

**FY 2016 (July 1, 2015 – June 30, 2016) Survey**  
**Supporting Individuals and Families Information Systems Project (FISP)**  
**Residential Information Systems Projects (RISP)**

**About:** This is a survey of the University of Minnesota's Residential Information Systems Project (RISP) and the Supporting Individuals and Families Information Systems Project (FISP). It is part of a 39-year longitudinal study tracking the types and sizes of residential and in home supports provided to people with Intellectual or Developmental Disabilities (IDD). The survey is fielded annually in conjunction with the National Association of State Directors of Developmental Disabilities Services (NASDDDS). It serves as the basis for your state's representation in FISP and RISP national reports, thus complete responses are important to ensure that your state's system is accurately portrayed.

**Timelines:** FY 2016 surveys are due March 30, 2017. Late responses may not be included in our FY 2016 annual report. Questions reference June 30, 2016 or the time period from July 1, 2015 through June 30, 2016.

**Target Population:** This survey asks about people with IDD receiving Medicaid or state-funded long-term supports or services (LTSS) as well as those known to the state IDD agency who are waiting for LTSS.

**Key Changes for FY 2016:**

- Part 3 was restructured and now includes an automatic calculation to determine average cost per person of each funding authority type.

**Instructions:** This survey should be completed by the state director of developmental disability services or his or her designee. Please consult your state's Medicaid office or other relevant state agencies as needed to provide accurate responses. Your assigned 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.

- Be sure to click the **save and continue** button on each screen before you move to another section of the survey so that your data entries are saved.
- Answer each question, entering 0's when applicable. Partial information is preferred to no information.
- If you are unable to answer a question select DNF "Did not Furnish" code in the **Date and Code** tab.
  - Note: 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. If you are unable to furnish a data point, the charts and graphs developed for your state may not be a fully accurate summary.
- If your answer is an estimate select the "estimate" code in the **Date and Code** tab.
- If you use a different time period for any question, indicate the alternate date in the **Date and Code** tab.
- Use the **Note** tab to add comments 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.
- For any question you answer using data from a date other than June 30, 2016 (FY 2016), please provide the data date.
- Add an explanatory note as needed to understand your response (especially if you are reporting a number that is significantly different from previous years.)

**Tips for using the Online Survey:**

**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

- The system automatically tracks all entries by log in ID. Each person should have his or her own user name and password. Please do not use another person's ID to log in.
- You can view data from previous years by selecting the **prev years** tab.
- If you notice inaccuracies in data from previous years, please let your RISP staff team member know so we can update the data base and use updated data for subsequent reports.
- Definitions for selected terms can be viewed by moving your cursor over the "?" symbol highlighted in blue.
- The FISP/RISP project team member assigned to your state is listed on the "contact us" section.
- Click on the **Ask a Question** button to submit questions to project staff.

Thank you for your ongoing support of these Administration on Intellectual and Developmental Disabilities Projects of National Significance.

Sherri Larson and the FISP RISP Team

This survey was designed to be completed on the RISP project website but is provided here as a convenience to respondents. Please see the website version of the survey to see what your state reported for each item in previous years.

RISP contacts for states:

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**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

**Background**

**State:**

**For this question, please include all people on the state IDD agency caseload who received or were waiting for long-term supports and services.**

- Long-term supports and services (LTSS) include institutional or community based supports to assist an individual with ongoing support needs related to their disability such as residential supports, in-home supports, personal care assistance, family supports, day or employment supports, case management, 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 and other similar services provided under the auspices of the state IDD agency.

**Funded by the following funding authorities**

- Medicaid Waiver including 1115 demonstration waivers; 1915 (a), (b), (b/c) managed care waivers; and 1915(c) home and community based services waivers,
- Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities,
- Other Medicaid State Plan including 1915(i) Home and Community Based Service, 1915(k) Community First Choice, and Targeted Case Management
- State funded IDD programs (such as family support)
- Include people with IDD of all ages living in
- State operated or nonstate settings

**Settings of any size**

- Settings of any type such as group homes, nursing homes, psychiatric facilities, IDD facilities, a host family or family foster care, a home owned or rented by one or more persons with IDD, the home of a family member, or settings such as assisted living settings, board and care facilities, intentional communities, communes, or farm collectives shared by groups of people with disabilities.

