# Background

**About:** This is a survey of the University of Minnesota's Residential Information Systems Project (RISP). It is part of a 40-year longitudinal study tracking Medicaid and state-funded long-term supports and services (LTSS) provided under the auspices of State Intellectual and Developmental Disability (IDD) Agencies. The survey is fielded annually in conjunction with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI). It is used to create state and national profiles of LTSS recipients, settings, and expenditures.

**Timeline:** FY 2018 surveys are due March 30, 2019. Late responses may not be included in our FY 2018 annual report. Questions reference June 30, 2018, or the period from July 1, 2017 through June 30, 2018.

**Target Populations:** Parts 1 and 2 of the survey ask about people, served by **State IDD Agencies**, who receive one or more Medicaid or state-funded long-term support or service (**LTSS**) in addition to case management or service coordination (LTSS Recipients with IDD). This group includes people receiving in-home or residential supports, as well as people receiving other types of LTSS such as day habilitation or vocational services even if the person does not receive services in their home or in a residential facility. It also includes people served by the **State IDD Agency** who live in Nursing Homes or **Psychiatric Facilities**.

Parts 3 through 5 include a broader target population.

* People on the **State IDD Agency Caseload** (Parts 3 and 4). This group includes **LTSS Recipients** with IDD plus people with IDD receiving only case management or services coordination services, people waiting for services, and people known to the **State IDD Agency** but not currently receiving LTSS. It does not include people whose eligibility for services has not been determined.
* All people with IDD (Part 5), whether on the **State IDD Agency Caseload** or not, who live in **Nursing Homes**, **Psychiatric Facilities**, or other **Congregate Settings** housing four or more LTSS recipients (for people birth through age 21 years), or housing 16 or more LTSS recipients (for people ages 22 years and older).

**Survey Changes for FY 2017 to 2018 – None.**

**Clarifications for FY 2018**

1. Caseload should be for any individual who is known to the state agency to have either applied for services or is currently receiving services related to IDD. It is not about IDD prevalence or eligibility, but more about who is access the state agency (or agencies) for services and supports. This has always been the intention for caseload, but a question arose during FY 2017 that led to this clarification.
2. Age 21 and under is for anyone birth up to their 22nd birthday. The cut off date for FY 2018 is June 30, 1996 for age 21 and under. Likewise, age 22 and older would be anyone born after June 30, 1996 (i.e. on or after July 1, 1996).
3. In this document, the table borders that are black indicate editable, requested information for the online survey.

Instructions

This survey should be completed by the state director of IDD services, or his or her designee. Please consult your state's Medicaid office, or other relevant state agencies, as needed to provide accurate responses.

Complete responses are important to ensure that your state’s system is accurately portrayed. We estimate values not provided when we compute estimated United States totals. We prefer to use estimates provided by states whenever possible. If you do not furnish complete information, the charts and graphs for your state may be incomplete or inaccurate.

The RISP survey is designed for online use. The online survey offers many tools, such as access to responses to previous year surveys, notes about data sources and explanations about specific values, interactive and context based instructions, and automated validation checks to confirm the accuracy of the reported data.

**General Instructions**

* Do not leave questions blank.
* Enter “0” when there are no people/settings/expenditures in a particular category or Funding Authority.
* Provide totals, even if you are unable to provide breakdowns by type of operation, age, setting type, or setting size.
* Use a “DNF” (Data Not Furnished) to indicate that you are unable to furnish a value, and you do not have a reasonable estimate that you could use.
* Use an “e” to designate estimated numbers.
* If the data are from a date other than June 30, 2018, please specify the date.
* Leave notes to explain anything the reader of the technical report needs to know to interpret the data correctly.
* Shaded boxes show values that are automatically computed in the online version of the survey.
* Definitions for words can be found in the end of the Word version of the survey, or by a dotted underline in the online version.

**Online Survey Instructions**

The web-based survey has been reorganized to mirror the Word version more closely to make data entry easier.

Expand

In the **Expand** menu, you can designate a value as an estimate (**e**), add notes, change the data date, or specify that you are unable to furnish a value (**DNF**). You can also see previous year data, validation warnings about possible data errors, and calculations used in the report.

