Residential Information Systems Project
Operational Definitions
FY 2019 Survey

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Survey Overview and Definitions

The RISP project is directed by Sheryl Larson at the University of Minnesota. The research team also includes Heidi Eschenbacher from the University of Minnesota, and Brittany Taylor from the Human Services Research Institute. Each state is assigned a specific staff member for ongoing project communication. You can see who is assigned to your state in the survey introduction at https://risp.umn.edu/survey-dashboard.

RISP technical assistance is available to state staff and the public. See the RISP website for contact information: https://risp.umn.edu/contactus. General RISP questions can be emailed to risp@umn.edu. Someone from the RISP project team will get back to you as soon as possible.

Technical Assistance is available about:

- How to interpret a specific finding in the annual technical report
- Comparisons between two or more states, or comparing a state to the nation as a whole
- How RISP findings relate to a story being developed by the press or media
- How to use RISP findings in policy development, strategic planning, and policy advocacy
- Other topics

Abbreviations and Acronyms

CMS 64	Centers for Medicare & Medicaid Services Quarterly Expense Report
DNF	Data not furnished
FY	State Fiscal Year July 1 to June 30, unless otherwise specified
HCBS	Home and Community-Based Services
HSRI	Human Services Research Institute
IDD	Intellectual and Developmental Disabilities
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
LTSS	Long-term supports and services
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NHIS-D	National Health Interview Survey-Disability Supplement
PD	Partial data reported
PRF	Public residential facility (a state-operated IDD facility serving 16 or more individuals)
RISP	Residential Information Systems Project (University of MN)
RTC	Research and Training Center on Community Living (University of MN)

Special designators for the RISP survey and annual technical report

"d" Other date.

If the provided data was not from June 30, please specify the alternate date used.

"e" Estimate.

The reported value is the closest available approximation when the exact value is not known.

"DNF" Data not furnished

Use the DNF code ***only*** if a value is not known or not available, and it cannot be estimated. Please limit the use of the DNF code. If the state does not provide a value or an estimate, project staff must impute the value to generate the US estimated totals. Do not use zero "0" to

reflect unknown values.

"i" imputed. For use by the RISP team only.

No value or incomplete data were provided. RISP project staff estimated the value so that a US estimated total could be computed. Imputed values are based on previously reported data, and/or proportional estimates based on states with complete data.

"N/A" Not applicable.

This code is only used in reference to per-person expenditures for services provided in state-operated IDD facilities of 16 or more people for states that do not operate any facilities of that type. On all of the other questions, indicate that you do not use the service with a "0," meaning no participants/facilities/expenditures etc.

"PD" Partial Data. Used by the RISP team.

PD is noted on tables that include values computed using two or more survey items when some, but not all, of the components were reported by the state.

"s" Other source. Used by the RISP team. Examples of other sources include:

- Publicly available data from a federal data source are used for values such as the total state population by age, total income taxes paid by the state, and Federal Medical Assistance Percentages.
- Reports published quarterly by the American Health Care Association based on the Centers for Medicare and Medicaid Services CASPER reportsfICF/IID recipients, and number of people with IDD in Nursing Homes.
- IBM Watson (formerly Truven) has a contract with the Centers for Medicare and Medicaid Services to publish an analysis Medicaid long-term supports and services program expenditures as reported by states in their quarterly CMS 64 forms for each Federal Fiscal Year. However, those reports generally are based on date of payment rather than date of service, and are subject to revision for up to 2 years after the fiscal year ends.

Key Definitions

Intellectual Disability

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability is characterized by "significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, duration of disability, and the need of people with this disability for individualized services and supports. Every individual who is, or was, eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability". Alternative definitions are offered by the American Psychological Association (APA) in the *DSM V*, and by the World Health Organization (WHO) in the *International Classification of Diseases and Related Health Problems*. The International Statistical Classification of Diseases in Related Problems (ICD) version 10 (http://www.icd10data.com/) defines codes used in health care settings. States may use one of these definitions, or may use another definition in rule and statute.

