National Core Indicators®
Intellectual and Developmental Disabilities

In-Person Survey
2024-2025

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Before you start…

The following are instructions for completing the parts of this survey.

- **Survey Status.** This information *must* be completed for all potential respondents approached to participate in the survey.
- **Pre-Survey.** This information may be useful for scheduling and conducting the face-to-face surveys. It is not analyzed by HSRI and cannot be downloaded from the Online Data Entry Survey Application (ODESA).
- **Background Information**. Most items in the Background Information Section come from state records. There are only certain questions that may be collected during the survey from the person or proxy. (Those "field appropriate" questions are indicated in the survey with a symbol of people meeting: 👪.) **If any of the "field appropriate" questions are collected during the survey, either from the person or proxy, those questions should be asked *after* completing the main survey sections—Section I, Section II, and any supplements, if applicable.**
- **Proxy Determination.** This section must be completed prior to conducting the survey. This section will determine whether a proxy is required to complete the survey on behalf of the person.
- **Section I**. These questions may only be answered by the person receiving services and supports. Proxy responses are not permitted. These are subjective, satisfaction-related questions that may not be answered by anyone else. An interpreter or other communication support may be used at any time.
- **Section II**. These questions may be answered by the person or someone who knows the person well (proxy respondent)—such as a family member, friend, staff person, guardian, or advocate. Service coordinators or case managers are not allowed to respond to questions in this section. If the individual is answering, the questions need to be asked face-to-face.
- **Surveyor Feedback Sheet**. This asks questions about survey administration. Please fill out one sheet for each survey you complete.

Survey Status

PLEASE NOTE: THIS SECTION IS REQUIRED.

Survey Code: Click or tap here to enter text.

SURVEY STATUS

SC-1 Was a survey scheduled?

[Check YES if the survey was scheduled, even if the survey meeting didn't end up taking place.]

2 ☐ Yes

1 ☐ No →GO TO SC-4

SC-2 Was the survey conducted?

2 ☐ Yes

1 ☐ No →GO TO SC-4

SC-3 If the survey was conducted, what survey mode was used?

1 ☐ In-person

3 ☐ Videoconference

SC-4 If the survey was not scheduled or conducted, please enter the reason [CHECK ONE]:

1 ☐ Contact information is incorrect

2 ☐ Contact information is correct, but the person could not be reached

3 ☐ Refused by individual receiving supports

4 ☐ Refused by parent/guardian

5 ☐ Deceased

6 ☐ Person is not receiving services

7 ☐ Face-to-face survey is not possible and there are technology-related barriers to remote surveying (e.g., no access to the necessary technology, no internet access) →GO TO SC-5

8 ☐ Person cancelled or did not show for survey meeting

9 ☐ Other: Click or tap here to enter text.

SC-5 If the survey was not scheduled or conducted due to barriers/challenges related to technology, what was the specific barrier/challenge [CHECK ALL THAT APPLY]:

1 ☐ Does not have access to internet

2 ☐ Does not have access to needed equipment (e.g., webcam, computer, tablet)

3 ☐ Does not have support needed to participate in survey (e.g., help with technology set-up or use)

4 ☐ Does not have access to phone or phone plan with data available

5 ☐ Other: Click or tap here to enter text.

Pre-Survey Form

Data from the Pre-Survey Form are not included in data reports. Procedures for using the Pre-Survey Form should be determined by the state's NCI coordinator and communicated to surveyors during training.

ADVICE TO SURVEYORS. Please fill out and review as many of the Pre-Survey items as possible ***before*** the survey meeting. Using familiar names and terms helps the respondent understand the questions being asked and facilitates the survey process.

You can also use this form to fill in familiar names and terms in Sections I and II of the survey: look for items marked with a bell symbol 🔔. (This will be done automatically for you if you are completing this form in ODESA.)

Additional instructions regarding your state's specific Pre-Survey administrative procedures:

Click or tap here to enter text.

A. Person(s) completing this Pre-Survey Form

Name(s) Click or tap here to enter text.

Date Click or tap here to enter text.

B. Person to be surveyed

Individual's Name: Click or tap here to enter text.

Gender: 1 ☐ Male 2 ☐ Female 3 ☐ Other

Age Click or tap here to enter text.

Phone Click or tap here to enter text.

Email Click or tap here to enter text.

Address Click or tap here to enter text.

C. Legal guardian information, if applicable

Guardian's Name Click or tap here to enter text.

Relationship to Individual Click or tap here to enter text.

Phone Click or tap here to enter text.

Email Click or tap here to enter text.

Address Click or tap here to enter text.

PS-1. Contact

Who should the surveyor call to arrange the survey? (Should the surveyor contact the person directly, or should the surveyor contact the parent/guardian, day or residential program staff, etc.)

Name Click or tap here to enter text.

Relationship to this person Click or tap here to enter text.

Phone Click or tap here to enter text.

Email Click or tap here to enter text.

Meeting Companion:

When possible and appropriate, surveyors should aim to conduct the face-to-face survey with the person alone. However, some of the individuals being surveyed may feel uncomfortable with strangers, and/or they may have medical, behavioral, or other reasons for supervision or assistance from a designated support person.

Should a support person be present? 2 ☐ Yes 1 ☐ No

If yes, please explain:

Click or tap here to enter text.

Does this person need any accommodations?

Examples: Communication accommodations might include a sign language interpreter, a communication device, a voice amplifier, someone familiar with the person's communication style, or an interpreter if the primary language is something other than English; Accessibility accommodations might include transportation; Other accommodations might include specific medical needs during the survey or needs related to allergies.

2 ☐ Yes 1 ☐ No

Please explain the accommodations needed for the face-to-face survey:

Click or tap here to enter text.

PS-2 Proxy Respondents

Some questions in this survey allow for a "proxy respondent" – someone who knows the person well – to answer some questions on the person's behalf. The proxy respondent ***must know the person well*** and be able to speak to the person's experience with services and daily routines.

If this person wants or needs help from a proxy respondent, who may be able to provide responses for this person? Family members, guardians, friends, and staff may respond; **case managers and/or service coordinators may not respond**.

Name 1 Click or tap here to enter text.

Relationship Click or tap here to enter text.

Phone Click or tap here to enter text.

Email Click or tap here to enter text.

Name 2 Click or tap here to enter text.

Relationship Click or tap here to enter text.

Phone Click or tap here to enter text.

Email Click or tap here to enter text.

PS-3 Case Manager/Service Coordinator

What is the name and contact information of this person's case manager/service coordinator?

This should be referenced when asking Questions 45-47, 54, 81, 91, 96-97.

Name Click or tap here to enter text.

Phone/email Click or tap here to enter text.

PS-4 Living Arrangement

Please indicate who this person lives with.

This should be referenced when asking Question 73.

1 ☐ Lives alone

2 ☐ Lives with parent/relatives

3 ☐ Lives in a large residential care facility.

4 ☐ Lives in house or apartment with other people.

5 ☐ Lives with partner, spouse, and/or children

Name of facility (if applicable): Click or tap here to enter text.

If applicable, provide first names of roommates or housemates: Click or tap here to enter text.

PS-5 Support Staff

If there are any people who are paid to provide supports in this person's home, at their work, or at their day program, please indicate their first names. If there are several workers, please list the primary support worker(s) who spend the most time with this person.

This should be referenced when asking Questions 37-43 and 82.

Staff person name: Click or tap here to enter text.

Staff person name: Click or tap here to enter text.

Staff person name: Click or tap here to enter text.

PS-6 Paid Community Job

If applicable, please indicate the place of work (employer or work program names) for this person's paid community job(s). A paid community job refers to paid work—either competitive or supported employment—in the community. Examples include both individual and group employment, such as a work crew or enclave. It ***does not*** include work done in a facility-based setting (e.g., sheltered workshop) or volunteer activities. Use the term or abbreviation the person is most familiar with.

This should be referenced when asking Questions 6, 8, and 74.

Place of work Click or tap here to enter text.

PS-7 What activities does the person typically do at least once a week? Where possible, please include the name of the place where this person does each activity.

This should be referenced when asking Questions 11, 75, and 76.

Goes to a day program or workshop, either online or in-person (program or center where other people with disabilities spend their days)

2 ☐ Yes 1 ☐ No

Place where activity is done: Click or tap here to enter text.

Volunteers

2 ☐ Yes 1 ☐ No

Place where activity is done: Click or tap here to enter text.

Does job training

2 ☐ Yes 1 ☐ No

Place where activity is done: Click or tap here to enter text.

Goes to school or takes classes

2 ☐ Yes 1 ☐ No

Place where activity is done: Click or tap here to enter text.

Does things in the community with paid support

2 ☐ Yes 1 ☐ No

Place where activity is done: Click or tap here to enter text.

Other regularly scheduled activities:

2 ☐ Yes 1 ☐ No

Details: Click or tap here to enter text.

PS-8 Service Plan

What terminology should be used when asking about the person's service plan/service planning meeting?

Some people may refer to the service plan as the ISP or IPP. Some people may refer to the service planning meeting as the ISP meeting or the IPP meeting. This should be referenced when asking Questions 48-54.

Service plan terminology the person will be familiar with: Click or tap here to enter text.

Service planning meeting terminology the person will be familiar with: Click or tap here to enter text.

PS-9 Self-Advocacy Organization

What self-advocacy groups are active and well-known in the person's area (e.g., People First, Self-Advocates Becoming Empowered, Speaking for Ourselves)?

This should be referenced when asking Question 70.

Click or tap here to enter text.

PS-10 Self-Directed Supports

Is this person currently using a self-directed/participant-directed supports option and using a financial management service (also called a fiscal agent, fiscal intermediary, intermediary service organization, etc.)?

These options offer individuals (and their representatives) the opportunity to manage some or all of their services. For example, they may hire and fire their own support workers and/or have control over their budget or services.

(NOTE: If "yes," this person should be asked the questions in the Self-Directed Supports Module at the end of Section II.)

2 ☐ Yes

1 ☐ No

- **If yes, what is the term used to describe the participant-directed budget (e.g., individual budget, DDS budget, etc.)?**

This should be referenced when asking Questions 113-115.

Please note the term that would be most familiar to the person:

Click or tap here to enter text.

PS-11 Financial Management Service

This should be referenced when asking Questions 113-115.

If the individual uses a self-directed supports option and uses a financial management service (FMS) (also called a fiscal agent, fiscal intermediary, intermediary service organization, etc.) to manage their services and supports budget, what is the name of that organization? Please note the term that would be most familiar to the person: Click or tap here to enter text.

• END OF PRE-SURVEY FORM •

Background Information

This section should be completed along with the Pre-Survey Form by the appropriate agency staff member, such as a case manager/service coordinator, according to state-specific protocols.

For ***some*** items either the individual receiving services, a residential staff person, or a family member may inform the response to the questions. Questions that can be asked during the face-to-face survey are marked with a meeting symbol:

Personal

BI-1. Zip Code (where person resides): **Click or tap here to enter text.**

Please note that the zip code will not be stored. When entered into the online data entry system, it will be converted into a rural/urban designation and the area median income.

BI-2. Date of Birth: (mm/yyyy) _____/_____

Please note that the individual's date of birth (DOB) will not be stored. After you enter DOB, it will be converted to the individual's age at the end of the survey year. This is the age that will be used in ODESA validations.

BI-3. Sex

Please refer to individual's sex assigned at birth. Please note that this question is used as context for recommended medical tests and comes from administrative records.

1 ☐ Male

2 ☐ Female

99 ☐ Don't know

BI-4. What is this person's race and ethnicity? Check ONE or MORE boxes to indicate what this person considers themselves to be.

1 ☐ American Indian or Alaska Native

2 ☐ Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or Other Asian)

3 ☐ Black or African-American

4 ☐ Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander)

5 ☐ White

6 ☐ Hispanic/Latino (Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, or Other Spanish/Hispanic/Latino)

7 ☐ Other race not listed: Click or tap here to enter text.

99 ☐ Don't know

BI-5. Does this person have a legal appointed guardian/conservator (a person who is legally granted authority to make decisions on behalf of the individual)? Check ONE.

1 ☐ No, person **does not have** a guardian/conservator →GO TO BI-7

2 ☐ Yes, **limited guardianship** (a person has authority over certain decisions, such as entering into contracts, medical procedures, etc.)

