNF
OH	12%	1%	1%	4%	2%	2%	11%	21%	8%	15%	10%	12%
OK	11%	10%	8%	14%	7%	DNF	6%	22%	14%	18%	14%	DNF
OR	5%	0%	0%	30%	N/A	N/A	19%	0%	21%	30%	N/A	N/A
PA	4%	3%	6%	0%	2%	5%	7%	31%	2%	7%	12%	16%
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	0%	3%	2%	4%	2%	DNF	3%	6%	11%	14%	20%	DNF
SD	5%	5%	0%	0%	4%	5%	23%	5%	5%	5%	8%	18%
TN	9%	5%	0%	16%	5%	0%	7%	11%	5%	22%	6%	21%
TX	3%	4%	5%	4%	6%	DNF	13%	12%	12%	13%	5%	DNF
UT	2%	2%	4%	2%	12%	0%	15%	10%	7%	15%	7%	8%
VA	4%	4%	4%	4%	9%	6%	4%	9%	5%	11%	15%	18%
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WA	1%	0%	3%	8%	1%	2%	10%	9%	15%	15%	4%	8%
WI	6%	2%	3%	0%	1%	3%	5%	13%	10%	18%	4%	11%
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WY	DNF	2%	2%	N/A	7%	6%	DNF	18%	11%	N/A	19%	18%
<b>Total</b>	<b>8%</b>	<b>7%</b>	<b>5%</b>	<b>6%</b>	<b>6%</b>	<b>7%</b>	<b>13%</b>	<b>18%</b>	<b>13%</b>	<b>12%</b>	<b>10%</b>	<b>14%</b>

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities; N = 77 long form facilities reporting supervisor vacancy rate; N=76 long form facilities reporting supervisor turnover; N = 78 long form facilities reporting supervisor starting and average salaries

between 2010 and 2012 in Arizona (130%), Florida (222%), Maryland (61%), South Dakota (113%), and Tennessee (165%).

In 2012, the starting annual salary for a frontline supervisor in a large state facility was \$33,118 (See Table 7.28). One state paid newly hired frontline supervisors less than \$25,000 per year (Arkansas) while seven states paid new FLS hires more than \$40,000 per year (Connecticut, Iowa, Illinois, Maryland, Nevada, Washington, and Wyoming). FLS starting salaries decreased an average of 6% between 2010 and 2012. Eight states reported that the starting salary for new FLS decreased during this period (Arkansas, Florida, Kentucky, Missouri, North Carolina, North Dakota, Ohio and Virginia). Average starting salaries increased by more than 20% between 2010 and 2012 in fourteen states: Arizona (0.1%), Connecticut (6%), Iowa (11%), Idaho (2%), Illinois (10%), Kansas (8%), Maryland (13%), Nevada (3%), Pennsylvania (11%), South Dakota (3%), Tennessee (4%), Washington (7%), and Wisconsin (0.1%).

Average salaries for frontline supervisors were \$38,062 in 2012, a 10% decrease from 2010 (See Figure 7.12). Average FLS salaries ranged from

\$25,862 in Florida to \$60,441 in Illinois. Three states reported average FLS salaries of less than \$30,000 in 2012 (Arizona, Florida, Utah), while two reported average salaries of more than \$55,000 (Connecticut and Illinois).

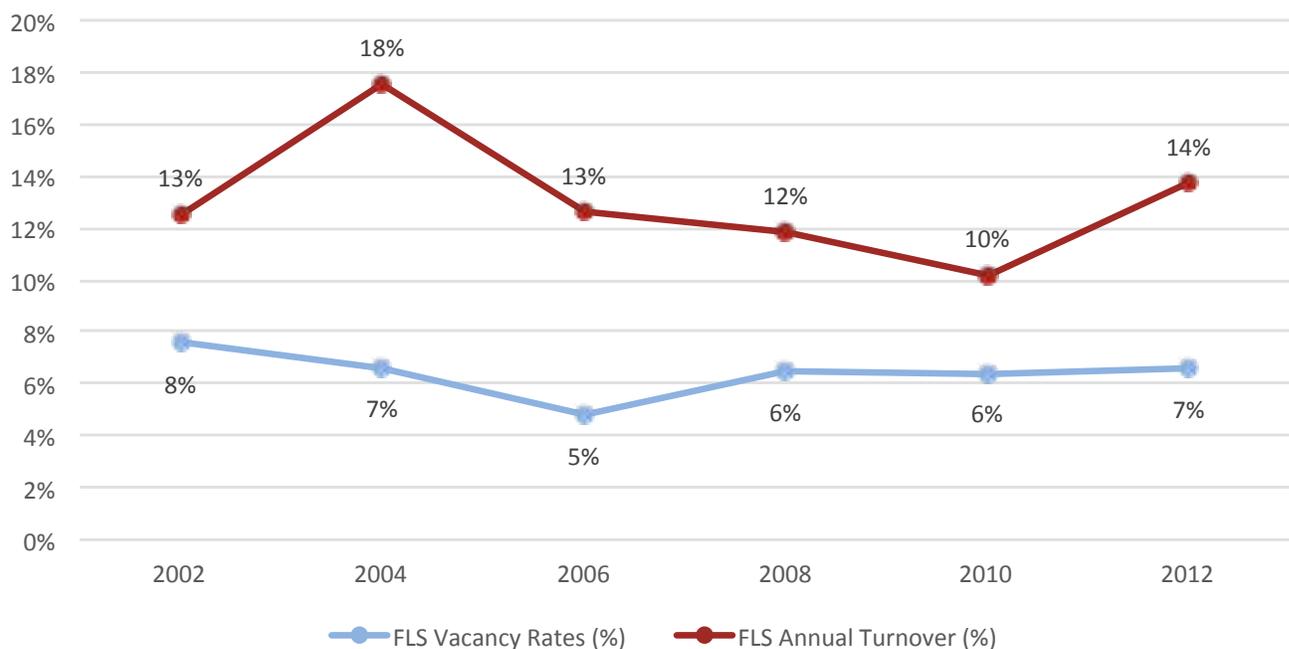
Between 2002 and 2012 average FLS salaries increased 14% nationally. Average salaries for FLS decreased in five states (Arkansas, Arizona, Florida, Nevada, and Ohio). Average FLS salaries increased by more than 30% in three states: Illinois (65%), Wisconsin (31%), and Wyoming (103%).

### Factors Associated with Turnover

Analyses were conducted to identify factors associated with differences in direct support professional turnover rates in large state facilities in 2012. Pearson Correlation Coefficients were computed to analyze basic relationships between turnover and the factors hypothesized to be associated with it in 73-86 large state facilities that reported the data elements (See Table 7.29).

Case mix is a composite measure of intensity of supports with scores ranging from one to 15 based on the proportion of residents that had the following characteristics. Level of ID was ranked on a 5-point scale (1 =no ID, 5 = profound ID). Two and a half

**Figure 7.11** Vacancy Rate and Annual Crude Separation Rate for Supervisors of DSPs in Large Public Facilities 2002 to 2012



points were assigned for having a condition requiring psychiatric assistance, and 2.5 points for having a behavior disorder requiring staff attention. One point each was given for needing assistance to walk, dress, eat, or use the toilet; and one point was given for not being able to communicate basic needs by talking. These scores were combined to create a single case mix score for each facility. A facility in which 100% of the residents had profound ID, a behavior disorder, a condition requiring psychiatric assistance, needed assistance with walking, dressing, eating and toileting, and were unable to communicate basic needs by talking received a score of 15 while a facility in which 100% of the residents had no ID, none had a diagnosis of mental illness, none needed psychiatric assistance and all could walk, dress, eat, use the toilet and communicate basic needs by speaking received a score of 1.

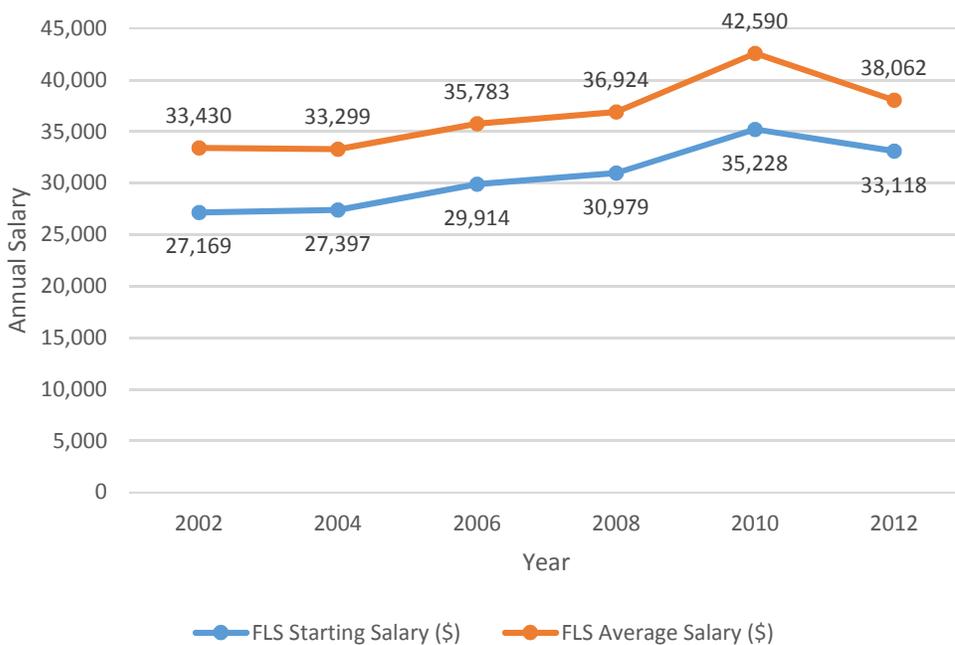
The average case mix score for the facilities in the analysis was 9.4. Average frontline supervisor turnover 13.7%. The average number of residents in the 86 reporting facilities was 199.

The average ratio of direct support professionals to residents in the 81 facilities was 1.90. The average per day per person rate in these facilities was \$641.23, the average starting wage for direct support professionals was \$11.99. Finally, 44% of the reporting facilities were from the southern census region.

In 2012, variables significantly correlated with direct support turnover included average starting DSP wage ( $r = -0.42, p < .001$ ), frontline supervisor turnover ( $r = 0.27, p < .05$ ) and region (turnover was correlated with being in the South or Midwest regions).

A multiple regression analysis was conducted using the same set of variables (See [Table 7.30](#)). Overall, the variables tested accounted for an adjusted 21.7% of the variability in direct support turnover. When all of the variables were taken into account DSP turnover rates were significantly higher in facilities paying lower DSP hourly wages, and in facilities with higher frontline supervisor turnover. Once those two factors were taken into account, no additional variability was accounted for by being located in the Midwest or South region.

**Figure 7.12** Annual Starting and Average Salary for Supervisors of DSPs in Large Public Facilities 2002 through 2012



**Table 7.28** Frontline Supervisor Starting and Average Annual Salary FY 2002 to FY 2012

State	FLS Starting Salary (\$)						FLS Average Salary (\$)					
	2002	2004	2006	2008	2010	2012	2002	2004	2006	2008	2010	2012
AK	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
AL	19,094	20,181	17,000	27,500	27,500	N/A	23,433	23,197	20,000	32,700	31,500	N/A
AR	22,447	23,093	24,108	22,524	25,693	24,710	35,478	31,430	31,936	28,319	33,306	30,896
AZ	23,400	24,400	24,765	25,508	25,508	25,608	27,324	29,200	26,765	27,676	26,800	26,850
CA	44,748	39,633	54,359	DNF	70,072	DNF	54,414	40,245	64,326	DNF	77,104	DNF
CO	35,268	30,468	31,584	38,940	54,341	DNF	42,456	39,322	43,261	48,120	54,732	DNF
CT	38,344	DNF	46,593	52,189	46,225	49,000	48,463	DNF	49,187	60,390	55,215	60,000
DC	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
DE	DNF	34,505	33,668	26,654	DNF	32,000	DNF	41,000	37,586	34,553	DNF	38,000
FL	24,947	25,703	25,131	26,047	25,890	25,425	28,813	28,678	27,057	28,889	28,317	25,862
GA	20,941	22,954	25,154	25,000	DNF	DNF	27,541	27,586	30,947	32,250	DNF	DNF
HI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
IA	32,340	33,880	36,876	39,787	36,827	40,742	42,144	46,263	53,340	55,228	55,437	49,653
ID	29,245	DNF	31,720	32,700	32,000	32,700	36,421	DNF	33,987	43,100	45,400	46,000
IL	31,534	30,628	31,366	36,506	43,900	48,129	36,587	41,037	41,678	44,056	45,210	60,441
IN	26,042	27,459	DNF	32,531	52,059	N/A	33,533	35,050	DNF	DNF	67,857	N/A
KS	32,024	27,893	32,781	36,307	36,306	39,244	34,975	31,495	35,280	39,249	38,449	40,777
KY	30,171	25,613	25,222	25,000	34,320	34,008	35,352	28,955	31,888	41,233	32,175	36,587
LA	16,978	19,281	22,452	24,622	25,375	DNF	22,511	27,303	28,340	31,057	34,300	DNF
MA	27,384	28,882	31,218	30,049	32,761	DNF	32,947	35,255	36,743	38,343	37,188	DNF
MD	39,156	35,458	36,539	47,511	45,512	51,500	45,607	44,799	45,665	57,203	50,886	54,569
ME	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
MI	35,921	35,142	36,858	40,617	DNF	N/A	35,921	46,781	48,589	59,904	DNF	N/A
MN	37,730	37,730	38,482	41,948	41,662	N/A	57,691	57,002	59,607	65,234	71,656	N/A
MO	22,603	27,067	26,091	31,108	29,834	29,442	26,476	32,126	30,074	30,707	36,882	31,025
MS	19,311	19,973	21,752	22,581	25,271	DNF	21,294	21,299	23,798	25,221	26,811	DNF
MT	21,054	23,774	25,605	22,560	DNF	DNF	27,498	26,395	29,536	33,970	DNF	DNF
NC	24,974	23,915	25,606	27,411	29,449	28,645	31,173	28,128	29,183	28,475	33,606	32,471
ND	DNF	19,365	21,156	23,520	39,492	31,212	DNF	23,400	24,096	24,000	47,520	33,036
NE	32,379	31,926	DNF	38,397	38,958	DNF	38,279	38,145	DNF	45,982	34,939	DNF
NH	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NJ	30,279	30,477	32,784	35,829	38,530	DNF	37,367	36,109	38,978	41,645	50,006	DNF
NM	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NV	36,426	37,764	36,049	40,946	39,250	40,560	46,817	44,081	41,096	54,446	41,038	46,176
NY	30,557	30,054	31,926	DNF	DNF	DNF	36,569	38,241	38,647	DNF	DNF	DNF
OH	33,823	35,073	37,016	37,890	37,789	37,773	43,912	42,071	42,603	46,537	44,711	42,395
OK	20,280	21,341	23,689	26,203	25,310	DNF	DNF	25,525	25,682	29,208	26,592	DNF
OR	31,836	31,836	33,282	42,179	DNF	N/A	36,744	42,336	42,937	59,326	DNF	N/A
PA	30,945	28,777	31,973	35,231	34,344	38,221	38,963	37,341	42,536	44,074	44,354	44,384
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
SC	18,568	18,988	20,443	21,437	22,050	DNF	21,063	22,312	24,662	26,165	25,777	DNF
SD	24,648	25,990	25,080	29,039	28,933	29,806	27,000	29,239	25,080	21,000	32,552	33,530
TN	20,775	23,163	23,860	29,000	26,000	26,941	24,994	27,617	28,000	35,100	30,000	31,966
TX	24,038	22,929	21,872	24,820	28,459	DNF	25,053	24,968	23,116	26,860	31,500	DNF
UT	23,504	23,338	23,920	25,703	26,998	27,000	25,979	25,210	25,605	27,290	28,677	28,080
VA	24,710	26,061	29,366	27,123	27,605	27,442	30,921	29,537	31,594	33,001	34,663	34,003
VT	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WA	33,983	35,534	34,965	38,700	38,460	41,064	40,398	44,735	38,288	47,943	46,332	46,164
WI	20,411	23,281	32,716	35,033	35,733	36,064	30,585	28,096	41,280	42,394	71,019	40,010
WV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
WY	19,152	20,717	28,728	N/A	46,332	46,332	24,159	24,710	31,470	N/A	46,332	49,080
<b>Total</b>	<b>27,169</b>	<b>27,397</b>	<b>29,914</b>	<b>30,979</b>	<b>35,228</b>	<b>33,118</b>	<b>33,430</b>	<b>33,299</b>	<b>35,783</b>	<b>36,924</b>	<b>42,590</b>	<b>38,062</b>

N/A = Not applicable (state without large state facilities); DNF = Data not furnished or insufficient reporting (60% or less) from among the large state facilities

**Table 7.29** Correlates of Direct Support Professional Turnover in Public Residential Facilities FY 2012

	N	Mean	SD	Correlation w/ turnover	Sig
Direct Service Staff Turnover (%)	78	24.488	18.334		
<b>Correlates</b>					
Average Starting Hourly DSP Wage	82	11.99	2.66	-0.42	0.000***
Ratio of DCS to Residents	81	1.90	0.80	-0.04	0.756
Number of Residents at the End of Year	86	198.85	128.15	-0.04	0.722
Front Line Supervisor Vacancy Rate	77	6.57	7.03	-0.03	0.803
Average Per Diem	83	641.23	733.75	-0.09	0.443
Front Line Supervisor Turnover	76	13.71	12.62	0.27	0.022*
Overall Casemix Score	73	9.43	1.45	-0.07	0.553
Number of Direct Services to Community	84	3.25	4.30	0.13	0.270
Direct Service Staff Vacancy Rate (%)	80	6.88	5.56	0.04	0.722
Region		Yes	No		
Northeast	86	16.3%	83.7%	-0.21	0.061
Midwest	86	27.9%	72.1%	-0.24	0.039*
West	86	11.6%	88.4%	-0.03	0.767
South	86	44.2%	55.8%	0.40	0.000***

\* p < .05, \*\* p < .01, \*\*\* p < .001

**Table 7.30** Factors Associated with Turnover of Direct Support Staff in Large State Institutions (Multiple Regression), June 2012

Variable	Unstandardized Coefficients b	SE	Standardized Coefficient Beta	t	Sig.
Constant	43.75	10.99		3.98	0.000 ***
Average Starting Hourly DSP Wage	-2.21	0.80	-0.37	-2.77	0.007 **
Frontline Supervisor Turnover	0.33	0.14	0.26	2.39	0.020 *
Located in the Midwest region	1.55	4.54	0.04	0.34	0.734
Located in the South region	3.70	4.89	0.11	0.76	0.451

N=74 (cases missing any of the variables excluded); R2 = 0.260, Adj R2 = 0.217; F(4,69) = 6.059, p < 0.001; \* p < .05, \*\* p < .01

## RESIDENTIAL INFORMATION SYSTEMS PROJECT (RISP) FY 2012 STATE PROFILES

The following profiles highlight key findings from the FY 2012 RISP report for each state and for the United States as a whole.

**Figure RISP Profile 1** shows residential setting types and sizes for people with IDD receiving or determined to be eligible for Long-Term Supports and Services (LTSS) under the auspices of the state IDD agency as of June 30, 2012. The size of each circle shows the relative number of people living in each setting type. The actual values for each circle can be found on Table RISP Profile 1. No circle is shown if a state did not furnish the number of people in a specific size or type of residence for FY 2012. No circles are shown for group settings with 1 to 3 and 4 to 6 residents for states that did not report them separately. Section 1 of the full report has more information about individualized settings and Section 2 has more information about congregate settings.

**Figure RISP Profile 2** shows average annual per person expenditures for people with IDD living in HCBS Waiver funded settings and in ICF/IIDs. All of the states provided HCBS Waiver funded supports to people with IDD and most have ICF/IID facilities but some did not report both the number of recipients and total expenditures. No bar is shown for states that did not provide complete information. See Section 4 of the full report for more information about Medicaid HCBS Waiver and ICF/IID expenditures.

**Figure RISP Profile 3** shows the number of people with IDD who lived in an ICF/IID, received Medicaid HCBS Waiver-funded supports, lived in a state psychiatric facility or in a nursing home (NH), and the number who were receiving or determined to be eligible for LTSS under the auspices of state IDD agencies but who were not living in an ICF/IID, state psychiatric facility or nursing home and who also were not receiving HCBS Waiver funded supports. People in this group may have been receiving other Medicaid State Plan LTSS or receiving supports through a state program, or they may not have had any Federal- or State-funded LTSS as of June 30, 2012.

**Table RISP Profile 1** summarizes living arrangement type and size, waiting lists, total people with IDD served, and HCBS Waiver and ICF/IID expenditures and utilization rates for selected years from 1977 to 2012. Individualized residential settings include a home owned or leased by a person with IDD; a home shared with a family member; a host home or family foster care setting with 1-3 residents, and any type of IDD group home shared by three or fewer people with IDD. Congregate settings included all IDD group settings in which four or more people with IDD live together as well as state psychiatric facilities and nursing homes. See RP3 for the total number of people with IDD in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) and in settings funded by a Medicaid Home and Community Based Waiver (HCBS).

RISP Profile 1 also show the number of people with IDD waiting for residential services while living in the home of a family member, and the unduplicated estimated total people with IDD served by the state IDD.

Finally, RISP Profile 1 shows average annual per person expenditures for people with IDD who receive LTSS in a Medicaid ICF/IID or funded by a Medicaid HCBS Waiver computed using the average number of recipients for FY 2012. Finally, it shows an index reflecting the number of people with IDD receiving ICF/IID or HCBS Waiver funded supports per 100,000 of a state's population.

National data on people living in their own home, the home of a family member or a host home or foster family setting were first reported in 1996. Residential settings serving six or fewer people with IDD were separated by size (1 to 3 people versus 4 to 6 people) in 1982, and annually since 2000. Large IDD facilities were separated into state and nonstate operated settings in 1991. Waiting list data were first reported in 1996. Large changes from one year to the next typically reflect a change in how a state compiled or reported data, the use of a different data source, or the addition of a category of services or type of HCBS Waiver that had previously not been included in the RISP annual data collection. State notes describing these circumstances can be found in the full report appendix.

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# ALABAMA

Figure RP1: Residence Size and Type on June 30, 2012

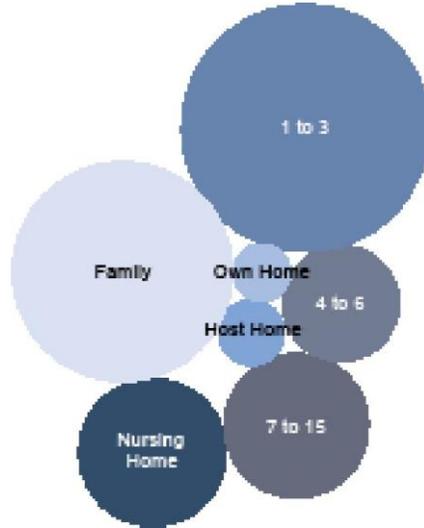


Figure RP2:  
Annual Medicaid  
Expenditures  
Per Person

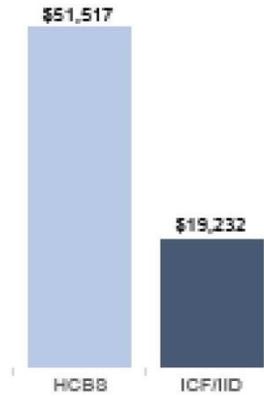


Figure RP3: Number and Percent of Recipients  
by Funding Authority on June 30, 2012

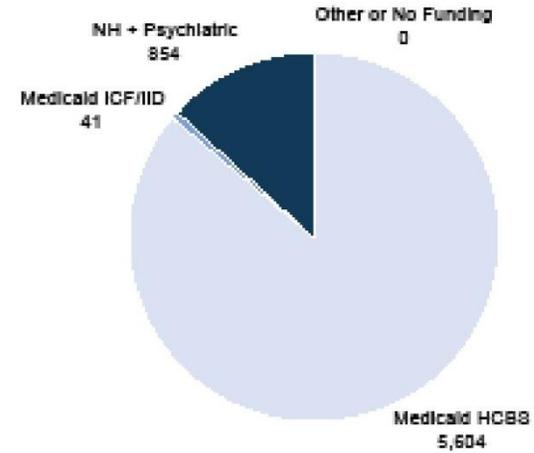


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					202	27	222	213	127
		Family					3941	66	3441	3EE9	1999
		Host Home					0	101	247	220	166
		1 to 3 Group Home						975	1202	1715	2110
Congregate IDD settings by size and type	4 to 15	4 to 6						253	399	488	527
		1 to 6	49	121	173	295	650	1228	1601	2203	2637
		7 to 15	61	183	256	585	712	795	897	907	816
	16+	16+ Private				0	31	32	0	0	0
		16+ Public				1258	800	633	214	173	0
		16+ Total	1995	1639	1447						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				1321	162	26	971	777	854
		Psychiatric Facility				0	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					1171	214	807	2372	2901
		Estimated Total	2105	1943	1976	2133	6336	2882	6622	7375	6495
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				6136	13379	23518	44111	48505	51517
		HCBS Recipients 100,000				49	79	92	109	119	116
	ICF/IDD	ICF/IDD Expenditures per Person				56475	75694	101021	113534	16289	19232
		ICF/IDD Per 100,000				32	19	14	5	5	1

## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# ALASKA

Figure RP1: Residence Size and Type on June 30, 2012

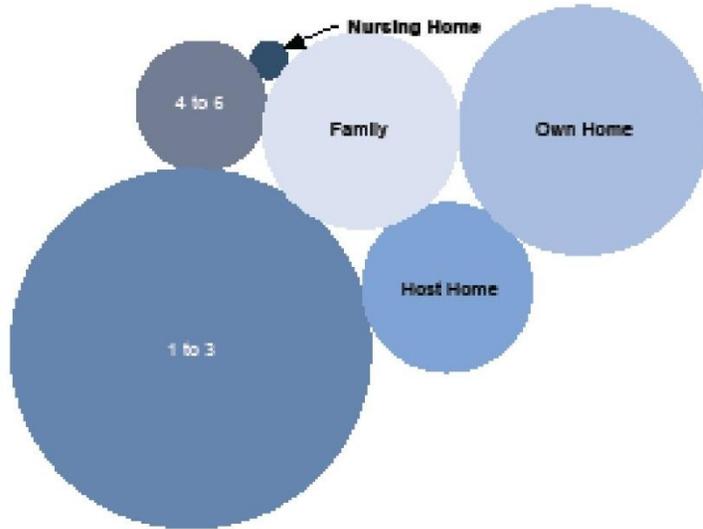


Figure RP2: Annual Medicaid Expenditures Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

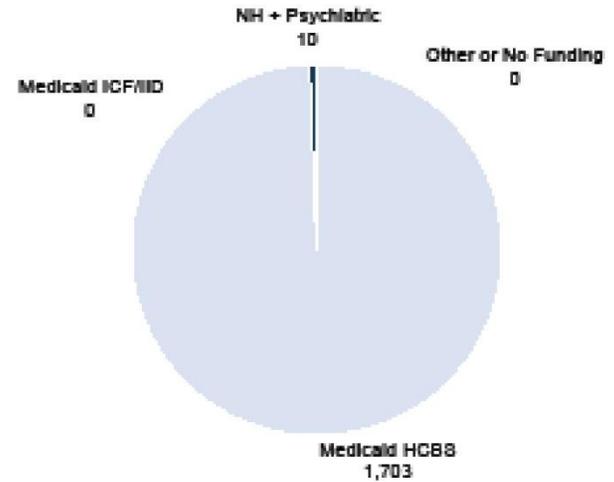


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012	
Individualized Settings	1 to 3	Own Home					156	365	224	399	473	
		Family					975	3737	3700	231	292	
		Host Home					114	423	172	209	218	
		1 to 3 Group Home						285	239	234	300	
Congregate IDD settings by size and type	4 to 15	4 to 6						145	291	1D5	139	
		1 to 6	53	122	202	291	222	430	440	340	423	
		7 to 15	17	38	45	37	73	25	0	5	0	
	16+	16+ Private				0	0	0	0	0	11	0
		16+ Public				51	15	0	9	0	0	
		16+ Total	173	88	33							
Other IDD										0		
Non IDD Specific	16+	Nursing Facility				48	28	0	8	29	10	
		Psychiatric Facility				1	0	0	0	0	0	
Number of People with IDD	All Size	Waiting list					318	958	1400	662	461	
		Estimated Total	213	348	330	379	1559	4982	4536	1195	1431	
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				0	37217	46043	82822	75164	78988	
		HCBS Recipients 100,000				0	29	105	151	189	233	
	ICF/IDD	ICF/IDD Expenditures per				109041	108524	0	0	0	0	
		ICF/IDD Per 100,000				16	9	0	0	0	0	

