

RISP and FISP Annual Data Collection Operational Definitions FY 2016 Survey

General Instructions

Your assigned FISP/RISP project team member is available by phone or email to answer your questions throughout the year and will contact you by phone or email during the editing process if we find missing or possibly incorrect information, or notice a change in a trend that has not been explained in your comments. You can contact your RISP project team member by clicking on your state on the RISP survey dashboard found at <https://risp.umn.edu/survey-dashboard> or by emailing risp@umn.edu.

Sample Frame: This survey focuses on people with Intellectual or Developmental Disabilities (IDD) who are on the caseloads of your state IDD agency.

- The sample frame includes
 - People with IDD receiving Medicaid or state-funded long-term supports or services (LTSS), and
 - People with IDD on the caseloads of the state IDD agency who do not currently receive Medicaid or state-funded long-term supports and services (They may or may not be on a waiting list for services) and
 - People with IDD receiving Medicaid funded employment or day services
- The sample frame does not include people with IDD **not** on the caseload of the state IDD agency.
 - For example, it does not include people receiving services exclusively through a non-state IDD agency or non-Medicaid agency such as
 - educational services,
 - child welfare services,
 - vocational rehabilitation services
 - income supports
 - unless those individuals also receive case management or at least one other services under auspices of the state IDD agency

Time Frame: Questions ask either about the number of people in a particular group on June 30, 2016, or services or expenditures for services delivered in FY 2016 (July 1, 2015 and June 30, 2016). If you provide data based any other time period please specify the time period or date you used.

Key Changes for FY 2016: An additional question was added to Part One to identify transfers of individuals with IDD between large state (16+) public residential facilities in FY 2016. Part 3 was restructured and now includes an automatic calculation to determine average cost per person of each funding authority type.

Abbreviations and Acronyms

FISP	Supporting Individuals and Families Information Systems Project (University of MN)
FY	Fiscal Year July 1 to June 30
HCBS Waiver	Medicaid Home and Community Based Services Waiver – one of several Medicaid Waiver funding authorities
HCBS	Home and Community-based Services (Medicaid)
HSRI	Human Services Research Institute
IDD	Intellectual and Developmental Disabilities
LTSS	Long-term supports and services

NASDDDS	National Association of State Directors of Developmental Disabilities Services
PASRR	Pre-admission Screening Resident Review
RISP	Residential Information Systems Project (University of MN)
RTC	Research and Training Center on Community Living (University of MN)

Intellectual or developmental disabilities (IDD): Includes anyone eligible for IDD services in your state based on the following definitions:

- According to the American Association on Intellectual and Developmental Disabilities Intellectual disability, intellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18. The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, duration of disability, and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.
- 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:
 - “(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (ii) is manifested before the individual attains age 22;
 - (iii) is likely to continue indefinitely;
 - (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - (I) Self-care.
 - (II) Receptive and expressive language.
 - (III) Learning.
 - (IV) Mobility.
 - (V) Self-direction.
 - (VI) Capacity for independent living.
 - (VII) Economic self-sufficiency; and
 - (v) 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: Some states define eligibility for IDD services to include people with a related condition that results in the need for the same type, intensity and duration of support as needed by a person with intellectual disabilities. Common related conditions include autism, cerebral palsy, Down Syndrome, Spina Bifida, Hydrocephalus and epilepsy. Several states offer different programs to people with certain related conditions such as autism spectrum disorder. States choose whether to include the diagnosis of any of the listed conditions or other similar conditions such as Fragile X syndrome as one basis for eligibility for IDD services.

Nursing home: A state or nonstate Medicaid-funded institutional setting offering skilled nursing or medical care and related services; rehabilitation supports needed due to injury, disability, or illness;

and/or long-term care including health-related care and services (above the level of room and board) not available in the community, needed regularly due to a mental or physical condition.

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

Other state-operated settings: state-operated facilities or units within facilities that are specifically designated to serve people with IDD that are funded with resources other than the Medicaid ICF/IID or HCBS Waiver programs.

