



NATIONAL CORE INDICATORS

ADULT CONSUMER SURVEY

2014-2015

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Description of NCI:

This survey was developed in conjunction with the **National Core Indicators (NCI)**, an effort that began in 1997 and is co-sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of NCI is to identify and measure **core indicators** of performance of state developmental disabilities service systems. Currently, 40 States, the District of Columbia, and 22 sub-state entities participate in NCI. This survey is intended to measure performance indicators originally identified by the NCI Operations Committee, which is made up of representatives from the participating states. For more information, go to www.nationalcoreindicators.org.

Organization of Survey:

The survey consists of five parts.

- ✧ The **Pre-Survey Form** requests information that may be useful for scheduling and conducting the face-to-face surveys. This information is not analyzed by HSRI and cannot be placed into the Online Data Entry Survey Application (ODESA).
- ✧ The **Background Information** section consists of information that will be analyzed in conjunction with the face-to-face survey responses. This information must be collected for all individuals surveyed. Most states collect this information from case manager or system records, however, some states use surveyors to collect some of this information directly from the individual, guardian, or family. The state will specify which elements need to be obtained directly by the surveyor.
- ✧ **Section I** contains questions that may only be answered by face-to-face meetings with the person receiving services and supports. These are subjective, "satisfaction" related questions that may not be answered by anyone else.
- ✧ **Section II** contains questions that may be answered by the individual 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 be Section II respondents. If the individual is answering, the questions need to be asked face-to-face. If a proxy respondent answers, questions need to be asked face-to-face if all possible. Only when necessary, questions for proxy respondents may be asked over the phone.

- ✧ The **Surveyor Feedback Sheet** is the last page of the survey. Please fill out one sheet for each survey you complete.

Pre-Survey Form

The Pre-Survey Form is intended to provide surveyors with the information they will need to schedule and conduct the face-to-face surveys. The state should review this form and decide what information will be provided to surveyors in advance (e.g., name, phone number, communication needs, etc.), how the information will be gathered (e.g., service coordinators, databases, surveyors etc.), and determine the administrative procedures (including informed consent) that must be followed when arranging the face-to-face surveys.

It is strongly suggested that as many Pre-Survey items as possible be filled out and reviewed before starting the face-to-face survey. Experience has shown that using familiar names and terms helps the respondent understand the questions being asked and facilitates the survey process. Surveyors can use the Pre-Survey items to fill in blanks in Sections I and II of the survey form where indicated with a  symbol. Doing this prior to the face-to-face survey helps the conversation flow more smoothly.

None of the Pre-Survey information is submitted to HSRI. **Actual procedures for using the Pre-Survey Form should be determined by the state's NCI coordinator and communicated to surveyors during training.** These procedures should also be communicated to HSRI.

Additional instructions regarding your state's specific administrative procedures may be noted below:

A. Person(s) completing this Pre-Survey form:

Name(s): _____

Date: ____ / ____ / ____

B. Person to be surveyed:

Individual Name: _____

Gender: ____ Male ____ Female

Age: _____

Phone: _____ - _____

Email Address: _____

Home address: _____

Street

City

State

Zip

C. Legal guardian information, if applicable:

Guardian Name: _____

Relationship: _____

Phone: _____ - _____

Home address: _____

Street

City

State

Zip

E-mail: _____

D. Consent Requirements and Procedures

Each state will follow its own specific consent requirements. However, at a minimum, the surveyor needs to obtain verbal consent from the individual (or his/her legal guardian, if applicable) before the face-to-face survey takes place.

Note: The consent questions at the bottom of page 25 must be answered.

PS-1. **Contact**... Who should the surveyor call to arrange a face-to-face survey with this person (individual, parent/guardian, day or residential program staff, etc.)?

Name: _____ Relationship: _____

Phone #1: _____ Phone #2: _____

E-mail address: _____

Note... We would like to conduct the face-to-face survey with persons alone, when appropriate. However, some persons may feel uncomfortable with strangers, may have community protection issues, or may have medical or behavioral challenges that require supervision by designated caregivers.

Do you recommend that a caregiver be present while this person is surveyed?

Yes No

If yes, please explain:

PS-2. **Accommodations...** Does this person need any accommodations? (Examples: Communication - e.g., interpreter if the primary language is something other than English, sign language, communication device, voice amplifier, someone familiar with the person's communication style; Accessibility - e.g., transportation, space issues; Other - e.g., medical, allergies). Please explain what arrangements are needed for the face-to-face survey.

PS-3. **Case manager/service coordinator...** What is the name and contact information of this person's case manager/service coordinator?

Name: _____ Phone: _____

Cell Phone: _____ E-mail address: _____

PS-4. **Person who can provide information about this individual's employment...** Please indicate the person (e.g., Job Coach, Case Manager) who can provide the most accurate information about this person's employment, such as hours worked and wages earned. This information is needed for questions BI-37 through BI-47 in the Background Information section.

Name: _____ Relationship: _____

Phone: _____ E-mail address: _____

PS-5. **Proxy Respondents...** If you believe this person may be unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who know the him or her well and could respond on his/her behalf. Family members, guardians, friends, and staff may respond; case managers/service coordinators may *not* respond.

Name: _____ Relationship: _____

Phone: _____ E-mail address: _____

Name: _____ Relationship: _____

Phone: _____ E-mail address: _____

PS-6. **Living Arrangement...** Please indicate who this person lives with.

- lives alone lives with parent/relatives
- lives in large residential care facility lives in shared house or apartment
- lives with partner, spouse, and/or children

If applicable, provide first names of roommates or housemates:

PS-7. **Support Staff...** If there are any people who are paid to provide supports in this person's home, or at work or day program, please indicate their first names. If there are several workers, please list the primary staff who spend the most time with this person.

Support Staff: _____

PS-8. **Employment ...** If applicable, please indicate the name(s) of this person's paid community job(s). A community job refers to paid work—either competitive or supported employment. 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 work. Use the term or abbreviation the person is most familiar with.

Place of work: _____

PS-9. **Day Program/Other Regularly Scheduled Daily Activities...** If applicable, please indicate this person's day program or what they do as a regularly scheduled daily activity (examples include attending a sheltered workshop, volunteering or attending a senior program). Note: this does not include a paid job in the community (see PS-8). Use the term or abbreviation person is most familiar with.

Day Program/Other Activity: _____

PS-10. **Self-Advocacy Organization...** What self-advocacy groups are active and well-known in the person's area? (Examples: People First, Self-Advocates Becoming Empowered, Speaking for Ourselves.)

PS-11. **Self-directed supports...** Is this person currently using a self-directed/participant-directed supports option? These options offer individuals (and their representatives) the opportunity to manage some or all of their services. For example, they may hire & fire their own support workers and/or have control over their budget or services.

Yes No

If yes, please provide additional information:

What is the term used to describe the participant-directed budget (e.g., individual budget, DDS budget, etc.)? Please note the term that would be most familiar to the person.

What is the name of the financial management service (also called fiscal agent, fiscal intermediary, intermediary service organization, etc.) that manages the budget? Please note the term that would be most familiar to the person.

Does this person employ his/her own staff?