* Use **Notes** 
  + If a value has changed substantially from the previous year, or from the trend in recent years
  + If you used a definition different from the operational definition provided
  + If you used a different methodology, or categorized people differently, than in the past
  + To help readers correctly interpret your response
  + To explain why you were only able to answer part of a question
  + To help the person completing the survey in subsequent years know how you arrived at the value
* As notes are entered, they are added to a notes menu. Once a note is added, it can be selected from the list to apply it to other survey items.
* Previous year data can be found in the **Expand** menu. If you notice inaccuracies in data from previous years, please let your RISP staff team member know (You can find the name of the staff assigned to your state at the end of the survey). We will update the database, and use the revised data for subsequent reports and products.
* **Validation Warnings** about possible errors have been added. Details about each warning can be viewed by clicking the expand button in the section titled “Validation checks that need your attention.”

**Notes** can be designated as private or public.

* **Private detail** – not for publication, but helpful for RISP staff or state staff who enter data, or
* **Public detail** – for publication in the state notes section of RISP reports and other products so that readers can correctly interpret your data

**Tips for using the Online Survey**

* **Login.** The system automatically tracks all entries by login ID. Each person should have his or her own user name and password. If someone forgets their password or needs to initiate a new account password, please go to “Reset your password” at <https://risp.umn.edu/user/password> and enter your email address. An email will be sent to you to regenerate a password as long as your email is in the system. Please do not use another person's ID to log in. Contact a RISP team member to get a new person added for your state.
* **Definition of Terms.** Definitions for selected terms can be viewed by moving your cursor over the term with a dotted underline. Additional instructions about specific survey items can be found in the “**Operational Definitions**” document.
* **Save.** The save button is on the top of each screen. You will receive a message if there are changes before you move to another screen to remind you to save the data. It is best to save data frequently. If you do not wish to save changes to the data that are active, refresh or reload your browser to cancel all active changes. Active changes are outlined by a green box.
* **Expand button.** Codes, explanatory notes, historic data, and warnings about potentially incorrect data are all found under the “Expand” button. You can also specify the following for each response: “e” for estimates; “DNF” for did not or unable to furnish.
* **Alternate Date.** By default, we assume that the data you provide is correct as of June 30, 2018. If you are reporting data from a different date (such as data from a previous year), please note that date in the Expand section.
* **Computed values** have a shaded background.Some computed totals could only be changed by returning to the screen where the component value(s) were first entered. Entering a zero in the total of a row or column will often make the remaining cells zero.

Your assigned RISP project staff member is available by phone or email, and will contact you during the editing process if we find missing or possibly incorrect information, or notice a change from previous years that has not been explained in your comments. Thank you for your ongoing support of this Administration on Intellectual and Developmental Disabilities (US Health and Human Services) Data Project of National Significance.

Sherri Larson

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# Funding Authorities

This section asks about federal and state **Funding Authorities** used to finance **long-term supports and services** for people with IDD as of June 30, 2018.

* Please respond “yes” to indicate any **Funding Authorities** for which you had expenditures in FY 2018 for people with IDD.
* Saying “no” will trigger the survey software to fill in 0’s for subsequent questions about the Funding Authority. You will not be able to enter recipients, settings, or expenditures for a Funding Authority if you say “no.”
* If you selected “no” by mistake, return to this section and change your “no” to a “yes” to enable data entry in other parts of the survey.
* If you are unsure, please verify your responses with your **State IDD Agency Director** or Medicaid office.

|  |  |  |
| --- | --- | --- |
| Which of these Funding Authorities were used to finance long-term supports and services for people with IDD on the State IDD Agency Caseload as of June 30, 2018? | | Yes/No |
| **Medicaid Waiver** | 1115 Demonstration Waiver |  |
| 1915 (a) (b) or (b/c) Managed Care Waiver with LTSS |  |
| 1915 (c) Home and Community Based Services Waiver |  |
| **Medicaid State Plan HCBS** | 1915(i) State plan Home and Community Based Services |  |
| 1915(k) Community First Choice |  |
| **Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)** | |  |
| **State Non-Medicaid** | State funding for LTSS for people with IDD not matched with Federal Medicaid funds |  |