Other nonstate-operated residence: nonstate settings in which a person with IDD lives that is not a group home, ICF/IID, foster family, host home, or own home setting. This could include for example, board care facilities, disability specific intentional communities or farms or assisted living facilities.

Long-term supports and services: institutional or community-based supports provided to assist an individual with ongoing health or other support needs related to their disability (see table below).

Long-term supports and services

Service Category	Brief description	Example Services
Family Caregiver Support	Services provided to help the family provide supports to the individual	Home delivered meals, home health aide, homemaker/chore, caregiver counseling, care giver training
Respite	Temporary relief from/for the family caregiver	Respite (in home, out of home), individual support (day or night)
Personal Care Supports	Direct one-to-one services to the individual provided in or out of home to provide instrumental support, community integration or skill training	Companion services, personal care/assistance
In-home Services	Services to direct skills development and training to the individual living in the home of a family member or the person's own home.	Home-based habilitation
Case Management	Services to assist an individual or family identify the supports they need, establish eligibility for funded supports, access needed supports, and monitor the extent to which available supports meet the needs of the individual	Case Management, Service Coordination
Residential Services	Services provided to a person with IDD who lives in a setting other than the home of a family member while receiving funded supports.	Residential Habilitation, Group Home, Semi-Independent Living Services, Supported living services, Shared Living, Corporate foster care, Host home, Family foster care

Service Category	Brief description	Example Services
Day Services	Services provided throughout the day to support the individual in community-based activities (i.e., supported employment, day programs, education)	Job development, supported employment (individual, group, competitive), prevocational services, day habilitation, early start programs
Behavior Supports	Supports to prevent or reduce behavior related issues or mitigate crisis needs. Includes services provided by professional staff, as well as preemptive solutions.	Mental health assessment, crisis intervention, behavioral support, counseling, assertive community treatment
Medical Supports	Long-term supports for individuals with medical complications. Includes clinical services, such as OT, PT, and speech therapies as well as in home nursing services.	OT, PT, speech and language therapies, skilled and private nursing, clinic services
Participant Directed Supports	Assistance to individuals/families who self-direct services. Such assistance may include the development of the person centered plan, managing individual budgets, recruiting workers and accessing generic services and supports.	Financial management services, participant training, goods and services, other, interpreter
Transportation	Supports to transport an individual to a community-based activity, including day services, employment services, or other community-based activities.	Community transportation services, non-medical transportation
Environmental Modifications and Technology	Services to accommodate physical disabilities	Personal emergency response systems, home modifications (such as ramps, bathroom modifications), vehicle modifications or repairs, other adaptive equipment, augmentative communication devices, and similar services.

Operating Entities. Services are classified as being operated by state agencies or by nonstate entities.

- State-operated: staffed by state employees or operated by a state agency.
- Nonstate-operated: long-term supports or services provided to people with IDD by staff who are not state employees. Organizations providing nonstate-operated LTSS may be for profit or not-for-profit or they may be a nonstate governmental entity such as a county.

Setting Size. The size category is based on the number of people with IDD who live in the setting or on the campus. Size categories include 1 to 3 people, 4 to 6 people, 7 to 15 people, and 16 or more people. Homes or facility units that are clustered on a single campus or at a single address such as a large state operated IDD facility are counted as one facility and are categorized based on the total number of people living on the campus or at the address.

Partial or missing data: Provide as much information as you can. Do not leave any questions blank. Partial information is preferred to no information. If you are not able to answer a question, please indicate by marking the question DNF “Did not furnish”. The FISP and RISP projects make national estimates by estimating a value for each item marked DNF. We strongly prefer to get estimates from the states rather than by extrapolating them or estimating them using another process. Historical trends are described in our annual report for many items. If you are unable to furnish a data point, the charts and graphs developed for your state may not be a fully accurate summary.