3 ☐ Yes, **full guardianship**

4 ☐ Yes, **unable to distinguish** between limited or full guardianship

99 ☐ Don't know →GO TO BI-7

BI-6. If this person has a legal/court-appointed guardian, what is the guardian's relationship to the individual? Check ONE.

98 ☐ Not applicable

1 ☐ Family

2 ☐ Friend

3 ☐ Public guardian/public administrator

4 ☐ Financial institution (e.g., bank)

5 ☐ Nonprofit guardianship agency

6 ☐ For-profit guardianship agency

7 ☐ Other: Click or tap here to enter text.

99 ☐ Don't know

BI-7. Field appropriate Marital status. Check ONE.

1 ☐ Single, never married

2 ☐ Married

3 ☐ Single, married in the past

99 ☐ Don't know

BI-8. Is this person a parent? (This includes adult children.) *Check all that apply*.

1 ☐ No, does not have a child →GO TO BI-10

2 ☐ Yes, parent of a child or children under 18

3 ☐ Yes, parent of a child or children over 18 →GO TO BI-10 *unless* option 2 is also checked

4 ☐ Yes, parent of a child or children, unknown age(s) →GO TO BI-10

99 ☐ Don't know →GO TO BI-10

BI-9. If the person has children under 18 years of age, does the child or children live with the person?

98 ☐ Not applicable – no child or child is an adult or age of child is unknown

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-10. Is this person diagnosed with an intellectual disability (ID)?

1 ☐ No →GO TO BI-12

2 ☐ Yes

99 ☐ Don't know →GO TO BI-12

BI-11. If yes, what level of ID?

98 ☐ Not applicable – no ID diagnosis

1 ☐ Mild ID

2 ☐ Moderate ID

3 ☐ Severe ID

4 ☐ Profound ID

5 ☐ Unspecified level of ID (individual has been diagnosed with ID but level of ID is unknown)

99 ☐ ID diagnosis unknown (only use this response if BI-10 is marked 'Don't know')

BI-12. What other conditions are noted in this person's record? *Check all that apply.*

1 ☐ Mood disorder (e.g., depression, mania, bipolar disorder, etc.)

2 ☐ Anxiety disorder (e.g., obsessive disorders, panic disorders, etc.)

3 ☐ Behavior challenges (e.g., aggression, self-injurious behavior, pica, etc.)

4 ☐ Psychotic disorder (e.g., schizophrenia, hallucinations, etc.)

5 ☐ Other mental illness/psychiatric diagnosis

6 ☐ Autism spectrum disorder (e.g., autism, Asperger syndrome, pervasive developmental disorder)

7 ☐ Cerebral palsy (spastic quadriplegia/diplegia)

8 ☐ Brain injury

9 ☐ Seizure disorder and/or neurological problem

10 ☐ Chemical dependency

11 ☐ Down syndrome

12 ☐ Prader-Willi syndrome

13 ☐ Fetal alcohol spectrum disorder (FASD)

14 ☐ Limited or no vision – legally blind

15 ☐ Hearing loss – severe or profound

16 ☐ Other disabilities not listed (please do not include items that will be captured in BI-13): Click or tap here to enter text.

17 ☐ No other disabilities other than ID (check this option if the person has no other disabilities)

BI-13. What health conditions are noted in this person's record? *Check all that apply.*

1 ☐ Cardiovascular disease (e.g., coronary heart disease, angina)

2 ☐ Diabetes (including Type 1 and Type 2)

3 ☐ Cancer (e.g., breast, prostate, colon, lung, etc.)

4 ☐ High blood pressure

5 ☐ High cholesterol

6 ☐ Dysphagia (difficulty swallowing)

7 ☐ Pressure ulcers (bedsores or pressure sores)

8 ☐ Alzheimer's disease or other dementia

9 ☐ Oral health or dental problems that cause ongoing pain or difficulty eating

10 ☐ Sleep apnea

11 ☐ Asthma

12 ☐ Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)

13 ☐ Chronic kidney disease

14 ☐ Long-term health problems associated with COVID-19 (also known as post-COVID syndrome, Long COVID, or Long-haul COVID)

15 ☐ Other health conditions not listed (please do not include items from BI-12): Click or tap here to enter text.

BI-14. In the past year, has this person had an unexpected hospital admission due to any of the following? *Check all that apply.*

1 ☐ Dehydration

2 ☐ Bowel obstruction

3 ☐ Seizure

4 ☐ Aspiration (food, liquids, saliva, or vomit breathed into the airways)

5 ☐ Gastroesophageal reflux disease (GERD)

BI-15. Field appropriate What is this person's preferred language? (What language does this person best understand?) Check ONE.

1 ☐ English

2 ☐ Spanish

3 ☐ Chinese (including Mandarin, Cantonese and Hokkien)

4 ☐ Tagalog (including Filipino)

5 ☐ Vietnamese

6 ☐ American Sign Language (ASL)

7 ☐ Other (please specify):Click or tap here to enter text.

BI-16. Field appropriate What is this person's preferred means of communication?

Recognizing that more than one means of communication may be used, please select the most frequently used method of communication that the person prefers to use. Check ONE—most frequently used.

1 ☐ Spoken

2 ☐ Gestures/body language

3 ☐ Sign language or finger spelling

4 ☐ Communication aid/device

5 ☐ Other: _____

99 ☐ Don't know

BI-17. Field appropriate How would you describe this person's mobility? Check ONE.

1 ☐ Moves self around environment without aids

2 ☐ Moves self around environment with aids or uses wheelchair independently

3 ☐ Non-ambulatory; always needs assistance to move around environment

99 ☐ Don't know

Health

BI-18. Field appropriate Does this person have a primary care doctor or primary care practitioner?

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-19. Field appropriate When was their last complete annual physical exam? (We're referring to a routine exam, not a visit for a specific problem or illness.) Check ONE.

1 ☐ One year ago or less (12 months ago or anytime less than 12 months ago)

2 ☐ More than one year ago (more than 12 months ago)

99 ☐ Don't know

BI-20.Field appropriate When was their last dentist exam (routine preventative dental care)? Check ONE.

1 ☐ Within the last 6 months

2 ☐ Within the past year (more than 6 months ago but less than 12 months ago)

3 ☐ One year ago or more

99 ☐ Don't know

BI-21. Field appropriate When was the last time this person had an eye exam/vision screening?

1 ☐ Within the past year (anytime less than 12 months ago)

2 ☐ Within the past 2 years (more than 1 year ago but less than 2 years ago)

3 ☐ Within the past 3 years (more than 2 years ago but less than 3 years ago)

4 ☐ Within the past 5 years (more than 3 years ago but less than 5 years ago)

5 ☐ 5 or more years ago

6 ☐ Has never had a vision screening

99 ☐ Don't know

BI-22. Field appropriate When was the last time this person had a hearing test?

1 ☐ Within the past 5 years (anytime less than 5 years ago)

2 ☐ 5 years ago or more

3 ☐ Has never had a hearing test

99 ☐ Don't know

BI-23.Field appropriate During the past 12 months, has this person had a flu vaccination?

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-24. Field appropriate How much does this person weigh?

Click or tap here to enter text. **lbs.**

BI-25. Field appropriate How tall is this person?

Click or tap here to enter text. **feet** Click or tap here to enter text. **inches**

BI-26. Field appropriate Does this person use nicotine or tobacco products (e.g., cigarettes, e-cigarettes, chewing tobacco, etc.)?

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

- **BI-27.Field appropriate If female, when was her last Pap test screening? (A Pap test is used to check women for cancer of the cervix.)**
  Check ONE. Please refer to individual's sex assigned at birth. Will be reported for females age 21 and over.

98 ☐ Not applicable – individual is not female or individual is under age 21

1 ☐ Within the past year (anytime less than 12 months ago)

2 ☐ Within the past 2 years (more than 1 year ago but less than 2 years ago)

3 ☐ Within the past 3 years (more than 2 years ago but less than 3 years ago)

4 ☐ Within the past 5 years (more than 3 years ago but less than 5 years ago)

5 ☐ 5 or more years ago

6 ☐ Has never had a Pap test

99 ☐ Don't know

BI-28. Field appropriate If female, when was her last mammogram? (A mammogram is an x-ray of each breast to check for breast cancer.)
Check ONE. Please refer to individual's sex assigned at birth. Will be reported for females age 50 and over.

98 ☐ Not applicable – individual is not female or individual is under age 50

1 ☐ Within the past year (anytime less than 12 months ago)

2 ☐ Within the past 2 years (more than 1 year ago but less than 2 years ago)

3 ☐ Within the past 3 years (more than 2 years ago but less than 3 years ago)

4 ☐ Within the past 5 years (more than 3 years ago but less than 5 years ago)

5 ☐ 5 or more years ago

6 ☐ Has never had a mammogram

99 ☐ Don't know

BI-29. Field appropriate Has this person received screening for colorectal cancer? Check ALL that apply. Will be reported for adults age 45 to 75.

98 ☐ Not applicable – individual is under age 45 or over age 75

1 ☐ Colonoscopy within the past 10 years

Note: A colonoscopy is a procedure in which a doctor uses a camera to look at the full colon.

2 ☐ Flexible sigmoidoscopy within the past 5 years

Note: A sigmoidoscopy is a procedure in which a doctor uses a camera to look at part of the colon.

3 ☐ Testing for colorectal cancer with stool sample, using a Fecal Occult Blood Test (FOBT) or Fecal Immunochemical Test (FIT) in the past year.

4 ☐ Has never had screening for colorectal cancer or screening was outside of the recommended timeframes reflected in the above response options

99 ☐ Don't know

BI-30. Does this person currently take medications to treat mood disorders, anxiety, and/or psychotic disorders?

Medications for mood disorders: Any drug prescribed to elevate or stabilize mood (reduce mood swings) – for example, to treat depression, mania, or bipolar disorder.

Medications for anxiety: Any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.

Medications for psychotic disorders: Any drug (e.g., anti-psychotic or “neuroleptic”) used to treat psychotic disorders such as schizophrenia or psychotic symptoms such as hallucinations.

1 ☐ No →GO TO BI-32

2 ☐ Yes

99 ☐ Don’t know →GO TO BI-32

BI-31. If yes, how many medications to treat mood disorders, anxiety, and/or psychotic disorders does this person take?

98 ☐ Not applicable — does not take medication for these disorders

1 ☐ One or two medications

2 ☐ Three or four medications

3 ☐ Five to ten medications

4 ☐ Eleven or more medications

99 ☐ Don't know

BI-32. Does this person currently take medications for behavioral challenges?

Medications for behavioral challenges: Any drug prescribed for a behavior modification purpose (e.g., stimulant, sedative, or beta-blocker to treat ADHD, aggression, self-injurious behavior, etc.).

1 ☐ No →GO TO BI-34

2 ☐ Yes

99 ☐ Don't know →GO TO BI-34

BI-33. If yes, how many medications for behavioral challenges does this person take?

98 ☐ Not applicable — does not take medication for these disorders

1 ☐ One or two medications

2 ☐ Three or four medications

3 ☐ Five to ten medications

4 ☐ Eleven or more medications

99 ☐ Don't know

BI-34. Does this person currently have a behavior plan?

Behavior plan: A plan based on an assessment of an individual's challenging behavior. The plan includes a description of the individual's strengths, preferences, and interests; goal(s) related to diminishing and/or eliminating the challenging behavior; and applicable information about the nature of the behavior and potential triggering events. The plan should describe the interventions and accommodations that will contribute to the goal(s). It should also include the ways in which progress will be monitored, the staff who will be responsible for the interventions, and the length of time the plan will be in place.

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

Residence

BI-35. Field appropriate How long has this person lived in their current residence?

98 ☐ Not applicable — homeless

1 ☐ Less than one year

2 ☐ One to three years

3 ☐ Four to five years

4 ☐ Over five years

99 ☐ Don't know

BI-36. How would you characterize the place where this person lives? CHECK ONE.

Intermediate care facility for persons with I/DD (ICF/IID) or other institutional setting

1 ☐ ICF/IID, 4-6 residents with disabilities

2 ☐ ICF/IID, 7-15 residents with disabilities

3 ☐ ICF/IID, 16 or more residents with disabilities

4 ☐ Nursing facility

5 ☐ Other specialized institutional facility

Group residential setting (e.g., group home). Operated by a service provider agency.