# Part 1: State-Operated IDD Recipients and Settings on June 30, 2018

**State-Operated IDD Settings** are residential settings staffed by state employees that serve people with IDD.

* Include state-operated IDD facilities and IDD units of facilities serving multiple populations such as Nursing Homes or Psychiatric Facilities.
* Multiple units, cottages, or homes located on a single campus should be counted as a single setting. Units, cottages, or homes located on different campuses should be counted separately.
* Setting size is based on number service recipients living in the facility/on the campus as of June 30. Do not count “empty beds” in determining setting size (for example, a campus licensed to serve up to 20 people that has 12 people in residence on June 30 should be listed in the 7-15 people category).

## 1A. How many State-Operated IDD Settings served people on the **IDD Agency Caseload** on June 30, 2018 (by Facility Size and Funding Authority)?

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| State-Operated IDD Settings | Settings by Size | | | | | | |
| Settings by  Funding Authority | 1-3 | 4-6 | 1-6 Total | 7-15 | 16+ | Size Unknown | All Sizes |
| **Medicaid Waiver** 1115; 1915 (a) (b) (b/c); and 1915 (c) |  |  |  |  |  |  |  |
| Medicaid ICF/IID |  |  |  |  |  |  |  |
| **Other** |  |  |  |  |  |  |  |
| Total |  |  |  |  |  |  |  |

## 1B. How many people with IDD lived in State-Operated IDD Settings on June 30, 2018 (by Setting Size and Funding Authority)?

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| State-Operated IDD Settings | People by Setting Size | | | | | | |
| People by  Funding Authority | 1-3 | 4-6 | 1-6 Total | 7-15 | 16+ | Size Unknown | Total People |
| **Medicaid Waiver** 1115; 1915 (a) (b) (b/c); and 1915 (c) |  |  |  |  |  |  |  |
| Medicaid ICF/IID |  |  |  |  |  |  |  |
| **Other** |  |  |  |  |  |  |  |
| Total |  |  |  |  |  |  |  |

## 1C. Describe people with IDD and daily costs in State-Operated IDD Settings serving 16 or more people for the Year ending June 30, 2018 by Funding Authority

| **State Operated IDD Settings** serving 16 or more people with IDD are also known as **Public Residential Facilities (PRF)** | Medicaid Waiver | Medicaid ICF/IID | Other Funding Authority | Total |
| --- | --- | --- | --- | --- |
| **ADMISSIONS/READMISSIONS** between July 1, 2017 and June 30, 2018 (Do not include short-term respite or crisis admissions of 90 days or less or transfers between **PRFs**) |  |  |  |  |
| **SHORT-TERM** **respite or crisis ADMISSIONS to PRFs** (for stays of 90 days or less) |  |  |  |  |
| **DISCHARGES** number of people who moved out of the facility between July 1, 2017 and June 30, 2018 (excluding short-term respite or crisis stays and transfers between **PRFs**) |  |  |  |  |
| **DEATHS** People who died between July 1, 2017 and June 30, 2018 while living in a PRF. |  |  |  |  |
| **AVERAGE DAILY RESIDENTS** between July 1, 2017 and June 30, 2018. |  |  |  |  |
| **PER DIEM** (average daily per person cost of care). Enter N/A if there were no **PRFs** in a Funding Authority category on June 30, 2018. |  |  |  |  |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Part 1 Data date if not June 30, 2018: | |  |  |  |  |
| Respondent Name: |  | Phone: |  | Email: |  |

# Part 2. Nonstate-Operated LTSS Recipients and Settings on June 30, 2018

**Section Instructions**

**Nonstate-Operated** settings LTSS settings staffed by employees of an entity other than the state.

**Setting Size** Number of service recipients living in the setting as of June 30, 2018. Do not count empty beds (for example, a campus licensed to serve 20 people with 12 people in residence on June 30 should be listed in the 7-15 people category).

## Nonstate-Operated Living Arrangement Types

Type I: **ICF/IID**. Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Type II: **IDD Group Home**. A residence owned, rented, or managed by the residential services provider, or the provider's agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD. Include corporate foster care settings and provider-owned or controlled housing.