Background Section (Items B1-B3)

Include all people with IDD who are on the caseloads of the state IDD agency.

- People getting no IDD services but known to the IDD agency
- People with IDD getting targeted case management, state IDD Agency program funding, or Medicaid funded supports (through ICF/IID, HCBS Waiver, State Plan).
- We are asking for the administrative prevalence of IDD in your state.
- We are only interested in the people with IDD who receive services through your agency for at least one support or service. People who only get public education, income supports, child protection, vocational rehabilitation but are not getting services administered through the state IDD agency would not be included.

Funding Authorities

The FISP/RISP survey asks specifically about utilization and expenditures for people with IDD under four broad categories of funding authorities:

- Medicaid Waiver Authorities (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers)
- ICF/IID – Intermediate Care Facilities for Individuals with Intellectual Disabilities
- Other Medicaid State Plan long-term supports and services (including 1915(i) State plan Home and Community Based Waiver Services; 1915(k) Community First Choice; and Targeted Case Management)
- Non-Medicaid – State-funded LTSS for people with IDD (e.g., family support program) operated state IDD agencies.

Medicaid Waiver Authorities

Information about Federal Medicaid Authorities comes from the *Guide to Federal Medicaid Authorities Used in Restructuring Medicaid Health Care Delivery or Payment* www.medicaid.gov. Additional analyses by NASDDDS www.nasddds.org/resource-library/medicaid-hcbs-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.

Unless otherwise specified please include all 1115 Demonstration Waivers, 1915 (a)(b) (b/c) and (c) through which services for people with IDD are funded when asked about “Medicaid Waiver Authorities”.

1115 Demonstration Waivers Section 1115 of the Social Security Act gives the Secretary of Health and Human Services authority to approve experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. The purpose of these demonstrations, which give States additional flexibility to design and improve their programs, is to demonstrate and evaluate policy approaches such as:

- Expanding eligibility to individuals who are not otherwise Medicaid or CHIP eligible
- Providing services not typically covered by Medicaid
- Using innovative service delivery systems that improve care, increase efficiency, and reduce costs

For this survey, please only include 1115 demonstration waivers that provide HCBS (modeled upon state plan or waiver) to individuals with IDD.

1915(a) States can implement a voluntary managed care program simply by executing a contract with companies that the state has procured using a competitive procurement process. CMS must approve the state's contract in order to make payment. A few states are utilizing 1915(a) authority for the delivery of institutional and community-based long-term services and supports.

For this survey, only include 1915(a) contracts that facilitate the provision of home or community based services (state plan or waiver) to individuals with IDD.

1915(b) States can also implement a managed care delivery system using waiver authority under 1915(b). Under a 1915(b) waiver participating states may require people who are dually eligible for Medicaid and Medicare, American Indians, and children with special health care needs to enroll in a managed care delivery system. 1915(b) waivers are typically used to allow the use of a managed care delivery system for traditional Medicaid State Plan services. Some 1915(b) waivers allow for the provision of community-based services to eligible individuals by using savings that the state has garnered through the introduction of managed care (1915(b)(3) services). In addition, states may allow contracted managed care entities to provide HCBS as 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.

For this survey, only include 1915(b) waivers that facilitate the provision of home or community based services (state plan or waiver, including 1915(b)(3) services) to individuals with IDD.

1915(b)/(c) States can provide traditional long-term care benefits (like home health, personal care, and institutional services), as well as non-traditional home and community-based "1915(c)-like" services (like homemaker services, adult day health services, and respite care) using a managed care delivery system, rather than fee-for-service. They accomplish this goal by operating a 1915(c) waiver concurrently with 1915(b) waiver (or any of the Federal managed care authorities). The managed care delivery system authority is used to 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.

For this survey, please only include 1915(b)/(c) concurrent waivers that facilitate the provision of home or community based services to individuals with IDD.

1915(c) 1915(c) is also known as the Home and Community Based (HCBS) waiver program. States can offer a variety of services under an HCBS Waiver to individuals needing an institutional level of care.