6 ☐ Group living setting, 2-3 people with disabilities

7 ☐ Group living setting, 4-6 people with disabilities

8 ☐ Group living setting, 7-15 people with disabilities

Own home or apartment

9 ☐ Lives in own home or apartment; may be owned or rented, or may be sharing with roommate(s) or spouse

10 ☐ Parent/relative's home (may include paid services to family for residential supports)

Foster or host home

11 ☐ Foster care or host home—Round-the-clock services provided in a single-family residence where **two or more people with a disability** live with a person or family who furnishes services

12 ☐ Foster care or host home—Round-the-clock services provided in a single-family residence where **only one person with a disability** lives with a person or family who furnishes services (sometimes called shared living)

Other

13 ☐ Homeless or crisis bed placement

14 ☐ Other (specify): Click or tap here to enter text.

99 ☐ Don't know

BI-37. Is the person's residence controlled by a service provider?

'Controlled' means the service provider is also connected to the property by lease or ownership. This includes foster care or host home settings.

Check "NO" if the following applies:

- The person owns or rents from a landlord who is not the provider agency and is not affiliated with the provider agency in any way.
- The person lives in the home of family/friends.
- The person is living in foster care and the foster care/host home is not controlled by a provider agency, nor is the foster care home under contract to the service provider agency to deliver foster care services.

Check "YES" if the following applies:

- If the person changed the provider agency providing their supports, he/she would need to move.

98 ☐ Not applicable — person is homeless

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-38. Is the person named on the lease, deed, or other legally enforceable rental agreement for their residence?

1 ☐ No

2 ☐ Yes, named on lease or deed

3 ☐ Yes, named on other legally enforceable rental agreement

99 ☐ Don't know

BI-39. What amount of paid support does this person receive? (Include any paid support, regardless of funding source.) Support may be remote and/or in-person. Check ONE.

1 ☐ 24-hour support or supervision (supporters available in-person or remotely at all times)

2 ☐ Daily support (for a limited number of hours per day, not round-the-clock)

3 ☐ Scheduled, less frequent than daily support

4 ☐ As-needed visitation and phone contact

5 ☐ None of the above

99 ☐ Don't know

BI-40. Does this person have any remote supports?

Remote supports combine technology and direct care to provide supports. Remote supports—including home-based sensors, cameras, and other devices—use two-way communication in real time to provide a less-invasive means of staff support and responding to the needs of people being supported.

1 ☐ No, none

2 ☐ Yes, 24-hour remote supports

3 ☐ Yes, less than 24-hour remote supports

99 ☐ Don't know

Employment/Other Daily Activities

See PS-6. Please provide data based on a **typical two-week period**.

Type of Activity *Definitions:* ***Community-based setting*** *is a place where most people* do not *have disabilities.* ***Facility-based setting*** *is a place where most people* do *have disabilities.*	a) Does this person do this activity during the typical **two-week period**?	If yes: b) Number of hours worked or spent at this activity during the typical **two-week period:**	c) Wage (not including benefits and before taxes or deductions) earned at this activity during the typical **two-week period**:	d) Does this person get publicly funded services or supports to participate in this activity?	e) Is the job or activity done primarily by a group of people with disabilities?
BI-41. Paid individual job in a community-based setting *A person working at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (e.g., competitive employment).* ***If the person does more than one activity of this type, please refer to the activity at which the person has spent the most time in the past two weeks.***	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	Number of hours for which person is paid in **typical two-week period**: __ __ __	HOURLY WAGE $ __ __ . __ __/hr	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	N/A

Type of Activity *Definitions:* ***Community-based setting*** *is a place where most people* do not *have disabilities.* ***Facility-based setting*** *is a place where most people* do *have disabilities.*	a) Does this person do this activity during the typical **two-week period**?	If yes: b) Number of hours worked or spent at this activity during the typical **two-week period:**	c) Wage (not including benefits and before taxes or deductions) earned at this activity during the typical **two-week period**:	d) Does this person get publicly funded services or supports to participate in this activity?	e) Is the job or activity done primarily by a group of people with disabilities?
BI-42. Paid small-group job in a community-based setting *The activity is done in an integrated setting, as part of a group of not more than 8 people with disabilities (e.g., enclave, work crew).* ***If the person does more than one activity of this type, please refer to the activity at which the person has spent the most time in the past two weeks.***	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	Number of hours for which person is paid in **typical two-week period**: __ __ __	HOURLY WAGE $ __ __ . __ __/hr	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	N/A

Type of Activity *Definitions:* ***Community-based setting*** *is a place where most people* do not *have disabilities.* ***Facility-based setting*** *is a place where most people* do *have disabilities.*	a) Does this person do this activity during the typical **two-week period**?	If yes:			
		b) Number of hours worked or spent at this activity during the typical **two-week period:**	c) Wage (not including benefits and before taxes or deductions) earned at this activity during the typical **two-week period**:	d) Does this person get publicly funded services or supports to participate in this activity?	e) Is the job or activity done primarily by a group of people with disabilities?
BI-43. Paid work in a community business that primarily hires people with disabilities *In this job, the employees with disabilities interact with the non-disabled population; this job is NOT in a traditional sheltered workshop and is NOT an enclave. Examples include bakeries, carwashes, thrift stores, etc.* ***If the person does more than one activity of this type, please refer to the activity at which the person has spent the most time in the past two weeks.***	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	Number of hours for which person is paid in **typical two-week period**: __ __ __	HOURLY WAGE $ __ __ . __ __/hr	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	N/A

Type of Activity *Definitions:* ***Community-based setting*** *is a place where most people* do not *have disabilities.* ***Facility-based setting*** *is a place where most people* do *have disabilities.*	a) Does this person do this activity during the typical **two-week period**?	If yes:			
		b) Number of hours worked or spent at this activity during the typical **two-week period:**	c) Wage (not including benefits and before taxes or deductions) earned at this activity during the typical **two-week period**:	d) Does this person get publicly funded services or supports to participate in this activity?	e) Is the job or activity done primarily by a group of people with disabilities?
BI-44. Unpaid activity in a community-based setting *(e.g., volunteer activities, skills training, community supports)* ***If the person does more than one activity of this type, please refer to the activity at which the person has spent the most time in the past two weeks.***	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	Number of hours spent at activity in **typical two-week period**: __ __ __	N/A	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	1 ☐ No 2 ☐ Yes 99 ☐ Don't know

Type of Activity *Definitions:* ***Community-based setting*** *is a place where most people* do not *have disabilities.* ***Facility-based setting*** *is a place where most people* do *have disabilities.*	a) Does this person do this activity during the typical **two-week period**?	If yes:			
		b) Number of hours worked or spent at this activity during the typical **two-week period:**	c) Wage (not including benefits and before taxes or deductions) earned at this activity during the typical **two-week period**:	d) Does this person get publicly funded services or supports to participate in this activity?	e) Is the job or activity done primarily by a group of people with disabilities?
BI-45. Paid work performed in a facility-based setting (*e.g., traditional sheltered workshop or work activity center; the location has been developed specifically to provide work activity exclusively for people with disabilities and people may be paid subminimum wage.*) ***If the person does more than one activity of this type, please refer to the activity at which the person has spent the most time in the past two weeks.***	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	Number of hours for which person is paid in **typical two-week period**: __ __ __	Total wages earned in **typical two-week period** $_ __ __ . __ __	N/A	N/A

Type of Activity *Definitions:* ***Community-based setting*** *is a place where most people* do not *have disabilities.* ***Facility-based setting*** *is a place where most people* do *have disabilities.*	a) Does this person do this activity during the typical **two-week period**?	If yes:			
		b) Number of hours worked or spent at this activity during the typical **two-week period:**	c) Wage (not including benefits and before taxes or deductions) earned at this activity during the typical **two-week period**:	d) Does this person get publicly funded services or supports to participate in this activity?	e) Is the job or activity done primarily by a group of people with disabilities?
BI-46. Unpaid activity in a facility-based setting *(e.g., day habilitation, seniors programs, drop-in centers)* ***If the person does more than one activity of this type, please refer to the activity at which the person has spent the most time in the past two weeks.***	1 ☐ No 2 ☐ Yes 99 ☐ Don't know	Number of hours spent at activity in **typical two-week period**: __ __ __	N/A	N/A	N/A

BI-47. Is community employment a goal in this person's service plan (also known as an Individual Service Plan, or ISP)?

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-48. Is this person enrolled in school?

1 ☐ No

2 ☐ Yes, high school

3 ☐ Yes, vocational school or certificate program

4 ☐ Yes, college

99 ☐ Don't know

Community Employment

If person has a paid community job—BI-41, BI-42, and/or BI-43 is "Yes"—please answer BI-49 and BI-50.

BI-49. Is this person self-employed?

Self-employment is the state of working for oneself rather than an employer.

98 ☐ Not applicable – no paid job in a community-based setting

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-50. Field appropriate What type of job does this person have? Check all responses that describe work done regularly by the individual.

98 ☐ Not applicable – no paid job in a community-based setting

1 ☐ Food preparation and food service

2 ☐ Building and grounds cleaning or maintenance

3 ☐ Personal care provider

4 ☐ Retail – such as sales clerk or stock person

5 ☐ General office and administrative support

6 ☐ Farming, fishing, forestry worker

7 ☐ Construction or repair occupation

8 ☐ Assembly, manufacturing, or packaging

9 ☐ Materials handling, mail distribution

10 ☐ Management, business, or financial operations

11 ☐ Professional or technical occupation

12 ☐ Other: Click or tap here to enter text.

99 ☐ Don't know

Other Supports and Services

BI-51. What is the funding for supports for this person? (Please obtain this information from a state data system or official record if possible.) Check ALL THAT APPLY.

1 ☐ ICF/IID Funded (Intermediate Care Facility for individuals with intellectual disabilities)

2 ☐ Medicaid HCBS Waiver-Funded Services (this includes: 1915(c) Home and Community-Based Waivers, 1915(i) State Plan Home and Community-Based Services, 1915(j) Self-Directed Personal Assistance Services Under State Plan, 1915(k) Community First Choice, and/or 1115 Demonstration Waivers that includes HCBS)

3 ☐ Medicaid State Plan Funded Services

4 ☐ Exclusively supported by State Funds (no Medicaid long-term services and supports, or LTSS) and **is not** receiving Medicaid health care

5 ☐ Exclusively supported by State Funds (no Medicaid LTSS) but **is** receiving Medicaid health care)

99 ☐ Don't know

BI-52. Does this person currently receive Medicare?

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-53. What was the date of this person's last Annual Service Planning meeting?
(An Annual Service Planning meeting is a meeting in which the individual and those close to him/her meet with a service coordinator to discuss a plan for supports to help the individual meet their goals. This meeting typically occurs at least once a year.)

(MM/DD/YYYY): Click or tap here to enter text.

BI-54. In this person's service plan, is there a goal to create, expand, strengthen and/or maintain friendships and relationships?

(A service plan is also known as an Individual Service Plan or ISP.)

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-55. In this person's service plan, is there a goal to increase this person's participation in activities in the community?

(A service plan is also known as an Individual Service Plan or ISP.)

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-56. In this person's service plan, is there a goal to increase independence or improve functional skill performance in activities of daily living (ADLs)?

(A service plan is also known as an Individual Service Plan or ISP.)

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-57. Is this person currently using a self-directed supports option?

Is this person currently using a self-directed/participant-directed supports option? Does he/she have a financial management service (also called a fiscal agent, fiscal intermediary, intermediary service organization, etc.)? These options offer individuals (and their representatives) the opportunity to manage some or all of their services. For example, they may hire and fire their own support workers and/or have control over their budget or services.

1 ☐ No →GO TO BI-59

2 ☐ Yes

99 ☐ Don't know →GO TO BI-59

BI-58. If yes, who employs this person's support workers?

98 ☐ Not applicable – not using self-directed/participant-directed supports option

1 ☐ The person (or their representative) is the common-law employer. A fiscal intermediary functions as the person's agent to perform payroll and other responsibilities required by law.

2 ☐ The person (or their representative) is the employer and manages all payroll and other employer responsibilities.

3 ☐ An "agency with choice" is the common-law employer of the support workers; selected/recruited by the individual, the agency performs necessary payroll and human resources functions. The person (or their representative) is the co-employer (managing employer).

99 ☐ Don't know

Behavioral Support Needs

Please identify the level of support the person needs to manage any of the behaviors listed below.