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# ARIZONA

Figure RP1: Residence Size and Type on June 30, 2012

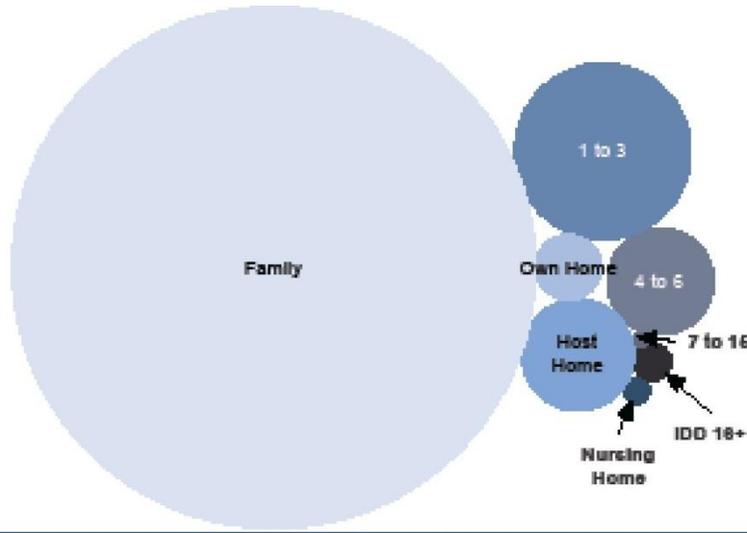


Figure RP2: Annual Medicaid Expenditures Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

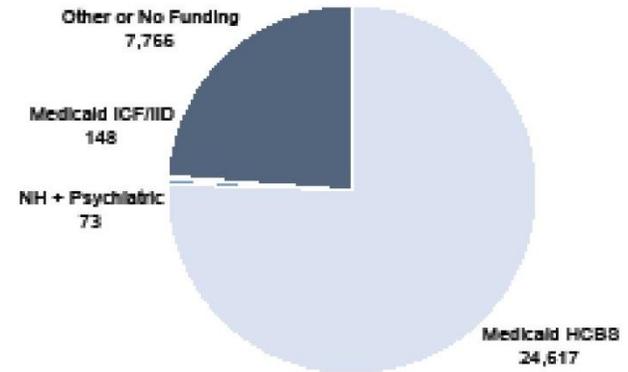


Table RP1

Category	Size	Type	1977	1982	1997	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					39	207	434	494	495
		Family					5315	15412	20914	26185	27983
		Host Home					212	623	749	1166	1281
		1 to 3 Group Home						731	1342	1422	1463
Congregate IDD settings by size and type	4 to 15	4 to 6						1848	1058	1117	1166
		1 to 6	120	689	1571	2263	2155	2569	2400	2539	2629
		7 to 15	116	137	225	91	108	70	40	32	25
	16+	16+ Private				45	83	59	49	38	35
		16+ Public				193	103	166	135	115	105
		16+ Total	116	323	433						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				89	67	96	53	49	73
		Psychiatric Facility				0	0	0	0	2	0
Number of People with IDD	All Size	Waiting list					DNF	DNF	173	29	79
		Estimated Total	1452	1733	2219	2592	11913	19106	24718	30529	32573
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				21112	24579	25541	23866	26632	26030
		HCBS Recipients 100,000				101	186	219	282	395	376
	ICF/IDD	ICF/IDD Expenditures per				33590	90542	98237	99082	DNF	220223
		ICF/IDD Per 100,000				4	5	3	3	3	2

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# ARKANSAS

Figure RP1: Residence Size and Type on June 30, 2012

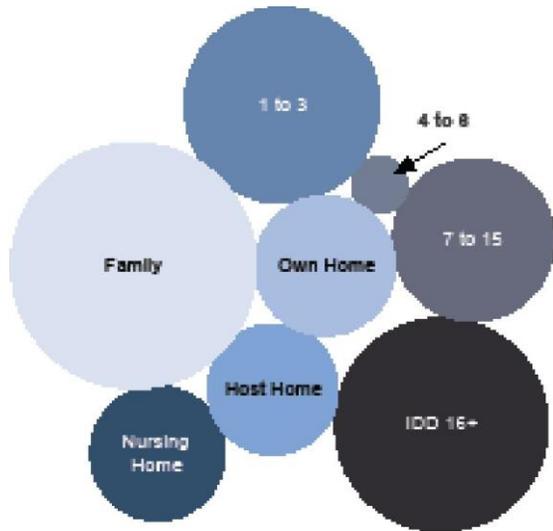


Figure RP2: Annual Medicaid Expenditures Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

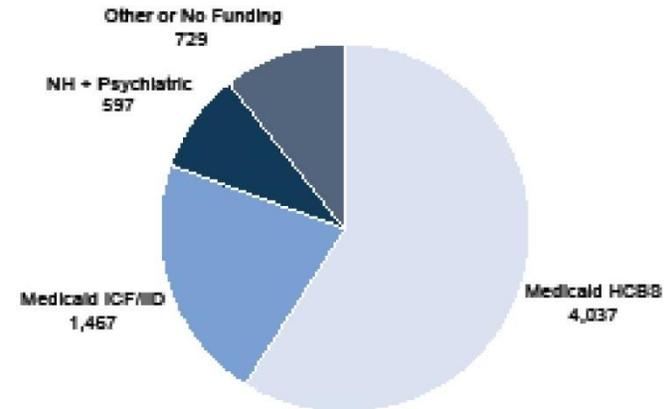


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					469	1126	534	641	642
		Family					2822	0	1567	2023	1994
		Host Home					0	0	436	574	560
		1 to 3 Group Home						16	184	113	111
Congregate IDD settings by size and type	4 to 15	4 to 6					90	61	53	53	
		1 to 6	12	42	117	228	34	106	245	166	164
		7 to 15	134	148	338	773	823	873	835	865	867
	16+	16+ Private				135	224	523	512	552	553
		16+ Public				1265	1272	1228	1068	1052	951
		16+ Total	1767	1505	1471						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				1100	0	867	900	0	597
		Psychiatric Facility				0	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					DNF	600	DNF	1522	2180
		Estimated Total	1913	1695	1926	2404	5644	3856	5197	5873	6328
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				2168	20847	16338	22709	35050	42887
		HCBS Recipients 100,000				8	19	78	120	137	137
	ICF/IDD	ICF/IDD Expenditures per Person				52234	67199	68652	88845	101207	106855
ICF/IDD Per 100,000					66	63	66	57	54	50	

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# CALIFORNIA

Figure RP1: Residence Size and Type on June 30, 2012

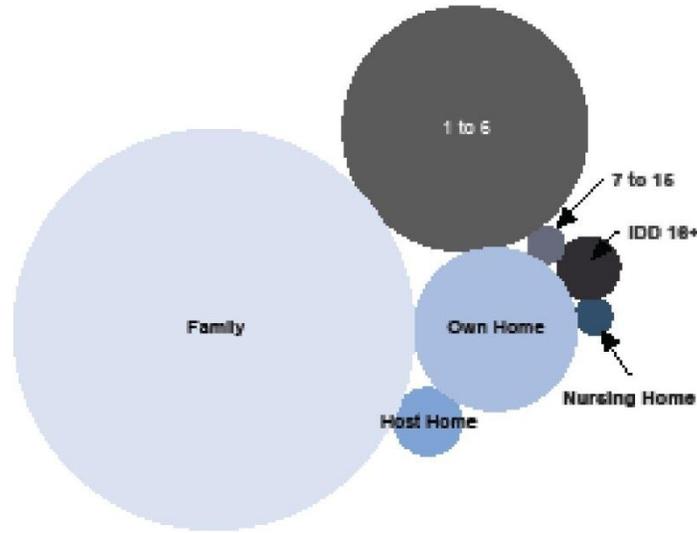


Figure RP2: Annual Medicaid Expenditures Per Person

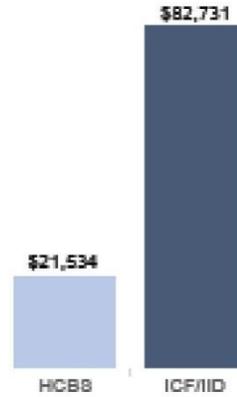


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

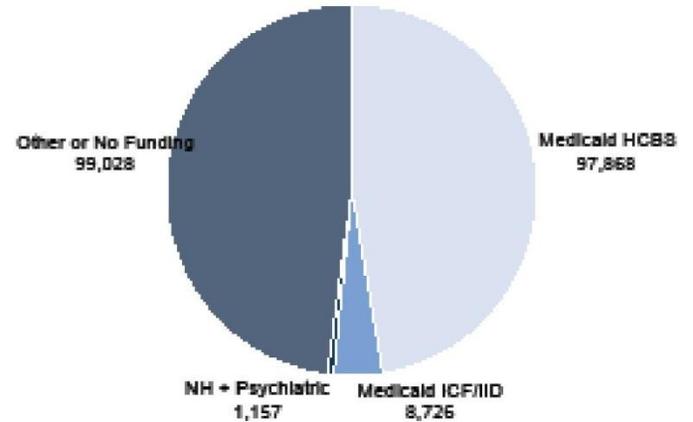


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					9843	14318	17571	21627	23097
		Family					118989	111311	149386	133809	140887
		Host Home					2	3900	3901	3559	3892
		1 to 3 Group Home					DNF	DNF	DNF	DNF	DNF
Congregate IDD settings by size and type	4 to 15	4 to 6					DNF	DNF	DNF	6235	DNF
		1 to 6	6942	8759	142012	17046	21539	39757	23994	25329	25593
		7 to 15	1947	2592	3347	3074	2433	2433	1487	1229	1152
	16+	16+ Private				5639	4566	3237	2488	1923	1708
		16+ Public				6692	4581	3850	3334	2070	1682
		16+ Total	17291	15715	11054						
		Other IDD								0	
Non IDD Specific	16+	Nursing Facility				1075	1258	1409	6902	1217	1157
		Psychiatric Facility				0	0	0	0	DNF	0
Number of People with IDD	All Size	Waiting list					DNF	0	0	0	0
		Estimated Total	26180	27066	28903	32451	161953	178806	202261	189546	199168
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				16085	10799	16940	19252	22740	21534
		HCBS Recipients 100,000				11	89	83	170	229	257
	ICF/IID	ICF/IDD Expenditures per Person				25966	42137	34703	62671	78119	32731
		ICF/IDD Per 100,000				37	31	33	29	24	23

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# COLORADO

Figure RP1: Residence Size and Type on June 30, 2012

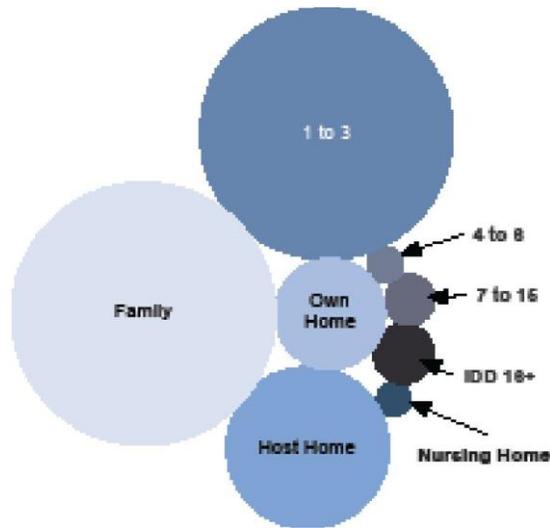


Figure RP2: Annual Medicaid Expenditures Per Person

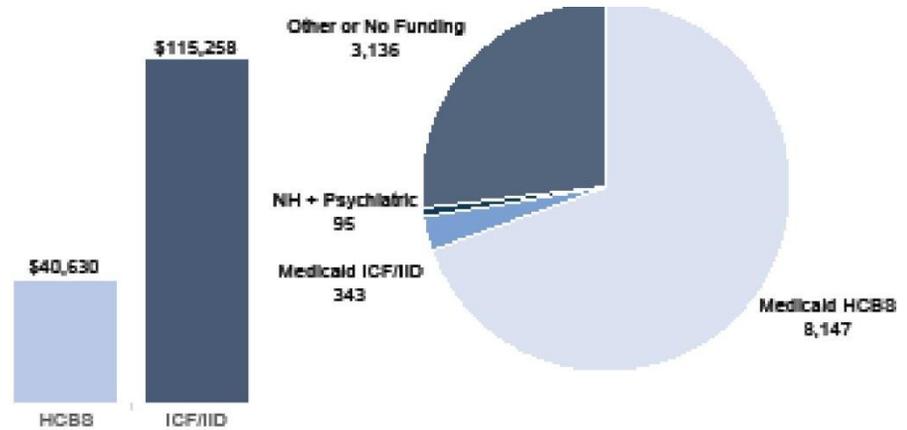


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					448	712	865	729	1028
		Family					7437	6540	5628	7517	5807
		Host Home					0	0	0	2492	2204
		1 to 3 Group Home						2288	33	DNF	2118
Congregate IDD settings by size and type	4 to 15	4 to 6						616	343	1370	110
		1 to 6	119	670	354	1819	632	2904	679	1378	222B
		7 to 15	421	670	1345	910	593	456	499	203	207
	16+	16+ Private				280	36	0	0	0	0
		16+ Public				386	197	122	105	67	296
16+ Total		2111	1960	1247							
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				428	258	270	161	57	95
		Psychiatric Facility				0	0	0	DNF	DNF	0
Number of People with IDD	All Size	Waiting list					2318	2692	940	1562	1794
		Estimated Total	2651	3300	2946	3395	9343	10734	7776	11878	11857
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				26450	31564	30214	36110	41127	40630
		HCBS Recipients per 100,000				59	153	147	145	133	157
	ICF/IDD	ICF/IDD Expenditures per Person				60300	87553	130331	481362	134414	115258
		ICF/IDD Per 100,000				27	7	3	3	4	7

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# CONNECTICUT

Figure RP1: Residence Size and Type on June 30, 2012

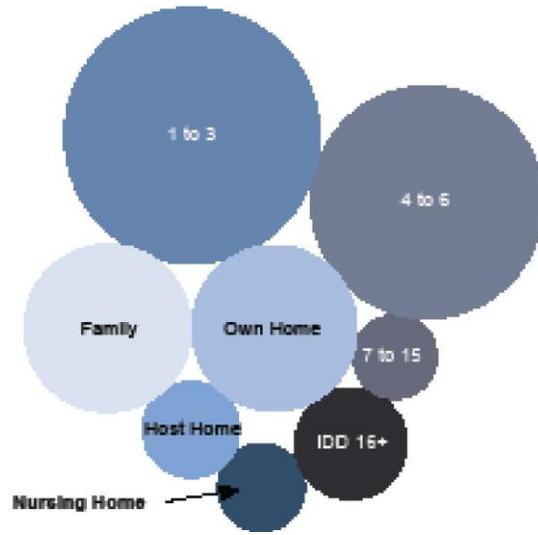


Figure RP2: Annual Medicaid Expenditures Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

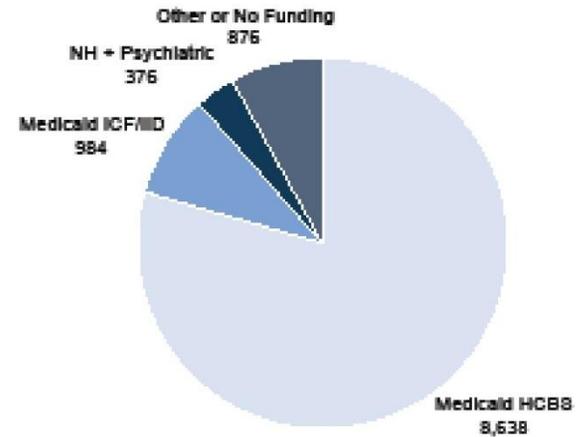


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					636	1363	859	1388	1349
		Family					121741	6612	7546	7896	1381
		Host Home					523	503	542	497	458
		1 to 3 Group Home						622	742	1293	1431
Congregate IDD settings by size and type	4 to 15	4 to 6						2197	2685	2696	2654
		1 to 6	251	353	1630	3113	2870	2819	3427	4000	4085
		7 to 15	364	540	806	570	383	452	472	354	338
	16+	16+ Private				0	0	0	0	0	0
		16+ Public				1652	1209	988	839	686	612
		16+ Total	3881	3660	2384						
		Other IDD								0	
Non IDD Specific	16+	Nursing Facility				482	391	358	411	382	376
		Psychiatric Facility				0	15	0	0	DNF	0
Number of People with IDD	All Size	Waiting list					1261	1405	680	531	612
		Estimated Total	4496	4553	4820	5335	17762	12737	13685	14821	8599
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				37205	34595	67965	64000	74492	83454
		HCBS Recipients 100,000				90	92	149	188	242	241
	ICF/IDD	ICF/IDD Expenditures per Person				135601	141190	180740	188575	279101	257596
		ICF/IDD Per 100,000				47	40	38	33	23	27

**Status and Trends in Residential and In Home Supports for**

**People with IDD FY 2012**

# DELAWARE

Figure RP1: Residence Size and Type on June 30, 2012

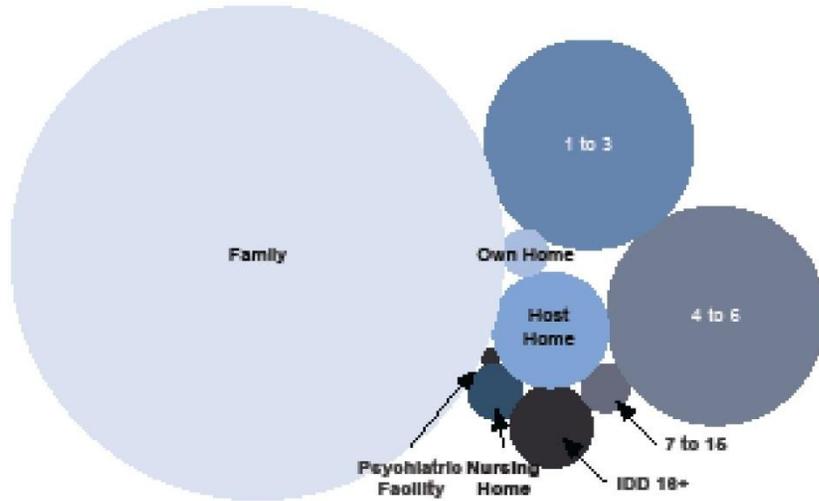


Figure RP2: Annual Medicaid Expenditures Per Person

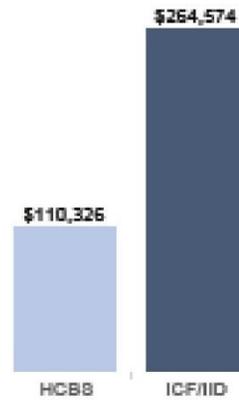


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

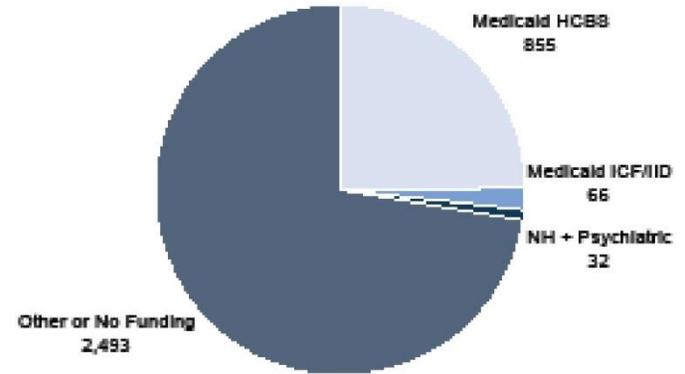


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					21	19	25	27	20
		Family					1499	1209	1691	2149	2428
		Host Home					159	154	206	146	132
		1 to 3 Group Home						160	207	259	283
Congregate IDD settings by size and type	4 to 15	4 to 6						217	340	467	474
		1 to 6	179	149	248	278	241	317	547	726	757
		7 to 15	9	10	49	89	31	0	0	0	23
	16+	16+ Private				0	0	0	61	48	0
		16+ Public				332	391	253	111	70	66
		16+ Total	622	606	383						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				60	0	78	60	43	29
		Psychiatric Facility				0	0	0	11	7	3
Number of People with IDD	All Size	Waiting list					479	145	7	174	17
		Estimated Total	810	764	680	699	2242	2012	2641	3166	3458
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				19204	66088	57032	73563	105893	110326
		HCBS Recipients 100,000				36	49	61	87	94	93
	ICF/IID	ICF/IDD Expenditures per Person				56016	100771	128636	150125	260454	264574
		ICF/IDD Per 100,000				62	41	32	20	13	7

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# DISTRICT OF COLUMBIA

Figure RP1: Residence Size and Type on June 30, 2012

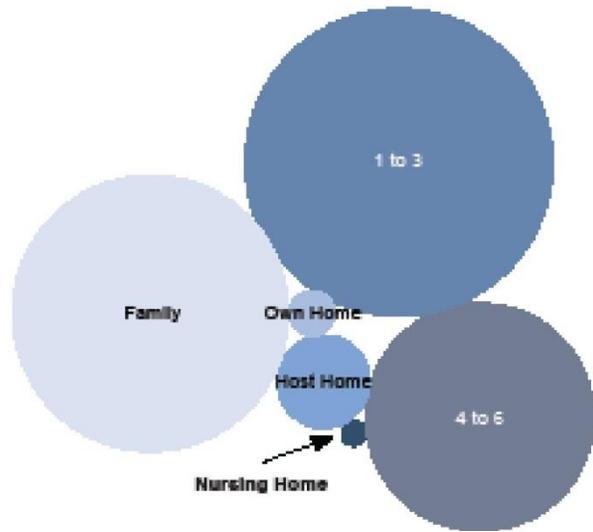


Figure RP2: Annual Medicaid Expenditures Per Person

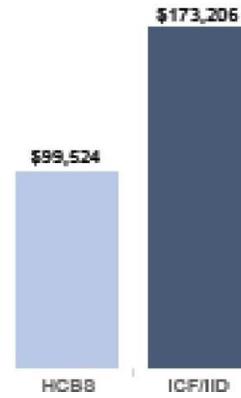


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

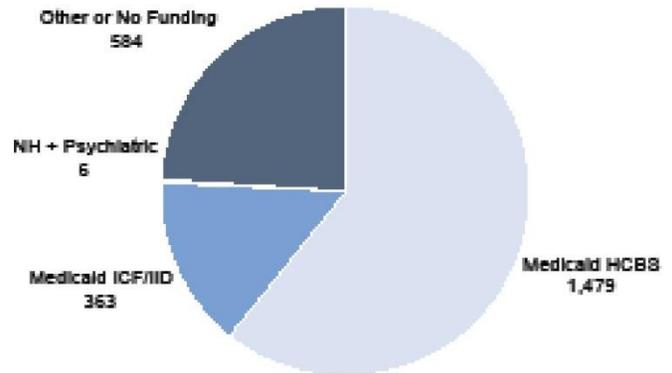


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					1	0	22	20	13
		Family					1077	0	540	510	715
		Host Home					84	70	82	72	81
		1 to 3 Group Home						4	DNF	687	789
Congregate IDD settings by size and type	4 to 15	4 to 6						601	DNF	487	489
		1 to 6	28	139	235	646	545	695	933	1193	1278
		7 to 15	0	76	235	304	374	340	118	52	0
	16+	16+ Private				60	0	0	0	0	0
		16+ Public				77	0	0	0	0	0
		16+ Total	960	671	258						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				34	28	0	1	10	6
		Psychiatric Facility				1	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					87	DNF	0	0	0
		Estimated Total	988	886	728	1087	2081	1105	1695	1855	2099
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				0	0	4140	14914	962741	995214
		HCBS Recipients 100,000				0	0	12	111	240	234
	ICF/IDD	ICF/IDD Expenditures per Person				36860	80861	83667	103254	169585	173206
		ICF/IDD Per 100,000				172	136	147	139	68	57

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# FLORIDA

Figure RP1: Residence Size and Type on June 30, 2012

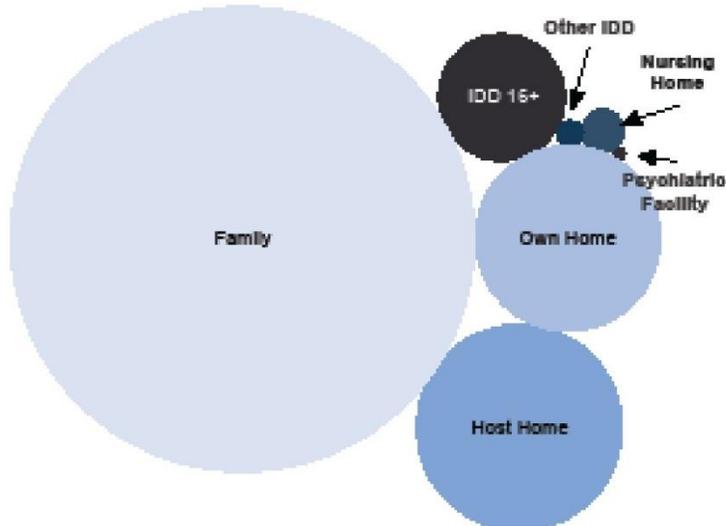


Figure RP2: Annual Medicaid Expenditures Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

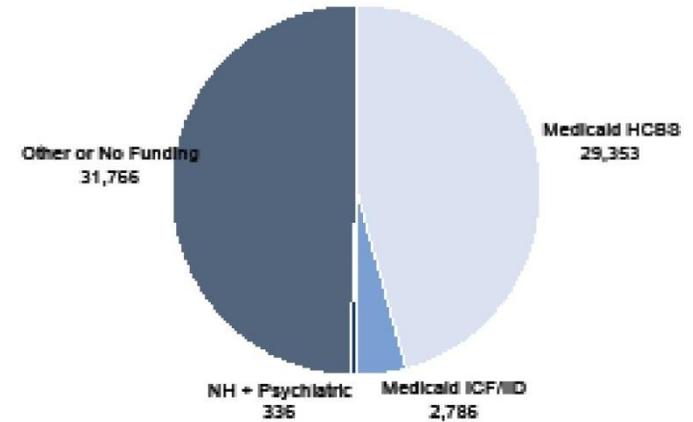


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					1937	3137	4013	5326	5883
		Family					25973	19417	31173	39218	37082
		Host Home					DNF	0	0	DNF	7254
		1 to 3 Group Home						173	235	359	396
Congregate IDD settings by size and type	4 to 15	4 to 6						3309	4515	5704	6343
		1 to 6	791	937	593	1967	2602	3482	4751	6063	7039
		7 to 15	1006	1474	2654	2244	1572	1359	1286	1233	1642
	16+	16+ Private				2651	2418	3160	2016	2009	1983
		16+ Public				1977	1459	1502	1331	916	781
		16+ Total	6304	5649	4952						
		Other IDD								118	
Non IDD Specific	16+	Nursing Facility				212	212	191	284	309	308
		Psychiatric Facility				4	0	0	0	0	28
Number of People with IDD	All Size	Waiting list					1951	618	3100	3835	4311
		Estimated Total	8103	8060	8199	8859	DNF	32047	4569	DNF	62118
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				6842	11385	11921	25536	31124	29975
		HCBS Recipients 100,000				20	69	132	145	160	152
	ICF/IDD	ICF/IDD Expenditures per Person				53117	64866	81728	89374	114326	117219
		ICF/IDD Per 100,000				24	24	22	19	16	14

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# GEORGIA

Figure RP1: Residence Size and Type on June 30, 2012

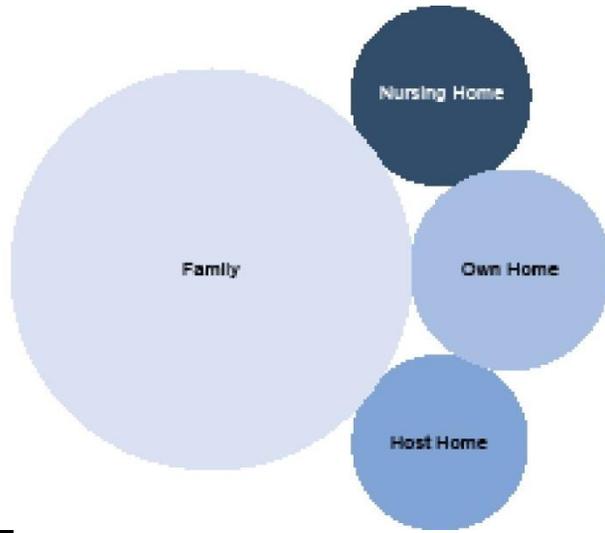


Figure RP2: Annual Medicaid Expenditures Per Person

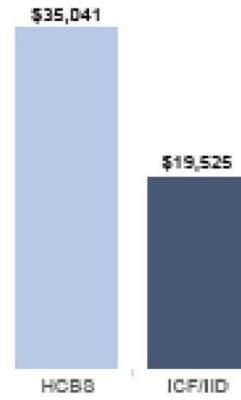


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

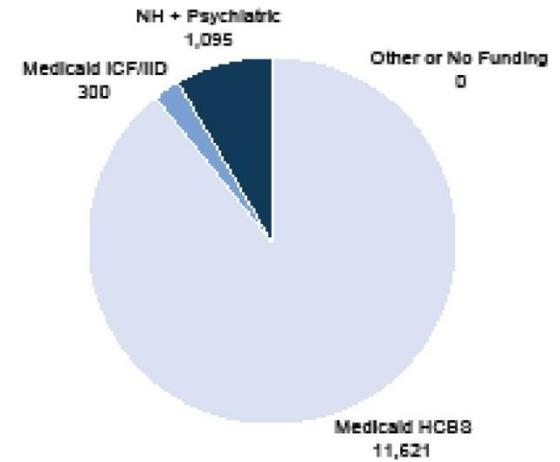


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012	
Individualized Settings	1 to 3	Own Home					433	1640	2228	3316	1366	
		Family					DNF	6186	4123	5344	5495	
		Host Home					351	462	542	1240	1044	
		1 to 3 Group Home						630	1004	1155	DNF	
Congregate IDD settings by size and type	4 to 15	4 to 6						419	598	1225	DNF	
		1 to 6	96	709	1181	1608	754	1049	1602	2380	DNF	
		7 to 15	236	138	61	11	0	0	0	0	DNF	
	16+	16+ Private					238	110	110	110	0	DNF
		16+ Public					2054	1909	1535	1190	751	300
		16+ Total	2994	2710	3469							
		Other IDD									0	
Non IDD Specific	16+	Nursing Facility				1941	2200	1800	1576	754	1095	
		Psychiatric Facility				6	36	0	0	0	0	
Number of People with IDD	All Size	Waiting list					1644	2004	1441	1640	2735	
		Estimated Total	3326	3557	4711	3911	DNF	10982	9795	13031	11414	
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				14348	34932	37301	26996	30311	35041	
		HCBS Recipients 100,000				5	23	30	93	120	117	
	ICF/IDD	ICF/IDD Expenditures per Person				56424	64554	67003	88878	137249	19525	
		ICF/IDD Per 100,000				29	28	20	12	7	3	