Yes No

BACKGROUND INFORMATION

BI-1. Survey Code: _____
(Unique Survey Code)

Note: This code should be provided by the state project coordinator and is for data analysis purposes only. A unique survey code should be assigned to each person. Do NOT use a number that could possibly identify the person (for example, do NOT use social security numbers). This code does not have to be limited to the amount of spaces above.

BI-2. Region or County: {if applicable} _____

The questions in this section are usually answered by reference to agency records or computer system reference (dependent upon availability by state). It is suggested that this section be completed along with the pre-survey form by the appropriate agency staff member, such as a case manager/service coordinator. Some items may be completed by the individual receiving services, a residential staff person or family member as necessary.

IMPORTANT: Background Information (BI) item numbers that are highlighted represent critical items for data analysis purposes. Please make every effort to provide this information so that your state’s data can be fully analyzed.

PERSONAL

BI-3. Date of birth:
(mm/dd/yyyy) ____ / ____ / _____

BI-4. Gender:
__ 1 Male
__ 2 Female

BI-5. Is this person Spanish/Hispanic/Latino? (Note: based on U.S. Census Bureau definitions, ethnicity is considered to be a separate question from race.)
__ 1 No, not Spanish/Hispanic/Latino
__ 2 Yes (Mexican, Mexican American, Chicano, Puerto Rican, Cuban, or Other Spanish/Hispanic/Latino)
__ 3 Don’t know

BI-6. What is this person's race? (Check ONE or MORE races to indicate what this person considers himself/herself 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 Other race not listed
- 7 Don't know

BI-7. Does this person have a legal/court-appointed guardian? (Check ONE)

- 1 No, person is independent of guardianship (legally competent or presumed competent)
- 2 Yes, limited guardianship
- 3 Yes, full guardianship
- 4 Don't know

BI-8. Marital status: (Check ONE)

- 1 Single, never married
- 2 Married
- 3 Single, married in past
- 4 Don't know

BI-9. Is this person diagnosed with an intellectual disability (ID)?

- 1 No → code BI-9a as NOT APPLICABLE
- 2 Yes
- 3 Don't Know → code BI-9a as NOT APPLICABLE

BI-9a. If BI-9 is answered 'yes', what level of ID?

- 0 NOT APPLICABLE – no ID diagnosis
- 1 Mild ID
- 2 Moderate ID
- 3 Severe ID
- 4 Profound ID
- 5 Unspecified level of ID
- 6 ID level unknown

BI-10. What other disabilities are noted in this person’s record? (Check one column for each disability)

No	Yes	Don’t Know	
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Mood disorder (e.g., depression, mania, bipolar disorder, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Anxiety disorder (e.g., obsessive disorders, panic disorders, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Behavior challenges (e.g., aggression, self-injurious behavior, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Psychotic disorder (e.g., schizophrenia, hallucinations, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Other Mental Illness/Psychiatric Diagnosis
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Autism Spectrum Disorder (e.g., Autism, Asperger Syndrome, Pervasive Developmental Disorder)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Cerebral Palsy
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Brain Injury
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Seizure Disorder/Neurological Problem
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Chemical Dependency
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Down Syndrome
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Prader-Willi Syndrome
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Other disabilities not listed _____
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	No other disabilities other than ID

BI-10a. What health conditions are noted in this person’s record? (Check one column for each health condition)

No	Yes	Don’t Know	
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Cardiovascular Disease (e.g., Coronary Heart Disease, Angina)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Diabetes (including Type I and Type II)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Cancer (e.g., Breast, Prostate, Colon, Lung, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	High Blood Pressure
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	High Cholesterol
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Dysphasia
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Pressure Ulcers
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Limited or No Vision- Legally Blind
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Hearing Loss- Severe or Profound
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Alzheimer’s Disease or other Dementia
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Other health conditions not listed _____

BI-11. What is this person’s primary language? (What language does s/he best understand?)

- 1 English
- 2 Other _____

BI-12. What is this person's primary means of expression? (Check ONE – most frequently used)

- 1 Spoken
- 2 Gestures/body language
- 3 Sign language or finger spelling
- 4 Communication aid/device
- 5 Other
- 6 Don't know

BI-13. 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
- 4 Don't know

HEALTH

BI-14. Overall, how would you describe this person's health?

- 1 Excellent
- 2 Very good
- 3 Fairly good
- 4 Poor
- 5 Don't know

BI-15. Does this person have a primary care doctor?

- 1 No
- 2 Yes
- 3 Don't know

BI-16. When was his/her last complete annual physical exam? (We are referring to a routine exam, not a visit for a specific problem or illness.) (Check ONE)

- 1 In the past year (anytime less than 12 months ago)
- 2 One year ago or more
- 3 Don't know

BI-17. When was his/her last dentist visit? (Check ONE)

- 1 Within the last six months (anytime less than 6 months ago)
- 2 Within the past year (6 months but less than 12 months ago)
- 3 One year ago or more
- 4 Don't know

BI-18. When was the last time this person had an eye examination/vision screening?

- 1 Within the past year (anytime less than 12 months ago)
- 2 Within the past 2 years (1 year but less than 2 years ago)
- 3 Within the past 3 years (2 years but less than 3 years ago)
- 4 Within the past 5 years (3 years but less than 5 years ago)
- 5 5 or more years ago
- 6 Has never had a vision screening
- 7 Don't know

BI-19. 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
- 4 Don't know

BI-20. During the past 12 months, has this person had a flu vaccination?

- 1 No
- 2 Yes
- 3 Don't know

BI-21. Has this person ever had a vaccination for pneumonia?

- 1 No
- 2 Yes
- 3 Don't know

BI-22. How much does this person weigh?

___ ___ ___ **lbs.**

BI-23. How tall is this person?

___ **feet** ___ ___ **inches**

BI-24. Does this person routinely engage in any moderate physical activity? (Moderate physical activity is an activity that causes some increase in breathing or heart rate. Examples include, but are not limited to, brisk walking, swimming, bicycling, cleaning, and gardening.) (Check ONE)

- 1 No
- 2 Yes
- 3 Don't know

BI-24a. If yes, does the moderate physical activity last 30 minutes or more? (Check ONE)

- 0 NOT APPLICABLE – does not do activity
- 1 No
- 2 Yes
- 3 Don't know

BI-24b. If yes, how many times per week? (Check ONE)

- 0 NOT APPLICABLE – does not do activity for at least 30 minutes
- 1 Five times or more per week
- 2 Three to four times per week
- 3 One to two times per week
- 4 Don't know

BI-25. Does this person smoke or chew tobacco?