Services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community. 1915(c) waivers can target specific populations, and each waiver includes a specified set of covered services

Medicaid State Plan Services

State Plan refers to the full array of Medicaid Services available under a number of provisions of the Social Security Act. The majority of these services are identified in 1905(a) of the Act, but other provisions that have been added to the State Plan include: 1915(i), 1915(j) and 1915(k).

For this survey, state plan services are divided into two groups: ICF/IID and "Other Medicaid State Plan Services". Other Medicaid State Plan Services for this survey include 1915(i) and 1915(k) and Targeted Case Management.

ICF/IID – Intermediate Care Facilities for Individuals with Intellectual Disabilities ICF/IID is an optional institutional Medicaid benefit that enables States to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence. Although it is an optional benefit, all States offer it, if only as an alternative to home and community-based services waivers for individuals at the ICF/IID level of care.

Other Medicaid State Plan

1915(i) States can offer a variety of services under a State Plan Home and Community-Based Services (HCBS) benefit. People must meet State-defined targeting and needs-based criteria. States may offer the same array of services that are available under 1915(c) such as respite, case management, supported employment, environmental modifications, and others. States may not limit the number of eligible individuals who receive 1915(i) services.

For this survey, only include 1915(i) SPAs that include individuals with IDD (either through programs targeted specifically to individuals with IDD or programs broadly targeted that are likely to include individuals with IDD).

1915(k) 1915(k) is the "Community First Choice Option" and permits States to provide home and community-based attendant services to Medicaid enrollees with disabilities under their State Plan. Community-based attendant services must include services and supports to assist in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, and/or cueing. 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.

For this survey, please include all 1915(k) SPAs. By statutory construction, 1915(k) SPA services must be available to individuals with IDD meeting and ICF/IID level of care.

Targeted Case Management Authorized by section 6052 of the Deficit Reduction Act of 2005. Case management consists of services which help beneficiaries gain access to needed medical, social,

educational, and other services. “Targeted” case management services are those aimed specifically at special groups of enrollees such as those with developmental disabilities or chronic mental illness. Case management services are comprehensive and coordinated, and include an assessment of an eligible individual; development of a specific care plan; referral to services; and monitoring and follow-up activities. It also includes contact with family members that are for the purpose of helping a Medicaid-eligible individual access services can be covered by Medicaid. (CMS Fact Sheet November 30, 2007 Medicaid Definition of Covered Case Management Services Clarified. Downloaded October 13, 2015 from www.cms.gov/Regulations-and-Guidance/Legislation/DeficitReductionAct/downloads/CM_Fact_Sheet.pdf)

For this survey, only include TCM SPAs targeted to individuals with IDD.

Other State Plan LTSS

- State plan home health, personal care services, or optional rehabilitation services
- The Program of All-Inclusive Care for the Elderly (PACE)
- Home and community care services defined under Section 1929(a)
- Private duty nursing authorized under Section 1905 (a)(8) provided in home and community-based settings
- Affordable Care Act, Section 2703, State Option Health Homes for Enrollees with Chronic Conditions

Medicaid Waiver authorities include 1115 Demonstration Waivers; 1915 (a) (b) (b/c) Managed care with long-term supports and services; and 1915 (c) Home and Community Based Waivers.

Medicaid State Plan services: supports provided to people with IDD funded by a state's Medicaid State Plan.

- Institutional State Plan services include Intermediate Care Facilities for Individual with Intellectual Disabilities, nursing facilities, inpatient psychiatric facilities for person under age 21, and mental hospital services for persons age 65 years or older
- Home and community based state plan services offered in home or community settings include 1915i state plan home and community based services, 1915k community first choice.
- Other state plan funded long-term supports and services include targeted case management, personal care, home health, rehabilitation services, adult day care, private duty nursing, and PACE. The RISP 2013-2015 surveys include specific questions about the use of targeted case management for people with IDD.