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# HAWAII

Figure RP1: Residence Size and Type on June 30, 2012

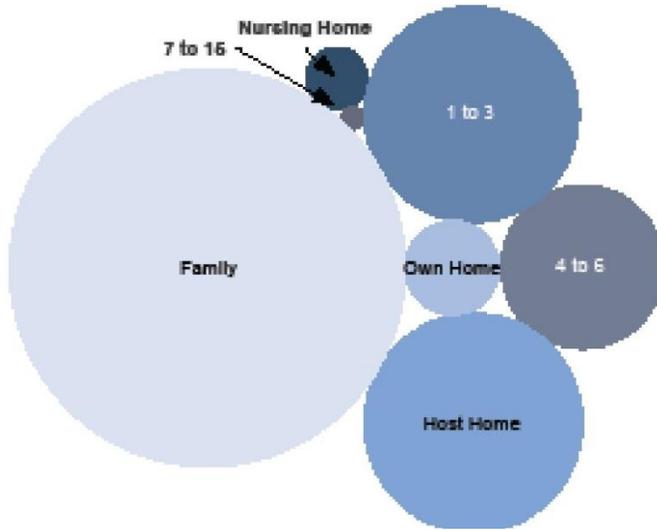


Figure RP2:

Annual Medicaid Expenditures Per Person

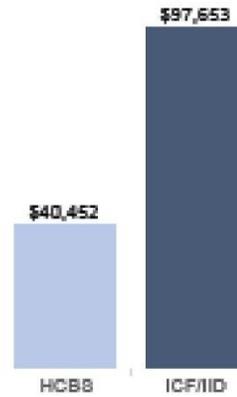


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

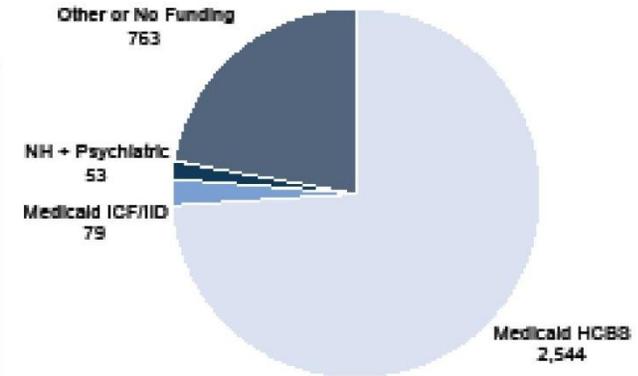


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					94	103	150	48	123
		Family					2461	1465	2108	1584	2202
		Host Home					719	767	740	554	569
		1 to 3 Group Home						569	3	3	0
Congregate IDD settings by size and type	4 to 15	4 to 6						606	164	163	227
		1 to 6	366	445	576	948	198	1175	157	155	227
		7 to 15	18	12	5	7	7	0	8	8	7
	16+	16+ Private				9	14	13	0	0	0
		16+ Public				137	49	0	0	0	0
		16+ Total	543	400	260						
Non IDD Specific	16+	Nursing Facility				138	87	55	103	87	53
		Psychiatric Facility				8	8	0	0	3	9
Number of People with IDD	All Size	Waiting list					778	0	0	0	0
		Estimated Total	927	857	841	1101	3532	3523	3173	2360	3281
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				16148	23175	21120	35279	40088	40452
		HCBS Recipients 100,000				17	42	90	183	183	183
	ICF/IDD	ICF/IDD Expenditures per Person				19406	86778	83079	97790	114104	97653
		ICF/IDD Per 100,000				34	10	8	7	6	6

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# IDAHO

Figure RP1: Residence Size and Type on June 30, 2012

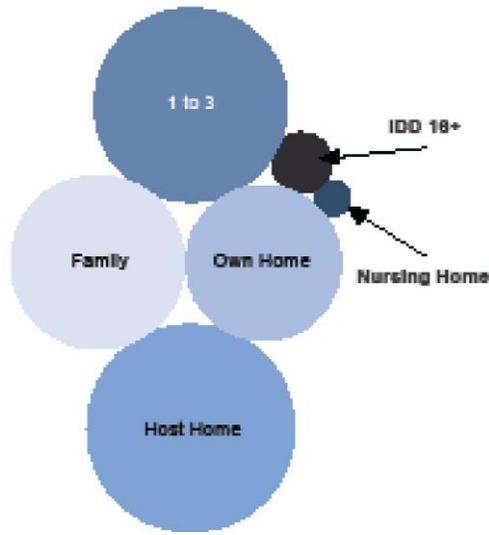


Figure RP2:  
Annual Medicaid  
Expenditures  
Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

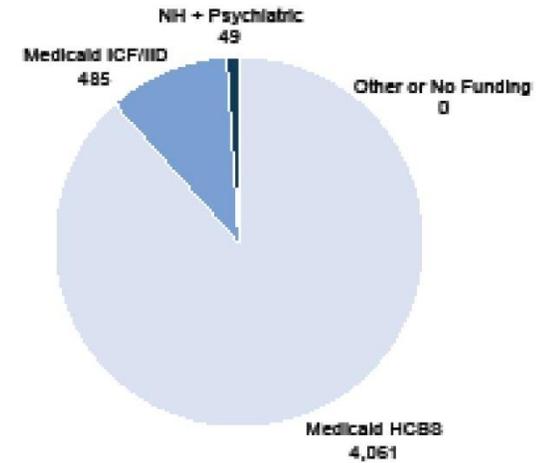


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					500	931	1228	1437	942
		Family					6061	6713	8992	12791	1182
		Host Home					517	1009	1215	1729	1694
		1 to 3 Group Home						41	38	23	0
Congregate IDD settings by size and type	4 to 15	4 to 6						211	206	196	DNF
		1 to 6	42	41	242	342	145	252	243	219	DNF
		7 to 15	76	180	531	475	521	481	507	515	DNF
	16+	16+ Private				477	316	326	190	399	94
		16+ Public				172	123	110	90	62	47
		16+ Total	698	639	521						
		Other IDD								0	
Non IDD Specific	16+	Nursing Facility					39	29	125	233	49
		Psychiatric Facility				0	0	0	0	DNF	0
Number of People with IDD	All Size	Waiting list					100	0	0	0	0
		Estimated Total	816	860	1294	1466	8186	9822	12465	17152	4595
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				13018	18831	20324	29689	33828	DNF
		HCBS Recipients 100,000				16	35	62	119	187	DNF
	ICF/IDD	ICF/IDD Expenditures per Person				63995	75272	89883	97655	126447	37585
		ICF/IDD Per 100,000				51	46	46	39	33	30

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# ILLINOIS

Figure RP1: Residence Size and Type on June 30, 2012

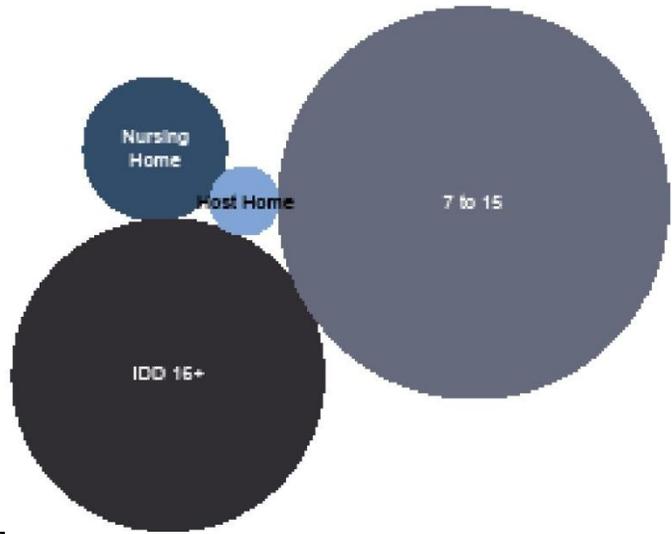


Figure RP2: Annual Medicaid Expenditures Per Person

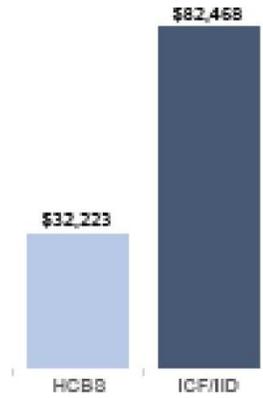


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

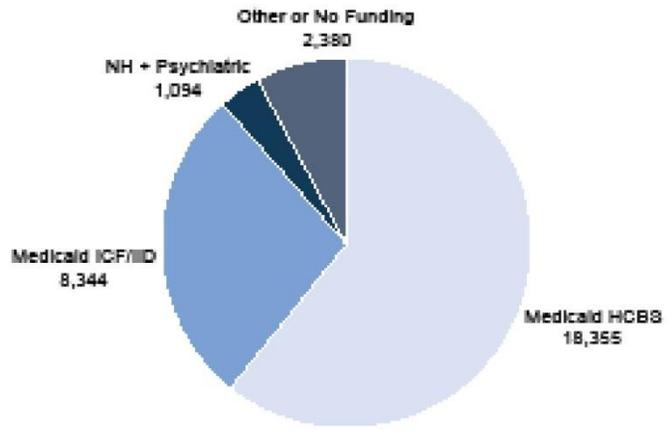


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					93	1579	3775	3999	DNF
		Family					23955	11854	11324	11996	DNF
		Host Home					145	93	245	254	244
		1 to 3 Group Home							76	155	403
Congregate IDD settings by size and type	4 to 15	4 to 6						3108	3640	3844	4366
		1 to 6	69	331	713	897	2178	3677	3716	3999	4769
		7 to 15	101	387	1707	3824	3442	5395	6463	7703	9202
	16+	16+ Private				7484	3501	4433	2397	3434	3295
		16+ Public				4340	9719	3191	2763	2111	1929
		16+ Total	12170	12170	10425						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility					2872	1267	635	DNF	1094
		Psychiatric Facility				7	17	0	0	0	0
Number of People with IDD	All Size	Waiting list					0NF	CNF	CNF	1EEM2	1J978
		Estimated Total	1398	12888	12845	16545	37032	30284	21183	33496	30173
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				12631	11094	20657	34341	31002	32223
		HCBS Recipients 100,000				12	44	55	82	132	143
	ICF/IDD	ICF/IDD Expenditures per Person				30741	55428	62958	71743	74255	82468
		ICF/IDD Per 100,000				109	87	83	75	67	65

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# INDIANA

Figure RP1: Residence Size and Type on June 30, 2012

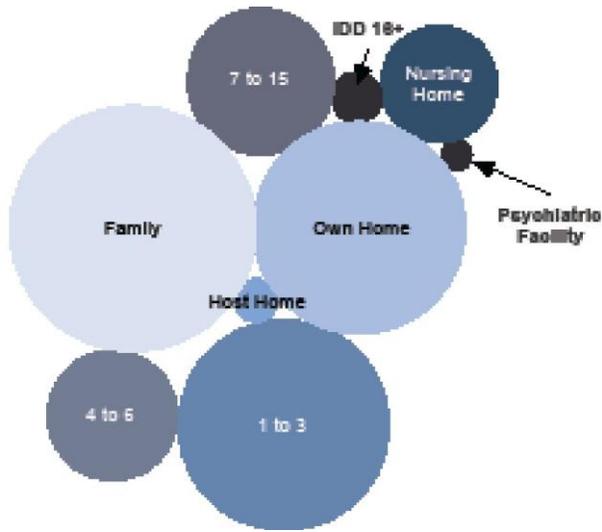


Figure RP2: Annual Medicaid Expenditures Per Person

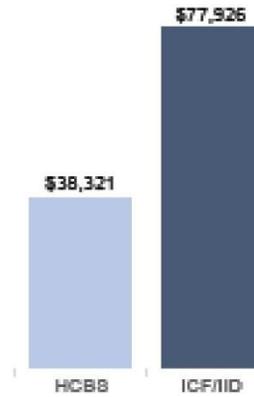


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

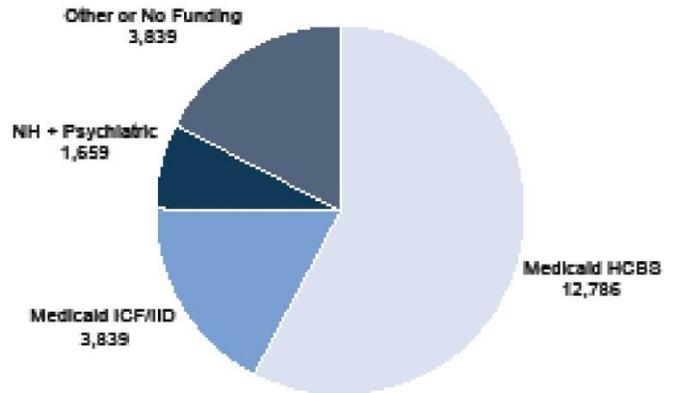


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					1157	1447	6553	4404	5136
		Family					9169	1358	5048	5881	6888
		Host Home					419	490	316	248	207
		1 to 3 Group Home						0	0	479	0
Congregate IDD settings by size and type	4 to 15	4 to 6						1037	3254	1682	1657
		1 to 6	466	487	914	2015	980	1037	3254	2151	1657
		7 to 15	172	243	1609	2424	2820	2754	0	2525	2447
	16+	16+ Private				892	984	835	321	318	290
		16+ Public				1756	1244	797	415	192	0
		16+ Total	4218	3231	2863						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				2587	2057	1933	1697	1533	1553
		Psychiatric Facility				0	65	33	0	12	106
Number of People with IDD	All Size	Waiting list					2067	DNF	DNF	17142	DNF
		Estimated Total	4856	3961	5386	7087	16773	8718	15907	15719	18284
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				0	28752	42563	40755	45301	38321
		HCBS Recipients 100,000				0	14	34	148	173	196
	ICF/IDD	ICF/IDD Expenditures per Person				32930	50668	47659	80963	77683	DNF
		ICF/IDD Per 100,000				108	102	89	63	62	59

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# IOWA

Figure RP1: Residence Size and Type on June 30, 2012

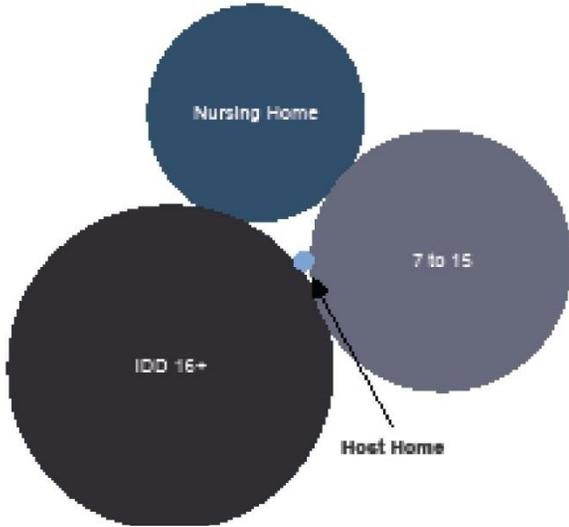


Figure RP2: Annual Medicaid Expenditures Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

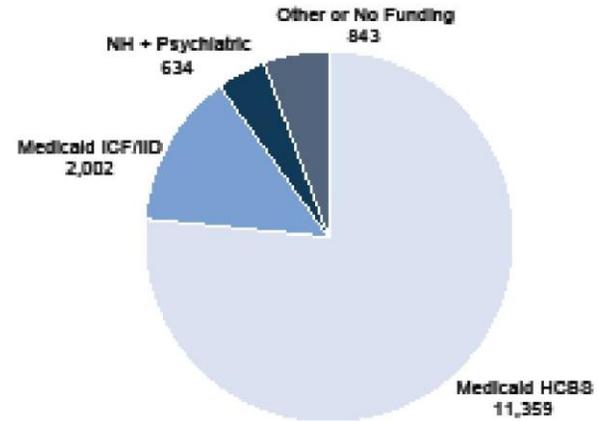


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					1135	2487	4866	5863	DNF
		Family					9435	2166	4145	5411	DNF
		Host Home					23	6	6	3	4
		1 to 3 Group Home						6	DNF	0	18
Congregate IDD settings by size and type	4 to 15	4 to 6						1126	DNF	380	467
		1 to 6	94	211	468	1860	1629	1132	691	380	485
		7 to 15	296	588	702	1571	1994	725	1060	796	920
	16+	16+ Private				1956	2551	3822	1098	1905	987
		16+ Public				1041	672	673	626	503	444
16+ Total		3109	3742	2183							
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				1379	148	150	808	619	634
		Psychiatric Facility				6	197	65	0	0	0
Number of People with IDD	All Size	Waiting list					DNF	DNF	79	34	0
		Estimated Total	3499	4541	3353	6428	17439	10011	12495	14860	14838
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				2842	12510	19242	20258	24238	34121
		HCBS Recipients 100,000				1	90	157	369	465	369
	ICF/IID	ICF/IDD Expenditures per Person				64095	87433	63161	114002	137290	150719
		ICF/IDD Per 100,000				76	76	104	74	69	63

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# KANSAS

Figure RP1: Residence Size and Type on June 30, 2012

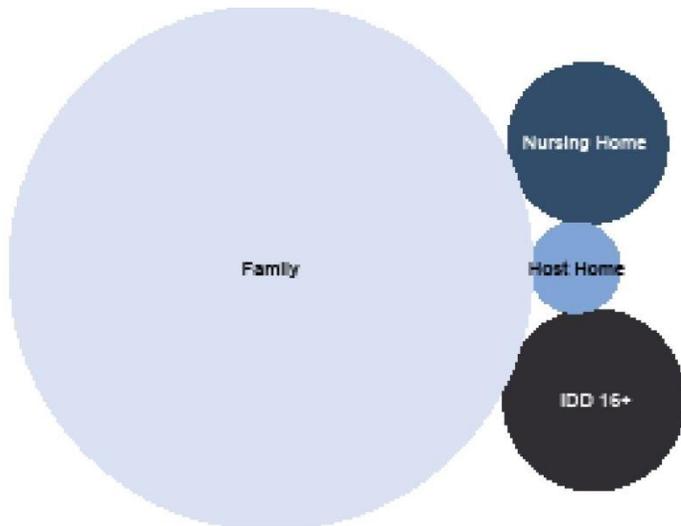


Figure RP2: Annual Medicaid Expenditures Per Person

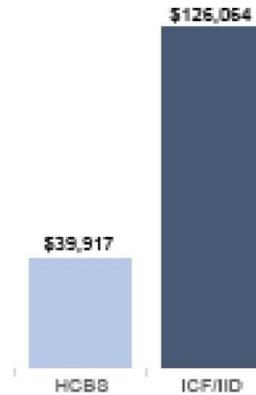


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

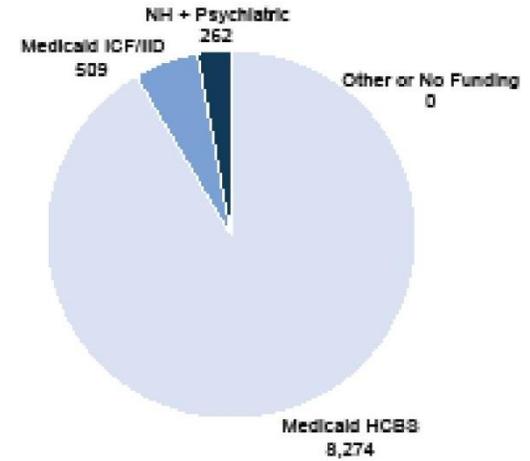


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					DNF	1005	1774	2561	DNF
		Family					DNF	2901	1590	22591	2811
		Host Home					DNF	129	141	217	82
		1 to 3 Group Home						1359	1873	650	1910
Congregate IDD settings by size and type	4 to 15	4 to 6						1305	1275	1493	DNF
		1 to 6	220	184	613	764	546	7664	3149	2143	DNF
		7 to 15	406	482	555	533	831	229	327	477	DNF
	16+	16+ Private				677	730	201	60	0	0
		16+ Public				1021	676	389	367	347	394
16+ Total		2080	2209	1974							
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				31	0	38	0	432	262
		Psychiatric Facility				4	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					16	206	1194	1287	DNF
		Estimated Total	2105	7975	3142	2995	DNF	7518	7407	8346	4045
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				23481	22749	31119	32107	36224	39917
		HCBS Recipients 100,000				20	120	202	247	272	287
	ICF/IDD	ICF/IDD Expenditures per Person				48846	61146	78458	105345	119983	DNF
		ICF/IDD Per 100,000				81	60	32	23	18	DNF

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# KENTUCKY

Figure RP1: Residence Size and Type on June 30, 2012

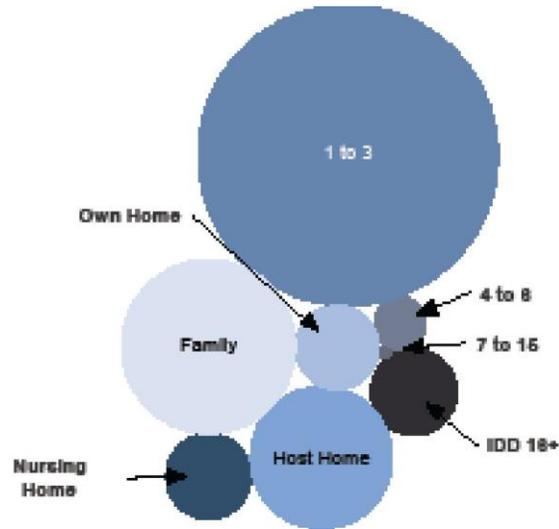


Figure RP2: Annual Medicaid Expenditures Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

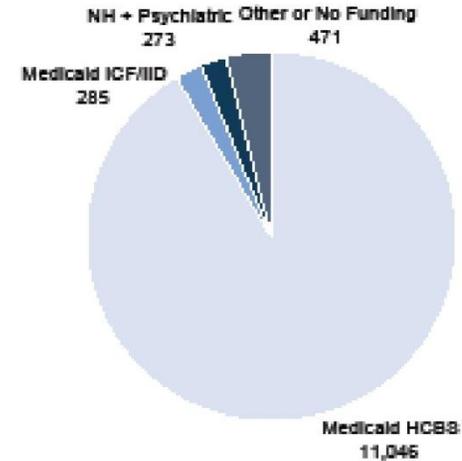


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					115	167	770	197	261
		Family					5231	4236	1073	1506	1135
		Host Home					331	368	512	644	761
		1 to 3 Group Home						691	1850	2275	2372
Congregate IDD settings by size and type	4 to 15	4 to 6						41	44	0	103
		1 to 6	44	112	327	747	556	732	1891	2275	2475
		7 to 15		63	103	150	334	274	114	34	6
	16+	16+ Private				513	529	513	208	422	136
		16+ Public				731	644	620	495	169	143
		16+ Total	1585	1685	1199						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility	317				0	1640	450	950	273
		Psychiatric Facility				5	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					DNF	1279	288	295	802
		Estimated Total	1658	1860	1629	2141	7640	6910	5066	5337	5190
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				21335	27838	47249	59076	48463	36794
		HCBS Recipients 100,000				21	24	32	64	127	253
	ICF/IDD	ICF/IDD Expenditures per Person				55764	49249	74575	148208	23622	457827
		ICF/IDD Per 100,000				32	30	28	17	14	7

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# LOUISIANA

Figure RP1: Residence Size and Type on June 30, 2012

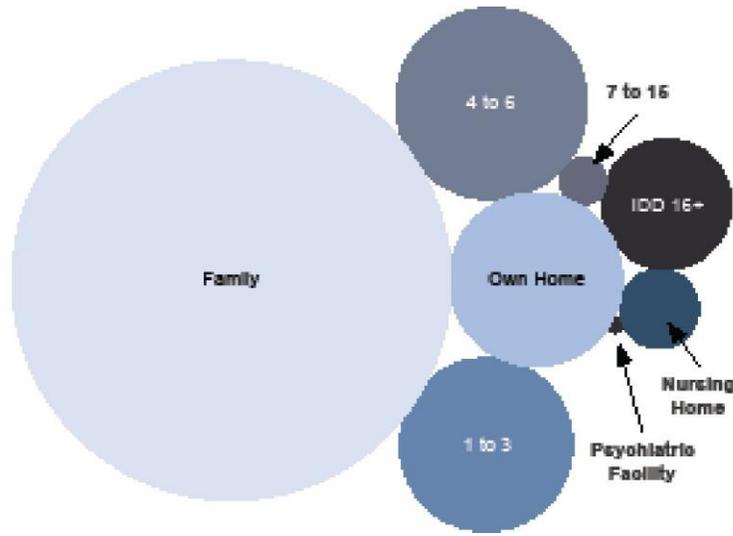


Figure RP2: Annual Medicaid Expenditures Per Person

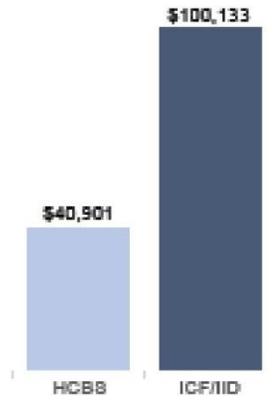


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

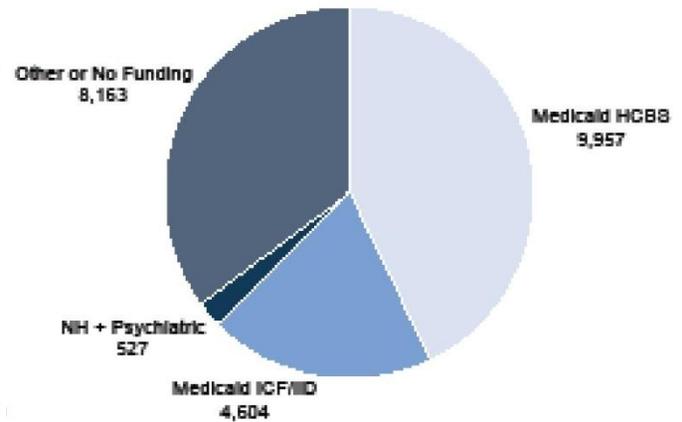


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					501	1391	1891	2340	2468
		Family					10574	1894	6512	13894	15946
		Host Home					181	108	53	54	0
		1 to 3 Group Home						0	37	0	0
Congregate IDD settings by size and type	4 to 15	4 to 6						2096	2026	2861	3035
		1 to 6	39	85	914	224	2493	2096	2063	2861	3035
		7 to 15	112	185	291	222	1187	779	1030	345	181
	16+	16+ Private				3010	1617	1002	945	507	549
		16+ Public				2408	2031	1743	1525	1124	839
		16+ Total	4296	4785	4436						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				1252	1267	1109	677	382	511
		Psychiatric Facility				0	0	0	0	16	16
Number of People with IDD	All Size	Waiting list					2254	530	DNF	DNF	DNF
		Estimated Total	4448	5055	5641	7864	18584	5013	14019	21126	23545
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				3643	20174	26281	45489	48370	40901
		HCBS Recipients 100,000				1	48	81	118	182	216
	ICF/IDD	ICF/IDD Expenditures per Person				39948	51437	61822	77963	97633	100133
		ICF/IDD Per 100,000				140	139	126	121	107	100