Developmental Disability (DD)

According to Congress, under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 "developmental disability" is a severe, chronic disability of an individual that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifested before the individual attains age 22;

3. is likely to continue indefinitely;
4. results in substantial functional limitations in 3 or more of the following areas of major life activity:
    a. Self-care
    b. Receptive and expressive language
    c. Learning
    d. Mobility
    e. Self-direction
    f. Capacity for independent living, or
    g. Economic self-sufficiency; and
5. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated."
   http://www.acl.gov/Programs/AIDD/DD_History/index.aspx

Related Conditions

States vary in whether related conditions qualify an individual for IDD agency services. In some states people with a condition closely related to intellectual disabilities that results in the need for the same type, intensity, and duration of support as needed by a person with intellectual disabilities are eligible for IDD services. Common related conditions include autism spectrum disorder, cerebral palsy, down syndrome, spina bifida, hydrocephalus, epilepsy, and fragile X syndrome.

Age

RISP defines children and youth as people ages birth to 21 years, and adults as people 22 years or older on June 30, 2019. These age groups were selected in cooperation with the NASDDDS Research Committee knowing that the age cutoff for children and youth varies by state. For the RISP survey, please use the 0-21 year age group if possible to permit meaningful comparisons across states. If your state uses a different age cutoff, or for some other reason you are unable to report using the 0-21 year group, please specify the age cutoff you used.

Include people born on or after July 1, 1997 in the birth to 21 years category. Include people born before June 30, 1997 in the 22 years or older category.

Long-Term Supports and Services

Long-Term Supports and Services (LTSS) assist people experiencing ongoing difficulties as a result of aging, chronic illness, or disability to perform activities of daily living (such as eating, bathing, and dressing), instrumental activities of daily living (such as cooking, housekeeping, and managing money or medications), and to participate in employment, educational, recreation, and community activities of their choice.

LTSS include, but are not limited to, residential supports, in-home supports, personal care assistance, family supports, day or employment supports, case management, behavioral supports, support for participant direction, therapeutic services, non-medical transportation, equipment, technology and modifications, home delivered meals, community transition services, family and caregiver training, respite, and financial management services.

- **Behavior Supports:** Supports to prevent or reduce behavior-related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions.

- Examples: Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment
- **Case Management:** Services to assist an individual or family to identify the supports they need, establish eligibility for funded supports, access needed supports, and monitor the extent to which available supports meet the needs of the individual.
  - Examples: Case management, service coordination
- **Day Habilitation & Employment:** Services provided to support the individual in community-based activities (i.e., supported employment, day programs, education)
  - Examples: Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, and early start programs
- **Environmental Modifications and Technology:** Services to accommodate physical disabilities
  - Examples: Personal emergency response systems, home modifications (such as ramps, bathroom modifications), vehicle modifications or repairs, other adaptive equipment, augmentative communication devices, and similar services
- **Family Caregiver Support:** Services provided to help the family caring for an individual with IDD
  - Examples: Home-delivered meals, home health aide, homemaker/chore, caregiver counseling, caregiver training
- **In-home Services:** Services to direct skills development and training to the individual living in the home of a family member, or the person's own home.
  - Examples: Home-based habilitation and training
- **LTSS Medical Supports:** Medical care needed to help individuals with disabilities to remain in their home, the home of a family member, or another home or community residential setting.
  - Examples: OT, PT, speech and language therapies, skilled and private-duty nursing
- **Participant-Directed Supports:** Assistance to individuals/families who self-direct services. Such assistance may include the development of the person-centered plan, managing individual budgets, recruiting workers, and accessing generic services and supports.
  - Examples: Financial management services, participant training, goods and services, other, interpreter
- **Personal Care Supports:** Direct one-to-one services to the individual provided in, or out of, home to provide instrumental support, community integration or skill training
  - Examples: Companion services, personal care/assistance
- **Residential Services:** Services provided to a person with IDD who lives in a setting other than the home of a family member while receiving funded supports.
  - Examples: Residential habilitation, group home, semi-independent living services, supported living services, shared living, corporate foster care, host home, family foster care
- **Respite:** Temporary relief from caregiving responsibilities for family caregivers
  - Examples: Respite (in home, out of home), individual support (day or night)
- **Transportation:** Supports to transport an individual to a community-based activity, including day services, employment services, or other community-based activities.
  - Examples: Community transportation services, non-medical transportation