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

Type IV. **Own Home**. A home owned or leased by one or more persons with IDD as the person(s)' own home, in which they receive personal assistance, instruction, supervision, and other supports. Do not include provider-owned or controlled housing. Include people sharing a home with a spouse/partner or other unrelated individuals. Do not include people living with a related family member.

Type V. **Family Home**. A residence of a person(s) with IDD who receives one or more long-term support or service such as respite care, personal assistance, day habilitation, or in-home supports in addition to case management services while living with a related family member.

Type VI. **Other Setting Type**. Other residential settings in which LTSS recipients with IDD on the caseload of the state IDD agency live. Other settings may include settings such as nonstate-operated hospitals, Nursing Homes, Psychiatric Facilities, assisted living facilities, board and care facilities, farmsteads, intentional, or gated communities. Do not include Type I ICF/IID settings or Type II IDD Group Homes in this category.

Type VII. **Unknown Setting Type**. The type of setting in which a LTSS recipient with IDD lives is not known (for questions 2B and 2C).

## 2A. In how many different Nonstate-Operated settings did LTSS Recipients with IDD live on June 30, 2018 (By Setting Size and Setting Type)?

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Nonstate–Operated | Settings by Size | | | | | | |
| Settings by  Residence Type | 1-3 | 4-6 | 1-6 Total | 7-15 | 16+ | Size Unknown | Total Settings |
| 1. ICF/IID |  |  |  |  |  |  |  |
| 1. IDD Group Home |  |  |  |  |  |  |  |
| 1. Host/ Foster Family Home |  |  |  |  |  |  |  |
| 1. Own Home |  |  |  |  |  |  |  |
| 1. Family Home | Not requested | | | | | | |
| 1. Other Settings (specify) |  |  |  |  |  |  |  |
| Total |  |  |  |  |  |  |  |
| Other Setting type(s) description: (General Note in the online survey) |  | | | | | | |

## 2B. How many LTSS recipients with IDD were served by nonstate entities on June 30, 2018 (By Setting Size and Residence Type)?

| Nonstate-Operated Settings | People by Setting Size | | | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- |
| People by  Residence Type | 1-3 | 4-6 | 1-6 Total | 7-15 | 16+ | Size Unknown | Total People |
| 1. ICF/IID |  |  |  |  |  |  |  |
| 1. IDD Group Home |  |  |  |  |  |  |  |
| 1. Host/ Foster Family Home |  |  |  |  |  |  |  |
| 1. Own Home |  |  |  |  |  |  |  |
| 1. Family Home | Not requested | | | | | |  |
| 1. Other Setting Types (specify) |  |  |  |  |  |  |  |
| 1. Unknown Setting Type | Not requested | | | | | |  |
| Total |  |  |  |  |  |  |  |
| Other Setting type(s) description: (General Note in the online survey) |  | | | | | | |

## **2C. Of the LTSS Recipients with IDD living in each setting type, how many received services funded by a** **Medicaid Waiver** (1115, 1915 (a), (b) or (b/c), 1915 (c)) **or State Plan Home and Community Based Services** (1915 (i) or 1915 (k)) **Funding Authority?** For each setting type, note the unduplicated total number of people with IDD who receive Medicaid Waiver and/or Medicaid State Plan funded LTSS.

| Number of people inNonstate Settingswho receive **Medicaid Waiver** and/or **Medicaid State Plan** funded LTSS |  | **In development: Not required** | |
| --- | --- | --- | --- |
| Medicaid Waiver  1115; 1915 (a) (b) (b/c); 1915 (c) | **Medicaid State Plan** 1915(i) or 1915(k) | Unduplicated  Total |
| 1. ICF/IID |  | Not applicable |  |
| 1. IDD Group Home |  |  |  |
| 1. Host/ Foster Family Home |  |  |  |
| 1. Own Home |  |  |  |
| 1. Family Home |  |  |  |
| 1. Other Setting Types (specify) |  |  |  |
| 1. Unknown Setting Type |  |  |  |
| Total in Nonstate settings |  |  |  |

Part 2 Data date if not June 30, 2018:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Respondent Name: |  | Phone: |  | Email: |  |

# Part 3: IDD Agency Caseload, LTSS Recipients, and Expenditures

This section asks about Medicaid and State **LTSS** expenditures for people on the **State IDD Agency** **Caseload**, by **Funding Authority**, age, and living arrangement (family home or other).