# Status and Trends in Residential and In People with IDD FY 2012

# MASSACHUSETTS

Figure RP1: Residence Size and Type on June 30, 2012

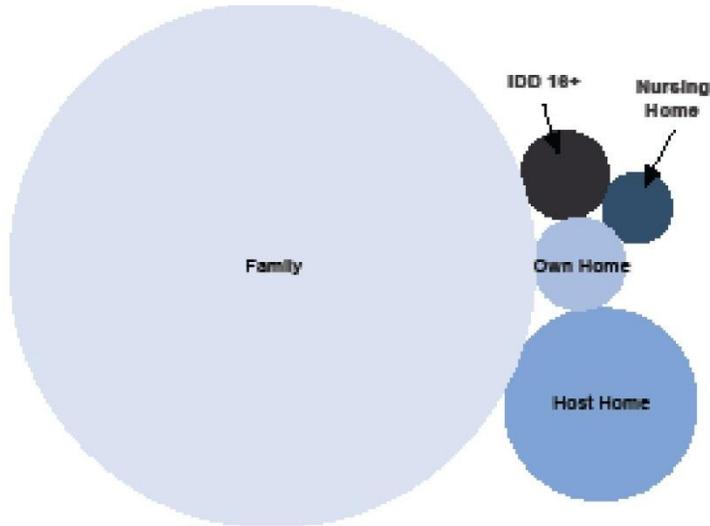


Figure RP2:  
Annual Medicaid  
Expenditures  
Per Person



Figure RP3: Number and Percent of Recipients  
by Funding Authority on June 30, 2012

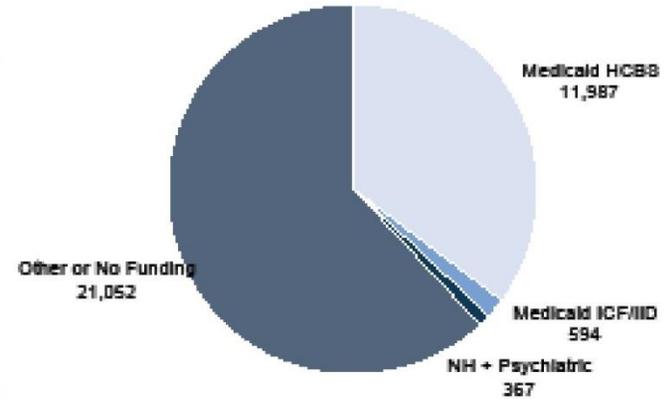


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					1119	1912	1308	2114	638
		Family					DNF	16700	19665	19916	21000
		Host Home					469	1133	934	1569	2807
		1 to 3 Group Home						1463	1725	1447	DNF
Congregate IDD settings by size and type	4 to 15	4 to 6						4126	5334	5024	DNF
		1 to 6	282	911	1104	3440	3250	5589	7059	6471	7809
		7 to 15	1012	1129	2658	1661	1364	740	885	1188	799
	16+	16+ Private				0	0	0	17	0	0
		16+ Public				2694	1824	1293	1075	786	580
		16+ Total	6429	4682	3430						
		Other IDD								0	
Non IDD Specific	16+	Nursing Facility				1600	1828	1499	1056	713	367
		Psychiatric Facility				8	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					2170	2227	372	0	DNF
		Estimated Total	7723	6722	7192	7795	DNF	27357	30943	32044	3400
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				33546	30946	40860	55719	56241	DNF
		HCBS Recipients 100,000				28	134	163	174	191	180
	ICF/IDD	ICF/IDD Expenditures per Person				101183	145936	165906	203152	49492	21483
		ICF/IDD Per 100,000				55	30	20	16	12	9

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# MAINE

Figure RP1: Residence Size and Type on June 30, 2012

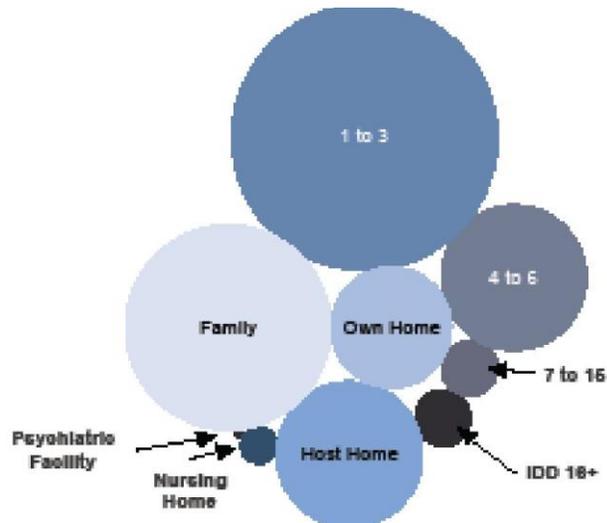


Figure RP2: Annual Medicaid Expenditures Per Person

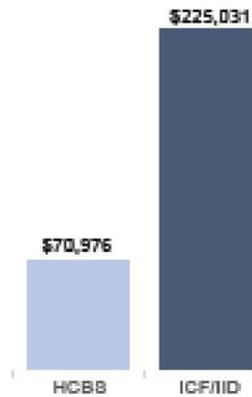


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

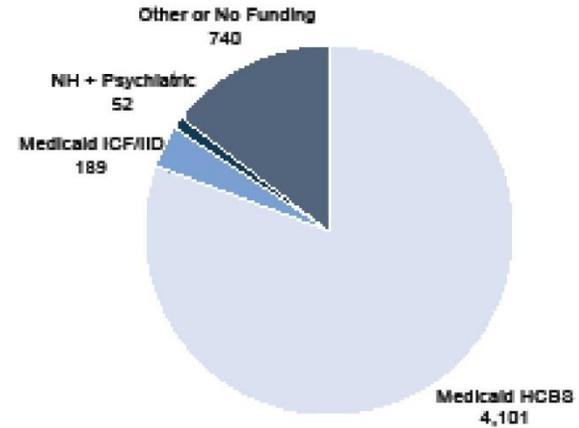


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					105	1000	568	303	541
		Family					2699	2000	599	387	1563
		Host Home					584	1850	728	418	793
		1 to 3 Group Home						960	936	1201	1304
Congregate IDD settings by size and type	4 to 15	4 to 6						309	596	657	775
		1 to 6	429	524	1165	1259	399	1269	1935	1858	2079
		7 to 15	75	179	140	187	310	330	202	65	116
	16+	16+ Private				307	130	78	49	32	117
		16+ Public				265	19	0	0	0	0
		16+ Total	989	761	568						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				190	45	0	112	72	49
		Psychiatric Facility				2	0	0	0	0	3
Number of People with IDD	All Size	Waiting list					DNF	494	105	337	85
		Estimated Total	1493	1464	1873	2018	4746	6527	4081	3063	5261
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				24558	15600	59074	74951	71657	70976
		HCBS Recipients 100,000				41	81	144	197	323	309
	ICF/IID	ICF/IDD Expenditures per Person				83983	106171	118477	236310	623838	225031
		ICF/IDD Per 100,000				53	36	23	18	7	14

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# MARYLAND

Figure RP1: Residence Size and Type on June 30, 2012

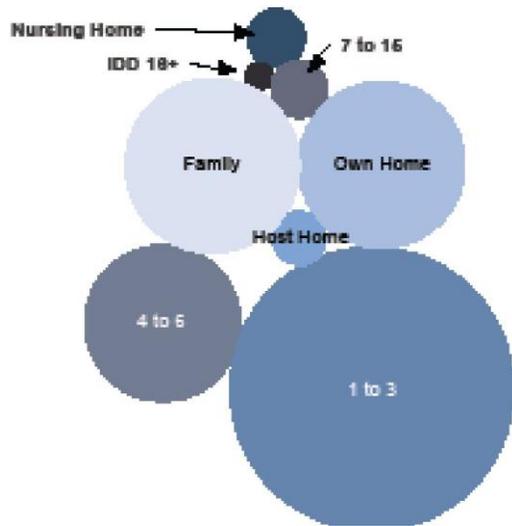


Figure RP2: Annual Medicaid Expenditures Per Person

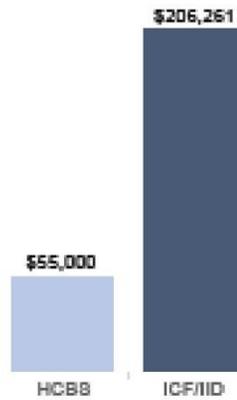


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

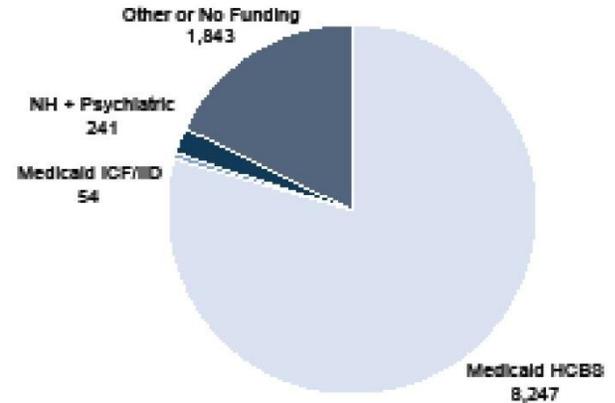


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					290	290	1509	1747	2014
		Family					9256	4329	2139	2228	2215
		Host Home					292	176	251	216	208
		1 to 3 Group Home						2285	2819	3544	3660
Congregate IDD settings by size and type	4 to 15	4 to 6						1393	1663	1629	1757
		1 to 6	62	352	2368	3325	3266	3678	4482	5173	5417
		7 to 15	71	163	256	0	361	385	313	256	236
	16+	16+ Private				80	74	74	25	0	0
		16+ Public				1079	652	525	367	144	54
		16+ Total	3238	2731	1532						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				537	336	121	843	DNF	241
		Psychiatric Facility				9	8	0	0	0	0
Number of People with IDD	All Size	Waiting list					DNF	3349	7710	2770	4065
		Estimated Total	3371	3246	4156	4484	14191	9457	9086	9764	10385
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				39722	39535	59787	39383	52511	55000
		HCBS Recipients 100,000				22	65	94	169	194	212
	ICF/IDD	ICF/IDD Expenditures per Person				58134	89130	112038	171896	12872374	DNF
		ICF/IDD Per 100,000				22	13	10	7	3	DNF

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# MICHIGAN

Figure RP1: Residence Size and Type on June 30, 2012

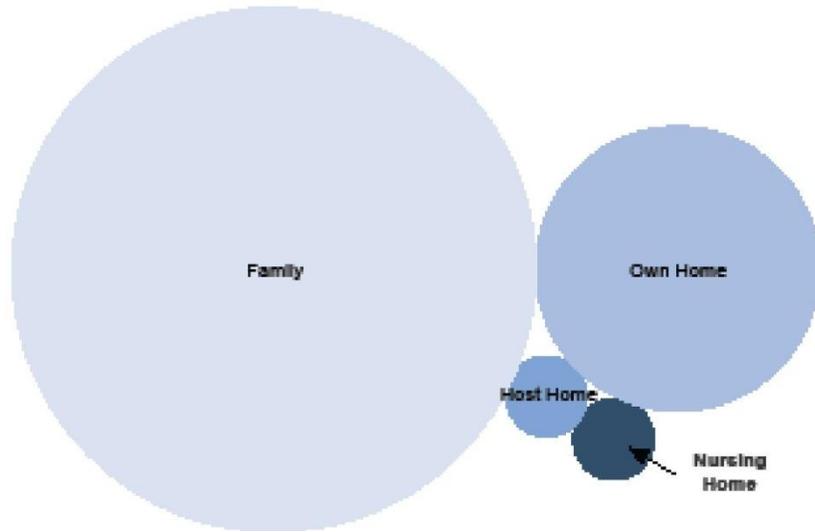


Figure RP2: Annual Medicaid Expenditures Per Person

HCBS ICF/IID

Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

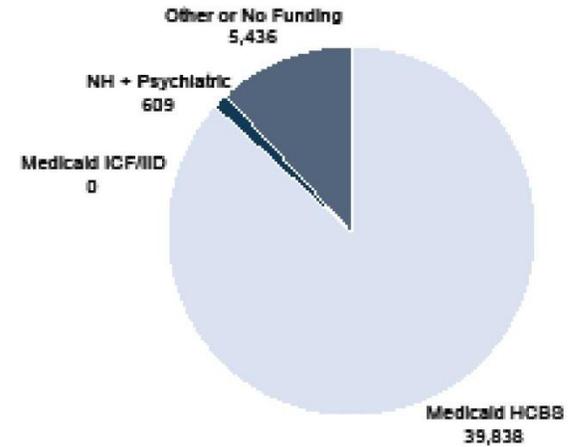


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					925	1760	2612	6319	7971
		Family					DNF	DNF	9421	19431	29772
		Host Home					1890	1196	766	564	600
		1 to 3 Group Home						0	DNF	1110	DNF
Congregate IDD settings by size and type	4 to 15	4 to 6						6469	DNF	7439	DNF
		1 to 6	1306	3529	4334	7513	8741	6469	10729	8549	DNF
		7 to 15				0	0	0	0	1904	DNF
	16+	16+ Private				253	0	0	0	794	DNF
		16+ Public				760	346	369	190	0	0
Other IDD										0	
Non IDD Specific	16+	Nursing Facility					240	502	557	509	605
		Psychiatric Facility				0	0	0	0	0	9
Number of People with IDD	All Size	Waiting list					DNF	DNF	0	DNF	DNF
		Estimated Total	1306	3929	4534	8526	DNF	DNF	23718	37921	47946
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				27632	31304	38728	38448	48974	DNF
		HCBS Recipients 100,000				23	54	81	85	87	403
	ICF/IDD	ICF/IDD Expenditures per				116394	145936	103657	109363	0	
		ICF/IDD Per 100,000				30	33	3	2	0	0

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# MINNESOTA

Figure RP1: Residence Size and Type on June 30, 2012

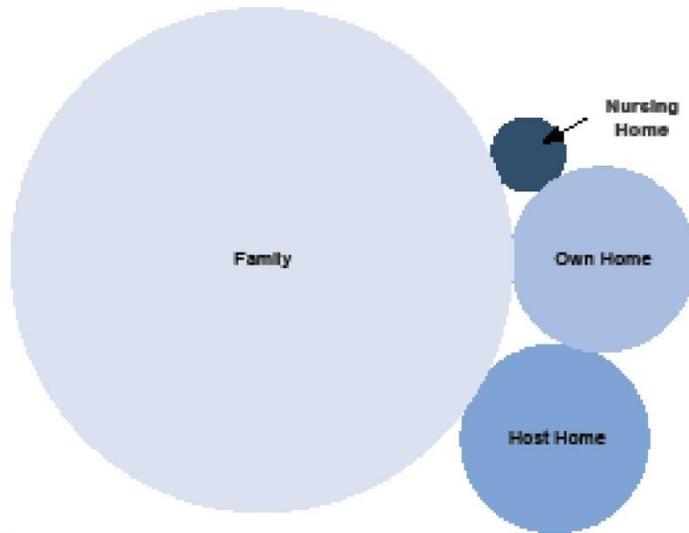


Figure RP2: Annual Medicaid Expenditures Per Person

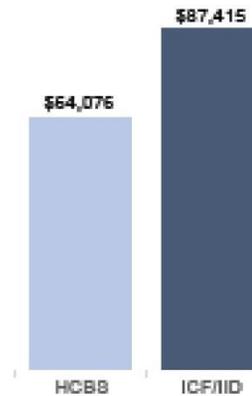


Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012

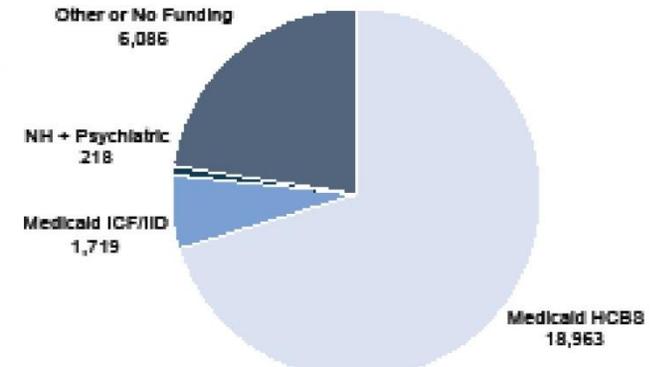


Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					881	2310	2092	2418	1384
		Family					16111	3088	15231	14678	10332
		Host Home				525	1890	1175	1507	922	1438
		1 to 3 Group Home						651	833	1067	DNF
Congregate IDD settings by size and type	4 to 15	4 to 6						5848	6909	8800	DNF
		1 to 6	286	652	2627	4504	6087	6499	7742	3857	DNF
		7 to 15		1805	2380	1853	1674	1225	1027	589	DNF
	16+	16+ Private				1875	107E	722	810	372	DNF
		16+ Public				1148	345	48	25	25	0
		16+ Total	4985	4612	3772						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				827	1144	491	245	218	218
		Psychiatric Facility				0	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					1064	1277	3855	3243	2718
		Estimated Total	6182	7069	8789	9909	28063	20067	23437	28875	14475
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				31103	39695	51362	58640	65005	64076
		HCBS Recipients 100,000				58	116	162	282	290	353
	ICF/IDD	ICF/IDD Expenditures per Person				50162	44404	75212	69387	96195	87415
		ICF/IDD Per 100,000				120	82	56	45	33	32

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# MISSISSIPPI

Figure RP1: Residence Size and Type on June 30, 2012

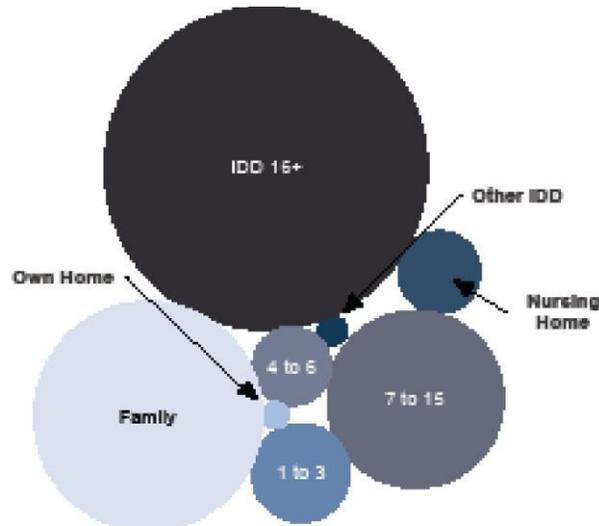


Figure RP2:  
Annual Medicaid  
Expenditures  
Per Person



Figure RP3: Number and Percent of Recipients by Funding Authority on June 30, 2012



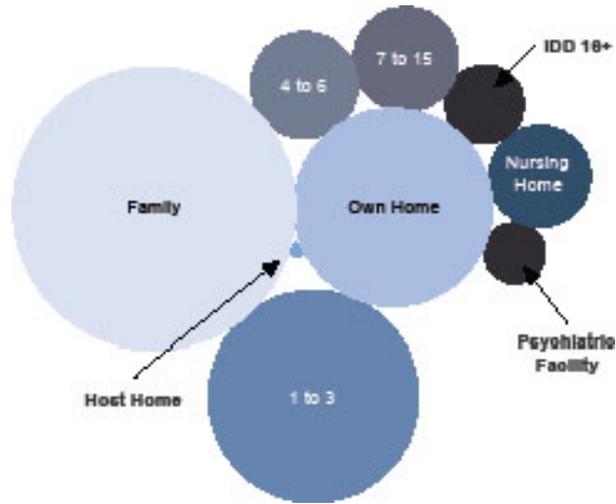
Table RP1

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					121	93	127	60	19
		Family					2838	157	1378	1693	1087
		Host Home					0	0	0	0	0
		1 to 3 Group Home						166	437	309	184
Congregate IDD settings by size and type	4 to 15	4 to 6						141	123	80	128
		1 to 6	17	67	205	310	346	307	560	388	312
		7 to 15	102	310	112	118	232	617	718	682	652
	16+	16+ Private				585	625	630	669	712	732
		16+ Public				1496	1424	1409	1367	1924	1441
16+ Total		2055	2201	2127							
		Other IDD									17
Non IDD Specific	16+	Nursing Facility				300	0	321	172	140	140
		Psychiatric Facility				0	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					DNF	DNF	DNF	DNF	DNF
		Estimated Total	2174	2478	2444	2506	5646	3213	4819	4859	4396
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				0	397	5202	18814	18869	DNF
		HCBS Recipients 100,000				0	24	47	66	84	DNF
	ICF/IDD	ICF/IDD Expenditures per Person				23736	48710	63611	78761	103469	97753
		ICF/IDD Per 100,000				70	79	87	91	64	99

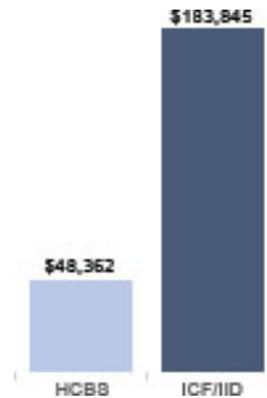
# Status and Trends in Residential and In-Home Supports for People with IDD FY 2012

# MISSOURI

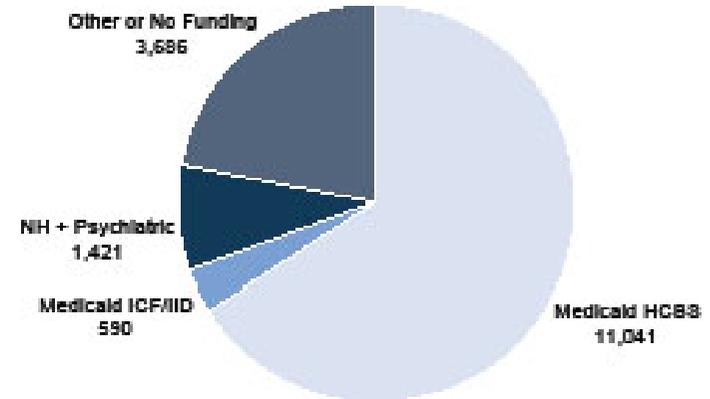
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



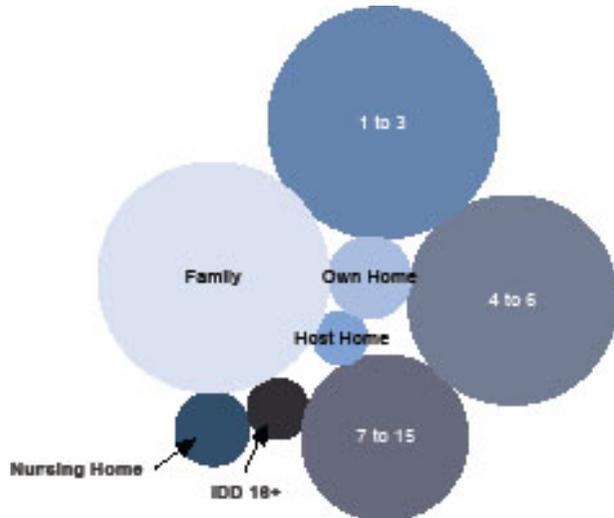
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					2024	2270	2391	3230	3984
		Family					10907	8582	7644	6199	8089
		Host Home					138	85	41	19	20
		1 to 3 Group Home						263	492	422	468
Congregate IDD Settings by size and type	4 to 15	4 to 6						778	330	1276	1156
		1 to 6	599	470	848	1368	822	1041	1313	1698	1624
		7 to 15	1059	1180	1432	1700	1315	1231	1224	976	1108
	16+	16+ Private				1101	725	471	252	119	113
		16+ Public				1703	1494	1278	1099	647	510
16+ Total		4847	4331	3671							
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				1400	1125	152	878	DNF	1045
		Psychiatric Facility				10	41	43	69	425	376
Number of People with	All Size	Waiting list					694	574	491	206	200
		Estimated Total	6505	5981	5951	5872	17425	14958	13964	12888	16869
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				19541	24139	24142	31379	50864	48362
		HCBS Recipients per 100,000				44	107	147	143	153	183
	ICF/IID	ICF/IID Expenditures per Person				51212	94255	72792	216630	183157	183845
		ICF/IID per 100,000				39	31	25	20	152	10

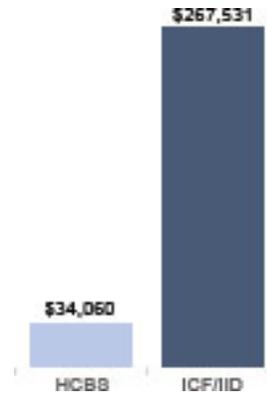
## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## MONTANA

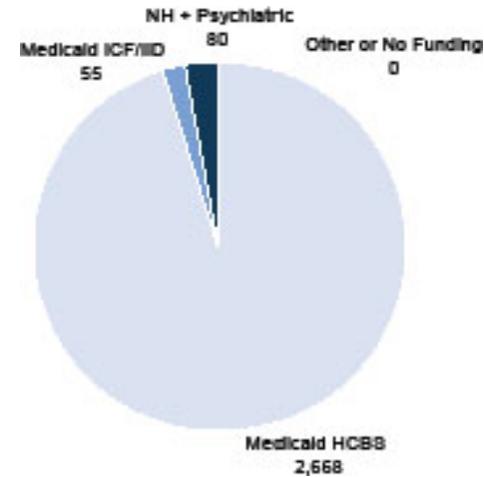
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



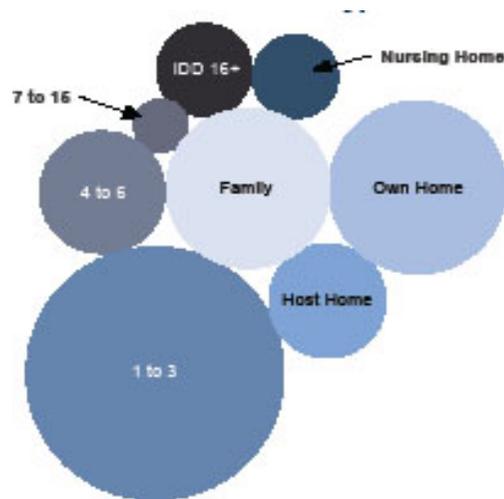
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					463	100	586	650	100
		Family					3155	2386	2068	2400	800
		Host Home					177	207	181	240	42
		1 to 3 Group Home						262	226	200	650
Congregate IDD Settings by size and type	4 to 15	4 to 6						226	286	380	661
		1 to 6	86	93	352	615	199	711	512	600	1311
		7 to 15	339	415	561	523	501	488	398	400	415
	16+	16+ Private				232	0	0	0	0	0
		16+ Public				190	157	130	79	55	55
		16+ Total	340	273	254						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				232	169	205	163	DNF	80
		Psychiatric Facility				1	0	0	1	0	0
Number of People with	All Size	Waiting list					536	200	560	691	635
		Estimated Total	765	781	1167	1560	4652	4022	3824	4345	2803
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				21670	22279	27829	28619	42448	34060
		HCBS Recipients per 100,000				44	92	134	216	236	265
	ICF/IID	ICF/IID Expenditures per				71236	89378	103439	156333	0	267531
		ICF/IID per 100,000				24	DNF	14	8	DNF	5

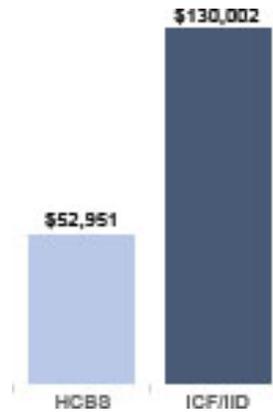
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## NEBRASKA

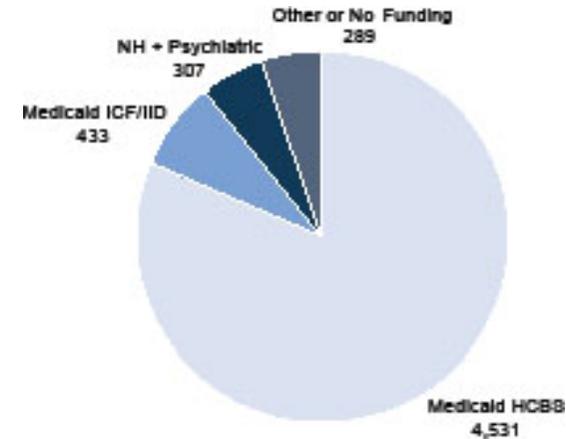
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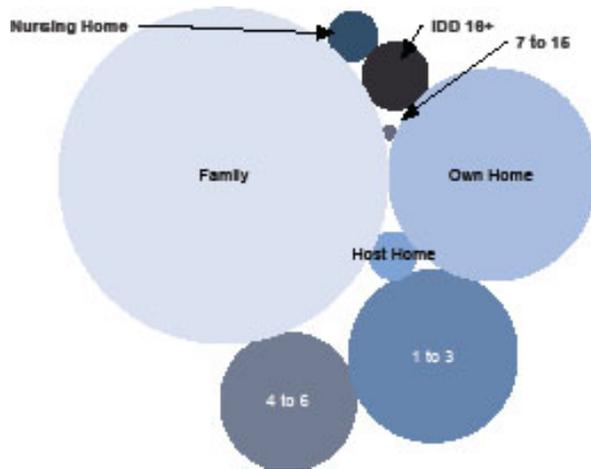
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					468	841	779	1132	1322
		Family					2398	233	210	904	1130
		Host Home					134	168	244	404	574
		1 to 3 Group Home						767	933	1025	904
Congregate IDD Settings by size and type	4 to 15	4 to 6						681	494	520	658
		1 to 6	195	344	950	1399	850	1448	1427	1545	1562
		7 to 15	551	598	399	308	240	309	213	89	121
	16+	16+ Private				254	240	240	232	229	244
		16+ Public				463	401	399	375	173	136
16+ Total	1553	980	816								
Other IDD											0
Non IDD Specific	16+	Nursing Facility				613	0	115	117	379	307
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					843	651	1227	1639	1875
		Estimated Total	2299	1722	2165	2424	4731	3638	3480	4476	5396
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				28652	24571	35609	40819	51323	52951
		HCBS Recipients per 100,000				43	111	136	165	219	244
	ICF/IID	ICF/IID Expenditures per Person				42086	54957	75404	96500	83283	130002
		ICF/IID per 100,000				45	39	38	35	23	23

## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## NEVADA

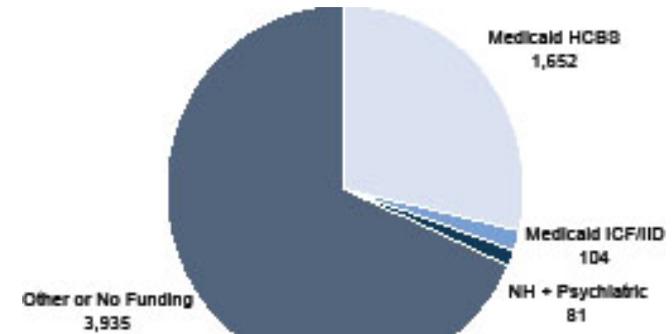
**Figure RP1:** Residence Size and Type on June 30, 2012



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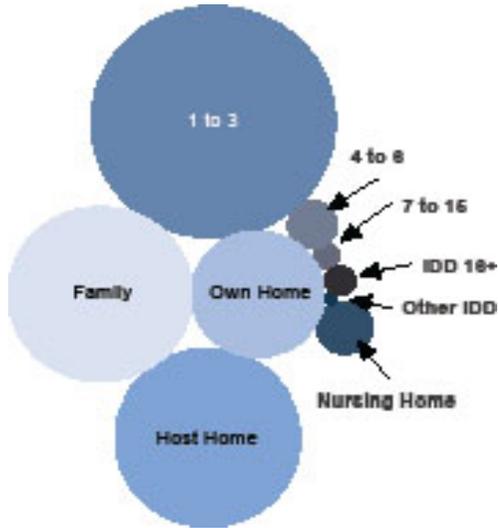
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					256	707	1293	1348	1530
		Family					964	1447	3418	3621	3826
		Host Home					77	47	39	70	75
		1 to 3 Group Home					0	0	0	0	10
Congregate IDD Settings by size and type	4 to 15	4 to 6					120	90	36	36	
		1 to 6	61	116	120	389	143	120	90	36	46
		7 to 15	20	25	138	15	19	39	0	0	6
	16+	16+ Private				0	4	0	18	60	104
		16+ Public				177	154	140	89	47	48
16+ Total		166	160	175							
		Other IDD								0	
Non IDD Specific	16+	Nursing Facility				31	32	40	31	88	81
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					115	188	407	109	188
		Estimated Total	247	301	433	581	1617	2500	3947	5182	5716
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				16563	12854	15403	32379	44517	47680
		HCBS Recipients per 100,000				11	24	40	55	60	60
	ICF/IID	ICF/IID Expenditures per Person				59091	106444	113080	134379	182906	171590
		ICF/IID per 100,000				17	15	13	8	4	4

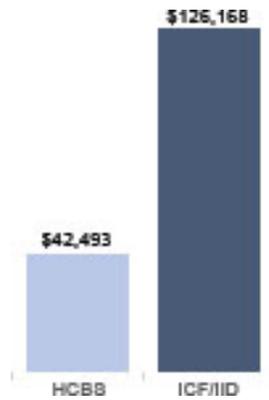
**Status and Trends in Residential and In Home Supports for People with IDD FY 2012**

**NEW HAMPSHIRE**

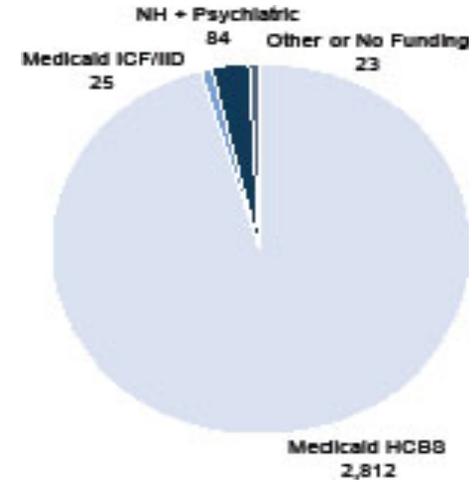
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**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



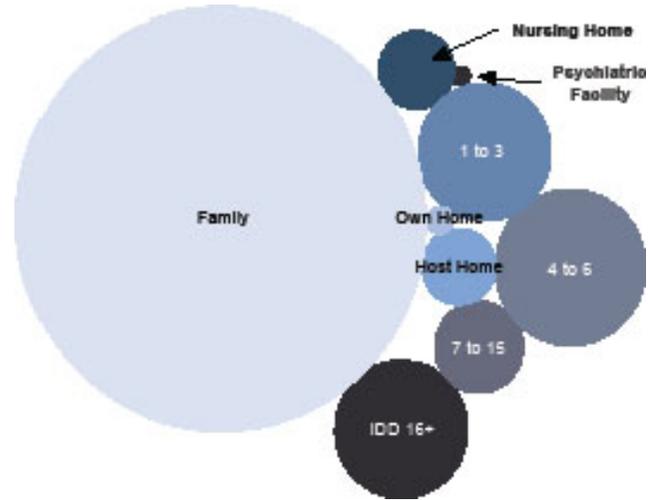
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					256	359	334	434	478
		Family					6768	165	424	506	824
		Host Home					731	952	1016	1139	933
		1 to 3 Group Home						332	283	310	227
Congregate IDD Settings by size and type	4 to 15	4 to 6						65	78	75	62
		1 to 6	62	152	648	1147	528	397	361	385	289
		7 to 15	81	141	265	132	58	0	22	22	12
	16+	16+ Private				25	22	24	25	25	25
		16+ Public				0	0	0	0	0	0
16+ Total		694	651	181							
		Other IDD									4
Non IDD Specific	16+	Nursing Facility				26	101	84	87	61	84
		Psychiatric Facility				1	6	0	0	0	0
Number of People with	All Size	Waiting list					97	84	119	19	49
		Estimated Total	837	944	1094	1304	8363	1897	2182	2511	2749
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				41047	42214	40300	40366	43152	42493
		HCBS Recipients per 100,000				86	167	200	241	308	342
	ICF/IID	ICF/IID Expenditures per Person				74815	70017	69184	93831	124423	126168
		ICF/IID per 100,000				8	2	2	2	2	2

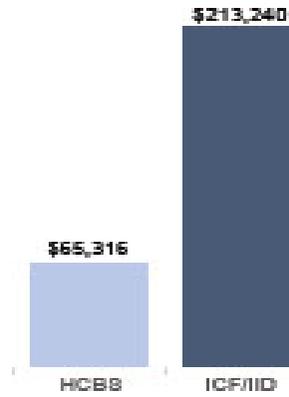
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# NEW JERSEY

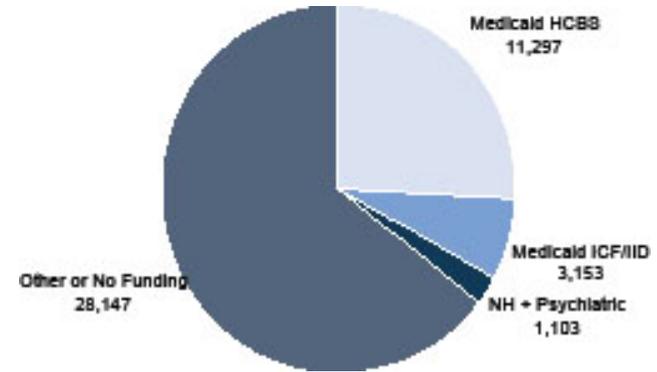
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



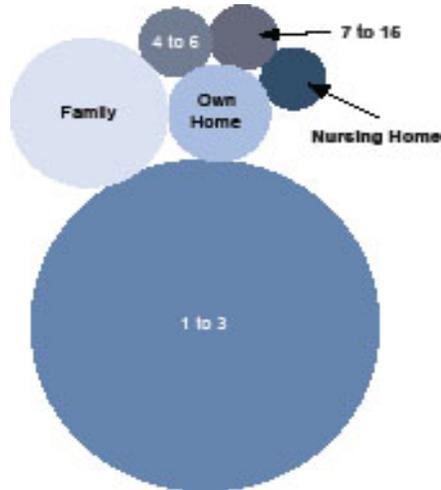
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					382	791	782	728	125
		Family					22417	16491	23095	30134	30529
		Host Home					1745	1779	1432	1126	999
		1 to 3 Group Home						1094	1404	3598	2100
Congregate IDD Settings by size and type	4 to 15	4 to 6						2065	2956	4329	4167
		1 to 6	280	1076	2556	3954	2378	3159	4359	7927	6267
		7 to 15	197	439	462	0	533	842	782	931	1437
	16+	16+ Private				0	690	73	713	368	806
		16+ Public				4932	4241	3514	3070	2703	2434
16+ Total		8836	7216	5376							
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				210	971	468	714	DNF	1043
		Psychiatric Facility				6	691	0	DNF	0	60
Number of People with	All Size	Waiting list					3944	5012	3386	DNF	DNF
		Estimated Total	9313	8731	8394	8886	32386	26589	34233	44517	43700
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				25035	29563	42973	43995	55351	65316
		HCBS Recipients per 100,000				47	66	82	104	115	127
	ICF/IID	ICF/IID Expenditures per Person				74922	88108	109142	185243	211403	213240
		ICF/IID per 100,000				49	51	41	35	33	39

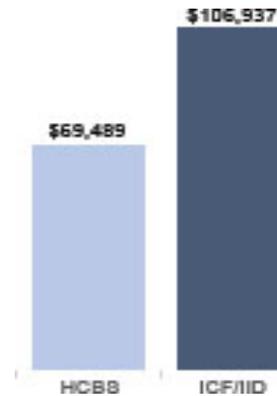
## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## NEW MEXICO

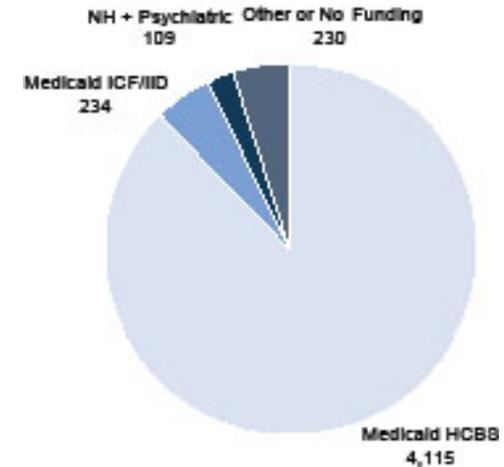
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:**  
Annual Medicaid  
Expenditures  
Per Person



**Figure RP3:** Number and Percent of Recipients  
by Funding Authority on June 30, 2012



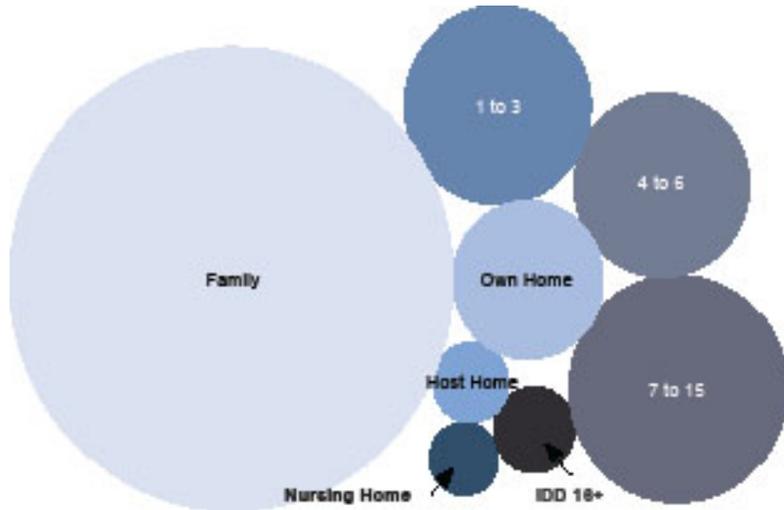
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					164	451	471	451	274
		Family					2538	393	942	1565	651
		Host Home					25	219	391	422	0
		1 to 3 Group Home						744	737	752	2934
Congregate IDD Settings by size and type	4 to 15	4 to 6						224	206	363	134
		1 to 6	113	139	423	396	127	968	943	1115	3068
		7 to 15	100	155	479	360	151	278	130	120	120
	16+	16+ Private				0	110	16	0	0	0
		16+ Public				473	145	0	0	0	0
16+ Total		581	552	500							
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				88	138	94	110	103	109
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					1790	190	3359	4998	4998
		Estimated Total	794	846	1402	1229	3290	2326	2877	3673	4222
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				19944	46259	52091	62374	73966	69489
		HCBS Recipients per 100,000				10	91	116	185	193	157
	ICF/IID	ICF/IID Expenditures per Person				49249	63075	68680	96016	108309	106937
		ICF/IID per 100,000				46	28	22	11	11	11

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# NEW YORK

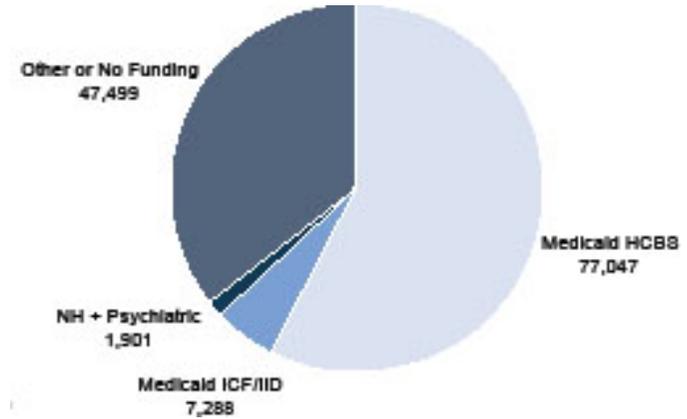
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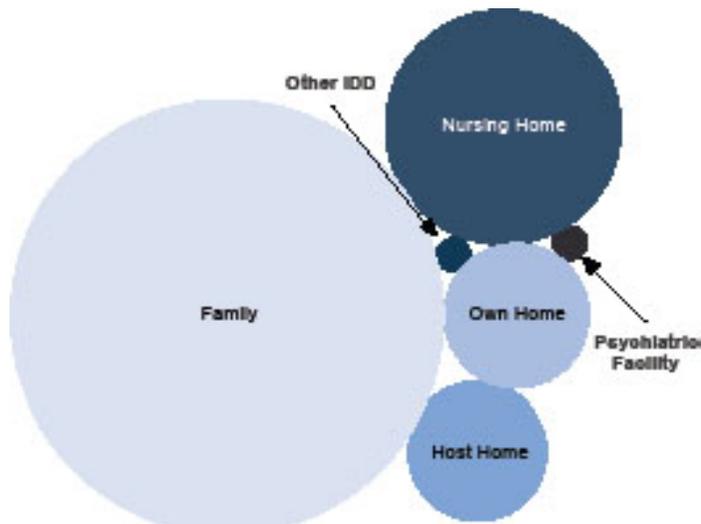
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					1063	1514	7690	7911	9109
		Family					82219	63343	79476	76814	78744
		Host Home					4144	4287	3322	2471	2307
		1 to 3 Group Home						3020	3234	3313	3348
Congregate IDD Settings by size and type	4 to 15	4 to 6						5855	8769	11420	11697
		1 to 6	3496	4271	7506	6165	6754	8875	12030	14703	15045
		7 to 15	1817	5609	8537	15751	17652	18238	19039	18788	18822
	16+	16+ Private				1641	1409	1282	1123	960	990
		16+ Public				7489	3399	2411	2225	1981	1633
16+ Total		21239	15437	11274							
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				1550	8454	1956	1215	DNF	1901
		Psychiatric Facility				20	150	DNF	0	0	0
Number of People with	All Size	Waiting list					5397	5959	5273	3864	6971
		Estimated Total	26552	25317	27317	31046	116640	99950	124905	123628	128551
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				0	26717	46937	61363	72031	70973
		HCBS Recipients per 100,000				0	150	190	267	342	394
	ICF/IID	ICF/IID Expenditures per Person				92299	174361	210643	317721	450043	444470
		ICF/IID per 100,000				99	65	53	44	39	37

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# NORTH CAROLINA

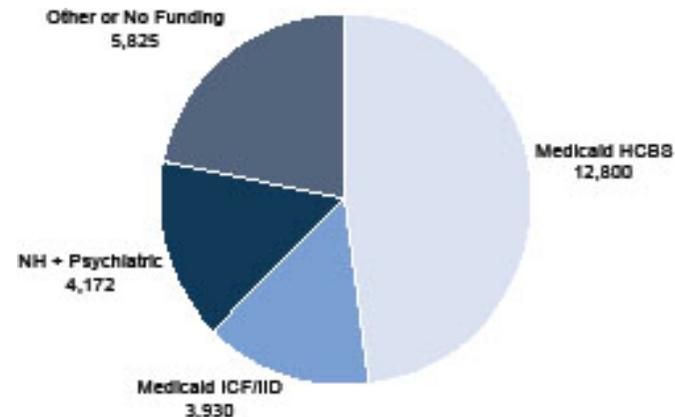
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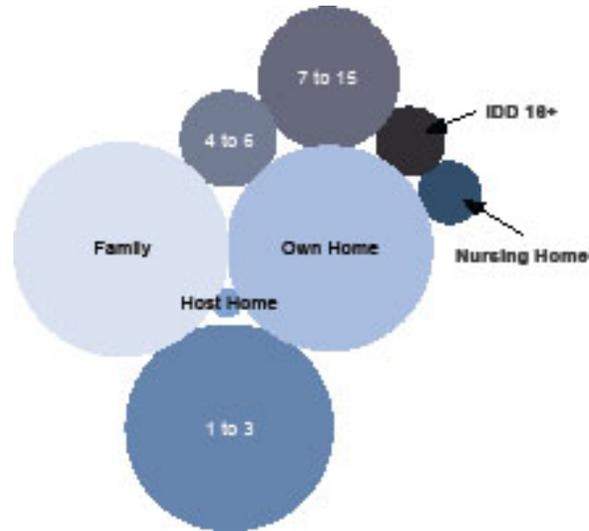
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					DNF	594	2292	1486	1536
		Family					DNF	7193	17058	13389	13765
		Host Home					160	358	295	1127	1400
		1 to 3 Group Home						1491	DNF	DNF	DNF
Congregate IDD Settings by size and type	4 to 15	4 to 6						5747	DNF	1526	DNF
		1 to 6	239	484	992	2643	3486	7238	5815	3575	3280
		7 to 15	153	179	237	251	751	596	1062	346	DNF
	16+	16+ Private				606	559	607	760	572	DNF
		16+ Public				2528	2227	1936	1708	1598	1424
		16+ Total	4032	3778	3261						
		Other IDD								82	
Non IDD Specific	16+	Nursing Facility				465	850	899	531	4257	4086
		Psychiatric Facility				4	0	0	91		86
Number of People with	All Size	Waiting list					DNF	2074	DNF	397	8425
		Estimated Total	4424	4441	4490	6028	DNF	18522	28990	22094	26727
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				16450	18286	34107	39530	54831	48422
		HCBS Recipients per 100,000				12	43	67	78	116	131
	ICF/IID	ICF/IID Expenditures per Person				57292	75742	87802	103802	124544	134533
		ICF/IID per 100,000				65	63	56	50	41	40

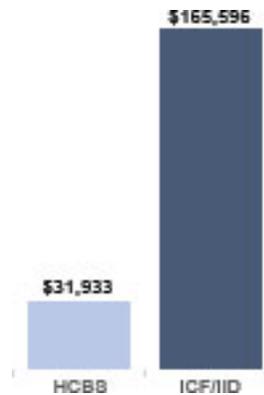
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# NORTH DAKOTA

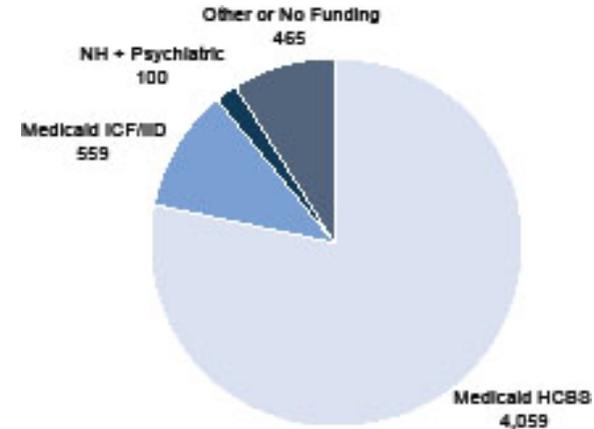
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**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



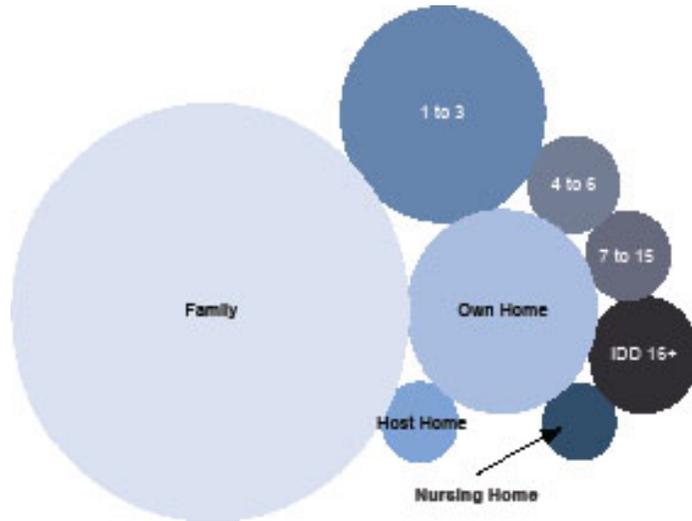
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					882	966	1070	1267	1126
		Family					2098	393	569	907	1225
		Host Home					42	38	27	27	20
		1 to 3 Group Home						0	0	0	0
Congregate IDD Settings by size and type	4 to 15	4 to 6						201	192	251	241
		1 to 6	23	12	269	965	198	201	192	251	241
		7 to 15	47	146	702	595	503	495	536	487	520
	16+	16+ Private				67	114	114	54	30	30
		16+ Public				211	148	153	140	115	94
		16+ Total	1306	1076	1412						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				182	175	105	118	193	100
		Psychiatric Facility				1	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					0	0	0	0	0
		Estimated Total	1376	1234	2383	1838	3985	2360	2588	3084	3356
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				14046	16342	21675	18683	25336	31933
		HCBS Recipients per 100,000				27	277	302	483	573	580
	ICF/IID	ICF/IID Expenditures per Person				64077	70090	79969	107014	155783	165596
		ICF/IID per 100,000				100	98	87	96	86	80

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# OHIO

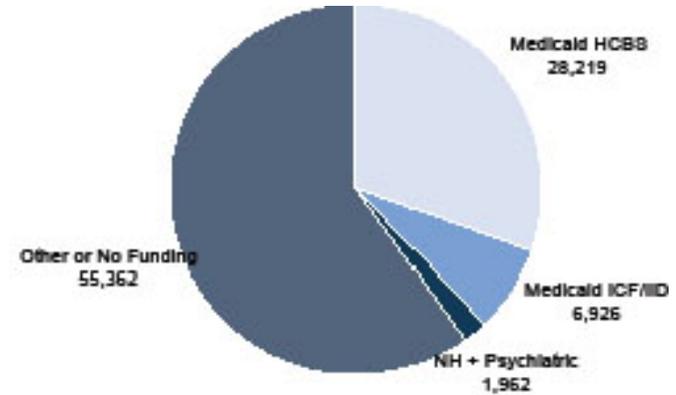
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**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



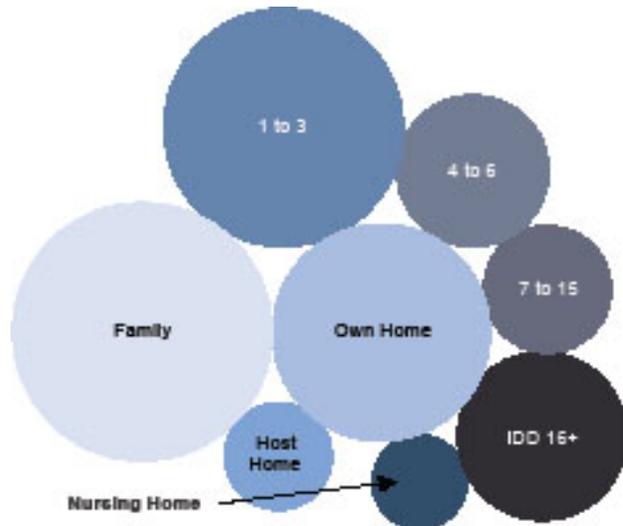
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					3058	4175	3110	11032	13641
		Family					26912	12725	12831	19939	58851
		Host Home					267	698	908	892	2123
		1 to 3 Group Home						DNF	DNF	DNF	873
Congregate IDD Settings by size and type	4 to 15	4 to 6						DNF	DNF	432	2245
		1 to 6	620	1347	2168	3707	2307	2415	2660	3623	3118
		7 to 15	768	1587	2270	2993	3099	2772	2609	2817	2618
	16+	16+ Private				4458	3686	3493	3086	2532	3230
		16+ Public				2449	2087	1990	1666	1329	1134
		16+ Total	9429	7939	6860						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				2823	2169	2213	DNF	DNF	1962
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					DNF	6816	DNF	DNF	DNF
		Estimated Total	10817	10872	11298	13607	41416	28269	26870	42164	86677
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				0	37549	31651	40623	40984	DNF
		HCBS Recipients per 100,000				0	23	50	102	232	DNF
	ICF/IID	ICF/IID Expenditures per Person				45433	60991	72632	144425	127512	112557
		ICF/IID per 100,000				75	69	68	61	52	60

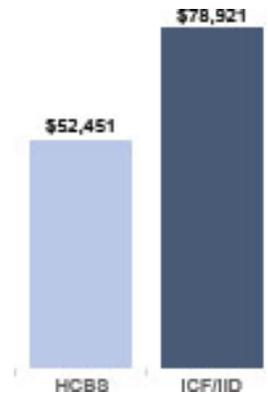
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# OKLAHOMA

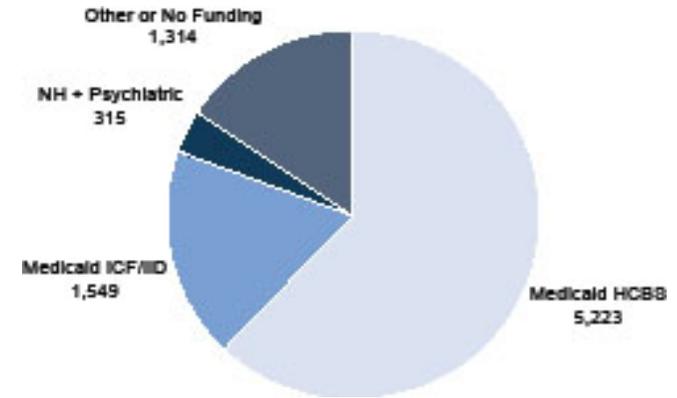
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



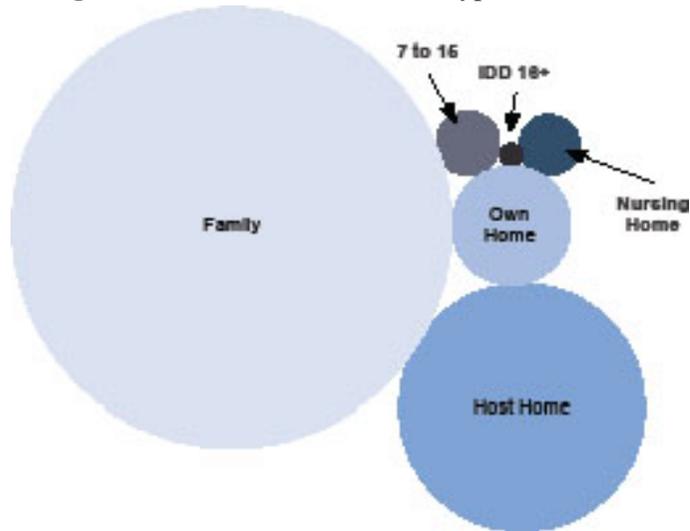
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					813	1560	2300	1636	1667
		Family					5239	1783	4460	2516	2363
		Host Home					236	363	542	429	407
		1 to 3 Group Home						6	21	0	0
Congregate IDD Settings by size and type	4 to 15	4 to 6						568	802	740	752
		1 to 6	11	6	393	720	474	574	823	743	752
		7 to 15	19	86	424	283	263	222	326	461	574
	16+	16+ Private				2915	1684	1339	906	839	774
		16+ Public				937	553	339	364	252	235
16+ Total		3082	2920	3014							
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				1850	930	837	805	406	315
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					1500	2482	3853	5737	6808
		Estimated Total	3112	3012	3831	4855	9262	6180	9721	6876	7087
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				14002	46455	49491	47916	54334	52451
		HCBS Recipients per 100,000				27	69	86	125	138	137
	ICF/IID	ICF/IID Expenditures per Person				38008	40458	57289	73396	80516	78921
		ICF/IID per 100,000				92	69	52	47	41	41