- 1 No
- 2 Yes
- 3 Don't know

BI-26. If female, when was her last Pap test screening? A Pap test is a test used to check women for cancer of the cervix. (Check ONE) (Will be reported for females age 18 and over)

- 0 NOT APPLICABLE – INDIVIDUAL IS MALE
- 1 Within the past year (anytime less than 12 months ago)
- 2 Within the past 2 years (1 year but less than 2 years ago)
- 3 Within the past 3 years (2 years but less than 3 years ago)
- 4 Within the past 5 years (3 years but less than 5 years ago)
- 5 5 or more years ago
- 6 Has never had a Pap test
- 7 Don't know

BI-27. If female, when was her last mammogram? A mammogram is an x-ray of each breast to check for breast cancer. (Check ONE) (Will be reported for females age 40 and over)

- 0 NOT APPLICABLE – INDIVIDUAL IS MALE or FEMALE IS UNDER 40
- 1 Within the past year (anytime less than 12 months ago)
- 2 Within the past 2 years (1 year but less than 2 years ago)
- 3 Within the past 3 years (2 years but less than 3 years ago)
- 4 Within the past 5 years (3 years but less than 5 years ago)
- 5 5 or more years ago
- 6 Has never had a mammogram
- 7 Don't know

BI-28. When was the last time this person had a screening for colorectal cancer (either sigmoidoscopy or colonoscopy)? (Check ONE) (Will be reported for all adults age 50 and over)

- 0 NOT APPLICABLE – INDIVIDUAL IS UNDER 50
- 1 Within the past year (anytime less than 12 months ago)
- 2 Within the past 2 years (1 year but less than 2 years ago)
- 3 Within the past 3 years (2 years but less than 3 years ago)
- 4 Within the past 5 years (3 years but less than 5 years ago)
- 5 5 or more years ago
- 6 Has never had a screening for colorectal cancer
- 7 Don't know

BI-29. How often does this person require medical care? (Check ONE)
(Medical care refers to care that must be performed or delegated by a nurse or physician. Do not include medication administration.)

- 1 Less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 4 Don't know

BI-30. If this person has seizures, how often do they occur? (Check ONE)

- 0 NOT APPLICABLE -- does not have seizures
- 1 Seizures are controlled
- 2 Less frequently than once/month
- 3 At least once/month, but not once a week
- 4 At least once/week, or more frequently
- 5 Don't know

BI-31. Does this person currently take medications to treat mood disorders, anxiety, and/or psychotic disorders?

[Medications for mood disorders- includes any drug prescribed to elevate or stabilize mood (reduce mood swings), e.g., to treat depression, mania, or bipolar disorder.]

[Medications for anxiety- includes any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.]

[Medications for psychotic disorders- includes any drug (e.g., anti-psychotic or "neuroleptic") used to treat psychotic disorders such as schizophrenia or psychotic symptoms such as hallucinations.]

- 1 No
- 2 Yes
- 3 Don't know

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

- 0 NOT APPLICABLE – does not take medications for these disorders
- 1 1-2 medications
- 2 3-4 medications
- 3 5-10 medications
- 4 11 or more medications
- 5 Don't know

BI-31b. Does this person currently take medications for behavioral challenges?

[Medications for behavioral challenges- includes any drug prescribed for a behavior modification purpose (e.g. such as a stimulant, sedative, or beta-blocker), e.g., to treat ADHD, aggression, self-injurious behavior, etc.]

- 1 No
- 2 Yes
- 3 Don't know

BI-31c. If 'Yes' to BI-31b, how many medications to treat behavioral disorders does this person take?

- 0 NOT APPLICABLE – does not take medications to treat behavioral disorders
- 1 1-2 medications
- 2 3-4 medications
- 3 5-10 medications
- 4 11 or more medications
- 5 Don't know

BI-31d. Does this person have a behavior plan?

A behavior plan is based on an assessment of an individual's challenging behavior. The plan includes a description of the individual's strengths, preferences and interests, the goal(s) related to diminishing/eliminating the 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 that the plan will be in place.

- 1 No
- 2 Yes
- 3 Don't know

BI-32. Does this person currently receive Medicare?

- 1 No
- 2 Yes
- 3 Don't know

RESIDENCE

BI-33. How long has this person lived in his/her current home?

- 1 Less than 1 year
- 2 1-3 years
- 3 3-5 years
- 4 Over 5 years
- 5 Don't know

BI-34. How would you characterize the place where this person lives?

(Check ONE)

- 1 Intermediate Care Facility for persons with ID/DD (ICF/ID)-1-3 residents with disabilities
- 2 Intermediate Care Facility for persons with ID/DD (ICF/ID)-4-6 residents with disabilities
- 3 Intermediate Care Facility for persons with ID/DD (ICF/ID)-7-15 residents with disabilities
- 4 Intermediate Care Facility for persons with ID/DD (ICF/ID)-16 or more residents with disabilities
- 5 Other Specialized Institutional Facility
- 6 Group home- 1-3 people with disabilities; or agency-operated apartment.
- 7 Group Home- 4-6 people with disabilities
- 8 Group Home- 7-15 people with disabilities
- 9 Independent home or apartment, or shared with a roommate
- 10 Parent/relative's home
- 11 Foster care or host home (round-the-clock services provided in a single family residence where one or more people with a disability live with a person or family who furnishes services)
- 12 Nursing facility
- 13 Homeless
- 14 Other (specify) _____
- 15 Don't know

BI-34a. If this person lives in an Intermediate Care Facility for persons with ID/DD (ICF/ID), a specialized institutional facility or a group home, is it publicly or privately operated? (Check ONE)

- 1 Public
- 2 Private
- 3 Don't know

BI-35. Who owns or leases the place where this person lives? (Check ONE)

- 1 Family, guardian, or friend
- 2 Foster care or host family
- 3 Private agency
- 4 State or County agency
- 5 Person rents home (name is on the lease)
- 6 Person owns home (name is on the title)
- 7 Don't know
- 8 Other

BI-36. What amount of paid support does this person receive at home?

(Include any paid support, regardless of funding source) (Check ONE)

- 1 24-hour on-site support or supervision (people living with or being available in his/her home during all hours that s/he is home)
- 2 Daily on-site support (for a limited number of hours/day, not round-the-clock)
- 3 Scheduled, less frequent than daily support
- 4 As needed visitation and phone contact
- 5 None of the above
- 6 Don't know

EMPLOYMENT / OTHER DAILY ACTIVITIES

 **See PS-4. Please provide data for the most recent typical two-week period possible.**

Type of activity Definitions: <u>Community-based setting</u> is a place where most people do not have disabilities. <u>Facility-based setting</u> is a place where most people do have disabilities.	a) Was this person engaged in this activity during the two-week period?	If yes:			
		b) Number of hours worked or spent at this activity during the two-week period:	c) Total gross wages (before taxes or deductions) earned at this activity during the 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-37. Paid job in a community-based setting (e.g., competitive or supported employment, enclave, work crew)	__ 1 No __ 2 Yes __ 3 Don't know	___ ___ ___	\$ _____ . ____	__ 1 No __ 2 Yes __ 3 Don't know	__ 1 No __ 2 Yes __ 3 Don't know
BI-38. Unpaid activity in a community-based setting (e.g., volunteer activities, skills training)	__ 1 No __ 2 Yes __ 3 Don't know	___ ___ ___	N/A	__ 1 No __ 2 Yes __ 3 Don't know	__ 1 No __ 2 Yes __ 3 Don't know
BI-39. Paid work performed in a facility-based setting (e.g., workshop, activity center)	__ 1 No __ 2 Yes __ 3 Don't know	___ ___ ___	\$ _____ . ____	N/A	N/A
BI-40. Unpaid activity in a facility-based setting (e.g., day habilitation, seniors programs)	__ 1 No __ 2 Yes __ 3 Don't know	___ ___ ___	N/A	N/A	N/A

BI-41. Is community employment a goal in this person's service plan?