BI-59. Self-injurious behavior

Refers to attempts to cause harm to one's own body; for example, by hitting or biting self, banging head, scratching or puncturing skin, or ingesting inedible substances.

1 ☐ No support needed

2 ☐ Some support needed; requires only occasional assistance or monitoring

3 ☐ Extensive support needed; frequent or severe enough to require regular assistance

99 ☐ Don't know

BI-60. Disruptive behavior

Refers to behavior that interferes with the activities of others; for example, by laughing or crying without apparent reason, yelling or screaming, cursing, or threatening.

1 ☐ No support needed

2 ☐ Some support needed; requires only occasional assistance or monitoring

3 ☐ Extensive support needed; frequent or severe enough to require regular assistance

99 ☐ Don't know

BI-61. Behavior that is destructive or harmful to others

Refers broadly to externally directed, defiant behavior; for example, taking other people's property, destroying property, stealing, or assaulting/injuring others.

1 ☐ No support needed

2 ☐ Some support needed; requires only occasional assistance or monitoring

3 ☐ Extensive support needed; frequent or severe enough to require regular assistance

99 ☐ Don't know

COVID-19

BI-62. Field appropriate Has this person ever been diagnosed or presumed diagnosed with COVID-19?

A person is considered to be diagnosed or presumed diagnosed with COVID-19 if the person has:

- Received a positive lab test for COVID-19 AND/OR
- Been informed by a physician that they are likely to have COVID-19 AND/OR
- Had signs and symptoms consistent with COVID-19 (e.g., fever, cough, shortness of breath or trouble breathing)

1 ☐ No →GO TO BI-64

2 ☐ Yes

99 ☐ Don't know →GO TO BI-64

BI-63. Field appropriate Has this person ever required in-patient hospitalization due to COVID-19?

98 ☐ Not applicable: Never diagnosed or presumed diagnosed with COVID-19

1 ☐ No

2 ☐ Yes

99 ☐ Don't know

BI-64. Field appropriate Is this person "fully vaccinated" with a CDC-accepted vaccine for COVID-19?

Fully Vaccinated[1]:

- *2 doses of Pfizer-BioNTech given 3-8 weeks apart*
- *2 doses of Moderna given 4-8 weeks apart*
- *1 dose of Johnson & Johnson's Janssen*
- *2 doses of Novavax given 3-8 weeks apart*

4 ☐ Yes, fully vaccinated (as per above definition) and has received at least one booster

A "booster" is an extra dose of the vaccine after having received the initial dose of 2 shots (or 1 shot, if received the Johnson and Johnson vaccine).

2 ☐ Yes, fully vaccinated (as per above definition)

3 ☐ Partially vaccinated—received one of two doses of Pfizer-BioNTech or Moderna or Novavax

1 ☐ Not vaccinated at all

99 ☐ Don't know

BI-65. What was the source(s) for the Background Information for this survey? Check ALL THAT APPLY.

1 ☐ Case Management Records

2 ☐ Service Provider Records

3 ☐ State DD Agency Database

4 ☐ State Medicaid Agency Database

5 ☐ Individual being surveyed/family member

6 ☐ Other: Click or tap here to enter text.

[1] As per the Centers for Disease Control definition of "fully vaccinated" as of May 1, 2023. For more information: https://www.cdc.gov/coronavirus/2019-ncov/vaccines/stay-up-to-date.html

State-Specific Background Information Supplement

• END OF BACKGROUND INFORMATION SECTION •

PROXY DETERMINATION

The following two questions (D-1 and D-2) are used to determine whether a proxy is required to complete Section II of the In-Person Survey on the behalf of the person receiving services.

For all people who are surveyed: The Proxy Determination questions are ***required. The Proxy Determination questions must be asked prior to proceeding with the survey with the person and/or a proxy.***

The person must be able to answer both questions validly in order to take part in Section I and Section II of the survey.

Answering validly means that the person's response reflects an understanding of the question. Each proxy determination question includes examples of reliable responses. However, it will ultimately be at the surveyor's discretion to decide whether the person answers in a reliable manner.

Reminder: **The proxy determination questions may help you gain insight into the person's communication style.** A response may be considered valid even if the person has help with communication, rephrasing, or follow-up. Use an interpreter to interpret the person's responses when needed (e.g., if the person does not communicate verbally or has a unique communication style). *It's important to remember that questions may be answered validly by people who do not communicate verbally or communicate only with yes/no responses.*

After asking both Proxy Determination questions, complete the scheduling for the survey with the appropriate people. It is best practice to include the person receiving services in the survey meeting even if you will only be conducting the survey with a proxy.

Example of how to introduce the Proxy Determination questions:

> When we do the survey, I am going to ask questions about your life, like about where you live and what you do during the day. There are no right or wrong answers, I just want to hear what you have to say. Some questions are just for you. I am going to ask a practice question. Is that ok?
>
> *If no…*
>
> *Ask if there is anything that will help the person feel more comfortable.*
>
> *If yes…*
>
> *Thank you! Remember this question is just for you [Participant].*

D-1 What is your favorite season?

Suggested rewording: What is your favorite time of year?

1 ☐ Winter

2 ☐ Spring

3 ☐ Summer

4 ☐ Fall

5 ☐ Other: Click or tap here to enter text.

99 ☐ Don't know/unclear response/unsure

D-1 Valid answers (examples):

- Any of the seasons
- A holiday typically associated with a season
- Weather that is typically associated with a season
- Sports season

D-1 Not valid answers (examples), follow-up if initial response is not valid:

- I don't know
- Monday
- My birthday

D-2 Why is that your favorite season?

Click or tap here to enter text.

D-2 Valid answers (examples):

- The weather
- Activities that happen during the season

D-2 Not valid answers (examples), follow-up if initial response is not valid:

- I don't know
- Just because it is

Required questions for surveyor

D-3. Were Proxy Determination questions answered validly?

2 ☐ Yes, both questions →GO TO D-5

3 ☐ Yes, only one

1 ☐ No

D-4. If Proxy Determination questions were not answered validly, why not?

1 ☐ Person did not respond

2 ☐ Person did not understand question

3 ☐ Could not understand communication and interpreter was not available

4 ☐ Other

D-5. Will you conduct the Section I with person receiving services? REMINDER: Section I may be completed with the support of an interpreter. The person is not required to answer *all* Section I questions.

2 ☐ Yes, will conduct Section I

1 ☐ No, Section I will not be conducted (only Section II will be completed with a proxy respondent)

In-Person Survey

General Instructions

- Section I may ***only be completed by directly surveying the person*** receiving services and supports. No proxy responses are permitted. An interpreter or other communication support may be used any time during the survey.

- Section II allows for proxy respondents if determined necessary using the Proxy Determination questions.

- For more information on the roles of interpreters and proxies, see section 'INFORMATION ON THE ROLE OF INTERPRETERS AND PROXIES' following the page on 'CONSENT'.

- Prior to the survey, surveyors should use the Pre-Survey Form to fill in the blanks throughout Sections I and II. Using familiar names and terms during the survey will help ensure that the person understands the questions. Questions that refer to information that can be found in the Pre-Survey Form are indicated with a bell: 🔔

- If possible, the survey should be conducted in private. If staff believe that a private survey may pose a risk to the surveyor, then staff should be present. For more information on the roles of interpreters and proxies, see section 'INFORMATION ON THE ROLE OF INTERPRETERS AND PROXIES' following the page on 'CONSENT'.

- Be sure to read all instructions carefully.

- Help the person with any words they do not understand. You may repeat or rephrase questions to improve understanding. For some questions, we provide a suggested rephrasing in parentheses—but you don't need to limit yourself to these suggestions.

- Do not read or show the list of response options to the person. Let them answer in their own words, and if the person provides a response that does not fit into a given response option, follow up and try to categorize the response.

- The person may choose to skip any question. If the person receiving services does not respond to a question or gives an unclear response, code the question as '99'.

- If you have any questions concerning the intent of a survey question or need additional help in rephrasing a question, refer to the Surveyor Handbook.

- A wide margin is provided for recording notes as necessary. Those should be notes to yourself.

- Ensure that response options are clearly coded.

- Please fill out the Surveyor Feedback Sheet after each survey.

CONSENT

First, take a few minutes to introduce yourself and make the person feel comfortable. Read or paraphrase the following introduction. Pause after each statement, making sure the respondent understands.

“Hi, my name is ____. I'm from _____, and I'm here to ask you some questions about where you live, where you work, your friends and family, and the people who help you. By answering these questions, you are helping us figure out how people in [State] are doing, and how to make supports and services better.”

“This is not a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer. Whatever answers you give, you will not get into trouble and no one will be mad at you.”

“You don't have to answer any questions that you don't want to. Just tell me if you don't want to answer. Whatever you tell me is private, unless you tell me something that makes me worry for your safety or someone else’s.”

“I'd like to know your opinions, how you feel about things. Do you mind if I ask you some questions?”

AGREEMENT TO PARTICIPATE: Did the person indicate to the surveyor that they agree to participate in the NCI survey discussion?

2 ☐ Yes

1 ☐ No → Section II may be completed if the person assents

INFORMATION ON THE ROLE OF INTERPRETERS AND PROXIES

The following describes how others present at the survey meeting can support the person during the meeting.

They can interpret questions and/or responses.

If you (surveyor) or the person receiving services communicates in a way that the other is unfamiliar with, an additional person can serve as an interpreter. As an interpreter, the person will communicate questions to the person and provide the person's responses back to you.

Here's how:

- You (the surveyor) will ask a question from the NCI survey.
- The interpreter will use the same words to ask the person the question. The interpreter should ***not*** add examples or definitions as part of the question.
- If the person needs help understanding the question, the interpreter can ask the surveyor for rewording, rephrasing and/or examples.
- The interpreter should give you all of the information the person communicates.

They can serve as a "proxy respondent" and help answer questions

Later in the survey (Section II), if the person wants help answering questions, or cannot or does not want to complete the survey, someone who knows the person well may serve as a "proxy respondent" and help answer questions.

SECTION I

HOME

I'm going to start by asking you some questions about where you live.

1. Do you like your home or where you live?

Suggested reword: Do you like living here?

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

2. Would you like to live somewhere else?

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

3. Do people who do not live with you ask you before they come into your home?

Note to surveyor: Do not include people who live in the home. Include staff who have keys (i.e., if they knock, come in only when scheduled or expected).

Suggested reword: Do people who do not live with you ring the doorbell or knock first and wait for an answer before coming into your home?

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

4. Do people ask you before coming into your bedroom?

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

5. Do you have a place to be alone in your home?

Suggested reword: Can you be by yourself somewhere in your home?

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Employment and Other Daily Activities

I have some questions about paid community work. This is not work that is done at a day program or in a workshop. This is work that you get paid for doing, and it is work done in the community around people who do not have disabilities.

6. Do you have a paid job in the community?

Note to surveyor: A paid community job refers to work the person does in an integrated setting, either with people who do not have disabilities or in a setting where people without disabilities go. The person may have a paid community job through their provider or day program. You may refer to the Employment and Daily Activities grid from the Background Information section (BI-41 through BI-46) for more information on the person's activities.

PS-6 *Do you work at Click or tap here to enter text.?*

2 ☐ **Yes** →GO TO Q8

1 ☐ **No**

99 ☐ Don't know, no response, unclear response →GO TO Q10

7. *If No, ask:* **Do you want a paid job in the community?**

98 ☐ Not applicable – has a paid job in the community

2 ☐ **Yes** →GO TO Q10

3 ☐ **In-between** →GO TO Q10

1 ☐ **No** →GO TO Q10

99 ☐ Don't know, no response, unclear response →GO TO Q10

8. *If person has a job, ask:* **Do you like working there?**

PS-6 *Do you like working at Click or tap here to enter text.?*

98 ☐ Not applicable – no paid job in the community

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

9. Do you use any special technology to help you do your job? These are things like specialized technology for communication, mobility, or vision or alerts to help you do tasks at work.

Note to surveyor: We are asking about assistive technology or adaptive equipment that is designed to support people to be more independent. This includes assistive technology that is used by the person to help them do tasks at their job. It does not include assistive technology used to get to or from their place of work.

98 ☐ Not applicable – no paid job in the community

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

10. Are you taking classes, training, or skills building to help you get a job/get a different job?

Note to surveyor: this includes job training/career development activities.

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Now I'd like to talk to you about other things you may do during the day.