Parts 1 and 2

When reporting the number of residents or facilities with 6 or fewer residents

- Please 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 DNF "data not furnished" for the 1-3 and 4-6 columns, and report the total in the 1-6 column.

Part 1. State-Operated Facilities

- State-operated: staffed by state employees or operated by a state agency.
 - Do not include people who stay in residential facilities for short-term respite only.
 - Do not include people admitted for 90 days or less for short term crisis or assessment purposes except in the item asking specifically about short term admissions.
- Setting types
 - Large IDD facilities and other large facilities with IDD units (16+ residents live on the campus).
 - Multiple units with or without separate licenses located on a single institution campus are considered one facility
 - Include ICF/IID units designed or licensed specifically for people with IDD that are located on the grounds of a state operated nursing home or psychiatric facility with 16 or more residents
 - IDD facilities with 15 or fewer residents.
 - Only include IDD facilities not located on the grounds or campus of a large state facility.
 - No more than 15 people live at this address/in this facility/on the campus
- Funding Authorities: Classify state operated settings based on how services in that setting are funded
 - Medicaid Waiver Authorities (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers)
 - ICF/IID – Intermediate Care Facilities for Individuals with Intellectual Disabilities
 - State funded (non-Medicaid) residential facilities with 15 or fewer residents in which people with IDD live and receive services under the auspices of the state IDD agency such as transition or half-way houses, board and care, assisted living facilities that do not have a designated IDD unit, and state operated housing with services.

Section 1A State Operated IDD facilities with 15 or fewer residents

- The number of Medicaid Waiver plus ICF/IID plus state-funded facilities of each size should sum to the total number of state operated facilities of that size.
- Mark 0 if there were no facilities of a certain size or funded by a certain funding authority. Do not leave any of the questions blank.

Section 1B People living in State-Operated IDD facilities with 15 or fewer residents

- Number of people with IDD living in the state operated IDD facilities reported in Section 1A.
- We will use the number of people together with the matching number of facilities of a specific size and funding authority to compute the average number of people per facility.
- Mark 0 if there were no people with IDD living in state operated facilities of a specific size funded by a specific funding authority.
- Use the date and code menu to select DNF if you are unable to provide a count.
- Use the date and code menu to select an “e” to designate estimated numbers.

Section 1C State-Operated IDD facilities with 16 or more people with IDD. The following questions are asked for large state facility by funding type (ICF/IID, Medicaid Waiver, Medicaid State Plan, and State-funded).

- SETTINGS number of different campuses serving 16 or more people with IDD. Campuses with

multiple units or buildings of any size housing a combined 16 or more people with IDD should be counted as a single facility.

- RESIDENTS with IDD at the end of FY 2016 (6/30/2016).
- ADMISSIONS/READMISSIONS - The number of people with IDD admitted during FY 2016 (7/1/2015 to 6/30/2016),
 - Include admissions or readmissions from a hospital, nursing home or other long-term care setting.
 - Exclude transfers between large state operated IDD facilities
 - Exclude people admitted only for respite care and crisis services lasting 90 days or less
- DISCHARGES - the number of residents with IDD who were released from state facilities during FY 2016 (7/1/2015 to 6/30/2016).
 - Include people released or discharged to a hospital, nursing home or other long-term care setting
 - Exclude transfers to other large state operated IDD facilities
 - Exclude people admitted only for respite care or crisis services lasting 90 days or less
- DEATHS - the number of residents with IDD who died while on the rolls between July 1, 2015 and June 30, 2016
 - Include any people who died prior to being discharged from the facility even if their death occurred during a temporary stay in a hospice, hospital, nursing home or other facility.
- AVERAGE DAILY RESIDENTS with IDD in FY 2016.
 - This is an aggregate average. It should include all people with IDD living in all large state IDD facilities or specialized IDD units during the year.
 - Please use a running average if you have it.
 - If you do not provide a response, this will be computed as the average of the residents with IDD in the facility at the beginning of the year (as reported on your prior year's survey) and the residents with IDD in the facility at the end of FY 2016.
- SHORT-TERM RESPITE OR CRISIS ADMISSIONS in FY 2016
 - Report the total number of admissions for respite care plus the total number of admissions for crisis services that were for stays of 90 days or less.
 - People with multiple respite or crisis services stays during a year should be counted for each stay.
- PER DIEM (average daily cost of care per resident) in FY 2016
 - If a facility has more than one per diem rate, provide the average per diem paid across all residents with IDD.