- 1 No
- 2 Yes
- 3 Don't know

BI-42. Is this person enrolled in the public school system?

- 1 No
- 2 Yes

BI-43. What agency or program pays for the employment or day supports this person receives? (Please check all that apply)

- 1 HCBS Waiver Program
- 2 State or County ID/DD Agency (non-waiver)
- 3 Vocational Rehabilitation Agency
- 4 ICF/ID Day Program
- 5 Other (e.g., Social Security Ticket to Work)
- 6 NOT APPLICABLE – does not receive employment supports or day services

Community Employment – If BI-37a above is checked "Yes," please answer BI-44 through BI-47:	
BI-44. Did this person work 10 out of the last 12 months in a community job? (Person may have changed jobs or had periods of unemployment/transition.)	<input type="checkbox"/> 1 No <input type="checkbox"/> 2 Yes <input type="checkbox"/> 3 Don't Know
BI-45. Does this person receive paid vacation and/or sick time at his/her job?	<input type="checkbox"/> 1 No <input type="checkbox"/> 2 Yes <input type="checkbox"/> 3 Don't Know
BI-46. How long has this person been working at his/her current job? (If multiple jobs, pick the job the person has worked at the longest).	<input type="text"/> years <input type="text"/> months
BI-47. What type of job does this person have? (check ONE - option that best fits)	
<input type="checkbox"/> 1 Food preparation and food service <input type="checkbox"/> 2 Building and grounds cleaning or maintenance <input type="checkbox"/> 3 Personal care provider <input type="checkbox"/> 4 Retail job such as sales clerk or stock person <input type="checkbox"/> 5 General office and administrative support <input type="checkbox"/> 6 Farming, fishing, forestry worker <input type="checkbox"/> 7 Construction or repair occupation <input type="checkbox"/> 8 Assembly, manufacturing, or packaging <input type="checkbox"/> 9 Materials handling, mail distribution <input type="checkbox"/> 10 Management, business, or financial operations <input type="checkbox"/> 11 Professional or technical occupation <input type="checkbox"/> 12 Self-employed <input type="checkbox"/> 13 Other	

OTHER SUPPORTS AND SERVICES

BI-48. Which of the following services/supports funded by the state (or county) agency does this person receive? (Check one column for each service):

No	Yes	Don't Know	
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Service coordination/case management
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Respite/family support
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Transportation
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Assistance finding, maintaining, or changing jobs
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Education or Training
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Health care
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Dental care
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Assistance finding, maintaining, or changing housing
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Social/relationships issues, meeting people
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Communication technology
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Environmental adaptations/home modifications
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Benefits/insurance information
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Other

BI-49. Does this person receive either ICF/ID or HCBS Waiver funding? (Check ONE) **(PLEASE OBTAIN THIS INFORMATION FROM A STATE DATA SYSTEM/OFFICIAL RECORD IF POSSIBLE)**

- 1 Yes, ICF/ID (Intermediate Care Facility for people with Intellectual Disabilities)
 - 2a Yes, HCBS (Home and Community-Based Services) Waiver Program- 1915 b
 - 2b Yes, HCBS (Home and Community-Based Services) Waiver Program- 1915 b/c
 - 2c Yes, HCBS (Home and Community-Based Services) Waiver Program- 1915 c
 - 2d Yes, HCBS (Home and Community-Based Services) State Plan- 1915 i
 - 2e Yes, HCBS (Home and Community-Based Services) State Plan - 1915 j
 - 2f Yes, HCBS (Home and Community-Based Services) State Plan Personal Care
 - 2g Yes, HCBS (Home and Community-Based Services) Community First Choice Option- 1915 k
 - 2h Yes, HCBS (Home and Community-Based Services) Waiver Program- Other
- _____
- 2i Yes, HCBS (Home and Community-Based Services)- Other Plan or Option (including MFP) _____
 - 3 Don't know
 - 4 No, receives other funding

BI-50. Is this person currently using a self-directed supports option?

“Self-directed” or “participant-directed” supports options offer individuals (and their representatives, including family members) the opportunity to manage some or all of their services. They may hire & fire their own support workers and/or control how their budget is spent.

- 1 No → code BI-51 and 39-44 as NOT APPLICABLE
- 2 Yes
- 3 Don't know → code BI-51 and 39-44 as NOT APPLICABLE

BI-51. If yes, who employs this person's support workers?

- 8 NOT APPLICABLE – not using self-directed/participant-directed supports
- 1 The person (or his/her 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 An “agency with choice” is the common-law employer of the support workers selected/recruited by the individual and performs necessary payroll and human resources functions. The person (or his/her representative) is the co-employer (managing employer).
- 3 Don't know

BEHAVIORAL SUPPORT NEEDS

Analyses of project data show that the extent of behavioral support needs is significantly related to many of the questions on the survey. The requested information is used to "adjust" the data in order to make valid comparisons of performance across states. The responses will not be used to identify any individual.

The person conducting this survey may ask a family member or staff person on site to fill out the questions on the following page. This information may also be obtained from service coordinators or through record review. These questions rely upon the assessment of someone who knows the individual well. Please identify the level of support the person needs to manage any of the types of behavior listed below.

Does person need support to manage:	Level of Support Needed (Check ONE)
<p>BI-52. Self-injurious behavior</p> <p><i>Refers to attempts to cause harm to one's own body, for example, by hitting or biting self, banging head, scratching or puncturing skin, ingesting inedible substances, or attempting suicide.</i></p>	<ul style="list-style-type: none"> <input type="checkbox"/> 1 No support needed <input type="checkbox"/> 2 Some support needed; requires only occasional assistance or monitoring <input type="checkbox"/> 3 Extensive support needed; frequent or severe enough to require regular assistance <input type="checkbox"/> 9 Don't Know

<p>BI-53. Disruptive behavior <i>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 violence.</i></p>	<p><input type="checkbox"/>_1 No support needed <input type="checkbox"/>_2 Some support needed; requires only occasional assistance or monitoring <input type="checkbox"/>_3 Extensive support needed; frequent or severe enough to require regular assistance <input type="checkbox"/>_9 Don't Know</p>
<p>BI-54. Destructive behavior <i>Refers broadly to externally-directed, defiant behavior, for example, taking other people's property, property destruction, stealing, or assaults and injuries to others.</i></p>	<p><input type="checkbox"/>_1 No support needed <input type="checkbox"/>_2 Some support needed; requires only occasional assistance or monitoring <input type="checkbox"/>_3 Extensive support needed; frequent or severe enough to require regular assistance <input type="checkbox"/>_9 Don't Know</p>

BI-55. Whose responsibility was it to obtain the Background Information?