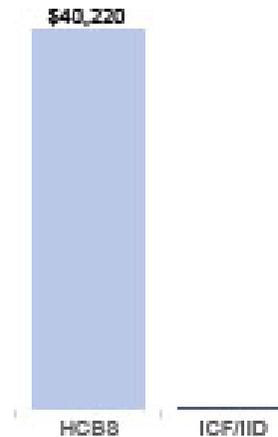
## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## OREGON

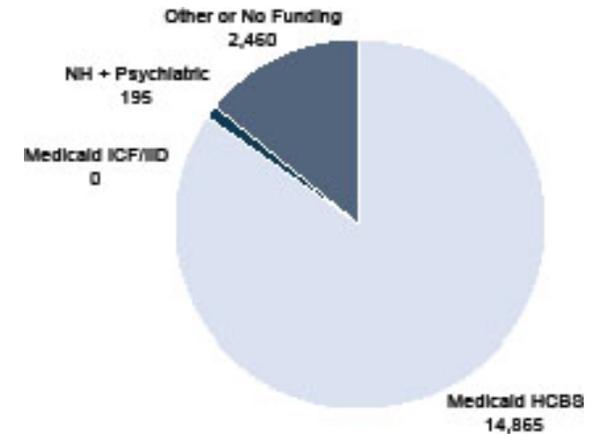
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



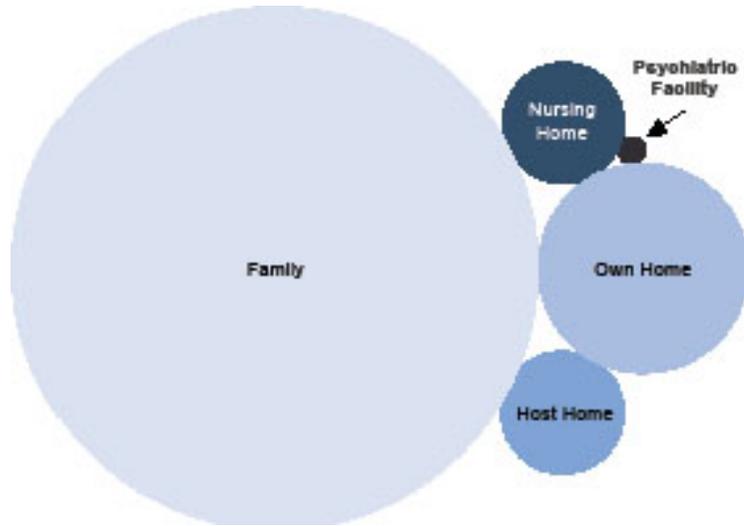
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					647	805	697	764	764
		Family					4600	3188	3468	8589	10479
		Host Home					667	1278	1967	2655	3373
		1 to 3 Group Home						292	182	300	546
Congregate IDD Settings by size and type	4 to 15	4 to 6						1858	1924	1720	2018
		1 to 6	49	11	1098	2344	1404	2150	2106	2020	2564
		7 to 15	325	490	568	555	561	509	434	216	218
	16+	16+ Private				239	192	161	100	626	27
		16+ Public				640	429	60	43	0	0
		16+ Total	2233	1979	14706						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				452	265		168	9	195
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					3505	2732	1570	3219	0
		Estimated Total	2607	2480	3142	3778	8500	8151	8815	14870	17520
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				18825	39292	39879	37526	41230	40220
		HCBS Recipients per 100,000				75	79	170	243	326	381
	ICF/IID	ICF/IID Expenditures per Person				127146	178120	408664	251996	99678	
		ICF/IID per 100,000				26	13	2	1	1	0

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# PENNSYLVANIA

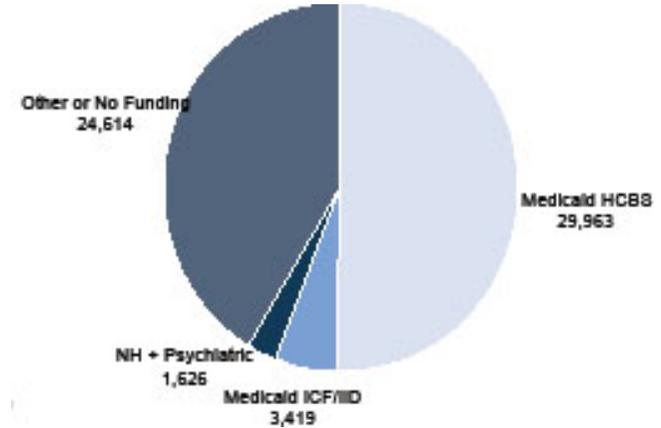
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



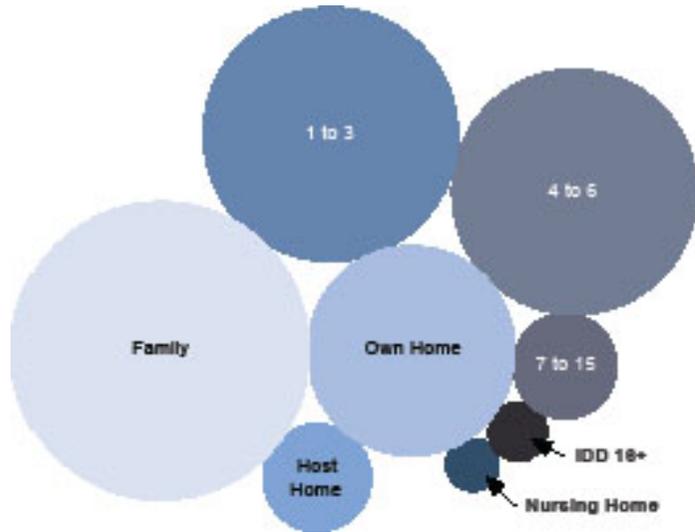
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					1703	1761	1519	5168	4656
		Family					16773	1076	13699	32417	29009
		Host Home					1145	3600	1600	1434	1590
		1 to 3 Group Home						6611	236	4715	DNF
Congregate IDD Settings by size and type	4 to 15	4 to 6						1835	8065	3838	DNF
		1 to 6	1078	2588	4774	7809	6979	8446	8301	9553	DNF
		7 to 15	1310	1075	1880	813	728	689	1296	2014	DNF
	16+	16+ Private				2411	2385	2057	1773	1804	DNF
		16+ Public				3878	3164	1969	1451	1189	1106
		16+ Total	14318	11904	8151						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				509	1544	2573	DNF	DNF	1549
		Psychiatric Facility				0	27	170	0	0	77
Number of People with IDD	All Size	Waiting list					9535	3442	5149	1613	1979
		Estimated Total	16706	15567	14805	14911	37877	19598	29639	53579	57309
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				51479	56073	40277	41809	50788	60618
		HCBS Recipients per 100,000				20	50	137	200	254	235
	ICF/IID	ICF/IID Expenditures per Person				65671	83596	100509	142243	174983	172884
		ICF/IID per 100,000				59	53	40	33	27	DNF

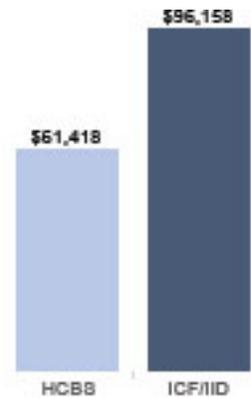
## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## RHODE ISLAND

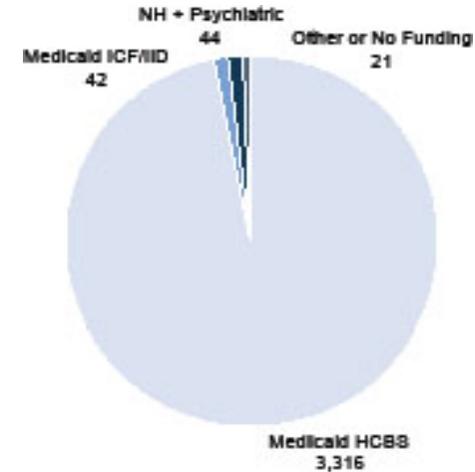
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



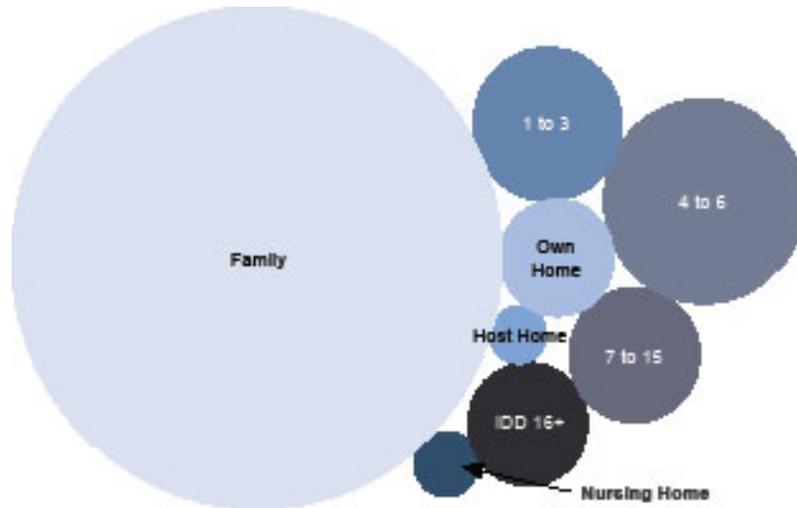
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					107	577	757	680	676
		Family					3014	693	696	879	1380
		Host Home					69	57	65	166	183
		1 to 3 Group Home						296	331	254	162
Congregate IDD Settings by size and type	4 to 15	4 to 6						774	817	927	949
		1 to 6	0	153	316	826	802	1070	1148	1177	1111
		7 to 15	98	228	545	345	337	180	177	147	166
	16+	16+ Private				18	0	0	23	25	21
		16+ Public				178	0	0	0	17	33
16+ Total			631	312							
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				40	0	162	91	92	44
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					100	0	0		0
		Estimated Total	1070	1012	1173	1367	4329	2577	2866	3091	3614
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				18079	42111	58935	72064	74206	61418
		HCBS Recipients per 100,000				79	191	236	278	311	316
	ICF/IID	ICF/IID Expenditures per Person				86564	128584	349560	176700	279563	96158
		ICF/IID per 100,000				76	23	2	4	4	4

## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## SOUTH CAROLINA

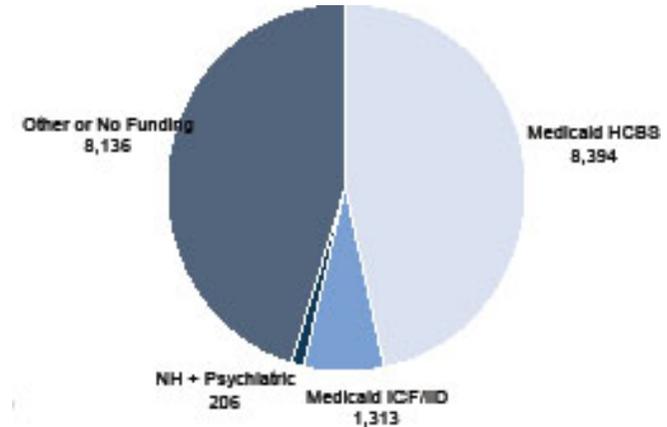
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



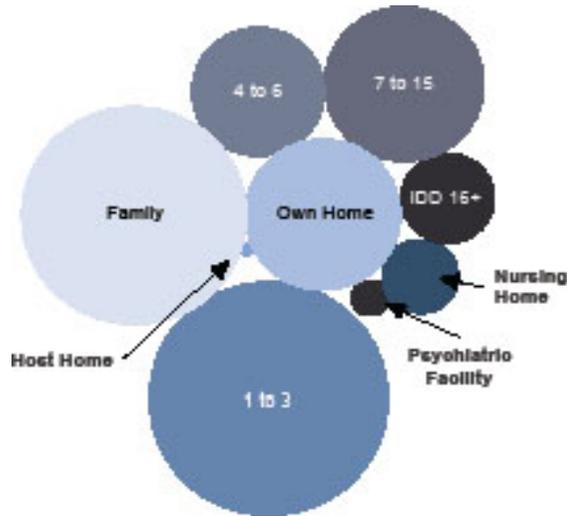
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					678	641	569	668	668
		Family					9995	12258	13306	12238	12427
		Host Home					131	123	141	139	160
		1 to 3 Group Home						607	517	368	328
Congregate IDD Settings by size and type	4 to 15	4 to 6						997	1436	1998	2057
		1 to 6	9	3	263	927	841	1604	1953	2366	2385
		7 to 15	135	191	988	973	1087	1028	910	897	890
	16+	16+ Private				92	78	90	0	0	0
		16+ Public				2199	1548	1103	933	797	745
		16+ Total	3982	3519	2610						
		Other IDD								0	
Non IDD Specific	16+	Nursing Facility				98	0	226	223	181	206
		Psychiatric Facility				0	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					1339	1513	1768	335	295
		Estimated Total	4126	3713	3861	4191	14358	16847	17812	17075	17481
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				0	15718	25423	32895	29356	DNF
		HCBS Recipients per 100,000				0	55	109	112	167	DNF
	ICF/IID	ICF/IID Expenditures per Person				45519	65377	79013	54295	100695	114938
		ICF/IID per 100,000				91	73	54	40	30	28

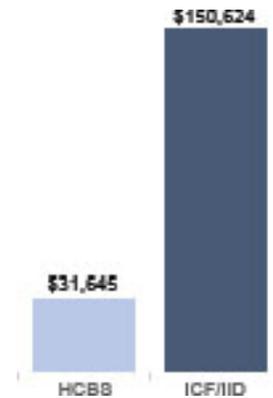
**Status and Trends in Residential and In Home Supports for  
People with IDD FY 2012**

**SOUTH DAKOTA**

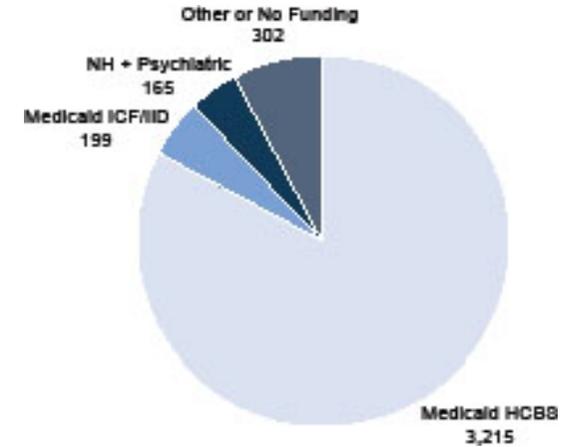
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:**  
Annual Medicaid  
Expenditures  
Per Person



**Figure RP3:** Number and Percent of Recipients  
by Funding Authority on June 30, 2012



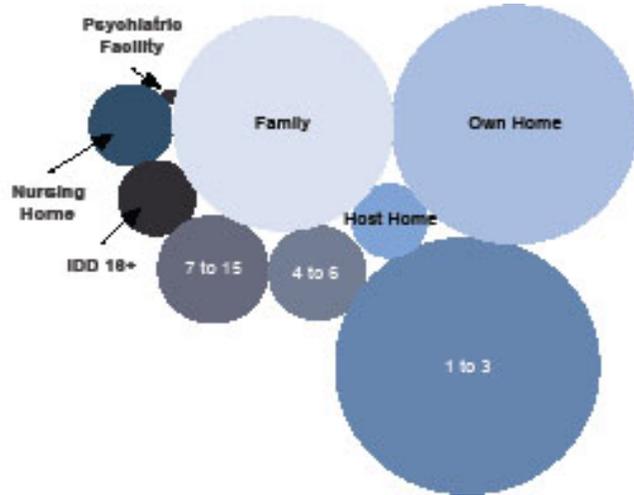
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					658	600	597	527	557
		Family					2052	551	761	1033	1161
		Host Home					23	24	7	5	4
		1 to 3 Group Home						435	568	725	747
Congregate IDD Settings by size and type	4 to 15	4 to 6						157	304	514	404
		1 to 6	10	8	248	555	283	592	872	1239	1151
		7 to 15	242	471	828	739	684	650	586	416	585
	16+	16+ Private				0	0	0	16	0	59
		16+ Public				378	252	196	169	144	140
16+ Total		925	736	485							
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				225	169	187	185	144	134
		Psychiatric Facility				1	16	15	21	31	31
Number of People with IDD	All Size	Waiting list					5	12	5	2	0
		Estimated Total	1177	1215	1561	1672	3952	2613	3008	3364	3822
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				16921	26180	25093	29625	31893	31645
		HCBS Recipients per 100,000				112	175	264	318	371	386
	ICF/IID	ICF/IID Expenditures per				48534	71760	77919	126015	170305	150624
		ICF/IID per 100,000				78	47	31	22	18	24

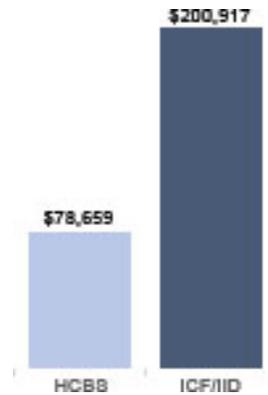
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# TENNESSEE

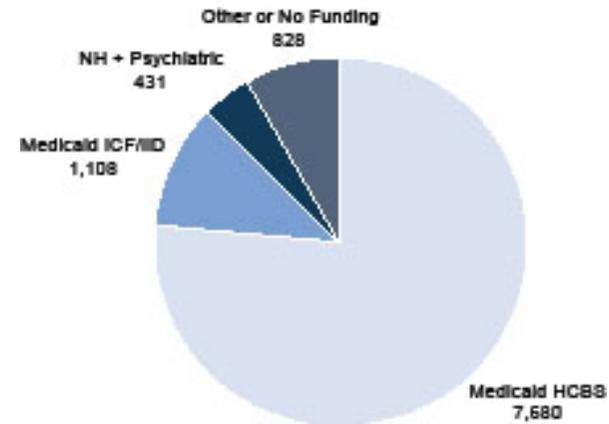
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



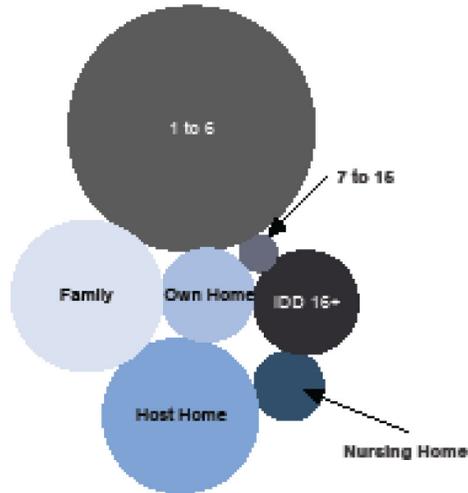
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012	
Individualized Settings	1 to 3	Own Home					567	1670	2420	3347	3647	
		Family					6852	3575	3363	3950	2928	
		Host Home				161	279	246	240	317	338	
		1 to 3 Group Home						28	309	233	233	
Congregate IDD Settings by size and type	4 to 15	4 to 6						307	371	357	558	
		1 to 6	210	343	708	654	370	335	680	610	791	
		7 to 15	495	729	778	1401	1461	1137	892	649	733	
	16+	16+ Private				226	144	144	144	144	144	168
		16+ Public				1941	1388	503	662	384	183	
16+ Total		2500	2456	2308								
		Other IDD									0	
Non IDD Specific	16+	Nursing Facility			1180	883	1351	892	895	369	420	
		Psychiatric Facility				5	0	0	29	35	11	
Number of People with IDD	All Size	Waiting list					659	910	1491	1158	1654	
		Estimated Total	3205	3528	3794	4383	11061	8000	9401	9401	9219	
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				19672	23645	37100	73704	75936	78659	
		HCBS Recipients per 100,000				12	57	84	90	119	119	
	ICF/IID	ICF/IID Expenditures per				42017	99360	155340	217565	207079	200917	
		ICF/IID per 100,000				48	38	27	81	17	17	

## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## TEXAS

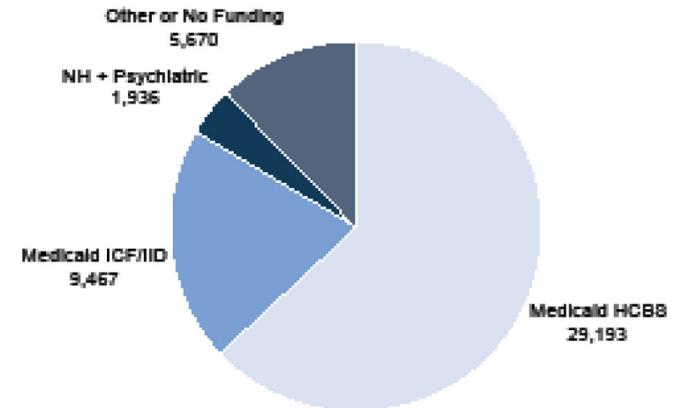
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



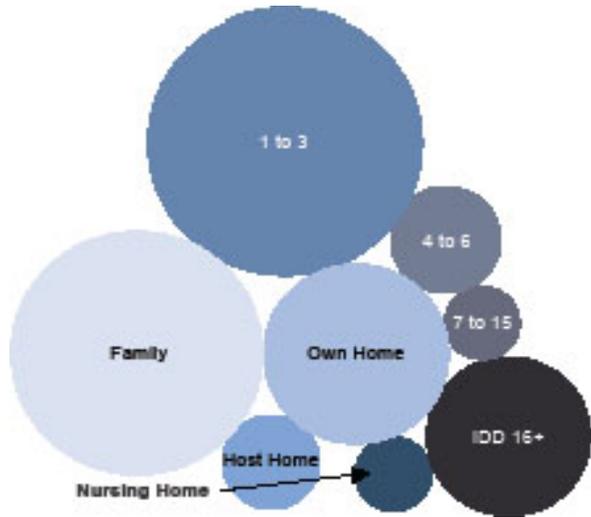
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					DNF	2282	2396	3605	3485
		Family					DNF	1797	3277	5080	9238
		Host Home					DNF	1053	3168	5665	9738
		1 to 3 Group Home						1400	DNF	DNF	DNF
Congregate IDD Settings by size and type	4 to 15	4 to 6						5865	DNF	4420	DNF
		1 to 6	101	76	910	1987	4263	7265	8153	4420	11283
		7 to 15	434	1053	1104	793	904	582	689	567	555
	16+	16+ Private				2780	2322	2491	1579	850	574
		16+ Public				6880	5735	5470	4989	4207	3787
		16+ Total	14370	14634	10894						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				3253	3258	2919	1145	DNF	1936
		Psychiatric Facility				0	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					DNF	4199	DNF	DNF	DNF
		Estimated Total	14905	15763	12908	12440	DNF	20941	24251	24394	40596
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per				14767	22685	42034	34128	41022	36170
		HCBS Recipients per 100,000				6	19	31	54	89	112
	ICF/IID	ICF/IID Expenditures per				41055	45511	54188	67570	96981	108735
		ICF/IID per 100,000				62	70	85	52	40	36

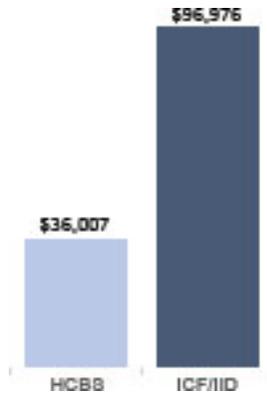
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012



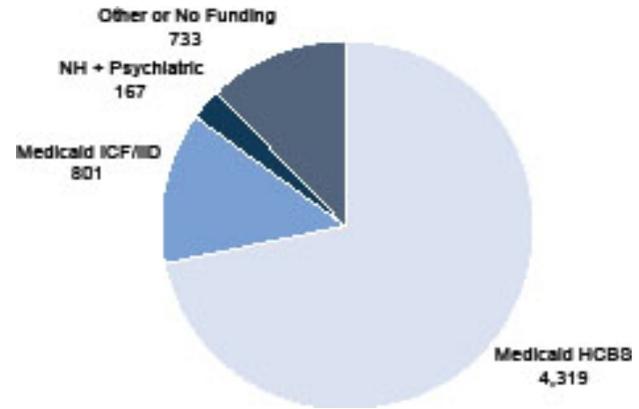
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



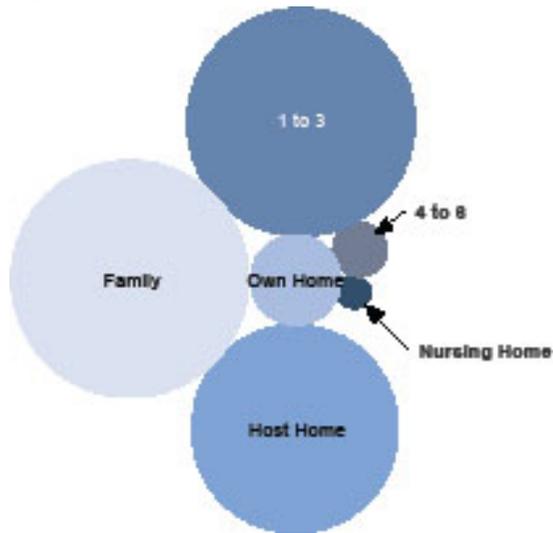
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					434	448	612	885	985
		Family					3367	1387	1614	1843	1814
		Host Home					83	143	247	263	269
		1 to 3 Group Home						782	816	893	909
Congregate IDD Settings by size and type	4 to 15	4 to 6						240	311	341	348
		1 to 6	68	50	349	782	724	1022	1127	1233	1257
		7 to 15	95	145	211	340	276	160	160	172	162
	16+	16+ Private				525	543	512	524	523	566
		16+ Public				423	311	236	230	216	207
16+ Total		1217	1155	1135							
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				283	241	191	248	95	167
		Psychiatric Facility				0	0	0	0	0	0
Number of People with	All Size	Waiting list					950	1303	244	1822	1834
		Estimated Total	1380	1350	1695	2070	5738	3908	4514	5135	5427
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				1B207	131B8	23573	26854	34643	36007
		HCBS Recipients per 100,000				BE	1D7	141	155	155	151
	ICF/IID	ICF/IID Expenditures per				7434?	735B2	70184	72435	73959	56976
		ICF/IID per 100,000				54	44	34	32	28	28

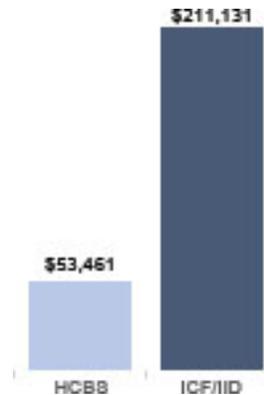
## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## VERMONT

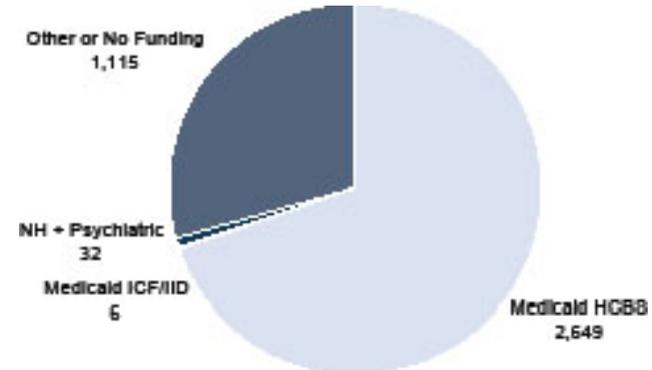
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



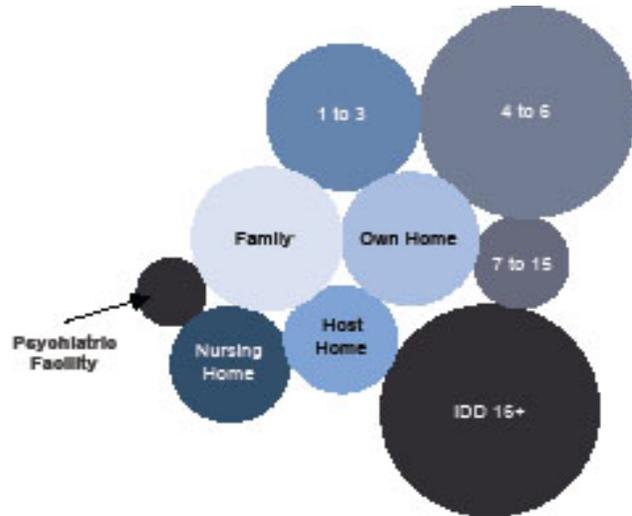
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					147	147	184	236	248
		Family					1454	1003	1258	1634	1725
		Host Home					559	613	979	1237	1300
		1 to 3 Group Home						30	42	56	47
Congregate IDD Settings by size and type	4 to 15	4 to 6						73	73	75	90
		1 to 6	262	322	285	504	146	103	115	131	137
		7 to 15	143	120	96	0	0	0	0	0	0
	16+	16+ Private				0	0	0	0	0	0
		16+ Public				160	0	0	0	0	0
		16+ Total	517	356	196						
Other IDD										0	
Non IDD Specific	16+	Nursing Facility				91	66	42	27	28	32
		Psychiatric Facility				1	0	0	DNF	DNF	0
Number of People with IDD	All Size	Waiting list					23	7	0	0	0
		Estimated Total	922	798	577	664	2306	2066	2563	3238	3442
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				21144	40775	35638	46017	54040	53461
		HCBS Recipients per 100,000				86	190	277	322	393	423
	ICF/IID	ICF/IID Expenditures per				92297	110397	138446	157468	DNF	211131
		ICF/IID per 100,000				38	3	2	1	1	1