Funding Authorities

The survey asks about the **funding authorities** used in your state to finance **long-term supports and services** for people with IDD as of June 30, 2019. We cluster funding authorities into four broad categories: Medicaid Waiver, Medicaid State Plan Home and Community Based Services (HCBS), Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), and non-Medicaid state funding sources.

Non-State Plan HCBS. Under the Social Security Act, certain provisions give the Secretary of Health and Human Services the authority to waive otherwise applicable provisions of the Medicaid statute. The RISP survey asks about people with IDD who receive LTSS funded by one or more of the following authorities:

1115 Demonstrations

Section 1115 Waivers allow states to test experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. They give states additional flexibility to design and improve their programs to demonstrate and evaluate policy approaches such as expanding Medicaid eligibility criterion, providing services not typically covered by Medicaid, and using innovative service delivery systems that improve care, increase efficiency, and reduce costs.

Managed Care

Several Medicaid authorities allow states to contract with Managed Care Organizations (MCOs) to manage Medicaid-funded services and supports, rather than using a fee-for-service financing structure. The authorities monitored by the RISP project include:

- **1915(a) Managed Care Waiver.** This authority allows states to enroll Medicaid recipients voluntarily into a managed care program as an alternative to offering those services using a fee-for-service model.
- **1915(b) Managed Care Waiver.** This authority allows states to mandate certain groups of Medicaid recipients to receive services through enrollment in a managed care program.
- **1915(b)/(c) Managed Care with Home and Community Based services.** This authority allows states to operate a 1915(c) Home and Community Based Services Waiver concurrently with a managed care wavier authority.

1915(c) Home and Community Based Services Waivers

This funding authority allows states to provide Medicaid-funded long-term supports and services to eligible recipients in a home or community-based setting rather than in a Medicaid-funded institution. 1915(c) waivers can target specific populations, and each waiver includes a specified menu of covered services that assist in diverting people from entering institutional settings and/or transitioning individuals from institutional settings into their homes and community. States may operate several different 1915(c) waiver programs targeting different populations or service menus.

Medicaid State Plan. Medicaid State Plan services include acute care, institutional long-term supports and services, and home and community based LTSS.

- **1915(i) State Plan Home and Community-Based Services.** The 1915(i) State Plan option allows states to target HCBS benefits to one or more Medicaid eligible population, define needs-based eligibility criteria, and provide a combination of acute care medical services such as dental services, and skilled nursing services, as well as LTSS, such as respite, case management, supported employment, or environmental modifications. This authority allows states to offer self-directed LTSS services. However, states must ensure that the benefit is available to all eligible individuals in the state.
- **1915(k) Community First Choice.** The 1915(k) funding authority is a State Plan Option that permits states to provide home and community-based attendant services and supports to eligible Medicaid enrollees. Participants must require institutional levels of care to qualify. It provides increased

federal matching dollars for expenditures. States must ensure that the benefit is available to all eligible individuals statewide.

- **Targeted Case Management** an optional state plan service used to fund case management services for individuals meeting specified criteria
- **Other Medicaid State Plan Home and Community Based Services** these are services such as personal care attendant or home health aide provided to a person living in their own home or in the home of a family member.
- **Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)** is an optional institutional State Plan Medicaid benefit that funds comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence.