This is what you reported in Parts 1 and 2 (for those using the online survey)

|  |  |
| --- | --- |
| **LTSS Recipients** Living in **State-Operated** Settings (Part 1B) | Total Part 1 |
| **LTSS Recipients** in **Nonstate** Settings (Part 2B) | Total Part 2 |
| **Total LTSS Recipients** | LTSS recipients |

State IDD Agency Caseload includes any individual who is known to the state agency to have either applied for services or is currently receiving services related to IDD.

* ***Include***
  + People with IDD known to the State IDD Agency who receive one or more long-term support or service in addition to case management
  + People receiving only case management or service coordination services
  + People waiting for services, and
  + People known to the **State IDD Agency** but not receiving LTSS
* ***Do not include*** people whose eligibility for services has not been determined or people in the general population who have accessed the IDD service system.

## 3. How many people with IDD were on the State IDD Agency Caseload on June 30, 2018 (By Age)?

Provide an unduplicated total.

|  |  |  |  |
| --- | --- | --- | --- |
| **State IDD Agency** Caseload | 21 years or younger | 22 years or older | Total All Ages |
| Number of People |  |  |  |

**LTSS Recipients with IDD and Expenditures by Recipient Age and Living Arrangement**

Report recipients and expenditures for FY 2018 (July 1, 2017 through June 30, 2018) for each **Funding Authority**. Medicaid expenditures include the Federal and the State/Local share. Annual per person expenditures are automatically computed in the on-line version of the survey.

## 3A: Medicaid Waiver Recipients and Expenditures by Age for FY 2018

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Medicaid Waiver  1115, 1915 (a)(b)or (b/c), 1915 (c) | 21 years and younger | 22 years and older | Total All Ages | Recipients Parts 1 & 2 |
| Recipients |  |  |  |  |
| Expenditures |  |  |  |  |
| Expenditures per person |  |  |  |  |

**3B. Medicaid Waiver Recipients and Expenditures by Living Arrangement and Age for FY 2018**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Medicaid Waiver**  1115, 1915 (a)(b)or (b/c), 1915 (c) | | 21 years  and younger | 22 years  and older | Total All Ages |
| Home of a Family  Member | Recipients |  |  |  |
| Expenditures |  |  |  |
| Expenditures per person |  |  |  |
| Other (non-family)  Setting | Recipients |  |  |  |
| Expenditures |  |  |  |
| Expenditures per person |  |  |  |
| Total Recipients by Living Arrangement | |  |  |  |
| Total Recipients by Age in 3A | |  |  |  |

**3C: Medicaid State Plan Home and Community Based Services Recipients and Expenditures by Age**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Medicaid State Plan HCBS1915(i) or 1915(k) | 21 years and younger | 22 years and older | Total All Ages | Recipients  (Part 2) |
| Recipients |  |  |  |  |
| Expenditures |  |  |  |  |
| Expenditures per person |  |  |  |

## 3D: Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) Recipients and Expenditures by Age

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Medicaid ICF/IID** | 21 years and younger | 22 years and older | Total All Ages | Recipients  (Parts 1 and 2) |
| Recipients |  |  |  |  |
| Expenditures |  |  |  |  |
| Expenditures per person |  |  |  |  |

## 3E: State-Funded Non-Medicaid LTSS Recipients and Expenditures by Age

|  |  |  |  |
| --- | --- | --- | --- |
| State-Funded Non-Medicaid | 21 years and younger | 22 years and older | Total All Ages |
| Recipients |  |  |  |
| Expenditures |  |  |  |
| Expenditures per person |  |  |  |

**3F: People with IDD on the State IDD Agency Caseload but not receiving funded LTSS on June 30, 2018**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| |  |  |  |  | | --- | --- | --- | --- | | No Medicaid or State-Funded LTSS | 21 years and younger | 22 years and older | Total All Ages | | People with IDD |  |  |  | |

Part 3 Data date if not June 30, 2018:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Respondent Name: |  | Phone: |  | Email: |  |

# Part 4: Medicaid Waiver Waiting List

## 4. How many people with IDD living with a Family Member, or in Own Home settings, were waiting for Medicaid Waiver-funded services on June 30, 2018?