Part 2. Non-State Living Arrangements for People with IDD by Size and Type

- “Non-state” living arrangements include all living arrangements for people with IDD on your state IDD agency caseload that were not reported in Part 1 of the survey.
- Include people with IDD who receive case management or long-term support services while living in homes of their own or in the home of a family member.
- Include people with IDD receiving services funded by the following funding authorities:
 - Medicaid Waiver services through an 1115 demonstration waiver, 1915 (a) (b) (b/c) or any 1915(c) waiver,
 - State Plan: ICF/IID, 1915(i), 1915 (k), or targeted case management
 - Non-Medicaid state funded residential settings
- Include **only** people who received at least one LTSS service under the authority of the state IDD

- agency
- Total number of settings by type should equal the sum of settings with 1 to 6 people, 7 to 15 people and 16 or more people.
 - Total number of people by type should equal the sum of people living in settings with 1 to 6 people, 7 to 15 people and 16 or more people.
 - Provide the total number of settings of each type and the total number of people with IDD in each setting type even if you are unable to provide a breakdown showing the size of places in which people lived.
 - Setting type
 - **Type I Intermediate Care Facilities for individuals with Intellectual Disability (ICF/IID)):**
A group home operated under the authority of the ICF/IID Medicaid State-Plan benefit that enables states to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence.
 - Includes all ICF-IDD settings except those staffed by state employees (reported in Part 1).
 - Multiple units on a campus or at a single address should be counted as a one facility
 - **Type II Group Home:** A residence of any size owned, rented or managed by the residential services provider, or the provider's agent, to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD.
 - Under the 2014 Medicaid HCBS Rule, all people receiving home and community based services must have legal protections such as a lease or rental agreement when living in settings owned or operated by provider organizations. If the person is renting or leasing a home owned or operated by a provider of residential or in-home services regardless of the number of people living together, the setting is classified as a group home.
 - Includes organizations operated by a public entity other than the state (county, municipality) unless the employees are considered "state" employees
 - It is a Type II facility unless it meets the criteria for another setting type
 - **Type III Host home/Foster Family:** A home owned or rented by an individual or family service provider in which the provider lives and provide care for one or more unrelated persons with IDD.
 - **Type IV Own home:** A home owned or rented by one or more persons with IDD as the person(s)' own home in which personal assistance, instruction, supervision and other support is provided as needed.
 - It is a Type IV setting only if
 - A person with IDD holds title or lease in his or her own name; or is named on the lease.
 - each unit/apartment or house has separately keyed entrance doors
 - each unit has a different mailbox number or separate address

- The person with IDD could continue to live in the home but discontinue services from a particular provider or substitute services from an alternative provider
 - The person with IDD decides which people if any will live in his/her home (with legal guardian assistance as needed)
- **Type V Family Home:** A home owned or leased by a family member in which the person with IDD and one or more family members live.
 - Include people receiving supportive services such as respite care, homemaker services, personal assistance, personal care assistance, behavioral supports, community inclusion support, certified nursing assistant care, in-home nursing, parent training or education.
 - **Type IV Other Nonstate Setting:** A nonstate residence other than those described in Type I through Type V. If you report people with IDD living in other residential settings please describe those settings.
 - Unless the state specifically reports having people in these settings, we will assume them to be 0 setting and 0 people.
 - Include settings in which people with IDD on the caseload of the state IDD agency live such as
 - Residential School
 - Commune, farm, or other type of intentional community
 - Hospital
 - Board care
 - Transition half-way houses
 - Housing with supports
 - Assisted living
 - Only count each person one time. Do not count them as living in the home of a family member and in one of the other types of settings. Report the place the person is living on June 30 of the Fiscal Year.
 - Include people with IDD on the caseload of the state IDD agency whose living arrangement is unknown.