Other Funding Authorities

- **State Non-Medicaid.** State funded LTSS not eligible for federal Medical matching funds. Common examples include family support funds, or semi-independent living services.
- **"Other" funding** (Used in Part 1). Any funding source other than Medicaid Waiver or Medicaid ICF/IID that funds state operated residential services for people with IDD.

Time Frame

- Each survey covers one Fiscal Year. For most states, FY 2019 is July 1, 2018 to June 30, 2019.
- Most questions reference people or settings as of June 30, 2019, or the last day of the fiscal year.
- Contact your RISP staff if you want to have a different fiscal year assigned as the default date for all questions in this year's survey.
- Report expenditures for services delivered between July 1, 2018 and June 30, 2019.

Populations of Interest

Target Population: Parts 1 and 2 ask about the size and type of residence for people with IDD on the caseload of the *state IDD agency* who receive one or more publicly funded long-term support or service (**LTSS**) in addition to case management or service coordination. All people living in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) should be included even if the facility is licensed or monitored by an agency other than the State IDD Agency. Include people with IDD receiving in-home or residential supports, as well as people only receiving personal care assistance, family supports, day or employment supports, 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. Do not report people with IDD living in nursing homes or psychiatric facilities in Parts 1 or 2. Instead report on them in Part 5.

Parts 3 and 4 ask about people with IDD who are **LTSS Recipients,** as well as those who receive only case management services, are waiting for LTSS, or are known to the **State IDD Agency** but are not receiving LTSS. Do not include people whose eligibility for services has not been determined.

Part 5 includes people with IDD living in **Nursing Homes**, **Psychiatric Facilities**, or other **Congregate Settings** regardless of whether they are currently on the state IDD agency caseload. All people with IDD (Part 5), whether on the **State IDD Agency Caseload** or not, who live in **Nursing Homes**, **Psychiatric Facilities**, or other **Congregate Settings** housing four or more LTSS recipients (for people birth through age 21 years), or housing 16 or more LTSS recipients (for people ages 22 years and older).

Operating Entity

Operating entity refers to the organization that directly employs staff providing long-term supports and services. The organization may be **State-operated or Nonstate-operated.**

Part 1: State-Operated Services

Part 1 Population of Interest: **LTSS recipients with IDD** living in state-operated IDD residential facilities or in ICF/IID certified units of state-operated Nursing Homes or Psychiatric Facilities. Include IDD facilities or units managed by state agencies other than the State IDD Agency. Do not include people with IDD living in nursing homes or psychiatric facilities (other than those in ICF/IID certified units) in Part 1. Instead report them in Part 5.

Setting size is based on number service recipients living in the facility/on the campus as of June 30. Do not count "empty beds" in determining setting size (for example, a campus licensed to serve up to 20 people that has 12 people in residence on June 30 should be listed in the 7-15 people category).

Public Residential Facilities (PRF): State-operated IDD residential facilities serving 16 or more people with IDD on one campus, or at one address. Multiple units located on a single institution campus are considered one facility regardless of the number of licensed units on the campus. This includes ICF/IID certified units in other institutions such as nursing homes or psychiatric facilities.

Admissions or Readmissions - The number of people with IDD admitted during FY 2019 (7/1/2018 to 6/30/2019) for stays of more than 90 days.

- Exclude transfers between large, state-operated IDD facilities with 16 or more people
- Exclude short-term admissions of 90 days or less for respite, crisis assessment or services or short-term emergency housing.

Short-term Admissions in FY 2019

- Report the total number of admissions for respite, crisis assessment or services, or short-term emergency housing for stays of 90 days or less
- Count each ***admission*** of less 90 days or less (some individuals may have multiple short-term admission in a single year).