(check all that apply)

- _1 Service coordinator/case manager
- _2 Other state staff
- _3 Contractor
- _4 Individual being surveyed
- _5 Family member
- _6 Provider staff
- _7 Other _____

SECTION I: Face-to-face Survey With Person Receiving Services and Supports

General Instructions:

- ✧ This section may only be completed by **directly surveying the person receiving services and supports**.
- ✧ Prior to the survey, surveyors should use the pre-survey form to fill in the blanks throughout the survey. Using familiar names and terms during the survey will help ensure that the person understands the questions. Questions that refer to pre-survey information are indicated with a bell symbol: 
- ✧ Do not use responses from any other person to complete this section.
- ✧ If possible, the survey should be conducted in private. Others may be present if the individual requests, or if another person is needed for interpretation purposes. If staff believe that a private survey may pose risks to surveyors, then staff should be present. If others are providing assistance, surveyors should emphasize that we are trying to find out the individual's perspective.
- ✧ Be sure to read all instructions carefully.
- ✧ Help the person with any words that are not understood. You may repeat or rephrase questions to improve understanding. Some questions have suggested rephrasing in italics - you do not need to limit yourself to these suggestions.
- ✧ Do not read or show the list of response options to the individual. Let them answer in their own words and then code the most appropriate response.
- ✧ Individuals may skip any question. If the person receiving services does not respond to a question or gives an unclear response, code the question as "9."
- ✧ If you have any questions concerning the intent of a survey question or need additional help in rephrasing a question, refer to the list of Core Indicators in your training packet.
- ✧ A wide margin is provided for recording notes as necessary. Just be sure your response choices are clearly marked.
- ✧ Please fill out the **Surveyor Feedback Sheet** after each interview.

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.”

“I'd like to know your opinions, how you feel about things. Whatever you tell me will be kept private, so you can be honest.”

Note: Before beginning Section I, make sure that the appropriate consent has been received from the individual or guardian (see questions below).

Consent Questions:

#CQ1. (Required)- Did the individual or legal guardian give consent to participate in this survey? Yes No

If required in your state, please answer the following questions (otherwise leave blank).

#CQ2. Did individual/legal guardian give verbal consent for the surveyor to contact him/her? Yes No

#CQ3. Is the signature of a legal guardian required for this individual to consent to participation in this survey? Yes No

#CQ4. If required, did individual/legal guardian give written consent to be surveyed? Yes No

EMPLOYMENT / OTHER DAILY ACTIVITIES

I'd like to start by asking you about what you do during the day – if you have a job or other place that you go to.

1) Do you have a paid job in the community?

A community job refers to paid work - either competitive or supported employment (includes both individual and group employment, such as a work crew or enclave). It does not include work done in facility-based settings like sheltered workshops. It also does not include volunteer work.

PS-8



(Do you work at _____?)

- _2 Yes → code Question 2 as NOT APPLICABLE
- _0 No → ask Question 2
- _9 Don't know, no response, unclear response

2) If No, ask: Would you like to have a job in the community?

- _8 NOT APPLICABLE – has job in the community
- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

If person does not have a job in the community, code Questions 3-4 as NOT APPLICABLE.

3) Do you like working there?

- _8 NOT APPLICABLE – no job in the community
- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

4) Would you like to work somewhere else? *(Would you like a different job instead of this one?)*

- _8 NOT APPLICABLE – no job in the community
- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

5) Do you go to a day program or do some other regularly scheduled activity during the day? This does not include a job in the community. Examples of an "other regularly scheduled activity" could include volunteering, a sheltered workshop, or attending a senior program.

PS-9



(Do you go to _____?)

- _2 Yes
- _0 No → code Questions 6-7 as NOT APPLICABLE
- _9 Don't know, no response, unclear response

6) Do you like going there/doing this activity?

- _8 NOT APPLICABLE – no day program or other activity
- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

7) Would you like to go somewhere else or do something else during the day?

- _8 NOT APPLICABLE – no day program or other activity
- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

8) Do you do any volunteer work? Do *not* include instances where individual is made or forced to spend time 'volunteering.' Volunteer work is *not* paid.

- _2 Yes
- _0 No
- _9 Don't know, no response, unclear response

HOME

Now I'm going to ask you about where you live.

9) Do you like your home or where you live? (*Do you like living here?*)

- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

10) Would you like to live somewhere else?

- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

11) Do you ever talk with your neighbors?

- _2 Yes, often (weekly or more)
- _1 Yes, but not often
- _0 No, or very rarely
- _9 Don't know, no response, unclear response

12) Do people let you know before they come into your home?

(Do they ring the doorbell or knock first and wait for an answer?) Do not include people who live in the home.

- _2 Yes
- _1 Sometimes
- _0 No
- _9 Don't know, no response, unclear response, **or people do not come into your home**

13) Do people let you know before coming into your bedroom?

- _2 Yes
- _1 Sometimes
- _0 No
- _9 Don't know, no response, unclear response, **or people do not come into your bedroom**

14) Do you have enough privacy at home? *(Can you have time to yourself?)* If person lives alone, code Q14 as NOT APPLICABLE.

Here we are looking at privacy (e.g. going in a room and closing the door), not the person's need for supervision (e.g. staying home alone).

- _8 **NOT APPLICABLE** - lives alone
- _2 Yes, has enough privacy
- _0 No, would like more privacy
- _9 Don't know, no response, unclear response

SAFETY

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

15) Are you ever afraid or scared when you are at home?

- _2 [Yes] - most of the time
- _1 Sometimes
- _0 [No] - rarely
- _9 Don't know, no response, unclear response

16) Are you ever afraid or scared when you are out in your neighborhood?

- __2 [Yes] - most of the time
- __1 Sometimes
- __0 [No] - rarely
- __9 Don't know, no response, unclear response

17) Are you ever afraid or scared at work or at your day program/other activity?

- __8 NOT APPLICABLE – no work or day program/activity
- __2 [Yes] - most of the time
- __1 Sometimes
- __0 [No] - rarely
- __9 Don't know, no response, unclear response

18) If you ever feel afraid, is there someone you can talk to?

Please ask question to all respondents.

- __2 Yes
- __1 Maybe, not sure
- __0 No
- __9 Don't know, no response, unclear response

FRIENDS AND FAMILY

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

19) Do you have friends you like to talk to or do things with?

If s/he answers "yes," ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: *Can you tell me their names? Are these friends staff or your family?*

- __2 Yes, has friends who are not staff or family
- __1 Yes, all friends are staff or family, or cannot determine
- __0 No, does not have friends
- __9 Don't know, no response, unclear response

20) Do you have a best friend, or someone you are really close to? (*Is there someone you can talk to about personal things?*) Can include staff or family member.

- _2 Yes
- _0 No
- _9 Don't know, no response, unclear response

If the person responds "NO" TO BOTH QUESTIONS 19 AND 20, code Question 21 as "NOT APPLICABLE."

21) Can you see your friends when you want to see them? (*Can you make plans with your friends when you want to?*)

We are trying to determine if person gets support to see friends. Try to factor out situations where friends are not available – this is not the issue.

- _8 NOT APPLICABLE – does not have any friends
- _2 Yes, can see friends whenever s/he wants to
- _1 Sometimes can't see friends (e.g., not enough staff or transportation)
- _0 No, often unable to see friends
- _9 Don't know, no response, unclear response

22) Can you go on a date if you want to?

