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.


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 ICI-IDD 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.

**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; Number of Type IV settings with 1-6 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.

**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.

**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


Centers for Medicaid and Medicare (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.


**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; “DNP” 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.

<table>
<thead>
<tr>
<th></th>
<th>IDD settings* with 1-3 residents</th>
<th>IDD settings* with 4-6 residents</th>
<th>IDD settings* with 1-6 residents</th>
<th>IDD settings* with 7-15 residents</th>
<th>IDD facilities and other facilities with IDD units (16+ residents)</th>
<th>IDD settings or units not funded by ICF-IDD or HCBS Waiver**</th>
<th>Psychiatric or other large facilities *** with residents with IDD not in special IDD units</th>
</tr>
</thead>
<tbody>
<tr>
<td>NUMBER of state (staffed by state employees) settings on June 30, 2011</td>
<td>ICF-IDD</td>
<td>HCBS</td>
<td>ICF-IDD</td>
<td>HCBS</td>
<td>ICF-IDD</td>
<td>HCBS</td>
<td>ICF-IDD</td>
</tr>
<tr>
<td>RESIDENTS with IDD beginning of Fiscal Year 2012 (7/1/11)</td>
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</tr>
<tr>
<td>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.</td>
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<tr>
<td>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.</td>
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<tr>
<td>DEATHS - the number of residents with IDD who died while on roll during Fiscal Year 2012 (7/1/11 to 6/30/12).</td>
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<tr>
<td>RESIDENTS with IDD at the end of Fiscal Year 2012 (6/30/12).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AVERAGE DAILY RESIDENTS with IDD on site in Fiscal Year 2012.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PER DIEM (average daily cost of care per resident) in Fiscal Year 2012.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

*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.

Part 1 Respondent Name: ____________________________, Phone: ____________________, Email: ____________________
### Residential Information Systems Project (RISP) Survey FY 2012

#### 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.

#### Type of Nonstate Residence:

- **Please exclude respite care placements.**
- **Please count only residents with IDD receiving services.**
- **Please do not make entries in the shaded cells.**

### Table: Number of Nonstate Residential Settings and Residents

<table>
<thead>
<tr>
<th>Type of Nonstate Residence</th>
<th>Number of Nonstate Residential Settings on June 30, 2012 with this Many Residents</th>
<th>Number of Residents in Nonstate Residential Settings of these Sites on June 30, 2012</th>
<th>Number of HCBS Recipients in Nonstate Settings by Type (on June 30, 2012)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1-3 4-6 1-6 7-15 Total</td>
<td>1-3 4-6 1-6 7-15 Total</td>
<td></td>
</tr>
<tr>
<td>Type I. Nonstate ICFs-IDD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td></td>
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</tr>
<tr>
<td>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 (e.g., host family/family foster care).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>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.</td>
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<td></td>
</tr>
<tr>
<td>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 (e.g., respite care, homemaker services, personal assistance).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type VI. Other residential types (please specify). Please record 0 if you do not have other nonstate residential service options for people with IDD.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Totals should equal the sum of 1-6, 7-15, and 16+.

**Data date (if other than June 30, 2012):** June 24, 2012

**Comments:**

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**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.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular ID/DD Waiver(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with ID/DD on other waivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**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.

<table>
<thead>
<tr>
<th>HCBS Waiver recipients with IDD by setting and age</th>
<th>HCBS Recipients with IDD on June 30, 2012</th>
<th>State and Federal Medicaid HCBS Expenditures for Fiscal Year 2012 (July 1, 2011 to June 30, 2012)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Birth thru 21 years</td>
<td>22 years or older</td>
</tr>
<tr>
<td>1. People with IDD on Regular IDD or Other HCBS Waivers who live in <em>Type V settings (Family Home)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. People with IDD on Regular IDD or Other HCBS Waivers in all other HCBS funded settings (<em>Types II, III, IV, VI and state operated</em>).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Total people with IDD on Regular IDD or other HCBS Waivers.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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) on 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 21 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 do 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 do 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.

For each data element reported, several special designators can be applied as needed

- Estimate – The exact number is not available.
  - 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.
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/IIDD 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/IIDD 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 collecting 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 21 year) 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 other types of residential services.

  » 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

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.

1 Text for this section came from The guide to Federal Medicaid Authorities Used in Restructuring Medicaid Health Care Delivery or Payment http://www.medicaid.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 Supports 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