Discharges - the number of people with IDD who moved out of a PRF during FY 2019,

- Include people released or discharged permanently to a hospital, Nursing Home or other long-term care setting
- Exclude transfers to other large state operated IDD facilities
- Exclude people admitted for respite, crisis assessment or services or short-term emergency housing stays of 90 days or less

Deaths - the number of people who died while a resident of a PRF between FY 2019

- Include people who died prior to discharge, even if their death occurred during a temporary stay in a hospice, hospital, Nursing Home or other facility

Average Daily Residents

- Average number of people living in any PRF in your state during the year.
- If not provided, average daily residents will be computed as the total number of PRF residents on June 30, 2018 plus the number of PRF residents on June 30, 2019 divided by 2.

Per Diem (average daily per person expenditures) in FY 2019

- If a facility has more than one per diem rate, provide the average per diem paid across all residents with IDD.
- Provide a single average for all facilities of the same type.

- Include both state and federal Medicaid expenditures when computing the average.

Part 2. Nonstate-Operated Living Arrangements

Part 2 Population of Interest: **LTSS recipients** on the State **IDD Agency Caseload** receiving LTSS from an employee of an entity other than the state.

Include all LTSS recipients with IDD who

a. Receive one or more Medicaid or state-funded long-term support or service (***LTSS***) in addition to case management or service coordination
b. Receive in-home or residential services,
c. Receive day habilitation, vocational services or other LTSS even if they do not receive in-home or residential services,
d. Live in an ICF/IID (even if it is licensed or monitored by an agency other than the State IDD Agency or it is housed in another type of facility),

Count LTSS recipients with IDD whose residence type is unknown in the Type VII Unknown Setting Type category. **Do not** report people with IDD living in nonstate operated nursing homes or psychiatric facilities in Part 2. Instead, report them in Part 5.

Nonstate-Operated Residences

Type I: ***ICF/IID***. Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities. (includes ICF/IID certified units in other types of facilties)

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

- Include corporate foster care settings in which services are provided by staff, none of whom consider the home their permanent residence.
- Excludes ICF/IID certified facilities.

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

Type IV. ***Own Home***. A home owned or leased by one or more persons with IDD as the person(s)' own home, in which they receive personal assistance, instruction, supervision, and other supports.

- Include settings in which people with IDD
  - live alone or share a home with a spouse/partner or roommates they have chosen.
  - hold the title or lease in his or her own name; or is named on the lease,
  - can continue to live after discontinuing services from a particular provider, and
  - can substitute services from an alternative provider at any time.
- Do not include provider-owned or controlled housing (count those in Type II group homes).
- Do not include people living with a related family member (count those as Type V family home).

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

Type VI. ***Other Setting***. Other residential settings in which LTSS recipients with IDD on the caseload of the state IDD agency live. Other settings may include settings such as nonstate-operated hospitals, 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. **Do not** report people with IDD living in nursing homes or psychiatric facilities.

Type VII. ***Unknown Setting***. The type of setting in which a LTSS recipient with IDD lives is not known.

- People known to be homeless should be counted as living in an unknown setting.
- All people on the IDD Agency caseload who receive one or more LTSS, and who live in a nonstate setting, should be accounted for except those living in a nursing home or psychiatric facility.
- If left blank, this question will be recoded to 0.

Setting Size

Setting size is computed based on the total number of service recipients residing in the home/facility on June 30, 2019. Setting size categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, and 16 or more people. Do not count empty beds (for example, a campus licensed to serve 20 people with 12 people in residence on June 30 should be listed in the 7-15 people category).

2A. Number of facilities by setting size. Homes or facilities that are clustered on a single campus or at a single address count as one facility. A facility or campus with multiple structures or licenses counts as one setting. For a facility in which 100 service recipients live, 10 of whom have IDD, report 1 facility of 16+ people and report 10 people living in a setting of 16+ people.

Assumptions:

1. There are no ICF/IID settings serving fewer than four people.
2. There are no host/foster family homes serving sixteen or more service recipients.
3. There are no own home settings in which seven or more service recipients live.

An override function is available for the online survey if any of these assumptions are untrue in your state.

We do not count the number of family homes in which people live.

We report the total number of facilities by size across all types of state-operated settings, and across all non-family nonstate-operated settings.