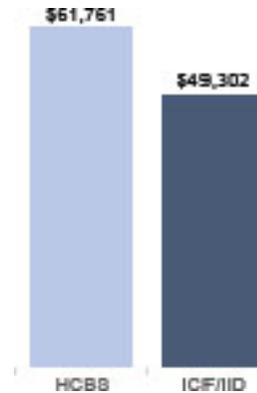
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# VIRGINIA

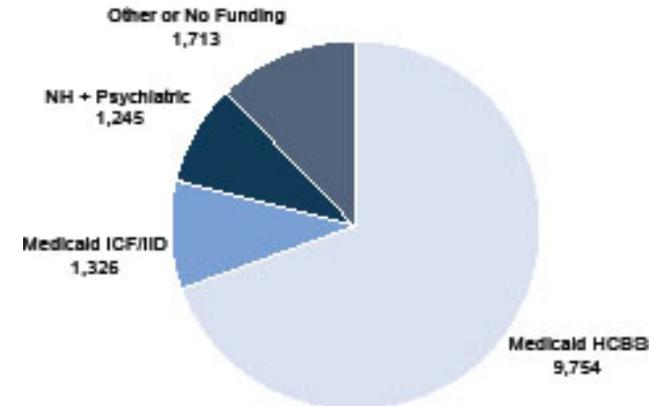
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



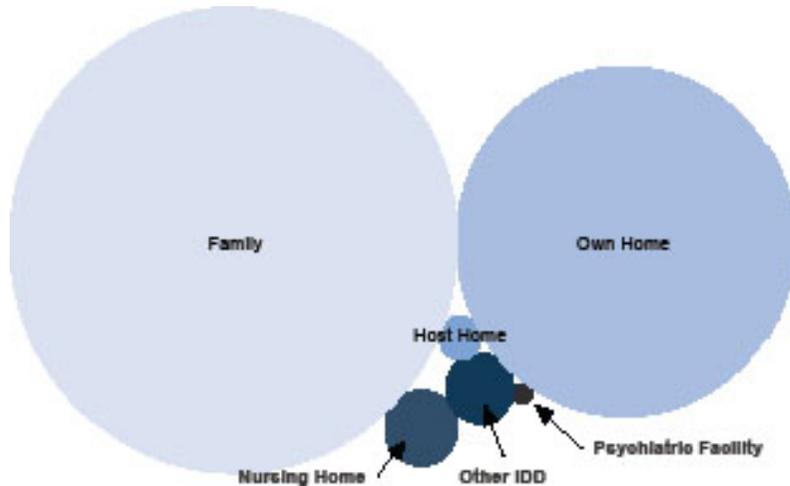
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					42	1463	1735	1656	1235
		Family					3810	2896	3213	1971	1445
		Host Home					31		351	578	801
		1 to 3 Group Home						DNF	DNF	1093	372
Congregate IDD Settings by size and type	4 to 15	4 to 6						DNF	DNF	1240	2166
		1 to 6	123	161	210	223	398	8	DNF	2333	2538
		7 to 15	153	281	144	394	713	75	DNF	411	594
	16+	16+ Private				92	0	132	DNF	1493	2217
		16+ Public				3575	2189	1653	1495	1153	948
		16+ Total	4441	3778	3078						
Non IDD Specific	16+	Nursing Facility				1993	0	1272	762	864	933
		Psychiatric Facility				9	0	140	148	345	312
Number of People with IDD	All Size	Waiting list					DNF	1316	2028	4395	4649
		Estimated Total	4717	4220	3432	3284	7183	6657	DNF	8695	11023
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				810	34741	31186	43142	60885	61761
		HCBS Recipients per 100,000				5	22	66	99	111	119
	ICF/IID	ICF/IID Expenditures per				56732	65205	98041	126770	176590	49302
		ICF/IID per 100,000				43	35	26	24	19	16

## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# WASHINGTON

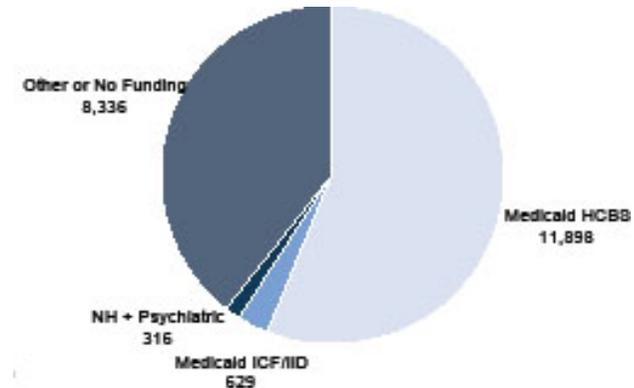
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:**  
Annual Medicaid  
Expenditures  
Per Person



**Figure RP3:** Number and Percent of Recipients  
by Funding Authority on June 30, 2012



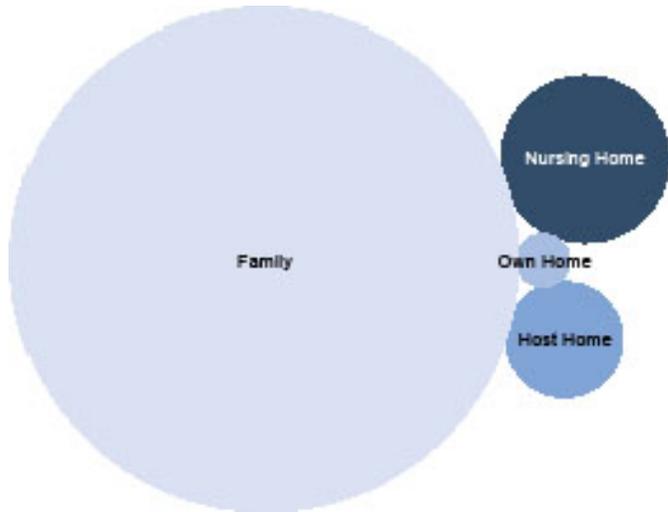
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					2417	3488	3724	3727	6370
		Family					8368	7030	12994	14442	11148
		Host Home				521	1812	2465	214	129	96
		1 to 3 Group Home						178	42	89	DNF
Congregate IDD Settings by size and type	4 to 15	4 to 6						131	1711	2015	DNF
		1 to 6	102	194	1881	3549	213	309	1753	2104	DNF
		7 to 15	347	473	845	402	400	260	307	169	DNF
	16+	16+ Private				471	223	216	240	160	DNF
		16+ Public				1575	1281	1128	961	901	576
		16+ Total	3979	3067	2823						
		Other IDD								257	
Non IDD Specific	16+	Nursing Facility			500	700	492	462	365	329	294
		Psychiatric Facility				2	0	0	0	0	22
Number of People with	All Size	Waiting list					125	DNF	DNF	DNF	DNF
		Estimated Total	4428	3734	5549	6518	14714	14896	20193	21632	21236
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				17427	20954	20462	36706	37018	46302
		HCBS Recipients per 100,000				35	83	152	151	169	173
	ICF/IID	ICF/IID Expenditures per				81681	102378	140429	158544	195388	213619
		ICF/IID per 100,000				39	21	16	13	11	3

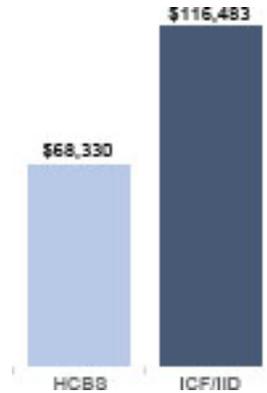
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# WEST VIRGINIA

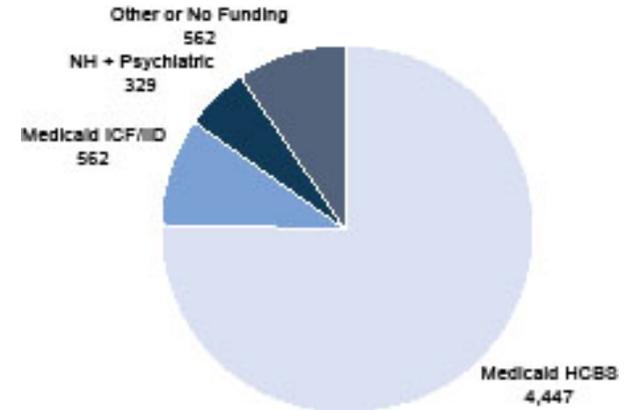
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



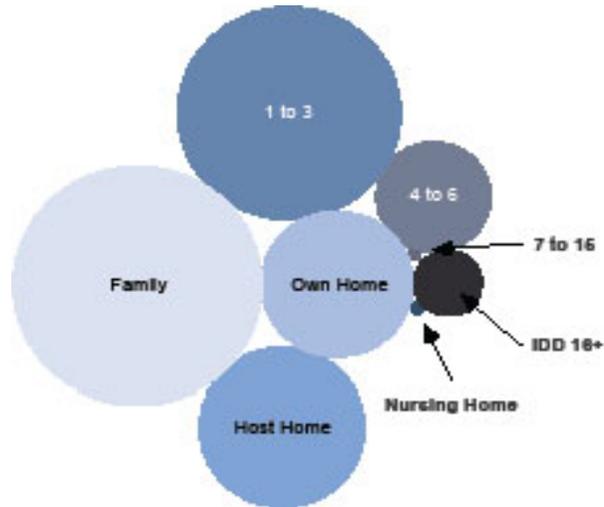
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					144	203	737	753	32
		Family					2594	873	2343	2846	2994
		Host Home					519	549	335	165	156
		1 to 3 Group Home						187	128	218	1165
Congregate IDD Settings by size and type	4 to 15	4 to 6						287	171	171	DNF
		1 to 6	24	29	352	446	459	474	298	389	DNF
		7 to 15	32	24	216	409	666	428	555	500	DNF
	16+	16+ Private				237	99	0	59	47	DNF
		16+ Public				136	75	0	0	0	0
16+ Total		950	978	523							
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				211	30	40	DNF	DNF	329
		Psychiatric Facility				2	0	7	22	0	0
Number of People with IDD	All Size	Waiting list					DNF	218	210	409	646
		Estimated Total	1006	1031	1091	1228	4556	2529	4327	4700	5338
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				24310	26982	45057	47540	55553	68330
		HCBS Recipients per 100,000				23	73	108	201	238	240
	ICF/IID	ICF/IID Expenditures per				23085	90564	106055	106992	131226	116483
		ICF/IID per 100,000				38	32	25	28	26	DNF

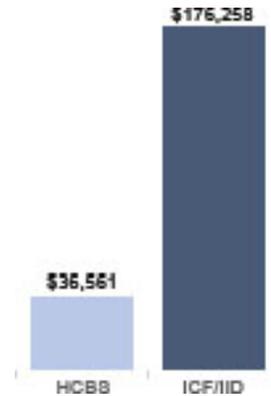
# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# WISCONSIN

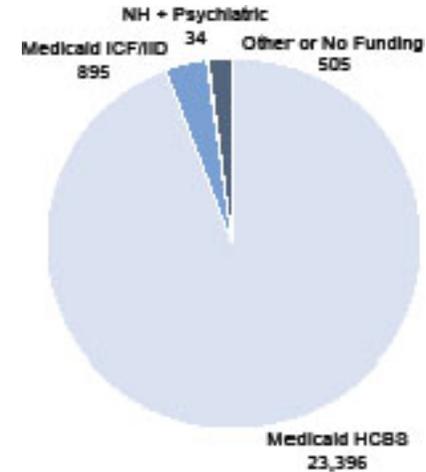
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



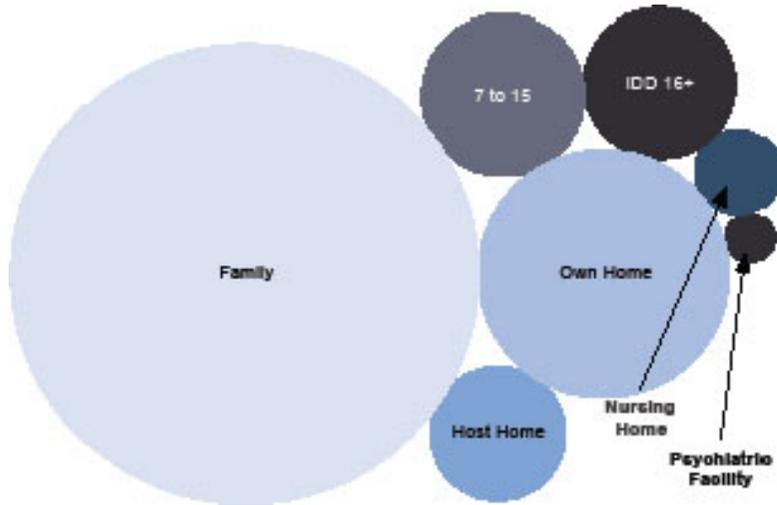
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					4315	5062	5677	5823	4307
		Family					30369	5633	2152	7663	11524
		Host Home					1800	2578	3390	1280	5085
		1 to 3 Group Home						0	0	0	0
Congregate IDD Settings by size and type	4 to 15	4 to 6						780	1016	2858	2465
		1 to 6	194	324	2404	4655	1757	780	1016	2858	2465
		7 to 15	960	1282	1786	1510	830	807	1083	2040	28
	16+	16+ Private				2438	2170	1969	1174	273	477
		16+ Public				1621	1137	871	581	449	390
		16+ Total	4494	4079	3528						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				995	672	471	89	153	34
		Psychiatric Facility				2	0	0	0	0	0
Number of People with IDD	All Size	Waiting list					2560	2250	DNF	4783	924
		Estimated Total	5648	5645	7718	10224	42438	17700	15073	20386	24324
Recipients and Expenditures by 100,000 of Population	HCBS	HCBS Expenditures per Person				18340	20344	28596	33071	35420	36561
		HCBS Recipients per 100,000				33	97	178	235	345	409
	ICF/IID	ICF/IID Expenditures per				41217	59285	88901	108328	188655	176258
		ICF/IID per 100,000				83	65	63	33	14	13

# Status and Trends in Residential and In Home Supports for People with IDD FY 2012

# WYOMING

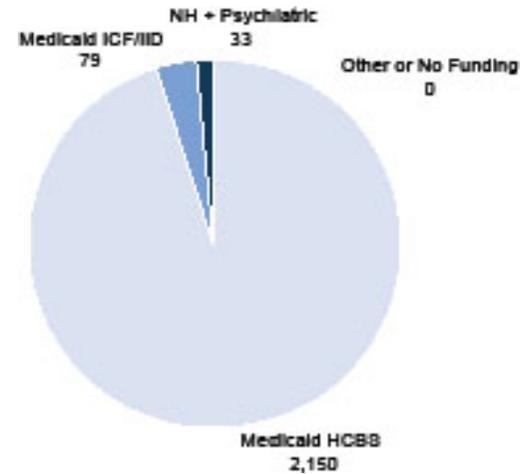
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Annual Medicaid Expenditures Per Person



**Figure RP3:** Number and Percent of Recipients by Funding Authority on June 30, 2012



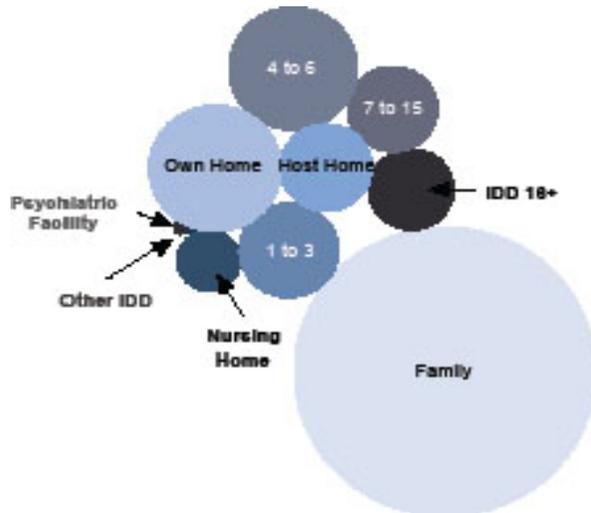
**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					35	292	102	253	216
		Family					1231	510	748	933	744
		Host Home					32	69	142	84	63
		1 to 3 Group Home						87	107	276	DNF
Congregate IDD Settings by size and type	4 to 15	4 to 6						263	393	495	DNF
		1 to 6	28	17	68	222	532	350	500	771	1036
		7 to 15	70	93	200	180	75	67	125	87	91
	16+	16+ Private				0	0	0	24	0	0
		16+ Public				290	145	106	96	83	79
		16+ Total	584	519	429						
		Other IDD									0
Non IDD Specific	16+	Nursing Facility				49	32	40	45	45	25
		Psychiatric Facility				0	0	0	0	0	8
Number of People with IDD	All Size	Waiting list					160	0	0	120	387
		Estimated Total	682	629	697	692	2050	1394	1737	2211	2262
Number of People with IDD	HCBS	HCBS Expenditures per Person				6768	33747	36006	41068	42463	DNF
		HCBS Recipients per 100,000				27	175	248	361	378	373
Recipients and Expenditures by	ICF/IID	ICF/IID Expenditures per Person				140278	71805	15146	208355	222932	364021
		ICF/IID per 100,000				13	29	22	17	15	14

## Status and Trends in Residential and In Home Supports for People with IDD FY 2012

## UNITED STATES

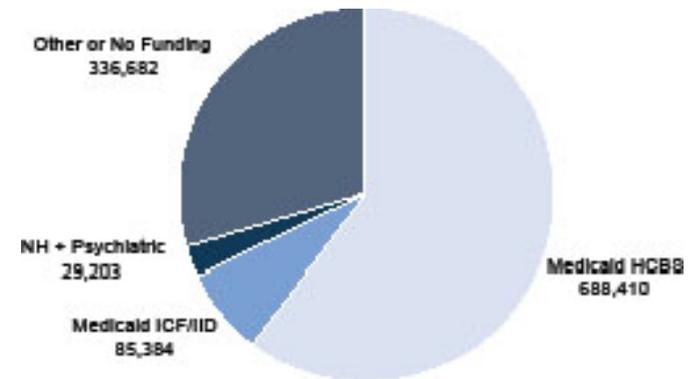
**Figure RP1:** Residence Size and Type on June 30, 2012



**Figure RP2:** Estimated Average Annual Medicaid Expenditures Per Person



**Figure RP3:** LTSS Recipients with IDD by Funding Authority on June 30, 2012



**Table RP1**

Category	Size	Type	1977	1982	1987	1991	1996	2000	2005	2010	2012
Individualized Settings	1 to 3	Own Home					46,608	73,147	101,143	127,455	122,665
		Family					590,180	391,859	533,048	592,180	634,988
		Host Home					24,675	37,367	35,386	40,060	58,783
		1 to 3 Group Home		15,702				33,360	49,037	62,584	68,781
Congregate IDD Settings by size and type	4 to 15	4 to 6		17,486				67,146	107,573	105,290	116,159
		1 to 6	20,400	33,188	69,933	108,479	100,915	124,469	156,610	167,874	184,940
		7 to 15	20,024	30,515	48,637	53,475	56,389	52,802	52,888	55,682	56,409
	16+	16+ Private				48,001	37,016	35,253	27,005	25,927	24,168
		16+ Public				79,407	58,320	47,329	40,061	31,101	26,503
16+ Total		207,356	180,146	137,103							
		Other IDD								478	
Non IDD Specific	16+	Nursing Facility	42,242	40,538	45,843	39,208	30,591	32,195	30,027	31,832	28,064
		Psychiatric Facility	15,524	7,865	2,520	121	1,269	488	392	873	1,139
Number of People with IDD	All Size	Waiting list					87,187	71,922	73,828	115,059	150,063
		Estimated Total	247,780	243,849	255,673	289,362	914,103	762,226	946,141	1,040,279	1,138,121
Recipients and Expenditures by 100,000 of	HCBS	HCBS Expenditures per Person	0	901	12,955	22,319	24,783	33,142	38,679	44,396	0
		HCBS Recipients per 100,000	0	6	94	20	72	103	150	192	219
	ICF/IID	ICF/IID Expenditures per Person	5,798	14,886	24,826	55,636	73,926	85,040	119,162	146,999	143,107
		ICF/IID per 100,000	48	61	60	58	49	41	34	28	27





**SECTION EIGHT**

**Appendices**

**FY 2012**



## APPENDIX A: STATE NOTES

**This appendix explains** exceptions to the specified operational definition for specific data elements to account for differences amongst states in what is possible to report. It also explains year over year changes that may affect longitudinal examination of results for particular states. These notes are primarily based on information submitted by states on their survey. It also includes information gathered by project staff from state respondents as surveys were proofed. Only states with notes are listed. For each note, the data element is listed first followed by the explanatory information.

**Alabama.** *State ICF/IID Setting size 16+; Per diem:* Closed last state ICF/IID on 12/28/11; *Total number of residents at the end of the year in Type IV settings; Number of HCBS recipient residents at the end of the year in Type IV settings:* Discrepancy due to data coming from different sources.

**Alaska.** *Number of residents at the end of the year in Other State Facilities:* In FY 2012 there were zero people with a primary diagnosis of IDD in the psychiatric facility; *Number of residents in Type II settings size 4-6 residents:* The settings reported here are at times dually licensed to provide services to IDD and Mental Health clients. A facility could have been licensed to provide services to people with IDD but never provided those services; *Total ICF/IID recipients age under 22; Total ICF/IID recipients age 22 and older; Total state & federal ICF/IID expenditures:* The people reported in these categories live in ICF/IID settings in other states.

**Arizona.** *Number of HCBS State Settings size 16+; Number of ICF/IID State Settings size 16+:* Reported ICF/IID and HCBS group homes separately, which was not done in FY 2011. There is one institution campus that has both ICF/IID and HCBS funded units.

**Arkansas.** *Total state and federal ICF/IID expenditures:* FY 2012 from Eiken, 2014.

**California.** *Total HCBS Recipients on Regular or Other Waivers:* Differences in reported HCBS recipient numbers due to data being pulled from different sources for different reporting purposes.

**Colorado.** *Number of state HCBS settings with 16+ residents:* People live in HCBS funded units within the two state campuses.

**Connecticut.** *Total number of residents at the end of the year in family settings:* In prior years this number included people living with their families and receiving no residential supports, but for FY 2012 this number only includes those living with their families and receiving residential supports; *Number of people on state waiting list:* This number represents people living in their family or own home with no current residential supports who need supports within a year. The supports could be provided either at their current residence or result in placement to a new residential setting; *Number of state HCBS settings with 1-3 residents:* Includes 11 group residential settings and 237 individuals supported in their own homes by state staff.

**Georgia.** *Number of residents at the end of the year in nursing home facilities:* Estimate from AHCA; *Number of state ICF/IID settings with 16+ residents:* Georgia is working towards the closure of all state funded facilities per the ADA settlement.

**Idaho.** *Total number of residents at the end of the year in ICF/IID settings:* Estimate from AHCA.

**Illinois.** *Number of residents at the end of the year in nursing home facilities:* Estimate from AHCA.

**Indiana.** *Number of ICF/IID State Settings size 16+:* The ICF/IID unit at Logansport State Hospital closed 6/21/2012. Residents of the unit transferred to non ICF/IID units within Logansport State Hospital and other state-operated facilities.

**Kansas.** *Total number of residents at the end of the year in Type I settings; Number of residents at the end of the year in nursing home facilities; Number of state ICF/IID residents at the end of the year in settings with 16+ people; Total number of Type I settings:* Estimate from AHCA; *Total state & federal ICF/IID expenditures:* FY 2011 from Eiken 2014.

**Kentucky.** *Total number of residents at the end of the year in Type IV settings; Number of residents at the end of the year in Type IV settings with 1-3 residents; Number of HCBS recipient residents at the end of the year in Type IV setting:* Discrepancy between FY 2011 and FY 2012 numbers due to database issue which has been resolved with the reporting of the FY 2012 numbers.

**Maryland.** *Number of residents at the end of the year in nursing home facilities:* Estimate from AHCA.

**Massachusetts.** *Number of residents at the end of the year in Type II settings with 1-6 residents:* Includes all types of nonstate settings with 1-6 residents; *Number of residents at the end of the year in other state facilities:* The division of developmental services does not have any of the people who are under its auspices living in a psychiatric facility, though there may be people with IDD who are served through other parts of the state government; *Number of residents at the end of the year in Type II settings with 7-15 residents:* Includes all nonstate settings with 7-15 residents; *Total number of residents at the end of the year in Type III settings:* Includes 860 people in host homes and 1,938 people in adult foster care. Most individual caregivers for adult foster care are family members; *Total HCBS recipients on regular or other waivers under age 22:* There are zero children on 1915(c) IDD waivers, but 200 children are on the Autism waiver; *Total state & federal ICI-IDD expenditures:* FY 2011 from Eiken, 2014.

**Michigan.** *Number of residents at the end of the year in nursing homes settings:* Estimate from AHCA. HCBS Waiver recipients. People with IDD in the 1915(b/c) managed care waiver historically were not included in the RISP data collection but were added beginning in FY 2011.

**Minnesota.** *Total number of residents at the end of the year in Type IV settings; Number of people on the state waiting list:* Discrepancy between FY 2011 and FY 2012 numbers due to double counting of people who received PCA services in FY 2011; *Total number of residents at the end of the year in other settings:* Includes people in group residential housing, short term rehabilitation, private IMD hospitals, and short term stays in ICF/IID settings; *Total number of Type III settings; Number of Type III settings with 1-6 residents:* Licensed family foster care settings serve people with and without IDD. There is no way to determine how many of the settings serve people with IDD; *State and*

*Federal Medicaid HCBS expenditures for people with IDD on regular or other waivers in Types II, III, IV, VI and state-operated settings age 22 and older:* Expenditures are for the 11,322 people for whom age and setting type is known; *HCBS recipients on regular or other waivers in Types II, III, IV, VI and state-operated settings:* Age is known and reported here for 11,322 people in other settings but is not known for the 1,021 people with IDD on waivers for whom setting type is not known. Does not include people in state-operated HCBS homes; *Total HCBS recipients on regular or other waivers:* Includes 1,021 people in non-family settings for whom age was unknown.

**Mississippi.** *Total number of residents at the end of the year in Type II settings:* Last year's data was erroneous; *Number of residents at the end of the year in Type II settings with 1-3 residents:* Data was erroneous; *Total number of residents at the end of the year in Type I settings:* Estimate from AHCA; *Number of residents at the end of the year in Type I settings with 16+ residents:* Estimate from AHCA report and previous year; *Number of residents at the end of the year in Type II settings with 1-6 residents:* Data was erroneous; *Number of state ICF/IID settings with 16+ residents:* One was omitted last year - there have been no new facilities opened; *Number of Type II settings with 1-3 residents:* Last year's data was erroneous; *Total number of Type II settings:* Last year's data was erroneous; *Number of Type IV settings with 1-3 residents:* Last year's data was erroneous; *Total number of Type I settings:* Estimate from AHCA; *Number of Type I settings with 16+ residents:* Estimate from AHCA and previous year.

**Missouri.** *Number of residents at the end of the year in nursing home facilities:* Estimate from AHCA.

**Montana.** *Total number of residents at the end of the year in family settings; Number of residents at the end of the year in Type IV settings with 1-3; Number of residents at the end of the year in Type III settings with 1-3; Number of Type IV settings with 1-3 people:* Due to more availability of specific data in our computer system it has been discovered that this number was overstated last year; *Total number of residents at the end of the year in Type II settings:* Due to access to more information it has been discovered this amount was understated in previous years.

**New Hampshire.** *HCBS Recipients on Regular IDD Waivers:* In previous years we combined the “Other ID waiver” into this number. We reported the 300 recipients separately this year; *Total HCBS Recipients on Regular IDD Waivers under age 22; Total HCBS Recipients on Regular IDD Waivers age 22 and older:* In New Hampshire the system cutoff age is 21 years, not 22 years; *Total number of residents at the end of the year in Type II settings; Total number of residents at the end of the year in Type III settings; Number of HCBS recipient residents at the end of the year in Type II settings; Number of HCBS recipient residents at the end of the year in Type III settings:* Discrepancy due to data coming from different sources.

**New Mexico.** *Total state & federal ICI-IDD expenditures:* FY 2011 from Eiken, 2014.

**New York.** *Number of residents at the end of the year in nursing homes:* Estimate from AHCA.

**North Carolina.** *Total number of Type II settings:* In some Type II homes persons with IDD hold individual leases for their housing.