Part 2C. Waiver Recipients by setting type. Number of people with IDD who live in each type of nonstate setting (other than ICF-IDD) who received Medicaid Waiver services through an 1115 demonstration waiver, 1915 (a) (b) (b/c) or any 1915(c) waiver.

- The number of Medicaid Waiver recipients may be the same as or less than the total number of people living in a setting type but should not be more than the total number living in a setting type.

Part 3. Age and Expenditures

- For FY 2016 people with IDD born on or after June 30, 1996 should be counted in the 21 years or younger category, those born before June 30, 1996 should be counted in the 22 years or older category.
- Please use recipient and expenditure data from the same date in this section because we will compute average annual expenditure per person for each funding authority and age group

based responses to 3A and 3B. If you are using a date other than June 30 of the fiscal year, please specify the date you used.

The following funding authorities are used for Part 3

- **Medicaid Waiver Authorities** (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers).
- **ICF/IID** – Intermediate Care Facilities for Individuals with Intellectual Disabilities
- Other **Medicaid State Plan** services (including 1915(i) State plan Home and Community Based Waiver Services; 1915(k) Community First Choice; and Targeted Case Management)
- **Non-Medicaid – State-funded LTSS** for people with IDD (e.g., family support program) operated state IDD agencies.
- **No LTSS funding** –People with IDD who are on the caseloads of the state IDD agency who were not receiving long-term supports and services from one or more of the listed funding authorities as of June 30 of the fiscal year.

P3-1 Age of People with IDD on State IDD Agency Caseloads on June 30, 2016

Use the date and code menu to designate estimated numbers or to designate data you are not able to furnish; “0” for none.

- Report the total number of people with IDD on the state IDD agency caseload by age for each funding authority.
- Individuals receiving services through more than one funding authority and their expenditures should be counted in each of the categories in use on June 30, 2016.

P3-2 Total State and Federal Expenditures for People with IDD by Age and Funding Authority

- Total state portion plus federal match dollars for Home and Community Based Waiver Services during the fiscal year.

Section 3C Medicaid Waiver Recipients and Expenditures for People with IDD by Age and Living Arrangement (Family Home versus all other HCBS Waiver funded settings)

- Section 3C asks for information about the subset of people with IDD on the caseloads of state IDD agencies who were receiving supports under one of the Medicaid Waiver Authorities (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers)
- To respond to Section 3C you will need a break down of recipient and expenditures by age and living arrangement.
- Living arrangements in Section 3C collapse all living arrangements into two categories
 - People with IDD receiving supports funded by a Medicaid Waiver Authority living in the home of a family member (reported in Type V in Section 2)
 - All other people with IDD receiving supports funded by a Medicaid Waiver Authority (including those in Medicaid Waiver funded state-operated settings plus those in non-state setting types II, III, IV, V, and VI whose supports were funded by a Medicaid Waiver Authority)

Part 4. Waiting List

The waiting list question changed in FY 2013. Previously we asked for the number of people waiting to live in a setting other than the home of a family member who were living in the home of a family member on June 30 and who had requested services to begin **within 12 months**. That is now the third question.