11. Do you do any of these activities at least once a week? *Read responses, check all that apply.*

Note to surveyor: This question is about regular activities the person takes part in – activities they *typically* do at least once a week. You may refer to the Employment and Daily Activities grid from the Background Information section (BI-41 through BI-46) and PS-7 for more information on the person's activities.

Suggested reword: Are any of these activities part of your usual daily schedule?

1 ☐ **Go to a day program or workshop, either online or in-person** (program or center where other people with disabilities spend their days)

Note to surveyor: ***Day programs*** *for people with I/DD are typically segregated and may provide socialization, habilitation, prevocational and skills training, social and/or recreational activities.* ***Sheltered workshops*** *are facility-based day programs where people with I/DD spend their days in a segregated setting to carry out specific tasks (often piece-work).*

2 ☐ **Volunteer**

3 ☐ **Job training**

Note to surveyor: ***Job training*** *is education that prepares people for employment. Job training includes services like job development, job placement, job site training, employer follow-up, and school to work support services.*

4 ☐ **Go to school or take classes**

5 ☐ **Do things in the community with paid support**

6 ☐ **Other regularly scheduled activity:** Click or tap here to enter text.

7 ☐ **No regularly scheduled activity**

99 ☐ Don't know, no response, unclear response

Feeling Safe

Now I'm going to ask you some personal questions about your safety. Remember, you don't have to answer any questions that you don't want to.

12. Are there any places where you feel afraid or scared? *Read responses, check all that apply.*

1 ☐ **Home**
2 ☐ **Day program**
3 ☐ **Work**
4 ☐ **Walking in your neighborhood**
5 ☐ **In transport (on the bus, van, etc.)**
6 ☐ **Other:** Click or tap here to enter text.
98 ☐ **Does not feel afraid anywhere**
99 ☐ Don't know, no response, unclear response

13. If you ever feel afraid, is there someone you can talk to?

2 ☐ **Yes**
3 ☐ **Maybe, not sure**
1 ☐ **No**
99 ☐ Don't know, no response, unclear response

Friends & Family

Now I'm going to ask you about friends and family.

14. Do you have friends you like to talk to or do things with?

Note to surveyor: Follow up a "yes" response to determine whether there are friends other than staff and family.

2 ☐ **Has friends who are not staff or family**
3 ☐ **All friends are staff or family, or cannot determine**
1 ☐ **No, does not have friends** →GO TO Q18
99 ☐ Don't know, no response, unclear response →GO TO Q18

15. Do you have a best friend, or someone you are really close to?

Note to surveyor: Can include staff or family member.

98 ☐ Not applicable – does not have friends

2 ☐ **Yes, has a best friend**

1 ☐ **No, does not have a best friend**

99 ☐ Don't know, no response, unclear response

16. Can you meet up with your friends in-person when you want to?

98 ☐ Not applicable – does not have friends

2 ☐ **Yes, always**

3 ☐ **Sometimes cannot see friends**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

17. Do you use other ways of talking, chatting or communicating with your friends when you do not see them in-person?

Suggested reword: Do you talk with your friends over the phone, through email, texting, messaging, social media?

98 ☐ Not applicable – does not have friends

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

18. Do you want more help to meet new people, make new friends or keep in contact with your friends?

2 ☐ **Yes**

3 ☐ **Maybe**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

19. Can you go on a date if you want to?

Note to surveyor: Be sure to follow up a "yes" response to determine whether there are rules or restrictions around dating. Follow up a "no" response to determine whether there are actually restrictions or whether the person does not want to date. If the person does not want to date, code "98".

98 ☐ Not applicable – does not want to date

2 ☐ **Yes, can go on date without restrictions or rules or is married**

3 ☐ **There are some restrictions or rules about dating**

1 ☐ **No, cannot go on a date if wants**

99 ☐ Don't know, no response, unclear response

20. Do you ever feel lonely?

Suggested reword: Do you ever feel like you don't have anyone to talk to?

2 ☐ **Yes, often**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

21. Can you see and/or talk to family who do not live with you when you want to?

Suggested reword: Can you talk to family who do not live with you on the phone, or make plans and see them when you want to?

Note to surveyor: If family is not available or doesn't wish to have contact, code as 'Not applicable'. If the person has family but doesn't want to see them, code as 'Yes, **can see or talk to** family when they want to, or chooses not to see family'.

98 ☐ Not applicable – lives with family, family not available, person doesn't have family, or family doesn't have contact

2 ☐ **Yes, can see or talk to family when they want to, or chooses not to see family**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Community Participation & Leisure

Now I'm going to ask you about the things you like to do when you go out.

What kinds of things do you like to do outside of your home? Click or tap here to enter text.

Note to surveyor: Response should be used to ask Questions 22 and 23 to replace "[***things person likes to do outside home***]"

22. Do you do [*things person likes to do outside home*] as much as you want to?

98 ☐ Not applicable – does not like to do things outside of the home →GO TO Q24

2 ☐ **Yes**

3 ☐ **Some activities or sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

23. Do you do [*things person likes to do outside home*] with the people you want?

98 ☐ Not applicable – does not like to do things outside of the home

2 ☐ **Yes**

3 ☐ **Sometimes, some activities or some people**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

24. Do you like how you usually spend your time during the day?

2 ☐ **Yes, always, or almost always**

3 ☐ **Some days, or sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

25. Do you get help to learn new things?

Suggested reword: Does someone help you find out more about things you are interested in?

Note to surveyors: We are trying to find out whether the person is being encouraged to explore new interests, try new activities and/or have new experiences. This is sometimes referred to as "lifelong learning."

2 ☐ **Yes**

3 ☐ **Maybe or sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Now I'm going to ask you a couple of questions about transportation.

26. Are you able to get places when you want to do something outside your home, like going out to see friends, for entertainment, or to do something fun?

Suggested reword: Do you always have a ride to get places you want to go, like meeting up with friends, going out for entertainment, or going somewhere fun? Can you get a ride when you want one?

2 ☐ **Yes, almost always**

3 ☐ **Sometimes**

1 ☐ **No, almost never**

99 ☐ Don't know, no response, unclear response

27. Do you have a way to get places you need to go (like work, appointments, etc.)?

Suggested reword: Can you get a ride when you need one?

2 ☐ **Yes, almost always**

3 ☐ **Sometimes**

1 ☐ **No, almost never**

99 ☐ Don't know, no response, unclear response

28. When you are at home, do you have enough things you like to do?

Suggested reword: Do you have things to do so you are not bored at home?

2 ☐ **Yes, always**

3 ☐ **Sometimes**

1 ☐ **Not enough**

99 ☐ Don't know, no response, unclear response

29. Sometimes people need help with things like getting dressed, taking a shower, brushing their teeth. Do you ever need help with these?

Note to surveyor: In this question we are asking whether the person needs any support for activities of daily living (ADLs). This support can take the form of physical assistance, reminders, cues, etc.

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No** →GO TO Q31

99 ☐ Don't know, no response, unclear response →GO TO Q31

30. Do you want to learn to do more of these things (like getting dressed, taking a shower, or brushing your teeth) for yourself or on your own?

98 ☐ Not applicable – does not need help with self-care

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Rights & Privacy

31. Do people read your mail or email without asking you first?

98 ☐ Not applicable – does not get mail/email

2 ☐ **Yes, mail/email is read without permission**

1 ☐ **No, person reads own mail/email or others read with permission**

99 ☐ Don't know, no response, unclear response

32. Are there rules about having friends or visitors in your home? Like times of day they can be over, who can be over, places in the house where they can be.

Note to surveyor: Do not include rules the person makes on their own (like they do not want friends or visitors in their bedroom).

2 ☐ **No rules about having friends or visitors in the home**

1 ☐ **There are rules against having friends or visitors in the home**

99 ☐ Don't know, no response, unclear response

33. Are there rules about using phone or internet?

98 ☐ Not applicable – doesn't have access or unable to use phone/internet

4 ☐ **No rules about using phone or internet**

3 ☐ **Rules about *internet only***

2 ☐ **Rules about *phone only***

1 ☐ **Rules about using phone ***and*** internet**

99 ☐ Don't know, no response, unclear response

34. Do you have a cell phone or smartphone?

2 ☐ **Yes** →GO TO Q37

1 ☐ **No**

99 ☐ Don't know, no response, unclear response →GO TO Q37

35. *If no cell phone or smartphone, ask:* **Do you want a cell phone or smartphone?**

98 ☐ Not applicable – has a cell phone

2 ☐ **Yes**

1 ☐ **No→GO TO Q37**

99 ☐ Don't know, no response, unclear response

36. *If wants cell phone or smartphone, ask:* **Why don't you have one?** *Check all that apply.*

98 ☐ Not applicable – has a cell phone or does not want a cell phone

1 ☐ **Costs too much**

2 ☐ **It's not allowed**

3 ☐ **Had one but lost it or it broke**

4 ☐ **Other:** Click or tap here to enter text.

99 ☐ Don't know, no response, unclear response

Staff

37. Do you have staff who help you?

PS-5 *Does Click or tap here to enter text.help you?*

2 ☐ **Yes**

1 ☐ **No** →GO TO Q45

99 ☐ Don't know, no response, unclear response →GO TO Q45

REQUIRED QUESTION FOR SURVEYOR

Note to surveyors: The "paid support questions" (Questions 38-44) may only be asked if paid support workers are <u>not present</u> *for the survey (or cannot hear survey questions). If paid support workers are present, ask them to step out of the room for these questions.* ***If they refuse or need to be present, skip these questions and go to Question 45.***

S-1. SURVEYOR QUESTION Are "paid support questions" applicable and are the paid support staff out of the room?

98 ☐ Not applicable - person does not have paid support workers →GO TO Q45

1 ☐ No - person has paid support workers, but they are present and did not leave →GO TO Q45

2 ☐ Yes - questions are applicable and paid support workers are not present

Now I have some questions about staff who may help you at your home, job, or day program, or out in the community.

38. Are your staff respectful of your culture? This can be things like respecting your religion, your beliefs, the food you prefer, or the holidays you celebrate.

PS-5 *Does Click or tap here to enter text. respect your culture?*

98 ☐ Not applicable – doesn't have staff or staff are present

2 ☐ Yes, all staff, always

3 ☐ Sometimes or some staff

1 ☐ No

99 ☐ Don't know, no response, unclear response

39. Do your staff treat you with respect?

PS-5 *Does Click or tap here to enter text. treat you with respect?*

Suggested reword: Are your staff polite and kind to you?

98 ☐ Not applicable – doesn't have staff or staff are present

2 ☐ **Yes, all staff, always**

3 ☐ **Sometimes or some staff**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

40. Can you talk or communicate with your staff in your preferred language?

PS-5 *Can you talk with Click or tap here to enter text. in your preferred language?*

98 ☐ Not applicable – doesn't have staff or staff are present

2 ☐ **Yes, all staff, always**

3 ☐ **Sometimes or some staff**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

41. When staff are with you in the community, do they support you the way you want? For example, do they help you too much or too little?

PS-5 *Does Click or tap here to enter text. support you the way you want when you are in the community?*

98 ☐ Not applicable – doesn't have staff or staff are present

2 ☐ **Yes, all staff, always**

3 ☐ **Sometimes or some staff**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

42. Do staff do things the way you want them done?

PS-5 *Does Click or tap here to enter text. do things the way you want them done?*

Suggested reword: Do staff help you in the way you want?

98 ☐ Not applicable – doesn't have staff or staff are present

2 ☐ **Yes, all staff, always**

3 ☐ **Sometimes or some staff**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

43. Do your staff come and leave when they are supposed to?

PS-5 *Does Click or tap here to enter text. come and leave when they are supposed to?*

Suggested reword: Do they show up on time and stay until they are supposed to? Do they leave when they are supposed to?

98 ☐ Not applicable – doesn't have staff, or all staff are live-in or staff are present

2 ☐ **Yes, all staff, always**

3 ☐ **Sometimes or some staff**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

44. Sometimes people's staff change, and new staff start working. Do your staff change too often? Do you get new staff too often?

Note to surveyor: This is about staff turnover, not daily shift changes.

98 ☐ Not applicable – doesn't have staff or staff are present

2 ☐ **Yes, staff *do change* too often**

3 ☐ **Sometimes or some staff**

1 ☐ **No, staff *do not* change too often**

99 ☐ Don't know, no response, unclear response

Note to surveyors: If paid staff left the room, they may come back in.