**Ohio.** *Number of residents at the end of the year in Type III settings with 7-15 residents; Total number of Type III settings:* One setting had 19 people; *Number of residents at the end of the year in nursing home facilities:* Estimate from AHCA; *Number of people on state waiting list:* The Ohio Department of Developmental Disabilities (DODD) Newsletter, DD Pipeline, reports recent estimates from the Ohio College of Medicine’s Government Resource Center which indicate that more than 40,000 Ohioans with disabilities are waiting for Waiver-funded home and community-based services (HCBS); *State and Federal Medicaid HCBS expenditures for people with IDD on other waivers; HCBS Recipients with IDD on other waivers:* We recently took over an additional waiver type which was previously run by another agency.

**Oregon.** *Number of residents at the end of the year in nursing homes:* Estimate from AHCA; *Total number of residents at the end of the year in Type II settings; Number of HCBS recipient residents at the end of the year in Type II settings:* Discrepancy due to data coming from different sources.

**Pennsylvania.** *Number of residents at the end of the year in nursing homes:* Estimate from AHCA.

**South Carolina.** *HCBS Recipients on Regular IDD Waivers:* FY 2011 data did not include an additional waiver type; *Type III settings with 7-15 residents:* This number is based on contracts with providers, and each contract may have multiple settings.

**Texas.** *Number of residents at the end of the year in nursing homes:* Estimate from AHCA.

**Utah.** *Number of residents at the end of the year in nursing homes:* Estimate from AHCA.

**Washington.** *Number of residents at the end of the year in other state facilities:* The two state psychiatric hospitals which existed in previous years but were not previously reported to RISP. Person counts include only those stated to be “long-term stay” in our data system; *Average Daily Residents in other state facilities:* Because our June 30, 2012 count was only an estimate, we cannot reasonably determine an accurate average daily count; *Number of releases from Non-ICF/IID state facilities:* Includes 30 residents who transferred from ICF/IID to NF beds and 1 resident who transferred from NF bed to ICF/IID; *Number of residents at the beginning of the year in ICF/IID facilities with 16+ residents:* The number of residents includes only long-term stays because state data system does not distinguish short term stay admissions by respite/crisis/assessment; *Number of residents at the beginning of the year in state ICF/IID facilities; Number of state ICF/IID facilities with 16+ residents:* One large state facility closed in FY 2012 leaving four open. Of the four, two have both nursing facility beds and ICF/IID beds, one is exclusively ICF/IID (these three have been reported as ICF/IID facilities), and one is exclusively nursing facility beds (which has been reported as an IDD setting not funded by ICF/IID or HCBS). Person counts, however are reported by bed type. That is, the person counts reported under IDD setting not funded by ICF/IID or HCBS include persons from the facilities that are part NF beds as well as the one facility that is solely NF beds; *Number of other state facilities:* These are the two state psychiatric hospitals which existed in previous years but were not reported to RISP. Person counts include only those stated to be “long-term stay”; *per diem for state HCBS facilities with 1-3 residents; per diem for state HCBS facilities with 4-6 residents:* Our data systems do not distinguish cost by individual factors such as size of residence. An average daily rate across the program has been provided; *per diem for other*

*state facilities:* This is not a DDA service, and it is not possible to tell how a facility-wide average daily rate might differ if the person also has a diagnosis of IDD.

**West Virginia.** *Total number of residents at the end of the year in Type I settings; Number of residents at the end of the year in nursing homes:* Estimate based on AHCA report; *Total number of residents at the end of the year in Type II settings:* A different mechanism for collection of data was used resulting in a discrepancy between FY 2011 and FY 2012 numbers.

**Wisconsin.** *Number of people on state waiting list:* 24 counties reached entitlement in 2012 which means that they no longer had people on waitlists; *Total HCBS recipients on regular or other waivers age 22 and older:* Totals do not sum because Wisconsin allows individuals on the HCBS waiver to be in an institution.

**Wyoming.** *Number of residents at the end of the fiscal year in Nursing Homes; Total ICF/IID recipients age under 22; Total ICF/IID recipients age 22 and older:* Estimate from AHCA; *State and Federal Medicaid HCBS expenditures for People with IDD on other waivers; HCBS Recipients with IDD on other waivers:* There are other waivers types but recipient data isn't available for them.

## APPENDIX B: REFERENCES AND RELATED MATERIALS

- (42 CFR 435.1010 (b)(2)) Downloaded from: <http://www.gpo.gov/fdsys/granule/CFR-2010-title42-vol4/CFR-2010-title42-vol4-sec435-1010/content-detail.html>.
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- Centers for Medicare and Medicaid (2014) 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; Final Rule. *Federal Register*, 79 (11), 2948-3039. Final Regulation CMS-2249-F/CMS-2296-F.
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# APPENDIX C: FISP/RISP FY 2012 SURVEY

Residential Information Systems Project (RISP) Survey FY 2012

State: \_\_\_\_\_ Date: \_\_\_\_\_

## Part 1 Residents with Intellectual or Developmental Disabilities (IDD) living in State (staffed by state employees) Residential Settings and Facilities

Use an "e" to designate estimated numbers; "DNF" to designate data you are not able to furnish; "0" for none.

Please exclude respite care placements. Please count only residents with IDD receiving services. Include all settings staffed by state employees serving people with IDD.	IDD settings* with 1-3 residents		IDD settings* with 4-6 residents		IDD settings* with 1-6 residents		IDD settings* with 7-15 residents		IDD facilities and other facilities with IDD units (16+ residents)		IDD settings or units not funded by ICF-IDD or HCBS Waiver**	Psychiatric or other large facilities *** with residents with IDD not in special IDD units
	ICF-IDD	HCBS	ICF-IDD	HCBS	ICF-IDD	HCBS	ICF-IDD	HCBS	ICF-IDD	HCBS		
NUMBER of state (staffed by state employees) settings on June 30, 2011												
RESIDENTS with IDD beginning of Fiscal Year 2012 (7/1/11)												
ADMISSIONS - The number of residents with IDD admitted during Fiscal Year 2012 (7/1/11 to 6/30/12), including residents with IDD who had at one time lived in a state facility. Please exclude transfers between large state facilities.												
RELEASES - the number of residents with IDD who were released from state facilities during Fiscal Year 2012 (7/1/11 to 6-30-12). Please exclude transfers to other large state facilities.												
DEATHS - the number of residents with IDD who died while on roll during Fiscal Year 2012 (7/1/11 to 6/30/12).												
RESIDENTS with IDD at the end of Fiscal Year 2012 (6/30/12).												
AVERAGE DAILY RESIDENTS with IDD on site in Fiscal Year 2012.												
PER DIEM (average daily cost of care per resident) in Fiscal Year 2012.												

\*Not located on the grounds of a large state facility. ICF-IDD Intermediate Care Facility for Persons with Intellectual or Developmental Disabilities (formerly ICF-MR)

\*\*Include state settings or units specifically for persons with IDD that are not funded by the ICF-IDD program or the HCBS Waiver program.

\*\*\*A state psychiatric or other facility designated primarily for persons with disabilities other than IDD with one or more residents with a primary or formal dual diagnosis of IDD. (Do not include facilities with special IDD units in this category).

Data date (if other than June 30, 2012): \_\_\_\_\_. Comments: \_\_\_\_\_

If you have specific questions about this form please contact your assigned RISP project staff member (assignments are posted on <http://rtc.umn.edu/risp>). For other questions contact Sherri Larson, Research and Training Center on Community Living, University of Minnesota, 214B Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. Phone 612-624-6024, Fax 612-625-6619. Email: [larso072@umn.edu](mailto:larso072@umn.edu).

Part 1 Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Residential Information Systems Project (RISP) Survey FY 2012**

**State:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Part 2 Nonstate Residences of Persons with Intellectual or Developmental Disabilities (IDD) receiving Publicly-Funded Services**

Use an "e" to designate estimated numbers; "DNF" to designate data you are not able to furnish; "0" for none.

<b>Type of Nonstate Residence:</b> Please exclude respite care placements. Please count only residents with IDD receiving services. Please do not make entries in the shaded cells.	Number of Nonstate residential settings on June 30, 2012 with this many residents					Number of residents in Nonstate residential settings of these sizes on June 30, 2012					Number of HCBS recipients in nonstate settings by type (on June 30, 2012)		
	1-3	4-6	1-6 Total	7-15	16+	Total Settings*	1-3	4-6	1-6 Total	7-15		16+	Total Residents*
Type I. Nonstate ICFs-IDD.													
<b>Please do not report ICFs-IDD, nursing homes or "congregate personal care facilities" in Types II through VI.</b>													
Type II. A residence <b>owned, rented or managed by the residential services provider, or the provider's agent</b> , to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD.													
Type III. A home <b>owned or rented by an individual or family</b> in which they live and provide care for one or more unrelated persons with IDD (e.g., <b>host family/family foster care</b> ).													
Type IV. A home <b>owned or rented by one or more persons with IDD</b> as the <b>person(s)' own home</b> in which personal assistance, instruction, supervision and other support is provided as needed.													
Type V. A residence of <b>person(s) with IDD</b> which is also the <b>home of related family members</b> in which the person(s) with IDD and/or their family members receive <b>supportive services</b> (e.g., respite care, homemaker services, personal assistance).													
Type VI. Other residential types (please specify). Please record 0 if you do not have other nonstate residential service options for people with IDD.													

\*Totals should equal the sum of 1-6, 7-15, and 16+.

Data date (if other than June 30, 2012): \_\_\_\_\_ June 24, 2012 \_\_\_\_\_

Comments: \_\_\_\_\_

Part 2 Respondent Name: \_\_\_\_\_, Phone: \_\_\_\_\_, Email: \_\_\_\_\_

**Residential Information Systems Project (RISP) Survey FY 2012**

State: \_\_\_\_\_ Date: \_\_\_\_\_

**Part 3 Medicaid funded long-term supports and services for persons with IDD on June 30, 2012**

Please indicated estimated numbers with “e”; enter “DNF” to indicate data not furnished; enter “0” to indicate none; indicate actual date of data [e.g., “1,234 (4-30-11)”] if other than date requested.

**A. Total Persons with IDD Receiving Medicaid Home and Community Based Services (HCBS) on June 30, 2012**

Include all types of HCBS Waivers, all settings, and both state operated and non-state operated settings.

HCBS Waiver Category	Recipients on June 30, 2012	State and Federal Expenditures for Fiscal Year 2012 (July 1, 2011 to June 30, 2012).
Regular ID/DD Waiver(s)		
People with ID/DD on other waivers		
Total		

**B. People with IDD receiving Medicaid Home and Community Based Services (including IDD Waivers and “Other” HCBS Waivers) By Setting type and Age Group.**

Refer to Part 2 of this survey for complete descriptions of setting types. Include all types of HCBS Waivers, all settings, and both state operated and non-state operated settings.

HCBS Waiver recipients with IDD by setting and age	HCBS Recipients with IDD on June 30, 2012		State and Federal Medicaid HCBS Expenditures for Fiscal Year 2012 (July 1, 2011 to June 30, 2012)	
	Birth thru 21 years	22 years or older	Birth thru 21 years	22 years or older
1. People with IDD on Regular IDD or Other HCBS Waivers who live in <b>Type V settings (Family Home)</b>				
2. People with IDD on Regular IDD or Other HCBS Waivers in <b>all other HCBS funded settings (Types II, III, IV, VI and state operated).</b>				
3. <b>Total</b> people with IDD on Regular IDD or other HCBS Waivers.				

**Residential Information Systems Project (RISP) Survey FY 2012**

State: \_\_\_\_\_ Date: \_\_\_\_\_

**Part 3 Section C. Medicaid Intermediate Care Facilities for [Persons with] Intellectual or Developmental Disabilities, ICF-IDD; (previously ICF-MR) o June 30, 2012**

Total state and federal ICF-IDD expenditures July 1, 2011 through June 30, 2012 \_\_\_\_\_

Total number of ICF-IDD recipients ages **birth through 2 years** on June 30, 2012 \_\_\_\_\_Total number of ICF-IDD recipients **22 years or older** on June 30, 2012 6522**Part 3** Respondent Name: \_\_\_\_\_, Phone: \_\_\_\_\_, Email: \_\_\_\_\_**Part 4 Persons with Intellectual or Developmental Disabilities Waiting for Residential Services on June 30, 2012**

Please d not include people with IDD who were already receiving residential services while living outside their family homes on June 30, 2012 who were on waiting lists for another type of residential setting. Please **d report** the number of persons with IDD living in the home of a family member on June 30, 2012 on waiting lists for in-home services or residential services to live outside their family home.

**State Waiting List:** How many persons with intellectual or developmental disabilities in your state were on waiting lists for, but not receiving, residential services on June 30, 2012 and required such services within 12 months? 6,971

**Part 5 Persons with Intellectual Disabilities and/or Developmental Disabilities Living in Generic Medicaid Nursing Homes on June 30, 2012**

**Nursing Home Residents with IDD:** How many persons with intellectual or developmental disabilities in your state were living in generic, Medicaid-funded nursing homes on June 30, 2012? \_\_\_\_\_.

**Parts 4 and 5** Respondent Name: \_\_\_\_\_, Phone: \_\_\_\_\_, Email: \_\_\_\_\_

We encourage states to enter their data for FY 2012 in the RISP project website (<http://rtc.umn.edu/risp/main/>). Log in to access 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, 214B Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. General RISP Phone 612-624-6328, Fax 612-625-6619. General Email: rtc@umn.edu.

## APPENDIX D: OPERATIONAL DEFINITIONS

### Residential Information Systems Project (RISP) Annual Data Collection

#### Operational Definitions: Working Draft for the FY 2012 Survey (*Updated March 2013*)

##### General instructions:

- Please note the name, phone number and email address of the person/people who reported data for each Part of the survey.
    - » In some states, different people provide data for different parts of the survey.
  - Publicly-Funded Services include long-term supports and services funded by
    - » Federal sources (most commonly Medicaid), including ICF/IID [formerly ICF-MR] funded residences and long-term supports and services funded under one of the Medicaid Home and Community-based Waiver Programs.
    - » State sources (for example a family support program)
  - Do not include educational services and supports such as early intervention services offered to children and young adults ages birth to 21 years.
  - Do include children and young adults with IDD who receive institutional, or community-based long-term supports and services while living with family members, in homes of their own, or in a congregate setting of any size. Long-term supports and services include services such as case management supports, day habilitation, employment support as well as in-home and residential habilitation, home health and personal care attendant services. This includes people who receive long-term supports and services under a state Medicaid plan. State Plan Services – some states offer some types of long-term supports and services under their Medicaid State Plan. Most commonly these are personal care attendant services offered to people living in homes of their own or with family members. People receiving cash subsidies from states should be included according to where they live.
- » The number recorded is the best estimate of the correct count.
  - » If it is not possible to produce a reasonable estimate based on the reporting year but data were available in the previous fiscal year, you can estimate the number to equal the number for the previous fiscal year as long as it is identified as being data from a different year.
  - » If the estimate is based on a date other than the one specified (usually June 30, 2012), please specify the alternate date used.
- Data not furnished
    - » If the exact number is not known, and the estimate or report used in the previous year is not likely to accurately reflect the actual number please note this as DNF.
    - » Use this designation only when absolutely necessary because the United States estimated totals require us to impute a value for all missing data.
    - » When we impute a value for the purpose of making a US estimate, we do not report the imputed value for individual states with missing data in our public report except on the summary table showing all people served in a year, and the table estimating the proportion of people served who live in the home of a family member.
  - If you use a definition that differs from the one specified on the form, please provide the definition you used.
  - When reporting the number of residents or facilities with 6 or fewer residents
    - » Please report the number separately for 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 data not furnished for the 1-3 and 4-6 columns, and report the total in the 1-6 column.

For each data element reported, several special designators can be applied as needed

- Estimate – The exact number is not available.

**Part 1** requests data regarding *state residential settings and services* including state ICFs-IID.

- “State” residential facilities include settings staffed by state employees or operated by state agencies including the IDD agency.
- Settings staffed by contractors or organizations licensed or delegated the authority to provide services in which the employees are not employees of the state should be reported in Part 2.
- **Do not** include people who stay in residential facilities for the purpose of respite only except when reporting on number of short-term respite stays in large state facilities.
- **Do** include people who are admitted for short term crisis or assessment purposes.
- Count only people who have IDD.
- Setting types
  - » Large IDD facilities and other large facilities with IDD units (16+ residents live on the campus).
    - Include all units on the campus that house people with IDD.
    - Multiple units located on an institution campus are considered one facility
    - Include units designed or licensed specifically for people with IDD that are located on the grounds of a nursing home or psychiatric facility with 16 or more residents if those settings are staffed by state employees.
  - » IDD facilities with 15 or fewer residents.
    - Only include IDD facilities not located on the grounds or campus of a large state facility. The number of people with IDD in all units sharing a campus location should be summed together to determine the total number of residents with IDD
    - 1-3, 4-6, 1-6, 7-15 people live at this address/ in this facility
    - Within each size, report separately
      - › the number of people in units or sites licensed as Intermediate Care Facilities [for persons with] IDD [intellectual disabilities] and
      - › the number of people in units or sites whose operation is funded from the Medicaid Home and Community-based Waiver program (HCBS funded group homes should be counted in the HCBS category)
- » Facilities or units for people with IDD not funded by the ICF/IIDD or HCBS Waiver programs.
  - This category includes state-operated facilities or units within facilities that are specifically designated to serve people with IDD that are funded with resources other than the ICF/IIDD or the Medicaid Home and Community-based Waiver programs.
- » Psychiatric/other facilities include state residential facilities designed primarily for persons with disabilities other than intellectual disabilities, (for example a mental health facility) housing one or more persons with a primary diagnosis or formal dual diagnosis of intellectual or developmental disabilities.
  - Facilities with special IDD units (for example an ICF/IID unit housed in a nursing home) should be reported in the Large IDD column, not as “other facilities”
  - Provide the only the number of residents who have IDD living in other facilities. Do not include residents who do not have a primary or formal dual diagnosis of intellectual or developmental disabilities.
  - Includes people with a primary or official dual diagnosis of IDD living in *state-operated* facilities under the jurisdiction of state IDD agencies such as transition or half-way houses, board and care, assisted living facilities that do not have a designated IDD unit, and housing with services if the person receives any services under the auspices of the state IDD authority.
  - Do not include in this section people living in a generic nursing home here – report those in section 5
- » ICF/IIDD versus HCBS vs. Other for the IDD settings. Previously we asked only about ICF/IID and “other” settings. Here we have expanded the question to specifically identify settings funded by an HCBS Waiver. If your state has state-operated residential facilities designated specifically primarily for people with IDD that are not ICF/IIDD and are also not HCBS Waiver-funded settings, please count them in the Other IDD category.

- Data elements
    - » Number of state settings – settings staffed by state employees or operated by the state IDD agency as of June 30 of the fiscal year.
    - » RESIDENTS with IDD beginning of Fiscal Year 20xx
    - » ADMISSIONS - The number of residents with IDD admitted during Fiscal Year 20xx (7/1/20xx to 6/30/20xx),
      - READMISSIONS – The number of people with IDD who had at one time lived in a large state facility, left to live in a nonstate setting and returned to a large state facility.
        - › Exclude people with IDD who transferred from one large state facility to another large state facility
    - » RELEASES - 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 who are released or discharged to a hospital, nursing home or other long-term care setting
      - Exclude transfers to other large state IDD facilities
    - » DEATHS - the number of residents with IDD who died while on the rolls during Fiscal Year 20xx (7/1/20xx to 6/30/20xx).
      - Include any person who was not discharged from the facility prior to death even if their death occurred during a stay in a hospice, hospital, nursing home or other temporary facility if they had not been formally discharged from the facility.
    - » RESIDENTS with IDD at the end of Fiscal Year 20xx (6/30/20xx).
    - » AVERAGE DAILY RESIDENTS with IDD in Fiscal Year 20xx.
      - 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.
      - This number of average daily residents should be between the number of residents at the beginning of the year, and the number of residents at the end of the fiscal year.
      - If you have a running average please provide that
        - If you do not have a running average for the year, this will be computed as the average of the residents with IDD in the facility on July 1 and the residents with IDD in the facility on June 30.
  - » 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** requests data regarding *non-state residential settings and services* including non-state ICFs-IDD.
- “Non-state” for this survey, means residential settings in which people with intellectual or developmental disabilities that are staffed by non-state employees.
  - Residential services including long-term support services delivered to people living in homes of their own or in the home of a family member.
  - For this section please report the type of residence for all people with IDD who are known to the state IDD agency. These people may or may not be receiving ICF/IIDD or HCBS Waiver-funded services but they are receiving Federally or State financed support of some kind (such as case management, screening for Waiver eligibility, or state plan personal care services)
  - Setting type
    - » Type I. Nonstate ICFs-IDD – all ICF/IIDD settings except those reported in Part 1 that were operated by state agencies.
      - Multiple units on a campus or at a single address should be counted as a one facility
    - » Type II. A residence **owned, rented or managed by the residential services provider**, or the provider’s agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD.
      - Includes organizations operated by a public entity other than the state (county, municipality) unless the employees directly employed by the state
      - It is a residential facility if
        - › meals are served to people in more than one unit at a time in a place other than the person’s unit (e.g., a dining hall or cafeteria)

- particularly if the person does not have a fully functional kitchen
- › units do not have separately keyed entrance doors
- › units do not have a separate mailbox number or address
- » Type III. A residence owned, rented or managed by the residential services provider, or the provider’s agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD (e.g., host family/family foster care).
- » Type IV. 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.
  - A person with IDD holds title or lease in his or her own name; or is named on the lease.
  - These are settings in which
    - › each unit/apartment or house has separately keyed entrance doors
    - › each unit has a different mailbox number or separate address
    - › The person with IDD may choose to fire or discontinue services from a particular person or company and still retain his or her home
    - › The person with IDD decides which people if any will live in his/her home (with legal guardian assistance as needed)
- » Type V. A residence of **person(s) with IDD** which is also **the home of related family members** in which the person(s) with IDD and/or their family members receive **supportive services**
  - Examples of supportive services include respite care, homemaker services, personal assistance, personal care assistance, behavioral supports, community inclusion support, certified nursing assistant care, in-home nursing, parent training or education.
  - It is not necessary to provide residence size for people living in the home of a related family member. Simply provide the total number of people in that type of setting.
- » Type VI. Other residential types *not staffed by state employees*
  - Unless the state specifically reports having people in these settings, we will assume them to be 0 setting and 0 people.
  - Include the following setting types if
    - › the people with IDD in them are specifically tracked by the state
    - › the setting is not staffed by state employees (if they are staffed by state employees report them in Part 1)
      - Hospital
      - Board care
      - Transition half-way houses
      - Housing with supports
      - Assisted living centers
  - HCBS Recipients – number of people with IDD who live in each type of nonstate setting (other than ICF/IIDD) whose supports are funded by one of the Medicaid Home and Community-based Waiver programs.

**Part 3** requests data expenditures for people with intellectual or developmental disabilities (IDD) receiving supports through a Home and Community-based Services (HCBS) Waiver or an ICF/IIDD setting.

### Section A

- Section A asks for all Medicaid Home and Community-based Waiver services provided to people with IDD
- Include all people with IDD receiving services through a Medicaid HCBS Waiver – whether those supports are provided by state employees or by employees of other agencies.
- Waiver types
  - » Regular IDD Waivers – an HCBS Waiver program designed specifically to meet the needs of people with intellectual or developmental disabilities (this would include an “autism waiver”).
  - » Other Waivers – all HCBS Waiver programs not specifically designed to meet the needs of people with IDD through which one or more person with IDD receives support.
- Waivers for people disabilities who live with family members;

- Waivers for people with disabilities requiring the level of support typically provided in a nursing facility
- Traumatic Brain Injury Waivers
- Consumer Directed Community Support
- Cash and counseling waivers
- Recipients on June 30 – total number of people with IDD receiving long-term supports or services funded through a Medicaid Home and Community-based Waiver.
- State and Federal Expenditures for the FY – total amount of money (including both the state portion and the federal match) expended to provide Home and Community-based Waiver Services to people with intellectual or developmental disabilities.

### Section B (New in FY 2012)

- Section B asks for a more detailed description of HCBS Waiver recipients and expenditures broken down by
  - » the type of setting in which the person lives (in the home of a family member versus in any other setting), and
  - » the age of recipients (children and youth ages birth to 21 years versus adults ages 22 and older)
- The total number of children plus adults in Section B should equal the number of people with IDD in state-operated HCBS settings reported in Part 1 plus the number of people with IDD in Types II,III,IV,V, or VI in Part 2.
- This is a new section. Please complete as much as you are able. We will work with states over time to develop systems to support reporting information by setting type and age.

### Section C (New for FY 2012)

- Section C asks for total ICF/IIDD expenditures and for ICF/IID recipients by age.
  - » Include both state and non-state-operated ICF/IIDD settings in this section
  - » Include ICF/IID facilities of all sizes
  - » Parts 1 and 2 provide some information about the people living in ICF/IID settings. In this section we simply want a summary by age group of recipients (children and youth ages birth to 21 years versus adults ages 22 and older)

Note about Sections B and C. In 2011 the Administration on Intellectual and Developmental Disabilities funded a new project of national significance focused on families, and individuals with IDD who live with families. As part of that project we were asked to expand our RISP data collection to provide annual information about the number and proportion of HCBS recipients with IDD in each state who receive services in their family homes. We are also collection information about the age of people with IDD. This information will allow us to examine the current status of and trends in the use of Medicaid funding for children and youth (ages birth to 21year) versus adults (ages 22 years and older). This information is needed because of the great expansion of the HCBS Waiver program, to support children, and because of the increasing life expectancies for adults with IDD. The intent is to support policy analyses related to the changing demographics of the HCBS population. This will also provide a foundation for work describing the different types of family supports that may be needed by families of children versus families of adults with IDD.

**Part 4** asks how many persons with IDD in your state were on waiting lists for, but not receiving, residential services on June 30, 2010 and required such services within 12 months

- Please **do not report** persons who were receiving residential services while living outside their family homes on June 30, 20xx who were on waiting lists for other types of residential services.
- Please **do report** people who were living in homes of their own or with a family member on June 30, 20xx who were on waiting lists for in-home services or residential services to live outside the family home.
  - » People waiting for *residential services* may be receiving other funded supports while they continue to live with family members
  - » If your records include a designation of urgency, include only those people for whom residential services have been requested to begin within the next 12 months.
  - » Include people with IDD living in their own home or in the home of a family member who are waiting for funding through an HCBS Waiver.

**Part 5** requests data regarding *persons with intellectual disabilities and related developmental disabilities living in generic, Medicaid-funded nursing homes (e.g., Skilled Nursing 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 staffed by state or non-state employees.

## APPENDIX D: MEDICAID WAIVER AUTHORITIES<sup>1</sup>

*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.*

### 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*

*A number of states use 1115 Demonstrations for the delivery of institutional and community long-term services and supports.*

### 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.*

### 1915(b)

*States can also implement a managed care delivery system using waiver authority under 1915(b). Under a 1915(b) waiver:*

- *States are able to 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.*

- *States have to show that the managed care delivery system is cost-effective, efficient and consistent with the principles of the Medicaid program.*
- *A state's program can only run for a specific amount of time (up to 5 years) before CMS will have to give their approval of the program again.*

*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 cost-effective 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 waiver or other HCBS authority.*

### 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 either mandate enrollment into a managed care arrangement which provides HCBS services or simply to limit the number or types of providers which deliver HCBS services.*

### 1915(c)

*1915(c) is also known as the HCBS waiver program. States can offer a variety of services under an HCBS Waiver program to individuals meeting 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.*

<sup>1</sup> Text for this section came from *The guide to Federal Medicaid Authorities Used in Restructuring Medicaid Health Care Delivery or Payment* <http://www.medicare.gov>, or was provided by staff of the National Association of State Directors of Developmental Services.

### **1915(c) Comprehensive Waivers**

1915(c) Comprehensive Waivers refer to programs that offer a full array of services, up to and including services that support individuals in out of home settings, such as group homes or shared/living host home arrangements.

### **1915(c) Capped Support Waivers**

1915(c) Capped Support Waivers refer to waiver programs that have annual budgetary limits and typically offer a more narrow set of benefits, providing services to individuals who reside in their own homes or in their family homes.

### **1915(c) Autism Waivers**

1915(c) Autism Waivers refer to HCBS waiver programs that are targeted to individuals who have autism, and may offer an array of services important to assisting individuals with autism remain in and engage in their communities.

### **1915(c) Non-IDD Waivers**

1915(c) Non-IDD waivers refer to waivers within states that are targeted to individuals who do not have an intellectual disability. These waivers may also use a nursing facility level of care for eligibility and cost-comparison purposes.

### **State Plan**

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).

### **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 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.

### **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.

### **1915(j)**

1915(j) services are self-directed personal assistance services (PAS), which are personal care and related services provided under the Medicaid State plan and/or section 1915(c) waivers the State already has in place. Participation in self-directed PAS is voluntary and participants set their own provider qualifications and train their PAS providers. Participants determine how much they pay for a service, support or item.

### **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. Additionally, 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 the provision of 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.

### **Other State Plan LTSS**

In addition to 1915(i), (j) and (k), defined above, CMS has identified the following state plan services as being community-based LTSS for the purposes of the Balancing Incentive Program. The extent to which these authorities are utilized within a state for the provision of community-based state plan LTSS for individuals with IDD will vary.

- State plan home health
- State plan personal care services
- State plan 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 community-based settings only)
- Affordable Care Act, Section 2703, State Option to Provide Health Homes for Enrollees with Chronic Conditions