**Please provide an unduplicated count.**

**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

**B1. People with IDD on caseload of State IDD Agency**

B1. On June 30, how many people with IDD were on the caseload of the state IDD Agency? (Include people with IDD who receive Medicaid funded long-term supports and services, receive no services, receive state funded long-term supports or services or who are waiting for services).

	1. IDD Caseload: Ages 21 years or younger
	2. IDD Caseload: Ages 22 years or older
	3. IDD Caseload: Total all ages

B1b. Of the people you listed as being on the state IDD agency caseload, how many were receiving one or more Medicaid or state-funded long-term support or service as of June 30, 2016?

Number of long-term supports and services recipients with IDD

(Note: Parts 1 and 2 of the survey ask about the living arrangements of the people you report here.)

**B2. Medicaid Funding Authority for Long-Term Supports and Services (LTSS) for people with IDD**

Funding authorities used to support people with IDD receiving long-term supports and services by category (Medicaid Waiver, Medicaid State Plan, Other). Select yes or no for each funding authority.

(Please respond "yes" or "no" to each item.)

B2. Which <u>Medicaid Waiver</u> authorities does your state use to provide long-term supports and services to people with IDD?	Yes	No
1. 1115 Demonstration waiver		
2. 1915(a) (b) and (b/c) Managed care waiver with long-term support and services		
3. 1915 (c) Home and Community Based services Waiver		

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.

**B3. Medicaid State Plan Funding Authority for Long-Term Supports and Services (LTSS) for people with IDD** (Please respond yes or no to each item.)

Which Medicaid <u>State Plan</u> funding authorities does your state use to provide long-term supports and services to people with IDD?	Yes	No
1. ICF/IID (Intermediate Care Facilities for Individuals with Intellectual Disability)		
2. 1915(i) State plan Home and Community Based Waiver Services		
3. 1915(k) Community First Choice		
4. Targeted Case Management		

"Medicaid State Plan" funding authorities include 1915(j) and (k) and Targeted Case Management.

**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

**B4. Non-Medicaid Funding Authority for Long-Term Supports and Services (LTSS)**

Non-Medicaid Funding Authorities (e.g., State-funded family support or cash subsidy programs) used to provide long-term supports and services to people with IDD. If you answer yes, please describe the funding authority you use.

Does your state use <u>non-Medicaid</u> funding authorities to provide long-term supports and services to people with IDD?	Yes	No
1. Non-Medicaid Funding Authority		

Background Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Part 1: State-Operated Facilities and Units**

Section 1A. State Operated IDD *facilities* with **15 or fewer residents** on June 30, 2016

Please report the number of state-operated facilities with 1 to 15 residents by setting size and funding authority on June 30, 2016. Facility size refers to the total number of people with IDD living in the same facility or on the same campus.

Facility Size (People with IDD)	P1.1 Number of State Operated IDD <i>facilities</i> / <i>homes</i> (Total All funding authorities)	Number of State Operated IDD <i>Facilities</i> by Funding Authority		
		P1-2. Medicaid Waiver	P1-3 ICF/IID	P1-4 Other Funding Authority
1. Facilities w/ 1-6 people				
2. Facilities w/ 1-3 people				
3. Facilities w/4-6 people				
4. Facilities w/7 to 15 people				
5. Total Facilities with 1 to 15 people				

\*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.

Mark 0 if there were no facilities of a certain size or funded by a certain funding authority. Write DNF in the cell if you are unable to provide a count. Use an "e" to designate estimated numbers.

**FY 2016 (July 1, 2015 – June 30, 2016) Survey**  
**Supporting Individuals and Families Information Systems Project (FISP)**  
**Residential Information Systems Projects (RISP)**

**Part 1B. People** with IDD living in **State Operated** IDD facilities with **15 or fewer residents** on June 30, 2016

- Do not include people admitted solely for respite or for short-term (90 days or less) crisis or assessment purposes.
- Report people living in state-operated IDD facilities with 16 or more residents in the Part 1C.

Facility Size (People with IDD)	P1-5 <i>People</i> in State Operated IDD facilities (Total All Funding Sources)	Number of <i>People with IDD</i> in State-Operated IDD Facilities by Funding Authority		
		P1-6. Medicaid Waiver	P1-7. ICF/IID	P1-8. Other
1. 1 to 6 residents Total				
2. 1 to 3 residents				
3. 4 to 6 residents				
4. 7 to 15 residents				
5. Total people in facilities with 15 or fewer residents				

\*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.