Service Coordination

Now I'm going to ask you some questions about your services.

45. Have you met or spoken with your case manager/service coordinator?

PS-3 *Have you met Click or tap here to enter text.?*

98 ☐ Not applicable – doesn't have case manager/service coordinator →GO TO Q48

2 ☐ **Yes**

3 ☐ **Maybe, not sure** →GO TO Q48

1 ☐ **No** →GO TO Q48

99 ☐ Don't know, no response, unclear response →GO TO Q48

46. Does your case manager/service coordinator know what is important to you?

PS-3 *Does Click or tap here to enter text. know what is important to you?*

98 ☐ Not applicable – doesn't have case manager/service coordinator, or person hasn't communicated with case manager/service coordinator

2 ☐ **Yes**

3 ☐ **Maybe, knows some things that are important**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

47. Do you talk with your case manager/service coordinator when you want to? This can be by phone, email, text.

PS-3 *Do you talk with Click or tap here to enter text. when you want to?*

98 ☐ Not applicable – doesn't have case manager/service coordinator or hasn't communicated with case manager/service coordinator

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Now I'd like to talk about your service planning meeting. People have a "service plan" (PS-8 *Click or tap here to enter text.*)*. The plan includes things like your goals and services that you get to help meet those goals. Usually people meet with their case manager, family, and sometimes staff at least once a year to talk about the plan, set goals and talk about services* (PS-8 *Click or tap here to enter text.*)*.*

Instructions to surveyor: Please replace "service plan" with the terminology used in the state, such as "care plan," "ISP," "IPP."

48. Were you at the last service planning meeting?

PS-8 *Were you at your last Click or tap here to enter text.?*

Note to surveyor: If "no", follow up to determine if the person chose not to take part.

98 ☐ Not applicable – No service planning meeting →GO TO Q51

2 ☐ **Yes**

3 ☐ **Had the option but chose not to**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

49. Did the service planning meeting include the people you wanted to be there?

PS-8 *Did the last* Click or tap here to enter text. *include the people you wanted to be there?*

98 ☐ Not applicable – no service planning meeting or didn't want specific people at the meeting

2 ☐ **Yes**

3 ☐ **Some people**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

50. *If person was at the last service planning meeting, ask:* **At your service planning meeting, did you know what was being talked about?**

PS-8 *At your last* Click or tap here to enter text. *did you know what was being talked about?*

Suggested reword: Did they use words you understood? Did they have the meeting in your preferred language?

98 ☐ Not applicable – did not take part in the service planning meeting

2 ☐ **Yes**

3 ☐ **In between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

51. Do you have a service plan?

PS-8 *Do you have a/an* Click or tap here to enter text.*?*

Suggested reword: Do you have a list of services your case manager/service coordinator will help you get?

2 ☐ **Yes**

1 ☐ **No or not sure** →GO TO S-2

99 ☐ Don't know, no response, unclear response →GO TO S-2

52. Does your service plan include things that are important to you?

PS-8 *Does your* Click or tap here to enter text. *include things that are important to you?*

98 ☐ Not applicable – no service plan

2 ☐ **Yes**

3 ☐ **In between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

FOR THE SURVEYOR

S-2. Did person provide any valid responses to questions in Section I?

Reminder, the person may have provided valid responses to *some* questions in Section I. For those questions, you should code the appropriate "yes", "in between", or "no" response. For questions that the person did not provide a valid response, code "Don't know, no response, unclear response".

If the person provided NO valid responses, you can leave all questions blank, but be sure to respond to this question.

2 ☐ **Yes**, **person provided at least some valid responses to Section I questions** → continue to Section II with the person, remind them they can have help with the next questions if they want

1 ☐ **No**, **did not provide any valid responses to Section I questions** → Section II must be completed with a proxy respondent

SECTION II: SURVEY WITH PERSON RECEIVING SERVICES AND/OR PROXY RESPONDENTS

Reminders:

- When possible, the person should take part in Section II even if a proxy is used.
    - For each question in Section II, **indicate who the respondent was.**
    - Only one respondent is allowed for each question.
- If the person and a proxy both provide responses, code the respondent as the person who gave the majority of the response.
- A proxy respondent must know the person and their daily activities well. **The person's case manager/service coordinator cannot be a proxy respondent.**

IF THE PERSON WILL PROVIDE RESPONSES TO SECTION II WITH THE SUPPORT OF A PROXY…

Take a moment to remind the proxy how they can support the person to provide responses. Make sure the proxy knows:

- The proxy should let the person indicate when they want help.
- The proxy can give the person some definitions, examples, or other prompts that will help the person answer the question on their own.
- The proxy should answer the question as they believe the person would respond, not based on the proxy's personal feelings/opinions.
- When the proxy gives an answer, the surveyor will check if the person agrees.

Thank you. I have a few more questions about your service plan and the planning meeting. For these and the rest of my questions, if you want help someone can help you answer.

Note to surveyor: Only ask Questions 53 and 54 if the person and/or proxy are aware of having a service plan.

53. Did you help make your service plan? For example, did you get to set your own goals?

PS-8 *Did you help make your Click or tap here to enter text.?*

Other respondent: Did this person help make the service plan?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no service plan → GO TO Q55

2 ☐ **Yes**

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

54. Does your case manager review your service plan with you throughout the year?

PS-3, PS-8 *Does Click or tap here to enter text. review your Click or tap here to enter text. with you throughout the year?*

Suggested reword: Does your case manager talk with you throughout the year about what is in your service plan?

Note to surveyor: try to assess whether the case manager/service coordinator reviews the service plan outside of the regular service planning meeting.

Other respondent: Does this person's case manager/service coordinator review the service plan during the year?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no service plan

2 ☐ **Yes**

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

55. If you want to change something about your services, do you know who to talk to?

Other respondent: If this person wants to change something about their services, do they know who to talk to?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Community Inclusion

These next questions are about activities you may do in or around your community. Some of these activities you may do remotely, where you can see and talk with others in the community. I would like to know how many times you've done these activities in the past month. For each you can tell me if you've gone 1 to 2 times, 3 to 4 times, 5 or more times, or if you haven't done the activity at all in the past month.

56. How many times did you go shopping in the past month? (Examples: groceries, clothing)

Note to surveyor: Shopping online by clicking items and adding to a cart *does not count*.

Other respondent: In the past month, how many times did this person go shopping?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Did not go shopping**

2 ☐ **One or two times**

3 ☐ **Three or four times**

4 ☐ **Five or more times**

99 ☐ Don't know, no response, unclear response

57. Think about how often you went shopping in the past month. Would you like to go shopping more, less, or the same amount as now?

Other respondent: Think about the number of times this person went shopping in the past month. Do you think this person would like to go shopping more, less, or the same amount as now?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **More**

2 ☐ **Less**

3 ☐ **The same amount as now**

99 ☐ Don't know, no response, unclear response

58. How many times did you go out on errands or appointments in the past month? (Examples: bank, post office, hairdressers or barber)

Other respondent: In the past month, how many times did this person go out on errands or appointments?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Did not go on errands**

2 ☐ **One or two times**

3 ☐ **Three or four times**

4 ☐ **Five or more times**

99 ☐ Don't know, no response, unclear response

59. How many times did you go out for entertainment in the past month? (Examples: go to the movies or attend plays, concerts, sporting events, going out dancing)

Note to surveyor: "Livestreaming" or doing these activities using a remote platform *may* count toward this question, but it must be done live, using a platform that allows the person to interact with others during the activity, and must be open and used also by people without disabilities. Watching previously recorded videos, or a "live" platform that does not allow for interactions does not count toward community inclusion for this question.

Other respondent: In the past month, how many times did this person go out for entertainment?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Did not go out for entertainment**

2 ☐ **One or two times**

3 ☐ **Three or four times**

4 ☐ **Five or more times**

99 ☐ Don't know, no response, unclear response

60. Think about how often you went out for entertainment in the past month. Would you like to go out for entertainment more, less, or the same amount as now?

Other respondent: Think about the number of times this person went out for entertainment in the past month. Do you think this person would like to go out for entertainment more, less, or the same amount as now?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **More**

2 ☐ **Less**

3 ☐ **The same amount as now**

99 ☐ Don't know, no response, unclear response

61. How many times did you go to a restaurant or coffee shop in the past month?

Other respondent: In the past month, how many times did this person go out to a restaurant or coffee shop?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Did not go out to a restaurant or coffee shop**

2 ☐ **One or two times**

3 ☐ **Three or four times**

4 ☐ **Five or more times**

99 ☐ Don't know, no response, unclear response

62. Think about how often you went to a restaurant or coffee shop in the past month. Would you like to go out to a restaurant or coffee shop more, less, or the same amount as now?

Other respondent: Think about the number of times this person went to a restaurant or coffee shop in the past month. Do you think this person would like to go to a restaurant or coffee shop more, less, or the same amount as now?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **More**

2 ☐ **Less**

3 ☐ **The same amount as now**

99 ☐ Don't know, no response, unclear response

63. How many times did you go out to a religious service or spiritual practice in the past month? (Examples: church, synagogue, study, or other place of worship)

Note to surveyor: "Livestreaming" or doing a religious/spiritual practice using a remote platform *may* count toward this question, but it must be done live, using a platform that allows the person to interact with others during the activity, and must be open and used also by people without disabilities. Watching previously recorded videos, or a "live" platform that does not allow for interactions does not count toward community inclusion for this question.

Other respondent: In the past month, how many times did this person go out to a religious service or spiritual practice?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Did not go out for religious/spiritual practice**

2 ☐ **One or two times**

3 ☐ **Three or four times**

4 ☐ **Five or more times**

99 ☐ Don't know, no response, unclear response

64. Think about how often you went to a religious service or spiritual practice in the past month. Would you like to go to religious services or spiritual practices more, less, or the same amount as now?

Other respondent: Think about the number of times this person went to a religious service or spiritual practice in the past month. Do you think this person would like to go to a religious service or spiritual practice more, less, or the same amount as now?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **More**

2 ☐ **Less**

3 ☐ **The same amount as now**

99 ☐ Don't know, no response, unclear response

I'd like to ask you more about communities, groups, or organizations you take part in. These can be things like sports leagues, a religious community, LGBTQ+ community self-advocacy groups.

65. Are you a part of any groups, organizations, or communities? This can be done in-person or virtually.

Note to surveyor: This ***does not*** include a social network (for example, Facebook) in and of itself, but may include groups that take place on a social network.

Note to surveyor: Use the name of the groups, organizations, or communities the person says they take part in for the remaining questions in this section.

Other respondent: Does this person take part in groups, organizations, or communities—either in-person or virtually?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

66. Do you want to be a part of more groups in your community?

Other respondent: Do you think this person wants to be part of more groups in their community?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

My next questions are about [the groups, organizations, or communities the person takes part in] …

67. Are there people who do not have disabilities who are also members of [*the groups, organizations, or communities the person takes part in***]?**

Note to surveyor: We are trying to assess whether the group is integrated (meaning it is open to people with and without disabilities). This does not include staff who are there to support people.

Other respondent: Are there people who do not have disabilities who are members of the groups, organizations, or communities this person takes part in?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person doesn't take part in community groups, organizations, or community activities

2 ☐ **Yes**

3 ☐ **Some groups**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

68. Do you feel like you can be yourself when you are with the people in [*the groups, organizations, or communities the person takes part in***]?**

Suggested reword: Can you be honest and real with the people in the groups, organizations, or communities you take part in?

Other respondent: Does this person feel like they can be themselves in the groups, organizations, or communities they take part in?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person doesn't take part in community groups, organizations, or community activities

2 ☐ **Yes, all groups**

3 ☐ **Sometimes, some groups, and/or with some people in the group(s)**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

69. Do people in [*the groups, organizations, or communities the person takes part in***] include you in activities and events?**

Suggested reword: Do you feel included by others in the groups, organizations, or communities you take part in?

Other respondent: Does this person feel like they are included as part of the group with the groups, organizations, or communities they take part in?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person doesn't take part in community groups, organizations, or community activities

2 ☐ **Yes, all groups**

3 ☐ **Sometimes, some groups**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

70. Have you ever gone to a self-advocacy group meeting, conference, or event? Either online or in-person.

Note to surveyor: **If person has not taken part, ask whether they had the opportunity, but chose not to**. A self-advocacy group is where people with disabilities meet together to talk about things in their lives that are important to them. Some groups include People First, Speaking for Ourselves, and Self-Advocates Becoming Empowered – SABE.