- A total will be automatically computed if you provide a value of 0 or larger for all relevant setting types and sizes
- If complete setting type and size information are not provided, a DNF (did not furnish) or PD (Partial data) will appear in the report and on your state profile.
  Please enter a note explaining all DNF values.
- If you account for all LTSS recipients with IDD in state-operated and non-state operated settings by using the size unknown, and/or setting type unknown fields we will report the totals rather than showing DNF or PD.

2B. Number of LTSS recipients by setting size. Report the number of people with IDD living in settings of each size. If all service recipients in each setting have IDD, the number of people in a size category should be consistent with the number of settings in that size category. For example, if 100 people with IDD live in settings of 4 to 6 people, the total number of facilities serving 4 to 6 people should be between 17 (100 divided by 6) and 25 (100 divided by 4).

2C. Total Recipients by Funding Authority and Nonstate-Operated Residence Type

For each nonstate residential setting type, report the number of people with IDD whose services are funded by Medicaid Waiver (1115, 1915 a, b, b/c and c) and/or Medicaid State Plan HCBS (1915 i and k) funding authorities. Also, provide an unduplicated total number of Medicaid Waiver or Medicaid State Plan HCBS recipients for each residence type.

Part 3 Caseload, LTSS Recipients, and Expenditures

3. Caseload is about people accessing the supports and services related to IDD in the state. The **IDD Agency Caseload** includes people with IDD known to or served by the auspices of the state IDD agency who:

- receive one or more LTSS in addition to case management or service coordination (LTSS Recipients)
- receive only case management or service coordination services
- are waiting for LTSS, or
- are known to the state IDD agency but not receiving LTSS as of June 30, 2019
- includes people with IDD in nursing home or psychiatric facilities who are known to the state IDD agency

Do not include people

- whose eligibility IDD services through the IDD agency has yet to be determined or
- who receive services through another state entity (such as child welfare, education, or income supports) unless they also meet the inclusion criteria above

If you provided complete data, total LTSS recipients reported in state-operated or nonstate-operated settings in Parts 1 and 2 are shown for your reference. The number of people on the IDD Agency Caseload should be equal to or greater than the total number of LTSS recipients reported in Parts 1 and 2.

3A through 3F People on the State IDD Agency Caseload Receiving Services, and Expenditures by Funding Authority.

Report people on the caseload of your state IDD agency not receiving LTSS as of June 30, 2019 by age in question 3F.

Report the number of LTSS recipients and total LTSS expenditures by age and funding authority in questions 3A through 3E. Duplicate counts are allowed in questions 3A through 3E.

Questions 3A and 3B both ask about LTSS recipients whose services are funded by a Medicaid Waiver funding authority. Question 3A requests the number of Medicaid Waiver recipients and total Medicaid Waiver expenditures between July 1, 2018 and June 30, 2019 by age. Question 3B requests the number of Medicaid Waiver recipients and total Medicaid expenditures by living arrangement (family home or other) and age (21 years and younger or 22 years and older).

Medicaid Expenditures include both the state/local and federal match expenditures

Per Recipient Expenditures. The online survey automatically computes average per person annual expenditures for all categories in which complete information was provided. It is not necessary to

compute these totals when completing the Word version of the survey. Please be sure that the expenditures you report are for the number of recipients you report in each category (even if you report expenditures for only a subgroup of recipients). Please verify that the computed average expenditures per recipient are plausible for each category.

Part 4 Medicaid Waiver Waiting List

Part 4 population of interest: People on the **IDD Agency Caseload** waiting for **Medicaid Waiver**-funded **LTSS** while living in a **Family Home** or **Own Home** Setting as of June 30, 2019.