* ***Include people waiting for Medicaid Waiver-funded LTSS who***
  + Lived with a family member, or in their own home, as of June 30, 2018 and who
  + Did not receive Medicaid-funded LTSS other than case management/service coordination
* ***Do not include people***
  + Living in an **ICF/IDD**, or in another non-family setting (such as a Skilled Nursing Facility) or
  + Already receiving Medicaid Waiver-funded services in addition to case management/service coordination

|  |  |
| --- | --- |
| People Waiting for Medicaid Waiver 1115, 1915 (a)(b)or (b/c), 1915 (c) funding | Number of People |
| How many people with IDD living in their own home or the home of family member were waiting for (but not receiving) **Medicaid Waiver**-funded LTSS on June 30, 2018? |  |
| a. Of the people waiting, how many were receiving case management (including Targeted Case Management) services? |  |
| b. Of the people waiting, how many were waiting to move to a setting other than the home of a family member? |  |

# Part 5 Psychiatric, Nursing Facilities and Other Congregate Settings

***This section includes all people with IDD living in your state whether they are served by the State IDD Agency or not.***

## 5A. How many people with IDD lived in state or nonstate operated Nursing Homes or Psychiatric Facilities on June 30, 2018? Note: Include people with IDD on the State IDD Agency Caseload who live in Nursing Homes or Psychiatric Facilities.

|  |  |  |  |
| --- | --- | --- | --- |
| Number of People with IDD | State-Operated | Nonstate-Operated | Total People |
| In Nursing Homes |  |  |  |
| In **Psychiatric Facilities** |  |  |  |

**About this Section:** The Centers for Disease Control (CDC) uses the data you report here to monitor national progress toward the Healthy People 2020 goals of reducing the number of children and adults with IDD living in congregate settings. It is very important that we receive data from all of the states on these questions.

**Congregate Settings** are

* State- or nonstate-operated non-family residential settings, such as **PRFs**, **ICF/IID, IDD Group Homes, Nursing Homes, Psychiatric Facilities, Other Group Settings** or similar facilities.
* In which rotating (or shift) staff members provide supports and services

For people ages 21 years or younger, report the number of LTSS recipients with IDD in **Congregate Settings** of four or more people.

For people ages 22 years or older, report the number of LTSS recipients with IDD in **Congregate Settings** of 16 or more people.

**Congregate Settings** do not include **Own Home** settings.

**People in Congregate Settings do not include people with IDD who**:

* Live with birth or adoptive parents, or other family members (**Family Home**)
* Live in **Host/Foster Family Settings** in which no shift staff work
* Live only part of the year in a residential PreK-12 school
* Live in correctional or juvenile justice facilities
* Receive only respite services from a **Congregate Setting**
* Live in other states (do count people who live in your state whose services are paid by another state)

**5B: How many people with IDD 21 years or younger lived in Congregate Settings of four or more people on June 30, 2018?**

|  |  |
| --- | --- |
| People with IDD ages *21 years or younger* in congregate settings of *four or more people* | People |
| Nursing homes |  |
| Other **Congregate Settings** |  |
| Total |  |

5C: How many people with IDD 22 years or older lived in Nursing homes or other Congregate Settings of 16 or more people on June 30, 2018?

|  |  |
| --- | --- |
| People with IDD ages *22 years or older* in congregate settings of *16 or more people* | People |
| In Nursing homes |  |
| In Other **Congregate Settings** |  |
| Total |  |

Part 5: Data date if not June 30, 2018:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Respondent Name: |  | Phone: |  | Email: |  |

Thank you for completing the RISP survey. Please inform your RISP contact that you have completed the survey. The project team will review your data and your responses to any **validation warnings**. You can view **validation warnings** online by clicking “Expand,” or by viewing the Validation Summary. We will contact you if we have any questions about your responses. Contact your assigned RISP staff member listed at the end of the survey or contact the RISP project team at ([RISP@umn.edu](mailto:RISP@umn.edu)) if you have questions.