- _8 NOT APPLICABLE – does not want to date
- _2 Yes, can date, or is married or living with partner
- _1 Yes, but there are some restrictions or rules about dating
- _0 No
- _9 Don't know, no response, unclear response

23) Do you ever feel lonely? (*Do you ever feel like you don't have anyone to talk to?*)

If s/he responds "yes," probe to determine how often s/he feels lonely.

- _2 [Yes] – often feels lonely (more than half the time)
- _1 Sometimes (about half the time)
- _0 [No] – not often (less than half the time)
- _9 Don't know, no response, unclear response

24) Do you have family that you see?

If the person lives with family, ask about other family members that do not live in the home.

- __2 Yes
- __0 No
- __9 Don't know, no response, unclear response

25) Can you see your family when you want to? *(Can you pick the times you see them? Does someone help you make plans to see them?)*

If family is not available or does not wish to have contact, code as NOT APPLICABLE. If the person has family but does not want to see them, code as 2.

- __8 NOT APPLICABLE – family not available, person does not have family or family does not wish to have contact
- __2 Yes, sees family whenever s/he wants to, or chooses not to see family
- __1 Sometimes
- __0 No
- __9 Don't know, no response, unclear response

26) Can you help other people if you want to? *(Can you show other people how to do things if you want to?)*

- __2 Yes
- __1 Sometimes
- __0 No
- __9 Don't know, no response, unclear response

SATISFACTION WITH SERVICES/SUPPORTS

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

ASK QUESTIONS 27 and 30-32 ONLY IF PERSON HAS A CASE MANAGER/ SERVICE COORDINATOR. If person does not have a case manager/ service coordinator, code these questions as "NOT APPLICABLE".

PS-3



27) Have you met your case manager/service coordinator?

Have you met _____ ?

- _8 NOT APPLICABLE – does not have case manager/service coordinator
- _2 Yes, person has met case manager/service coordinator
- _1 Maybe, not sure
- _0 No, person has not met case manager/service coordinator
- _9 Don't know, no response, unclear response

28) Do you have a service plan? *(Do you have a list of services your case manager/service coordinator will help you get?)*

- _2 Yes
- _1 Maybe, not sure
- _0 No → code Question 29 as NOT APPLICABLE
- _9 Don't know, no response, unclear response

29) Did you help make your service plan? *(Did you help decide which services are on the list?)*

- _8 NOT APPLICABLE – does not have service plan
- _2 Yes
- _1 Maybe, not sure
- _0 No
- _9 Don't know, no response, unclear response

30) Does your case manager/service coordinator ask you what you want? *(Does your case manager/service coordinator ask what is important to you?)*

- _8 NOT APPLICABLE – does not have case manager/service coordinator, or person does not talk to case manager/service coordinator
- _2 Yes
- _1 Sometimes
- _0 No
- _9 Don't know, no response, unclear response

31) If you ask for something, does your case manager/service

coordinator help you get what you need?

- _8 NOT APPLICABLE – does not have case manager/service coordinator, or does not ask for help
- _2 Yes, does help
- _1 Sometimes helps
- _0 No, does not help
- _9 Don't know, no response, unclear response

32) If you call and leave a message, does your case manager/service coordinator take a long time to call you back, or does s/he call back right away?

- _8 NOT APPLICABLE – does not have case manager/service coordinator, or does not call case manager/service coordinator
- _2 Calls back right away
- _1 In-between
- _0 Takes a long time to call back
- _9 Don't know, no response, unclear response

33) Do you have staff who help you? (e.g., at your home, your job, your day program)

PS-7


(Does _____ help you?)

- _2 Yes
- _0 No → code Questions 34-36 as NOT APPLICABLE
- _9 Don't know, no response, unclear response

34) Do your staff treat you with respect? (Do they listen and talk to you?)

- _8 NOT APPLICABLE – does not have any staff
- _2 Yes, all staff, always
- _1 Sometimes or some staff
- _0 No
- _9 Don't know, no response, unclear response

35) Do your staff come when they are supposed to? (Do they show

up on time? Do they show up when they say they will?)

- 8 NOT APPLICABLE- does not have staff
- 2 Yes
- 1 Maybe, not sure
- 0 No
- 9 Don't know, no response, unclear response

36) If you have problems with your staff, do you get the help you want to fix these problems?

- 8 NOT APPLICABLE- does not have staff or problems with staff
- 2 Yes
- 1 Maybe, not sure
- 0 No
- 9 Don't know, no response, unclear response

Now, I am going to ask you a couple of questions about how you get around.

37) How do you usually get to places you need to go? (Check ALL that apply; however, we are looking for the **most frequent** mode(s) of transportation).

- 7 Transports self – walks, drives, rides bike
- 6 Gets ride from family or friends
- 5 Gets ride from staff in staff's car
- 4 Gets ride from staff in provider van or vehicle
- 3 Uses public transportation such as bus
- 2 Uses specialized transportation such as paratransit service
- 1 Uses taxi service
- 9 Don't know, no response, unclear response

38) When you want to go somewhere, do you always have a

way to get there? (Can you get a ride when you want one?)

- _2 Yes, almost always
- _1 Sometimes
- _0 No, almost never
- _9 Don't know, no response, unclear response

SELF-DIRECTED SUPPORTS

ASK QUESTIONS 39-44 ONLY IF PERSON USES A SELF-DIRECTED SUPPORTS OPTION (SEE **PS-11** and QUESTION **BI-50**).

If person does not use self-directed supports, code these questions as NOT APPLICABLE.

For those who are using self-directed supports, the surveyor may need to explain the term "budget" – for example, the money discussed at your planning meeting that you can use to hire your own staff or purchase things you need. This is different from spending money or a personal budget. Refer to **PS-11** for terms the person may be familiar with.

39) Does someone talk with you about your budget and the services you can get?

PS-11 

Does someone talk with you about your _____?

- _8 NOT APPLICABLE
- _2 Yes
- _1 Maybe, not sure
- _0 No → code Questions 40-44 as NOT APPLICABLE
- _9 Don't know, no response, unclear response

40) Is there someone who helps you decide how to use your budget/services?

- _8 NOT APPLICABLE
- _2 Yes
- _1 Maybe, not sure
- _0 No
- _9 Don't know, no response, unclear response

41) Can you make changes to your budget/services if you need to? (Can you decide to buy something different?)

- _8 NOT APPLICABLE
- _2 Yes
- _1 Maybe, not sure
- _0 No
- _9 Don't know, no response, unclear response

42) Do you want more help deciding how to use your budget/services, or do you have enough help?

- _8 NOT APPLICABLE
- _2 [Yes] – want more help
- _1 Maybe, not sure
- _0 [No] – have enough help
- _9 Don't know, no response, unclear response

43) Do you get information about how much money is left in your budget/services?

PS-11 :


Do you get information from _____ (financial management service)?

- _8 NOT APPLICABLE
- _2 Yes
- _1 Maybe, not sure
- _0 No → code Question 44 as NOT APPLICABLE
- _9 Don't know, no response, unclear response

44) If yes, is the information easy to understand?

- _8 NOT APPLICABLE
- _2 Yes
- _1 Maybe, not sure
- _0 No
- _9 Don't know, no response, unclear response

45) Surveyor: Could Section I be completed?