Include people waiting for Medicaid Waiver-funded LTSS who:

- Lived with a family member or in their own home as of June 30, 2019, and
- Did not receive Medicaid-funded LTSS, other than case management/service coordination as of June 30, 2019 but who had requested but not received services through a 1915(c) Waiver

Do not include people with IDD who:

- Received LTSS in a setting other than a **Family Home** or **Own Home** or who
- Received Medicaid Waiver-funded LTSS as of June 30, 2019

Report the number of people waiting who received case management service/service coordination (including through State Plan Targeted Case Management) on June 30, 2019.

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

Part 5 Population of Interest: All people with IDD living in congregate settings (whether on the **IDD Agency Caseload** or not).

Nursing Home

A state or nonstate institution offering skilled nursing or medical care and related services; rehabilitation supports needed due to injury, disability, or illness; and/or long-term care including health-related care and services (above the level of room and board) not available in the community, needed regularly due to a mental or physical condition. Admission to Medicaid Certified Nursing Homes requires a Preadmission Screening and Resident Review (PASSAR).

Psychiatric Facility

Residential facilities designed for persons with a psychiatric disorder, (for example a mental health facility or institute for mental disease). People living in an ICF/IID certified unit of a Nursing Home or Psychiatric Facility should be counted in the ICF/IID facility category.

About this Section: The Centers for Disease Control (CDC) uses the data you report here to monitor national progress toward the Healthy People 2020 goals of reducing the number of children and adults with IDD living in congregate settings.

It is very important that we receive data from all of the states on these questions.

If you are unable to furnish separate data for nursing homes and other congregate settings, enter the combined total and add a note saying that separate data are not available by type of congregate setting.

Congregate Settings are

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

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

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

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

People in Congregate Settings do not include people who:

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

Frequently Asked Questions

Where do I go to complete the RISP survey online?

- The URL for the RISP survey is https://risp.umn.edu/survey-dashboard.
- If you have not previously done so, you will need to contact your state's assigned RISP team member for login information to access the survey. Please do not use someone else's login information.

What if fewer people live in a facility on June 30 than the licensed capacity?

- Report only number of individuals with IDD residing in the facilities on June 30. Do not report the licensed capacity.

What should we do when we cannot report a certain data element because it is not available?

- Report DNF to indicate that a data element is not available.
- Report totals whenever possible, even if you cannot provide subtotals. Examples:
  - If you know the number of people in settings of 1 to 6 people, but do not know how many are in settings of 1 to 3 and 4 to 6, report the 1-6 total, and enter DNF for 1 to 3 and 4 to 6.
  - If you know the total number of Medicaid Waiver recipients by age, but do not know how many people in each age group live in the home of a family member, report the totals by age, and enter DNF for the living arrangement component of the question.
- In reports using RISP data:
  - For individual survey items, DNF indicates that a particular value was not provided.

- For tables that combine data from two or more separate elements, Partial Data (PD) indicates that at least one of the component values was reported, or DNF, if none of the component parts was reported.

What should we do if an entity other than the State IDD Agency manages some or all LTSS for people with IDD?

- Please request the data from the other entity (e.g., the managed care organization, the State Medicaid Agency).
- If you report data from another entity, and would like readers of the report to know the source, please identify the source in the public notes.

What if the State IDD Agency does not collect or report certain data (ever, or for a specific year)?

- Use the notes to explain why a data element is not available.
- Report data from the immediately prior year (if available). Do not repeat an estimate from earlier years.

Where do the Medicaid long-term care expenditure data used in the RISP report come from?