Mark 0 if there were no people with IDD living in state operated facilities of a specific size funded by a specific funding authority. Write DNF in the cell if you are unable to provide a count. Use an "e" to designate estimated numbers.

**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

**Part 1C. State Operated** IDD facilities and facilities with IDD units with **16 or more people** with IDD living in them on June 30, 2016

- Multiple units located on a single campus should be counted as one facility even if there are two or more units on the campus. Multiple units located on different campuses should be counted separately.
- Questions P1-9 through P1-10 refer to June 30, 2016.
- Questions P1-11 through P1-17 refer to Fiscal Year 2016 (July 1, 2015 through June 30, 2016).
- Questions about nursing homes and psychiatric facilities have been moved to Part 5 of the survey

State Operated IDD facilities/units with <b>16 or more residents</b>	Funding Authority			Total All funding Authorities
	Medicaid Waiver	ICF/IID	Non-Medicaid funded	
P1-9. Number of <b>settings</b> ( <i>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</i> )				
P1-10. <b>People</b> with IDD on June 30, 2016				
P1-11. <b>ADMISSIONS/READMISSIONS</b> –people who moved into the facility during FY 2015. <i>Do not include short-term respite or crisis admissions of 90 days or less. Report short-term admissions on Question P1-13.</i>				
P1-12. <b>DISCHARGES</b> – people who moved out of the facility during FY 2015 <i>excluding transfers to other large state facilities. Report deaths on Question P1-13.</i>				
P1-13. <b>DEATHS</b> – people who died while a resident of the facility between July 1, 2015 and June 30, 2016				
P1-14. <b>Average daily residents</b> FY 2016				
P1-15. Short-term <b>respite or crisis admissions</b> (90 days or less)				
P1-16. <b>PER DIEM</b> (average daily cost of care per resident)				

\*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.

Use an “e” to designate estimated numbers; “DNF” to designate data you are not able to furnish; “0” if there are no settings funded by the funding authority. Use N/A for question 8 if there are no state facilities in a given funding authority.

**Part 1** Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_  
Data date (if other than June 30, 2016): \_\_\_\_\_ Comments: \_\_\_\_\_

**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

**Part 2. Nonstate Living Arrangements for People with IDD on June 30, 2016**

- Report living arrangements for people with IDD who are **receiving one or more Medicaid or state funded long-term support or service (including targeted case management)**.
- **Long-term supports and services** assist an individual with needing ongoing supports such as residential supports, in-home supports, personal care assistance, family supports, day or employment supports, case management, 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 and other similar services.
- **Exclude** respite care placements, nursing homes and psychiatric facilities on this table.

Type of Nonstate Residence:	2A. Number of Nonstate residential settings by facility size						2B. Number of people with IDD in Nonstate residential settings by facility size						2C. Number of Medicaid Waiver recipients in Nonstate settings by type
	1-3	4-6	1-6 Total	7-15	16+	Total Settings*	1-3	4-6	1-6 Total	7-15	16+	Total People*	
<b>Type I. Nonstate ICF/IID</b> (Intermediate Care Facilities for Individuals with Intellectual Disabilities) <i>P2-1, P2-2</i>													
<b>Type II. A residence owned, rented or managed by the residential services provider, or the provider's agent</b> , to provide housing for persons with IDD in which staff provide care, instruction, supervision, and other support for residents with IDD. Do NOT include ICF/IID facilities in this row. <i>P2-4, P2-5, P2-6</i>													
<b>Type III. A home owned or rented by an individual or family</b> in which they live and provide care for one or more unrelated persons with IDD (e.g., <b>host family/family foster care</b> ). <i>P2-7, P2-8, P2-9</i>													
<b>Type IV. A home owned or rented by one or more persons with IDD</b> as the <b>person(s)' own home</b> in which personal assistance, instruction, supervision and other support is provided as needed. Do NOT include people with IDD living in the home of a family member in this category. <i>P2-10, P2-11, P2-12</i>													