**Final Question: Who should receive a print copy of the RISP report in your state?**

We want to send copies of the RISP report to those who will use them. Each time we send hardcopies of the report, we send copies to each IDD Director ([listed on NASDDDS website](https://www.nasddds.org/state-agencies/)).

1. **Who should receive a print copy of the RISP report in your state other than the IDD Director?**

|  |  |
| --- | --- |
| **Name** | **Mailing Address** |
|  |  |
|  |  |
|  |  |

1. **Who should be notified when an electronic copy (PDF) of the RISP report is available?**

| **Name** | **Email** |
| --- | --- |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
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## RISP Project Staff Members

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**Abbreviations**

**“d”** The data are correct as of a date other than June 30, 2018

**“e”** Estimate

**DNF**  Data not furnished

**HCBS**  Home and Community Based Services

**HSRI**  Human Services Research Institute

**ICF/IID** Intermediate Care Facility for Individuals with Intellectual Disabilities

**IDD**  Intellectual or Developmental Disabilities

**LTSS** Long-term supports and services

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

**PD** Partial Data reported

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

**RISP** Residential Information Systems Project

**Glossary**

**Alternate Date** By default, we assume that the data you provide is correct as of June 30, 2018. If you are reporting data from a different date (such as data from a previous year), please note that date in the Expand section.

**Annotate Data** Designate a value as an estimate, from a different date, or to record that a value cannot be furnished.

**Average Daily Residents** Computed as either the average of people in a setting on June 30, 2017 and June 30, 2018, or the running average number of residents between those dates.

**Computed values** have a shaded background.Some computed totals could only be changed by returning to the screen where the component value(s) were first entered. The computed values will appear when all component elements have been reported.

Congregate Settings

* State or nonstate non-family residential settings (any Funding Authority), such as group homes, ICF/IID, Nursing Homes, Psychiatric Facilities, or any other similar facility) in which rotating (or shift) staff members provide supports and services.
* **People in Congregate Settings does not include people who**:
  + Live with birth or adoptive parents, or other family members
  + Live in **Host/Foster Family Settings** in which no shift staff work
  + Live only part of the year in a residential PreK-12 school
  + Live in correctional or juvenile justice facilities
  + Receive only respite services from a **Congregate Setting**
  + Live in other states (do count people who live in your state whose services are paid by another state)

**Expand** In the **Expand** menu, you can designate a value as an **estimate**, add notes, change the data date, or specify that you are unable to furnish a value (**DNF**). You can also see previous year data, **validation warnings** about possible data errors, and calculations used in the report

**Funding Authorities** Federal, state, or local statutes that authorize funding for long-term supports and services. The RISP survey asks about the following **Funding Authorities**

* **Medicaid Waiver** Funding authorized in Sections 1115; 1915 (a) (b) (b/c); or 1915 (c) of the Social Security Act
* **Medicaid State Plan Home and Community Based Services** Funding authorized in Sections 1915(i) or 1915(k) of the Social Security Act
* **Intermediate Care Facilities for Individuals with Intellectual Disabilities** (ICF/IID)
* **State Funded-Non-Medicaid** Funding authorized by state or local jurisdictions that are not matched with Federal Medicaid funds

**Home and Community-Based Services (HCBS)** Long-Term Supports and Services provided in community settings designed to prevent the need for institutional placement, or to support a person to move out of an institution.

**IDD** Intellectual or developmental disabilities as defined in your state for service eligibility purposes. Some states require service recipients to have a condition such as an intellectual disability, autism, cerebral palsy, epilepsy, spina bifida, or a closely related condition. Other states define eligibility for IDD services based on the ***Developmental Disabilities Assistance and Bill of Rights Act of 2000*** definition, or based on the presence of specific functional limitations present before a specific age.

IDD Agency Caseload Caseload should be for any individual who is known to the state agency to have either applied for services or is currently receiving services related to IDD.

* ***Include***
  + People with IDD known to the State IDD Agency who receive one or more long-term supports and services in addition to case management
  + People receiving only case management or service coordination
  + People waiting for services, and
  + People known to the **State IDD Agency** but not receiving LTSS
* ***Do not include***
  + People whose eligibility for services has not been determined
  + People who receive services from another government agency, such as education or child welfare, unless they also are served by the State IDD Agency.