- The annual RISP state survey has been the primary source for expenditures since these dates:
  - FY 1982 for 1915(c) Waivers (referred to as "Home and Community Based Waivers," "regular ID/DD Waivers," or Medicaid Section 2176 HCBS Waiver" in earlier years of the survey).
  - FY 1982 Medicaid 1115, 1915 (a/c), (b), or (b/c), and "other Waivers" serving people with IDD. This category also included OBRA (Nursing Home) ID/DD Waivers and Model Waivers for people with ID/DD from FY 1994 to FY 2008.
  - FY 1990 to FY 1995 Medicaid Community Supported Living Arrangement option (used by 8 states)
  - FY 2012 ICF/IID
  - FY 2013 Medicaid State Plan 1915(i) and 1915(k)
- Other sources for Medicaid Expenditures (used only when states are unable to furnish the data)
  - Until FY 2010, a CMS contractor published a report summarizing Medicaid Waiver and ICF/IID expenditures based on CMS 64 reports in time to supplement data from non-reporting states for the annual RISP technical report. CMS no longer allows preliminary data to be released. This report is now released 21 to 24 months after the end of a fiscal year. As a result, the RISP technical report does not include data from the CMS 64 reports for the current year. Once they are released, those reports (currently produced by IBM Watson) are used to update our online database for states that furnished partial or no expenditure data.
  - ICF/IID expenditures for FY 2011 are from the State of the States survey
- Expenditure data are updated as follows
  - States can provide updated expenditure data as it becomes available. Data provided by states is preferred.
  - Historical data that came from Truven or IBM Watson reports are updated in the RISP database for all applicable years when the IBM Watson reports are released.

What other data sources are used for the RISP technical report?

- State populations by age are from US Census Data.

- Income taxes paid by state, and Medicaid federal match rates, are from the relevant federal databases.
- A summary of data from the Medicaid Certification and Survey Provider Enhanced Reporting (CASPER) reports for public and private ICF/IID and Nursing Homes is compiled quarterly by the American Health Care Association. Information from CASPER is used when a state is unable to furnish the number of people with IDD in ICF/IID or Nursing Home settings.
- The annual Public Residential Facility (PRF) survey is fielded by RISP staff to gather data about state-operated IDD facilities and IDD units in state operated Nursing Homes or Psychiatric Facilities. The sample frame for this survey was developed in 1977, and includes most, but not all, state-operated IDD facilities serving 16 or more people still in operation. Facilities are removed from the sample frame when they close, downsize to 15 or fewer people, are converted for use by a different population, or merge before June 30. The survey asks about the demographics of people served, and of those who enter or leave a facility during a fiscal year. It also asks about facility characteristics such as the number of full-time equivalent staff.

Are duplicate counts ok?

- Unduplicated counts should be used throughout the report, except in the expenditure section (Part 3). Service recipients may receive LTSS services through more than one Medicaid or state funding authority (e.g., 1915(c) Waiver and State Plan HCBS) and should be counted in each expenditure category for which they received funding during the FY
- We compute the average per-person expenditure overall, and for subgroups of recipients, so it is important that the number of recipients reported matches the expenditures in each category.

Why do some totals differ from one table to the next in the annual RISP technical report?

- Some totals could be calculated using items from more than one section of the survey. For example, the total number of Medicaid Waiver Recipients on June 30 is computed by summing the number of Waiver recipients in state-operated residences from Part 1 and the number served by non-state providers from Part 2. The number of recipients for whom expenditures were reported comes from Part 3. Totals for states that reported different numbers of people in Parts 1 and 2 than in Part 3 will not match.
- The survey asks for year-end recipients, but some states report recipients with expenditures in a fiscal year, regardless of whether they were recipients on June 30.
- By default, we report the data as it was reported on the survey. However, if the number of Waiver and ICF/IID recipients as of June 30 reported in Parts 1 and 2 are greater than the values in are reported in Part 3, Expenditures, then we use the number of people in Parts 1 and 2 as the total number of Waiver or ICF/IID recipients. The values from the expenditure section are used in conjunction with the expenditures, and for the total number of recipients so long as the number in Part 3 is greater than or equal to the number of people reported in Parts 1 and 2.

What is a validation check? What should I use it for?

- Validation checks are used in the online survey. They warn the user of discrepancies such as values that may have a misplaced decimal or a missing digit, large year-to-year changes, or inconsistencies between responses for questions in different sections of the survey.
- If you see a validation warning, look at the “Expand” menu to see “Validation checks that need attention.” Please correct data entry errors, or explain the reason for the discrepancy or notable change from previously reported values.