PS-9 *Have you ever gone to a Click or tap here to enter text. meeting or event?*

Other respondent: Has this person ever attended a self-advocacy group meeting or event?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

3 ☐ **Had the opportunity but chose not to participate**

1 ☐ **No and did not have opportunity to participate**

99 ☐ Don't know, no response, unclear response

71. Have you ever voted in a local, state, or federal election?

Other respondent: Has this person ever voted in a local, state, or federal election?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

3 ☐ **Had the opportunity to register or vote but chose not to**

1 ☐ **No and did not have opportunity to register or vote**

99 ☐ Don't know, no response, unclear response

Choices

I'm going to ask some questions now about some choices or decisions you may have made or helped make. For each question, I'd like you to tell me if you made the choice yourself, if you had some say about it, or if someone else decided for you.

72. *If person does not live in the family home, ask:* **Who chose (or picked) the place where you live?**

Suggested reword: Did you help pick the place where you live?

Other respondent: Who chose the place where the person lives? Did the person have any input in making the decision?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person lives in the family home →GO TO Q74

2 ☐ **Person made the choice**

3 ☐ **Person had some input**

1 ☐ **Someone else chose**

99 ☐ Don't know, no response, unclear response

73. *If person does not live in the family home, ask:* **Did you choose (or pick) the people you live with (or did you choose to live by yourself)?**

Suggested reword: Did anyone ask who you'd like to live with? Did you get to interview your housemates and decide if they can live with you?

PS-4 *Did you choose to live with Click or tap here to enter text.?*

Other respondent: Did this person choose any of the people that they live with? Or: Did this person choose to live alone?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person lives in the family home

2 ☐ **Person made the choice**

3 ☐ **Person had some input**

1 ☐ **Someone else chose**

99 ☐ Don't know, no response, unclear response

74. *If person has a paid community job, ask:* **Who chose (or picked) the place you work?**

PS-6 *Did you choose to work at Click or tap here to enter text.?*

Other respondent: Who chose the place where the person works? Did the person have any input in making the decision?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no paid community job

2 ☐ **Person made the choice**

3 ☐ **Person had help making the choice**

1 ☐ **Someone else made the choice**

99 ☐ Don't know, no response, unclear response

75. *If person goes to a day program or workshop, ask:* **Who chose (or picked) your day program or workshop? (Did you help make the choice?)**

PS-7 *Did you choose to go to Click or tap here to enter text.?*

Other respondent: Who chose this person's day program or workshop? Did the person have any input in making the decision?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no day program/workshop

2 ☐ **Person made the choice**

3 ☐ **Person had help making the choice**

1 ☐ **Someone else made the choice**

99 ☐ Don't know, no response, unclear response

Note to surveyor: Question 76 references regular activities the person does at least once a week, **aside from a paid community job and/or day program/workshop**. This could be volunteering, community supports, school, etc. These may be activities (e.g., volunteering) done through a day program). Please reference activities the person said they do in Question 11 if Section I was answered. You may also reference PS-7.

76. This question is about the *other* activities you do at least once a week-- these could be things like volunteering, getting staff support to be in the community, or taking classes. Who chose (or picked) the other regular activities you do?

PS-7 *Did you choose to go to/do Click or tap here to enter text.?*

Other respondent: Who chose the regular activities the person does at least once a week? Did the person have any input in making the decision?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no other regular activities

2 ☐ **Person made the choice**

3 ☐ **Person had help making the choice**

1 ☐ **Someone else made the choice**

99 ☐ Don't know, no response, unclear response

77. Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?

Other respondent: Who decides this person's daily schedule—like when to get up, when to eat, when to go to sleep? Does the person have any input in making the decision?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Person decides**

3 ☐ **Person has help deciding**

1 ☐ **Someone else decides**

99 ☐ Don't know, no response, unclear response

78. Who decides how you spend your free time?

Note to surveyors: This is asking about who chooses how the person spends their time when they are not working, attending a day program, or doing other regular daily activity with or without supports.

Other respondent: Who decides how this person spends their free time? Does the person have any input in making the decision?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Person decides**

3 ☐ **Person has help deciding**

1 ☐ **Someone else decides**

99 ☐ Don't know, no response, unclear response

79. Do you have enough choice about what to do in your free time?

Other respondent: Does this person have enough choice about what they do in their free time?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

80. Do you choose what you buy with your spending money?

Note to surveyor: Do not include things like rent or groceries.

Other respondent: Does this person choose how to spend their money?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person does not have spending money

2 ☐ **Person chooses**

3 ☐ **Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)**

1 ☐ **Someone else chooses**

99 ☐ Don't know, no response, unclear response

81. Can you change your case manager/service coordinator if you want to?

PS-3 *Suggested reword: Can you change_____ if you want to?*

Other respondent: Can this person change their case manager/service coordinator if desired?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no case manager/service coordinator

2 ☐ **Yes**

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

82. Do you choose (or pick) your staff?

Suggested reword: Do you choose the people who work with you? Do you get to interview them? Did you get to meet different people or was someone assigned to you? Could you ask to change to someone different?

PS-5 *Did you choose Click or tap here to enter text. to work with you?*

Note to surveyor: Follow up a "Someone else chose" response to determine whether the person can request a change in staff if wanted.

Other respondent: Does this person choose their staff?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – no staff

2 ☐ **Person chose staff**

3 ☐ **Staff are assigned but can be changed if requested by person**

1 ☐ **Someone else chose**

99 ☐ Don't know, no response, unclear response

Rights

Now I'd like to talk to you about privacy in your home.

83. Do you have a key to your home?

Other Respondent: Does this person have a key to their home?

Note to surveyor: A "key" may also refer to access codes, cards, or other "keyless" locks. If a person is physically unable to use a key, this question may be marked 'yes' only if the person always has someone (staff, family, friend) available to use the key at all times.

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes** →GO TO Q85

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response →GO TO Q85

84. *If person does not have a key to their home, ask:* **Do you want a key to your home?**

Other Respondent: Does this person want a key to their home?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

85. *If person lives with others, ask:* **When people in your house go somewhere, do you have to go too, or can you stay at home if you want to?**

Note to surveyor: If the person needs staff support and there is enough staff to stay at home with them if they decide to stay home, code "yes" or "sometimes" as appropriate.

Other Respondent: When people in this person's house go somewhere, does this person have to go with them, or can they stay at home if they want?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person lives alone

2 ☐ **Yes, can stay at home**

3 ☐ **Sometimes can stay at home; sometimes has to go**

1 ☐ **No, always has to go**

99 ☐ Don't know, no response, unclear response

86. Can you lock your bedroom if you want to?

Other respondent: Can this person lock their bedroom if they want to?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person lives alone

2 ☐ **Yes**

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Technology

87. Do you have access to the internet? This may be in your home, using your smartphone, in a local coffee shop where you go often, or somewhere you spend time during your day.

Suggested reword: Is there somewhere you can use the internet?

Other respondent: Does this person have access to the internet?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No** →GO TO Q90

99 ☐ Don't know, no response, unclear response →GO TO Q90

88. How often do you use the internet? Do you use it……*Read response options.*

Note to surveyor: Code "not at all" if the person has access to the internet but chooses not to use it.

Suggested reword: How often do you do things like going to websites you like, social media, connecting with people?

Other respondent: How often does this person use the internet?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not have access to the internet

1 ☐ **Every day**

2 ☐ **Several times a week**

3 ☐ **Several times a month**

4 ☐ **Several times a year**

5 ☐ **Not at all** →GO TO Q90

99 ☐ Don't know, no response, unclear response

89. How does your internet work at home? Would you say that your home internet…. *Read response options.*

Other respondent: How does this person's internet work in their home?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Always works**

2 ☐ **Sometimes works**

3 ☐ **Rarely or never works**

4 ☐ **Does not have internet at home**

99 ☐ Don't know, no response, unclear response

90. Do you use technology in your everyday life to help you do more things on your own? Like using an app to help you get places, using automatic alerts or reminders to do things like take medication, apps to show you how to do things like prepare meals.

Other respondent: Does this person use technology in their everyday life to help them do more things on their own?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

91. Has your case manager/service coordinator talked to you about technology that might help you in your everyday life to do more things on your own?

PS-3 *Has Click or tap here to enter text. talked to you about technology that might help you in your everyday life to do more things on your own?*

Other respondent: Has this person's case manager/service coordinator talked to them about technology that may help them in their daily life to do more things on their own?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Note to surveyor: For Questions 92 and 93, if the person told you what technology they use in Question 90, replace “technology that you use in your everyday life” with the technology the person uses.

92. Do you have enough help to use [*the technology that you use in your everyday life***]?**

Other respondent: Does this person have enough help to use their technology?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use technology

2 ☐ **Yes**

3 ☐ **Sometimes, or some technology**

1 ☐ **No**

99 ☐ Don’t know, no response, unclear response

93. Do you know who to talk to if there are problems with [*the technology you use in your everyday life***]? Like do you know who to talk to if it breaks?**

Other respondent: Does this person know who to talk to if there are issues with their technology?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use technology

2 ☐ **Yes**

3 ☐ **Maybe, not sure**

1 ☐ **No**

99 ☐ Don’t know, no response, unclear response

94. Have you talked with any of your health care providers using telehealth? That means using the phone or computer to do a videoconference with a doctor, therapist, or other health care provider.

Other respondent: Has this person talked with any of their health care providers using telehealth?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No** →GO TO Q96

99 ☐ Don't know, no response, unclear response →GO TO Q96

95. Do you like talking to health care providers using telehealth?

Other respondent: Does this person like talking to health care providers using telehealth?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – has not talked to health care providers using telehealth

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

96. Have you talked with your case manager/service coordinator using videoconference?

PS-3 *Have you talked with Click or tap here to enter text. using videoconference?*

Other respondent: Has this person talked with their case manager/service coordinator using videoconference?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No** →GO TO Q98

99 ☐ Don't know, no response, unclear response →GO TO Q98

97. Do you like talking to your case manager/service coordinator using videoconference?

PS-3 *Do you like talking to Click or tap here to enter text. using videoconference?*

Other respondent: Does this person like talking to their case manager/service coordinator using videoconference?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – has not talked to case manager/service coordinator using videoconference

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

98. Have you used videoconference for any other services? This could be doing job coaching, attending a day program, or doing other activities through a provider using videoconference.

Other respondent: Has this person used videoconference for any other services?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No** →GO TO Q100

99 ☐ Don't know, no response, unclear response →GO TO Q100

99. Do you like getting those other services using videoconference?

Other respondent: Does this person like getting those services using videoconference?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – has not gotten services using videoconference

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Health and Wellness

100. Overall, how would you describe your health?

Other respondent: Overall, how would you describe this person's health?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Excellent**

2 ☐ **Very good**

3 ☐ **Good**

4 ☐ **Fair**

5 ☐ **Poor**

99 ☐ Don't know, no response, unclear response

101. In the past 12 months, have you gone to the emergency room for any reason (to get care for yourself)?

Other respondent: In the past 12 months, has this person gone to the emergency room for any reason to get care for themself?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

102. In the past 6 months, have you fallen and hurt yourself?

Other respondent: In the past 6 months, has this person fallen and hurt themself?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

2 ☐ **Yes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

103. How many times a week do you do physical activities for at least 10 minutes at a time? Things like running, stretching, golf, gardening, or walking for exercise.

Other respondent: How many times per week does this person do physical activities like running, stretching, golf, gardening, or walking for exercise?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **None**

2 ☐ **One or two times**

3 ☐ **Three or four times**

4 ☐ **Five or more times**

99 ☐ Don't know, no response, unclear response

104. How many times a week do you do exercise that makes your muscles work hard? Things like lifting weights, pushups, sit-ups, physical therapy?

Other respondent: How many times per week does this person do physical activity designed to work their muscles?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **None**

2 ☐ **One or two times**

3 ☐ **Three or four times**

4 ☐ **Five or more times**

99 ☐ Don't know, no response, unclear response

Access to Needed Services/Supports

We've talked about a lot of areas of your life. My next question is about supports that you think will help you that you don't have now, or supports that you need more of. Again, we talked about a lot of this, so some things might sound familiar. Remember, you can let me know if you want me to give you some examples too.