- The first question asks about people with IDD who were eligible for and waiting for services funded by a Medicaid Waiver Authority (including 1115 Demonstration, 1915(a) (b) and (b/c) Managed care with long-term support and services and 1915 (c) Home and Community Based services Waivers).
 - People waiting for Medicaid Waiver funded supports may be receiving other supports funded by Medicaid State Plan or state only funding while they wait for services
 - Do not include people with IDD living in an ICF/IDD facility or in another non-family setting on June 30.
- The second question asks for the subset of people with IDD reported to be waiting for services in question 1 who were receiving Targeted Case Management State Plan services while waiting for services under a Medicaid Waiver Authority.
- The third question asks for the subset of people with IDD reported in the first question who requested funding for services to be delivered in a setting other than the home of a family member. This is the same as the waiting list question for FY 2012 and earlier.
 - Count those living with in a family home or own home who are looking to move to a non-family setting. Do not count people who are in a non-family setting who wish to move.

Part 5. Nursing homes and Psychiatric Facilities

- Do not include people reported in Part 1 or 2 as living in a special unit for people with IDD within a nursing home or psychiatric facility.
- Do include people with IDD who have a Preadmission Screening and Resident Review (PASSR) screening.

Part 6. Children in Congregate Care Settings

- This data is collected for the Centers for Disease Control and Prevention for the purpose of monitoring Healthy People 2020 goals. Please provide data whenever possible, including estimates. Include any children living in congregate settings defined as:
 - Non-family residential settings (state or nonstate settings of any size, type, or funding authority)
 - in which two or more people with IDD lives
 - in which rotating (or shift) staff members provide supports or services

Do not include children and youth who:

- Live with birth or adoptive parents or other family members
- Live in family “foster care” settings in which no shift staff work
- Live part of the year in a residential PreK-12 school
- Live in correctional facilities
- Live in nursing facilities (report those individuals in the nursing home section)
- Receive only respite services from a congregate care facility
- Live in other states (do count children who live in your state whose services are paid by another state)

Special designators

- “I” imputed. If you do not provide a value for an item we will use a set of decision rules to estimate a value for the purpose of developing US estimates. In most instances, DNF will be noted for your state for the data element in paper and online reports. We may publish the imputed value designated as such for certain summary tables. Imputations are estimates by the University of Minnesota.
- “o” Other source. Missing data were replaced with values from a source other than the state IDD agency (Note the specific source when this is used).
- “e” Estimate – The exact number is not available. Estimates are reported from the state IDD agency.
 - The number recorded is the best estimate of the correct count.
- “d” Other date. If you do not have an estimate for the designated Fiscal Year, but do have a value for the previous fiscal year please use the data from the previous year and note the date for the value reported.
 - “Date” If your data source is from a data other than the one specified, please note the data for which the data were provided.
- “DNF” Data not furnished
 - If the exact number is not known, and the estimate or report used in the previous year is not likely to 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 missing data.
- “N/A” Not applicable – Noted only when reporting Per Diem for state operated services if a size or funding authority is not used by the state.
- Note: (Respondent) Open ended comment box for each section or subsection to record explanations provided by the state during proofing, or with more detail than in the record for individual data elements.
 - If you use a definition that differs from the one specified, please describe what you provided.
 - Please add comments as needed to explain any unusual changes from FY 2015 to FY 2016. Relevant comments will be published with state summaries and in other FISP or RISP reports.
 - If you notice that data from previous years is inaccurate please let your staff team member know so we can update the data base and use updated data for subsequent reports we generate.

Administrative categories (for use by project staff only)**Completion status (auto generated by the system)**

- “No data” have been provided for the section
- “Partial data” have been provided
- “Complete data” have been provided for all items in the section

Approval status (Manually changed by project staff)

- **Not approved** – data have been submitted for one or more item in the section but project staff have not reviewed the data for accuracy and completeness.
- **Locked** – data are in the process of being verified by project staff. States may request changes but those changes have to be entered by project staff.

- **Verified** – data in the section have been reviewed for arithmetic errors, completeness, accuracy and consistency with other data elements and against the prior year.
- **Published** – data have been translated into tables for the report and those tables have been reviewed for arithmetic errors, completeness, accuracy and consistency with other data elements, against trends over time, and with US estimated Totals and reports from other states and are ready to be released for public use.