- _1 Yes, person answered independently or with some assistance
- _2 Yes, person answered using alternate/picture response format
- _3 No, person could not communicate sufficiently to complete this section
- _4 No, person was unwilling to participate
- _5 No, other reason

46) Surveyor: In your opinion, did the individual appear to understand most of the questions or not?

- _8 **NOT APPLICABLE** – did not complete Section I
- _2 Yes, appeared to understand most questions (even if prompted) and could give an opinion
- _1 Not sure
- _0 No, appeared to have very little understanding or comprehension

47) Surveyor: In your opinion, did the individual seem to answer the questions in a consistent manner? (Do you feel his/her responses were valid?)

- _8 **NOT APPLICABLE** – did not complete Section I
- _2 Yes, seemed to give consistent and valid responses
- _1 Not sure
- _0 No, did not seem to give consistent and valid responses

If you answered "yes" to questions 45-47, then determine now if s/he is willing to answer more questions. If the individual is not willing to continue, or if you believe comprehension or consistency was a problem and person does not have a proxy respondent, then say:

"Thank you for your help. It's been very nice talking to you. You've been very helpful."

If the person is willing to continue or has a proxy respondent available, please continue to Section II.

SECTION II: Survey with the Person Receiving Services or with Proxy Respondents

STOP - Please review Section 1 questions #45-47. Please make sure you have answered those questions before proceeding.

Ask the person receiving services the Section II questions if all possible. If the person is unwilling or unable to complete this section, other respondents may be surveyed (family, advocate, staff; however *not* the case manager or service coordinator). If the individual did not complete Section 1 or if you believe that s/he did not understand the questions and/or did not answer consistently, *do not* ask the individual the Section II questions...only ask the proxy respondent(s). **Proxy respondents must be knowledgeable in the areas below (they should know the person well and have frequent contact with him/her).** Use the alternate wording provided when questioning proxy respondents (e.g., *'Did this person...?'*).

For all questions, indicate who the respondent was; please check only one respondent for each question.

If both the individual and the proxy respondent contributed to the answer, and there is agreement between the two, check "individual" as the respondent.

If there is disagreement between the individual and the proxy respondent, you may need to ask follow up questions to determine the most valid response.

Ask the person if s/he wishes to continue with the questions, or if s/he would like to take a short break.

COMMUNITY INCLUSION

In this section, we are trying to find out if the person participates in integrated community activities (including people with and without disabilities). If the individual indicates they have only participated in a non-integrated activity (where only people with disabilities are participating) in the past month, then you should check 'no' as the response. If the person answers "yes," you may ask for an example to verify that the person understood the question and that the activity was indeed integrated.

48) In the past month, did you go shopping? (Examples: groceries, clothing)
(Other respondent: In the past month, did this person go shopping?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 2 Yes
- 0 No
- 9 Don't know, no response, unclear response

48a) If yes, how many times in the past month?

times in past month

48b) If yes, who did you usually go with?

(Check ALL that apply)

- 1 Alone
- 2 Friends or family
- 3 House-mates or co-workers
- 4 Staff
- 5 Others not listed
- 9 Don't know, no response, unclear response

49) In the past month, did you go out on errands or appointments?

(Examples: bank, post office, hair dressers/barber)

(Other respondent: In the past month, did this person go out on errands or appointments?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 2 Yes
- 0 No
- 9 Don't know, no response, unclear response

49a) If yes, how many times in the past month?

__ __ times in past month

49b) If yes, who did you usually go with?

(Check ALL that apply)

- 1 Alone
- 2 Friends or family
- 3 House-mates or co-workers
- 4 Staff
- 5 Others not listed
- 9 Don't know, no response, unclear response

50) In the past month, did you go out for entertainment? (Examples: movies, plays, concerts, attend sporting events)

(Other respondent: In the past month, did this person go out for entertainment?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other
--

- 2 Yes
- 0 No
- 9 Don't know, no response, unclear response

50a) If yes, how many times in the past month?

__ __ times in past month

50b) If yes, who did you usually go with?

(Check ALL that apply)

- 1 Alone
- 2 Friends or family
- 3 House-mates or co-workers
- 4 Staff
- 5 Others not listed
- 9 Don't know, no response, unclear response

51) In the past month, did you go out to a restaurant or coffee shop?

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

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __ 2 Yes
- __ 0 No
- __ 9 Don't know, no response, unclear response

51a) If yes, how many times in the past month?

__ __ times in past month

51b) If yes, who did you usually go with?

(Check ALL that apply)

- __ 1 Alone
- __ 2 Friends or family
- __ 3 House-mates or co-workers
- __ 4 Staff
- __ 5 Others not listed
- __ 9 Don't know, no response, unclear response

52) In the past month, did you go out to a religious service or spiritual practice? *(Examples: church, synagogue, study or other place of worship)*

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

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __ 2 Yes
- __ 0 No
- __ 9 Don't know, no response, unclear response

52a) If yes, how many times in the past month?

__ __ times in past month

52b) If yes, who did you usually go with?

(Check ALL that apply)

- 1 Alone
- 2 Friends or family
- 3 House-mates or co-workers
- 4 Staff
- 5 Others not listed
- 9 Don't know, no response, unclear response

53) In the past month, did you go out for exercise? (Examples: jogging, swimming, riding bike, YMCA, gym/health club). Reminder: We're looking for if the individual exercised in an *integrated setting*.

(Other respondent: In the past month, did this person go out for exercise?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other
--

- 2 Yes
- 0 No
- 9 Don't know, no response, unclear response

53a) If yes, how many times in the past month?

__ __ times in past month

53b) If yes, who did you usually go with?

(Check ALL that apply)

- 1 Alone
- 2 Friends or family
- 3 House-mates or co-workers
- 4 Staff
- 5 Others not listed
- 9 Don't know, no response, unclear response

54) In the past year, did you go away on a vacation?

(Other respondent: In the past year, did this person go away on a vacation?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other
--

- 2 Yes
- 0 No
- 9 Don't know, no response, unclear response

54a) If yes, how many times in the past *year*?

__ __ times in past *year*

54b) If yes, who did you usually go with?

(Check ALL that apply)

- 1 Alone
- 2 Friends or family
- 3 House-mates or co-workers
- 4 Staff
- 5 Others not listed
- 9 Don't know, no response, unclear response

CHOICES

The intent of these questions is to determine the extent to which persons receiving services are involved in decision-making.

- In this section, code "2" if this person played a major role in making the decision. The person may have consulted with others but ultimately made the decision for him/herself.
- Code "1" if the person had some input in making the decision but did not play a major role.
- Code "0" if the person did not have input in making the decision.
- Choices made with spouses/partners should be coded as "2- person made the choice".
- Do not overuse the "NOT APPLICABLE" code here. It is not appropriate to use "8" to indicate NOT ALLOWED or NOT CAPABLE of making decisions in this area. For those cases, code "0".

Read one of the following introductions to the respondent(s):

For Individuals:

I'm going to ask some questions now about some 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.

For Proxy Respondents:

I'm going to ask some questions now about decisions this person may have made. For each question, please indicate if s/he made the decision, if s/he had some input in making the decision, or if someone else made the decision for him/her.