**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

Type of Nonstate Residence:	2A. Number of Nonstate residential settings by facility size					2B. Number of people with IDD in Nonstate residential settings by facility size					2C. Number of Medicaid Waiver recipients in Nonstate settings by type		
	1-3	4-6	1-6 Total	7-15	16+	Total Settings*	1-3	4-6	1-6 Total	7-15		16+	Total People*
<b>Type V.</b> A residence of person(s) with IDD which is also the home of related family members in which the person(s) with IDD and/or their family members receive supportive services (e.g., respite care, homemaker services, personal assistance). Only count people with IDD who receive at least one funded long-term support or service such as targeted case management or in home supports. <i>P2-13, P2.14</i>													
Type VI. <b>Other</b> residential types (please specify). Please record 0 if you do not have other Nonstate residential service options for people with IDD. <i>P2-15, P2-16, P2-17</i>													

\*Totals should equal the sum of 1-6, 7-15, and 16+. Please provide the totals even if you are unable to provide all of the size breakdowns. Size refers to the number of people with IDD living together. Use an "e" to designate estimated numbers; "DNF" to designate data you are not able to furnish; "0" for none. Please do not make entries in the blacked out cells.

Data date (if other than June 30, 2014): \_\_\_\_\_ Comments: \_\_\_\_\_

**FY 2016 (July 1, 2015 – June 30, 2016) Survey**  
**Supporting Individuals and Families Information Systems Project (FISP)**  
**Residential Information Systems Projects (RISP)**

**Part 3: Fiscal Year Expenditures for People with IDD by Funding Authority, Age and Living Arrangement**

- Data from this part will be used to calculate average per person expenditures for the fiscal year.
- Report the number of people based on their age as of June 30, 2016
- Report total expenditures for July 1, 2015 through June 30, 2016
- Include both state and nonstate service recipients.

Part 3. On June 30, 2016, how many **people** with IDD received long-term supports and services by age and funding authority?

Recipient Age	Number of People by Funding Authority				
	P3a-1. Medicaid Waiver	P3a-2. Medicaid State Plan - ICF/IID	P3a-3. Other Medicaid State Plan	P3a-4. State-Funded (Non-Medicaid)	P3a-5. No LTSS funding
a. 21 years or younger					
b. 22 years and older					
Total					

\*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.

**Other Medicaid State Plan** funding authorities include 1915(j) and (k) and Targeted Case Management.

Use an “e” to designate estimated numbers; “DNF” to designate data you are not able to furnish; “0” for none.

Part 3. Combined **FY 2016** (July 1, 2015 through June 30, 2016) long-term support and services **Federal and State Expenditures** for people with IDD by age and funding authority

Recipient Age	Total Federal and State Expenditures by Funding Authority			
	P3a-1. Medicaid Waiver	P3a-2. Medicaid State Plan - ICF/IID	P3a-3. Other Medicaid State Plan	P3a-4. State-Funded (Non-Medicaid)
a. 21 years or younger	\$	\$	\$	\$
b. 22 years and older	\$	\$	\$	\$
Total	\$	\$	\$	\$

\*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.

**Other Medicaid State Plan** funds include 1915(i) and (k) and Targeted Case Management.

Use an “e” to designate estimated numbers; “DNF” to designate data you are not able to furnish; “0” for none.

**FY 2016 (July 1, 2015 – June 30, 2016) Survey**  
**Supporting Individuals and Families Information Systems Project (FISP)**  
**Residential Information Systems Projects (RISP)**

Part 3. Combined **FY 2016** (July 1, 2015 through June 30, 2016) long-term support and services **Federal and State Expenditures** for people with IDD by age and funding authority (Note: If you are entering this information into the on-line survey, the calculations will automatically be done for this section.)

Recipient Age	Annual Cost per Person by Funding Authority			
	P3a-1. Medicaid Waiver	P3a-2. Medicaid State Plan - ICF/IID	P3a-3. Other Medicaid State Plan	P3a-4. State-Funded (Non-Medicaid)
a. 21 years or younger	\$	\$	\$	\$
b. 22 years and older	\$	\$	\$	\$
Total	\$	\$	\$	\$

\*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.

**Other Medicaid State Plan** funds include 1915(i) and (k) and Targeted Case Management.

Use an "e" to designate estimated numbers; "DNF" to designate data you are not able to furnish; "0" for none.

Data date (if other than June 30, 2016): \_\_\_\_\_ Comments:

**FY 2016 (July 1, 2015 – June 30, 2016) Survey**  
**Supporting Individuals and Families Information Systems Project (FISP)**  
**Residential Information Systems Projects (RISP)**

Section 3B. Medicaid Waiver Recipients and Expenditures for People with IDD by Age and Living Arrangement on June 30, 2016.