**In development: Not required** Items marked “In development” are optional. We will use annotations on tables to reflect when data from “In development” items are reported, but will not designate totals as DNF based on whether these items are completed or not.

**Long-Term Supports and Services (LTSS)** can be provided in an institution such as an **ICF/IID**, Nursing Home or Psychiatric facility or can be provided in **Home and Community-Based Settings.** LTSS include, but are not limited to, residential supports, in-home supports, personal care assistance, family supports, day or employment supports, case management, behavioral supports, support for participant direction, therapeutic services, non-Medical transportation, equipment, technology and modifications, home delivered meals, community transition services, family and caregiver training, respite, and financial management services.

**LTSS Recipients** People with IDD served by **State IDD Agencies** who receive one or more Medicaid or state-funded LTSS in addition to case management or service coordination.

* ***Include*** people receiving LTSS such as day habilitation, vocational services, or transportation even if they do not also receive in-home or residential services and people served by or under the auspices of the **State IDD Agency**.
* ***Include*** people with IDD living in Nursing Homes or **Psychiatric Facilities** in parts 1 and 2 if they are on the IDD Agency caseload, and in Part 5 whether or not they are on the IDD Agency caseload.

**Did Not Furnish** A value that is not available, and for which a reasonable estimate cannot be made.

Estimate An exact value is unavailable. The state’s best approximation of what the value would be if it had been available. Estimates can be the value for the item in the previous or subsequent fiscal year, but an estimate can be carried forward for only one year.

**Expand** A section of the online survey where users can add annotations, notes, and different dates. The menu also allows users to see previous year data, validations related to warnings about possible data errors, and calculations used in the report.

* **Private Detail** A note that is not for publication, but is helpful for RISP staff or other people from your state who enter data.
* **Public Detail** A note for publication in the state notes section of the RISP technical report, and with state profiles, to help readers correctly interpret your data.

**Nonstate-Operated Settings** LTSS settings in which services are provided by people who are not employees of the state government.

**Other Date** A date other than June 30, 2018, or a Fiscal Year ending on a date other than June 30, 2018.

**Other Funding Authority** (Part 1) State-Operated **LTSS** funded by a source other than Medicaid Waiver or ICF/IID.

**Other Setting Type** (Part 2) Settings in which **LTSS recipients** with IDD live other than an ICF/IID, group home, own home, host/foster family home, or family home. Other settings include, but are not limited to, Nursing Homes and Psychiatric Facilities.

**Partial Data** Used in the RISP technical report to indicate that a state furnished some, but not all, of the data needed to compute a value.

**Psychiatric Facilities** Residential facilities providing LTSS to persons with a primary diagnosis of a Psychiatric disorder (for example a mental health facility). Report only the number of people with IDD living in those settings.

**Public Residential Facilities (PRF)** State-Operated IDD Facilities with 16 or more residents (includes IDD units in state-operated facilities serving other populations).

**Setting size** Number of long-term services and supports recipients living in the same home, facility, or campus as of June 30, 2018 (Categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, or 16 or more people). Do not count “empty beds” in determining setting size.

**State IDD Agency** the state entity responsible for overseeing Medicaid or State-funded long-term supports and services for people with IDD.

**State-Operated IDD settings** residential facilities staffed by employees of the state government.

**State-Operated Settings, “Other” Funding Authority** – LTSS settings staffed by employees of the state-government that are funded by a source other than Medicaid **ICF/IID** or a **Medicaid Waiver.**

**Unknown Setting Size** (Part 2, Questions 2A) Number of LTSS settings of each type for which the setting size is unknown. (Part 2, Question 2B) Number of people with IDD living in a setting type of an unknown size.

**Unknown Setting Type** (Part 2, Type 7, Questions 2B and 2C) Number of LTSS recipients on the caseload of the State IDD Agency living in a nonstate-operated setting, for whom residential setting type is unknown. If one or more people are reported to live in an unknown setting type, totals for all setting types will be coded as estimates.

**Warnings** Validations and computation checks have been built into the RISP online survey. They alert users about values that are inconsistent with previous values or other survey responses, and about possible arithmetic or data entry errors.