55) Who chose (or picked) the place where you live? *(Did you help pick the place where you live?)*

(Other respondent: Who chose the place where s/he lives? Did s/he have any input in making the decision?)

If the person lives in their family home, please code Q55 as "8- NOT APPLICABLE"

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 8 NOT APPLICABLE – person lives in the family home
- 2 Person made the choice
- 1 Person had some input
- 0 Someone else chose
- 9 Don't know, no response, unclear response

56) Did you choose (or pick) the people you live with (or did you choose to live by yourself)? *(Did anyone ask you who you'd like to live with? Were you given choices, did you get to interview people?)*

PS-6



Did you choose to live with _____ ?

(Other respondent – Did this person choose any of the people s/he lives with? Or: Did this person choose to live alone?)

If the person lives in their family home, please code Q56 as "8- NOT APPLICABLE"

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 8 NOT APPLICABLE – person lives in the family home
- 2 Yes, chose people s/he lives with, or chose to live alone
- 1 Chose some people or had some input
- 0 No, someone else chose
- 9 Don't know, no response, unclear response

57) 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?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _2 Person decides
- _1 Person has help deciding
- _0 Someone else decides
- _9 Don’t know, no response, unclear response

58) Who decides how you spend your free time (when you are not working, in school or at the day program)?

(Other respondent – Who decides how this person spends his/her free time?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _2 Person decides
- _1 Person has help deciding
- _0 Someone else decides
- _9 Don’t know, no response, unclear response

Question 59 refers to choices made concerning paid work in the community.

59) Who chose (or picked) the place where you work? *(Did you help make the choice?)*

PS-8



Did you choose to work at _____?

(Other respondent: Who chose the place where s/he works? Did s/he have any input in making the decision?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 8 NOT APPLICABLE – no job in the community
- 2 Person made the choice
- 1 Person had some input
- 0 Someone else chose
- 9 Don't know, no response, unclear response

Question 60 refers to choices made concerning day programs or other regularly scheduled activities during the day. This does not include paid work in the community.

60) Who chose (or picked) where you go during the day? *(Did you help make the choice?)*

PS-9



Did you choose to go to _____?

(Other respondent: Who chose the place where s/he goes during the day? Did s/he have any input in making the decision?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 8 NOT APPLICABLE – no day program or other activity
- 2 Person made the choice
- 1 Person had some input
- 0 Someone else chose
- 9 Don't know, no response, unclear response

61) Do you choose what you buy with your spending money?

Do not include things like rent or groceries.

(Other respondent – Does this person choose how to spend his/her money?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _2 Person chooses
- _1 Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)
- _0 Someone else chooses
- _9 Don't know, no response, unclear response

62) Did you choose or pick your case manager/service coordinator?

PS-3



Did you choose _____ to work with you?

(Other respondent – Did this person choose his/her case manager/service coordinator?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _8 **NOT APPLICABLE** - no case manager/service coordinator
- _2 Yes, chose case manager/service coordinator
- _1 Case manager/service coordinator was assigned but can be changed if requested by person
- _0 No, someone else chose case manager/service coordinator
- _9 Don't know, no response, unclear response

63) Do you choose (or pick) your staff? (Do you get to interview them?)

Did you get to meet different people or was someone assigned to you? Could you request someone different?)

PS-7


Did you choose _____ to work with you?
(Other respondent – Does this person choose his/her staff?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _8 NOT APPLICABLE - no staff
- _2 Yes, person choose staff
- _1 Staff are assigned but can be changed if requested by person
- _0 No, someone else chose
- _9 Don't know, no response, unclear response

RIGHTS

64) Do people read your mail or email without asking you first?
(Other respondent – Does anyone read this person's mail or email without permission?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _8 NOT APPLICABLE - does not get mail/email
- _2 [Yes] – mail/email is read without permission
- _0 [No] – person reads own mail/email or others read with permission
- _9 Don't know, no response, unclear response

65) Can you be alone with friends or visitors at your home, or does someone have to be with you? *(Are there rules about having*

friends or visitors in your home?)

(Other respondent – *can this person have privacy to be alone with friends when s/he wants to, or does someone else have to be present?)*

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _8 **NOT APPLICABLE** – no friends or visitors, or no friends visit your home
- _2 Can be alone with friends or visitors
- _0 There are rules against being alone with friends or visitors
- _9 Don't know, no response, unclear response

66) Are you allowed to use the phone and internet when you want to?

If person is unable to use the phone or internet, or doesn't have access, code as "NOT APPLICABLE."

(Other respondent – *is this person allowed to use the phone or internet when s/he wants to?)*

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _8 **NOT APPLICABLE** - doesn't have access or unable to use phone/internet
- _2 Yes, can use anytime, either independently or with assistance
- _0 No, there are rules/restrictions on use of phone/internet
- _9 Don't know, no response, unclear response

67) Have you ever participated in a self-advocacy group meeting, conference, or event? *(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. Do not include human rights groups sponsored by provider agencies.)



(Have you ever gone to a _____ meeting or event?)

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

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __8 NOT APPLICABLE – there is no self-advocacy group in the area
- __2 Yes
- __1 Had the opportunity but chose not to participate
- __0 No
- __9 Don't know, no response, unclear response

ACCESS TO NEEDED SERVICES

68) Do you get the services you need?

(Other respondent – Does this person get the services and supports s/he needs?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __2 Yes → code Question 68a as NOT APPLICABLE
- __1 Sometimes, or doesn't get enough of the services needed
- __0 No
- __9 Don't know, no response, unclear response

68a) If additional services are needed, please note type of

service or support below: (check all that apply):

- _0 NOT APPLICABLE - does not need additional services
- _1 Service coordination/case management
- _2 Respite/family support
- _3 Transportation
- _4 Assistance finding, maintaining, or changing jobs
- _5 Education or training
- _6 Health care
- _7 Dental care
- _8 Assistance finding, maintaining, or changing housing
- _9 Social/relationship issues, meeting people
- _10 Communication technology
- _11 Environmental adaptations/home modifications
- _12 Benefits/insurance information
- _13 Other _____

69) Do you feel your staff have the right training to meet your needs? (*Other respondent – Does this person’s support staff have the right training to meeting his/her needs?*)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other
--

- _8 NOT APPLICABLE- person does not have support staff
- _2 Yes
- _1 Maybe, not sure
- _0 No
- _9 Don’t know, no response, unclear response, **or respondent is staff**

70) Overall, how would you describe your health?

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

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- _1 Excellent
- _2 Very good
- _3 Fairly good
- _4 Poor
- _9 Don't know, no response, unclear response

71) 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

SURVEYOR FEEDBACK SHEET

Instructions to surveyors:

Please take a few minutes to complete a feedback sheet after each survey you complete. **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 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. 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 _____

I-2. 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 _____

I-3. Did you know/have you met the individual prior to conducting this survey?

- 1 No
- 2 Yes
- 3 Not sure

I-4. 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-5. Date of face-to-face survey:

(mm/dd/yyyy) ___ / ___ / _____

I-6. How was this survey administered? (check all that apply)

- 1 Paper
- 2 Laptop
- 3 Netbook
- 4 IPad
- 5 Smart phone (e.g., blackberry, palm pilot, iPhone)
- 6 Other _____