Age and Residence Type	Medicaid Waiver* Recipients with IDD	Total FY 2015 Federal plus State Medicaid Waiver* expenditures
<b>P3-5. Recipients 21 years or younger</b>		
1. Number living in the home of a <b>family member</b> (Type V)		\$
2. Number living in any <b>other setting</b>		\$
3.Total		\$
<b>P3-6. Recipients 22 years and older</b>		
1. Number living in the home of a <b>family member</b> (Type V)		\$
2. Number living in any <b>other setting</b>		\$
3.Total		\$

\*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.

Use an "e" to designate estimated numbers; "DNF" to designate data you are not able to furnish; "0" for none.

**Home of a family member** = nonstate Type V (family home);

**Other** settings include nonstate Types II (group home), III (host/foster), IV (own home), and VI (other); and state Medicaid Waiver funded settings

Part 3 Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Data Date if other than June 30, 2016: \_\_\_\_\_

Comments:

**FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)**

**Part 4: People with IDD waiting for Medicaid-funded residential or in-home long-term supports or services on June 30, 2016**

- Include people who were living in homes of their own or with a family member who
  - are waiting for in-home supports or residential services to live outside the family home
  - are not receiving but are waiting for one or more Medicaid funded long-term support or service
  - are receiving a state funded or Medicaid State Plan services but are waiting for Medicaid Waiver funding
- *Do not* include people with IDD living in an ICF/IDD facility or in another Medicaid funded non-family setting.

P4-1 How many people with IDD were waiting for HCBS Waiver funded in-home or residential long-term supports or services on June 30, 2016?

P4-2 On June 30, of the people with IDD waiting for Medicaid-funded long-term supports and services, how many were receiving Targeted Case Management (TCM) Services?

P4-3 On June 30, of the people with IDD waiting for Medicaid-funded long-term supports and services, how many were waiting to live in a setting other than the home of a family member?

Part 4 Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_  
Data Date if other than June 30, 2016: \_\_\_\_\_ Comments: \_\_\_\_\_

**Part 5. Nursing homes and Psychiatric Facilities**

**Nursing Homes**

1. How many people of all ages with IDD lived in State-Operated Nursing Homes on June 30, 2016?
2. How many people of all ages with IDD lived in Nonstate Nursing Homes on June 30, 2016?
3. Total people in ALL nursing homes on June 30, 2016.
4. Of the people with IDD living in nursing homes on June 30, 2016, how many were ages birth to 21 years?

**Psychiatric Facilities**

1. How many people of all ages with IDD lived in State-Operated Psychiatric Facilities on June 30, 2016?
2. How many people of all ages with IDD lived in Nonstate Psychiatric Facilities on June 30, 2016?
3. Total people in ALL psychiatric facilities on June 30, 2016.

Part 5 Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_  
Data Date if other than June 30, 2016: \_\_\_\_\_ Comments: \_\_\_\_\_

FY 2016 (July 1, 2015 – June 30, 2016) Survey  
Supporting Individuals and Families Information Systems Project (FISP)  
Residential Information Systems Projects (RISP)

Part 6. Children with IDD in Congregate Settings (for CDC Healthy People 2020 monitoring)

Congregate settings are:

- Non-family residential setting (state or nonstate settings of any size, type or funding authority)
- In which two or more individuals with IDD live
- In which rotating (or shift) staff members provide supports and 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 only 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)

P6-1. How many children and youth with IDD (birth to 21 years) lived in a congregate setting located in your state on June 30, 2016?

Part 6 Respondent Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Data Date if other than June 30, 2016: \_\_\_\_\_

Comments:

Contact the RISP project team at ([RISP@umn.edu](mailto:RISP@umn.edu)) if you have questions. Your RISP project staff can be found by clicking on your state at <https://risp.umn.edu/survey-dashboard>. We encourage states to enter their data in the RISP project website (<http://rtc.umn.edu/risp/main/>). Log in to complete your survey and to view resource documents including operational definitions, FAQ’s and webinar slides. Otherwise, **return your survey** to RISP team, Research and Training Center on Community Living, University of Minnesota, 210 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. Phone 612-624-6328, Fax 612-625-6619.