105. I am going to read a list of supports. Please tell me if you feel like you need the support, or if you need more of it. Do you want help with…….

Note to surveyor: read all responses. If the person mentioned needing help in any of these areas, you can use examples from that conversation to help people understand questions.

Other respondent: I am going to read a list, and I would like to know if you think this person needs or feels they need more of the support. Does this person need help with….

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ **Finding a new place to live**

2 ☐ **Making changes, updates or modifications to your home to make it easier to move around or live in (these are things like a ramp or grab bars)**

3 ☐ **Getting staff support to help you at home (this can be staff who help you in your home to do things like help you get dressed or take showers, help with cleaning, getting groceries, or it can be remote supports that let people check in when needed)**

4 ☐ **Working on job skills to get a job or get a different job**

5 ☐ **Finding or signing up for classes – either for school or to explore a hobby**

6 ☐ **Finding something different to do during the day (this does not include paid work)**

7 ☐ **Finding or getting more reliable transportation – being able to have a way to always get places you want or need to go**

8 ☐ **Getting or using technology to help in your everyday life to do more things on your own (like apps to get around, alerts to remind you of things to do like take medication)**

9 ☐ **Healthcare – finding a doctor, making appointments**

10 ☐ **Understanding medication – what medication is used for, side effects, how to take medication safely**

11 ☐**Finding, getting or setting up behavioral or mental health supports – like being able to meet with a therapist or counselor**

12 ☐ **Anything else:** Click or tap here to enter text.

13 ☐ Does not need any additional services

99 ☐ Don't know, no response, unclear response

106. Do you feel that your staff have the right training to meet your needs?

Other respondent: Do you feel that this person's staff have the right training to meet the person's needs?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person does not have support staff

2 ☐ **Yes**

3 ☐ **Maybe, not sure, or only some staff have the right training**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

107. What race and/or ethnicity do you identify as? I can read a list of options if you would like, and you don't have to answer if you don't want to. (Check all that apply)

Other respondent: What race and/or ethnicity does this person identify as?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ American Indian or Alaska Native

2 ☐ Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or Other Asian)

3 ☐ Black or African-American

4 ☐ Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander)

5 ☐ White

6 ☐ Hispanic/Latino (Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, or Other Spanish/Hispanic/Latino)

7 ☐ Other race not listed: Click or tap here to enter text.

99 ☐ Don't know

NOTE TO SURVEYOR:

- □ IF PERSON IS USING A SELF-DIRECTED SUPPORTS OPTION (BASED ON QUESTION BI-57), GO TO THE NEXT SECTION.
- □ IF THE PERSON IS NOT USING A SELF-DIRECTED SUPPORTS OPTION, ANSWER QUESTION S-4 AND ASK ANY BACKGROUND INFORMATION QUESTIONS YOU ARE REQUIRED TO COLLECT.
- □ IF THERE IS NO ADDITIONAL INFORMATION TO COLLECT, THANK THE PERSON FOR THEIR TIME, FOLLOW YOUR STATE'S "UNMET NEED" PROCEDURE IF ANY IS NEEDED. ANSWER QUESTION S-4.

SELF-DIRECTED SUPPORTS MODULE

SURVEYOR: Reference BI-57 *before this section*. Only ask if BI-57 is coded "yes".

Now I have some questions about using a self-directed supports option. Self-direction means people receiving services, their family, or sometimes other people in their life make decisions like the type of services they get, when they get services, and who helps them.

108. Who makes decisions about the services that are self-directed? Things like what services you use, hiring or firing staff, scheduling services.

Other Respondent: Who makes decisions about the services that are self-directed?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – person does not use self-directed supports option

1 ☐ **Person *mostly makes decisions***

2 ☐ **Person *has input*, and family/friend helps**

3 ☐ **Family/friend makes decisions, person *does not* have input**

4 ☐ **Decisions about what services are received are made by a case manager or another professional employed by the state** →End of survey, go to QS-4

99 ☐ Don't know, no response, unclear response →End of survey, go to QS-4

S-3 SURVEYOR: Does anyone participating in the survey meeting help make self-direction decisions (this may be the person, a proxy respondent or other person present at the meeting)?

Note to surveyor: if it is unclear whether anyone in the survey meeting participates in these decisions, ask: Do you [person, proxy, and/or other person present] help make self-direction decisions? Things like deciding what services are received, how to use the person's supports budget, hiring staff, or managing the services received?

2 ☐ **Yes** →GO TO Q109

1 ☐ **No or cannot determine** →End of survey, go to QS-4

109. Do you have enough help deciding how to direct your services? Things like making decisions about how and when you get services?

Other respondent: Do you and/or this person have enough help deciding how to direct your services?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use self-direction option or does not participate in self-direction decisions

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

110. Can you make changes to the services and supports you self-direct if you need to?

Other respondent: Can you and/or this person make changes to the services and supports you self-direct if you need to?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use self-direction option or does not participate in self-direction decisions

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

111. Do you have the amount of control you want with the services you self-direct?

Note to surveyor: This is about the person being able to self-direct in the way they want. It is not about availability of services, but about whether the respondent feels there are unfair or unreasonable restrictions over what services can be chosen.

Suggested reword: Can you direct services in the way you want?

Other respondent: Do you and/or this person have the amount of control you want with the services you self-direct?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use self-direction option or does not participate in self-direction decisions

2 ☐ **Yes**

3 ☐ **In-between**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

112. Are the services and supports you want to self-direct always available? This includes things like having the services that you want available when you want them and having enough staff to hire.

Other respondent: Are the services and supports this person wants to self-direct always available?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use self-direction option or does not participate in self-direction decisions

2 ☐ **Yes**

3 ☐ **Sometimes**

1 ☐ **No**

99 ☐ Don't know, no response, unclear response

Note to surveyor: For the following questions, use the terminology included in the Pre-Survey question PS-11 when referring to the "Financial Management Service" or "FMS." Some states may use terminology other than "financial management service (FMS)" (like "agency with choice").

Note to surveyor: If PS-11 is completed please read the following and replace "[PS-11 FMS terminology]" with the term from the pre-survey PS-11:

> *People sometimes work with an organization that helps manage the self-directed services and budgets. This organization might help with things like billing for services and help to track what is left in your budget. This may be called [**PS-11 FMS terminology**].*

Note to surveyor: If PS-11 is not completed please read:

> *People sometimes work with an organization that helps manage the self-directed services and budgets. This organization might help with things like billing for services and help to track what is left in your budget. This may be called a financial management service (FMS), a fiscal agent, fiscal intermediary, intermediary service organization, agency with choice, or another name. I am going to ask you some questions about that organization, which I will call an "FMS."*

113. Do you get information about your budget and services from your financial management service (FMS)?

Note to surveyor: Use the terminology included in the Pre-Survey. Some states may use terminology other than "financial management service (FMS)" (like "agency with choice").

> **PS-11** *Do you get information about your budget and services from* *Click or tap here to enter text.*?
>
> *Other respondent: Do you and/or this person get information about your budget and services from the financial management service?*
>
> Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use self-direction option or does not participate in self-direction decisions

2 ☐ **Yes**

3 ☐ **Maybe, not sure** →GO TO Q116

1 ☐ **No** →GO TO Q116

99 ☐ Don't know, no response, unclear response →GO TO Q116

114. Is the information you get from the FMS easy to understand?

PS-11 *Is the information you get from Click or tap here to enter text. easy to understand?*

Other respondent: Is the information you and/or this person get from the FMS easy to understand?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use self-direction option, does not participate in self-direction decisions, or does not get information from FMS

2 ☐ **Yes – easy to understand on own**

3 ☐ **Some information is easy to understand or understands with help from others**

1 ☐ **No – not easy to understand and does not get help to understand**

99 ☐ Don't know, no response, unclear response

115. How often do you get the information about your budget and services from your FMS? Do you get information…. *Read response options*

PS-11 *How often do you get information about your budget and services from Click or tap here to enter text.?*

Other respondent: How often do you and/or this person get information about your budget and services from the FMS?

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

98 ☐ Not applicable – does not use self-direction option, does not participate in self-direction decisions, or does not get information from FMS

2 ☐ **At least every three months**

3 ☐ **About twice a year**

1 ☐ **Once a year or less**

99 ☐ Don't know, no response, unclear response

116. I am going to read a list, I would like to know if you need help with any of these parts of self-direction. Do you need… *Read response options, check all that apply.*

Other respondent: Do you and/or this person need help with any of these parts of self-direction…

Respondent: 1 ☐ Person 2 ☐ Family/Friend 3 ☐ Staff 4 ☐ Other

1 ☐ Help with planning out your service needs and setting up a schedule for staff

2 ☐ Help with getting staff paid

3 ☐ Help finding or keeping the staff you want

4 ☐ Help training staff

5 ☐ Help managing benefits for staff

6 ☐ Help understanding information you get from the FMS

7 ☐ More information about what services and supports you can get

8 ☐ Other: Click or tap here to enter text.

9 ☐ Does not need help with any of these things

99 ☐ Don't know, no response, unclear response

*****END OF SURVEY*****

S-4. Surveyor: Please indicate all respondents to Section II. *Check ALL THAT APPLY.*

1 ☐ Person receiving services

2 ☐ Advocate, Parent, Guardian, Personal Representative, Relative, Friend

3 ☐ Staff who provides supports where person lives

4 ☐ Staff who provides supports at a day or other service location

5 ☐ Other

STATE SUPPLEMENT

[All state-specific added questions go here, if state chooses to add questions]

SURVEYOR FEEDBACK SHEET

Instructions

Please take a few minutes to complete a feedback sheet after each survey.

Please DO NOT INCLUDE any personally identifying information regarding yourself or the individual surveyed (e.g., names, addresses, phone numbers, etc.).

Surveyor's Initials or Code (optional) _____

1. How long did it take to complete the direct face-to-face survey(s) (Sections I and II only)?

___ ___ hours ___ ___ minutes

2. How long did it take to complete the entire form, including making phone calls, collecting background information, arranging and conducting the face-to-face survey, travel time, etc.?

___ ___ hours ___ ___ minutes

3. Were there any questions that were problematic?

___ Yes ___ No

If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement. Remember: Please DO NOT INCLUDE any personally identifying information regarding yourself or the individual surveyed.

Question Problem/Suggestions

Other Comments:

Additional Questions for Surveyor(s):

I-1 SURVEYOR, in what language was the survey conducted?

1 ☐ English
2 ☐ Spanish
0 ☐ Other: Click or tap here to enter text.

I-2 Was this survey conducted face to face, or remotely (via videoconference)

1 ☐ Face to face, in-person
2 ☐ Remotely via videoconference software

I-3 If the survey was conducted face to face, where was the face-to-face survey held?

Check ALL THAT APPLY.

1 ☐ Person's home
2 ☐ Person's workplace
3 ☐ Provider agency (e.g., provider agency office; not a home or workplace)
4 ☐ Public place
5 ☐ Other: Click or tap here to enter text.

I-4 What is your job title/relationship to the State agency (or County agency if applicable)?

If there is more than one surveyor, check ALL THAT APPLY. If a surveyor has more than one role, select the principal role for the state agency.

1 ☐ Quality assurance staff
2 ☐ Case manager/service coordinator
3 ☐ Contractor or consultant
4 ☐ Person receiving services/self-advocate
5 ☐ Parent/family member/guardian of a person receiving services
6 ☐ Student
7 ☐ Interested citizen (not a family member or provider)
8 ☐ Other: Click or tap here to enter text.

I-5 Did you know/had you met the individual prior to conducting this survey?

1 ☐ No
2 ☐ Yes
3 ☐ Not sure

I-6 How many surveyors conducted the survey with this person? (This includes 'shadow surveyors' or other silent observers. This does not include translators.)

1 ☐ One
2 ☐ Two
3 ☐ Three
4 ☐ Four or more

I-7 Date of face-to-face survey: (mm/dd/yyyy): Click or tap here to enter text.

I-8 How was this survey administered?

Check ALL THAT APPLY.

1 ☐ Paper
2 ☐ Wi-fi connected device
3 ☐ Other: Click or tap here to enter text.

I-9 If the person responded to all or part of the survey, how did he/she communicate with the surveyor?

1 ☐ Person answered independently
2 ☐ Person answered with some verbal assistance
3 ☐ Person answered using alternate/picture response format

• END OF IN-PERSON SURVEY •