

2009 Interview tool



Quality of Life Interview 2009

A tool adapted from
NCI ADULT CONSUMER SURVEY
2008-2009



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Description of NCI:

The Consumer 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, 30 states participate in NCI. The survey is intended to measure performance indicators identified by the NCI Steering Committee, which is made up of representatives from the participating states. For more information, go to www.nationalcoreindicators.org.

Quality of Life Interview Project Overview:

Maine has modified the Consumer Survey and is using the Quality of Life Interview (QOL) to assist in assessment of levels of consumer satisfaction and quality of service delivery as a quality assurance activity. The QOL has been incorporated into Developmental Services' overall Quality Assurance/ Quality Improvement plan and supports requirements of the Community Consent Decree and CMS waiver compliance. Results serve to inform the Office of Adults with Cognitive and Physical Disability Services (Developmental Services) and other interested stakeholders on system performance and outcome measures assisting in policy planning, decision making and for quality improvement purposes.

Organization of Survey:

The survey consists of five parts.

- The Pre-Survey Form requests information that may be useful for scheduling and conducting the interviews. This information is not analyzed.
- The Background Information section consists of information that will be analyzed in conjunction with the interview responses. This information must be collected for all individuals surveyed. Your state will specify which elements must be obtained directly by the interviewer.
- Section I contains questions that may only be answered by face-to-face interviews 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, such as a family member, friend, staff person, guardian or advocate. Interviews with other respondents may be conducted either in person or over the phone.
- The Interviewer Feedback Sheet is the last page of the survey. Please fill out one sheet for each interview you complete.

Guidelines: *(Refer to the QOL protocol for additional instructions.)*

- The interview is voluntary. Guardians/consumers may choose not to participate in the interview. Copies of the consent forms are to be maintained on file within the agency with the original survey, provided to the guardian/consumer and submitted with the survey to the Office of Quality Improvement.
- The QOL is a data collection tool. It is suggested that the interview occur a few months prior to pre planning. Information gathered during the interviewed may be shared only with explicit permission from the guardian/consumer.
- Required fields in the pre survey must be submitted for tracking purposes for all individuals selected to participate in the QOL. Information reported in the pre survey is critical for data analysis.
- Only trained interviewers are to administer the Quality of Life Interview. Consider the most appropriate person to conduct the interview. The person's direct service provider should not be the interviewer, but may be asked to answer questions on behalf of the consumer.
- Section 1 is for consumer responses ONLY.
- With consent, a proxy respondent may be interviewed when the consumer is unable or choosing not to participate in section 2 of the survey. It is strongly encouraged to coordinate with those who know the consumer well including family, friends, advocates, other service providers etc, when the consumer or guardian is not answering questions in Sec 2.
- Interviewers are asked to complete the Feedback form, providing additional information about the process for quality improvement purposes.

Pre Survey Form

The Pre-Survey Form is intended to provide interviewers with the information they will need to schedule and conduct interviews. Information is also used for tracking purposes.

It is strongly suggested that as many Pre-Survey items as possible be filled out and reviewed before starting the interview. Experience has shown that using familiar names and terms helps the respondent understand the questions being asked and facilitates the interview process. Interviewers 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 interview helps the conversation flow more smoothly.

Pre Survey

A. Person completing this form:

Name: _____ Agency: _____

Contact Number: _____ Region: _____ Interview Date: ___ / ___ / ___

B. Person to be interviewed:

Consumer Name: _____

Is this person a member of the Class? Yes(1) No(2)

Age: _____ Gender: _____ Male(1) _____ Female(2)

Phone: _____ - _____

Home Address: _____

Street

_____ City _____ State _____ Zip

C. Guardian information.

Guardian Name: _____ **or** Person is his/her own guardian

Phone: _____ - _____

Home Address: _____

Street

_____ City _____ State _____ Zip

D. Please answer the following questions and attach copy of signed consent form.

**A copy of the consent form must be provided to the consumer/guardian within 5 days
A copy of the consent form must be attached**

Was consent to conduct the interview obtained?

(2) No, date declined: ___ / ___ / ___ (Stop. Submit this page with consent form)

(1) Yes, date consent was obtained: ___ / ___ / ___

PS-1. Contact... Who should the interviewer call to arrange an interview with this person (individual, parent/guardian, service coordinator, day or residential program staff, etc.)?

Name: _____ Relationship: _____

Phone: _____

Note... We would like to talk with persons alone, when appropriate. Some persons may feel uncomfortable with strangers, may have community protection issues, or may have medical or behavioral issues that require supervision by designated caregivers. Also, an interpreter or someone who can assist with communication may be present.

Do you recommend that a caregiver be present while this person is interviewed? ___ Yes ___ No

If yes, please explain: _____

PS-2. Accommodations... Does this person need any accommodations? (Examples: Communication e.g., primary language 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 interview.

If yes, please explain: _____

___ (2) None. No special arrangements were needed for the interview.

___ (3) This person has limited communication/expressive skills and did not participate in Section of this interview.

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

This person has (1) an Individual Support Coordinator
 (2) a Community Case Manager

Name: _____ Phone: _____

PS-4. Job Coach or other person who can provide information about this individual's employment... Please indicate who can provide the most accurate information about this person's employment, such as hours worked and wages earned.

Name: _____ Relationship: _____

Phone: _____ Email: _____

PS-5. Other Interviewees... If this person is unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who know the person well and could respond on his/her behalf. Family members, guardians, friends, and staff may respond; case managers/service coordinators may not respond. The interviewer is also not an appropriate respondent.

Name(1): _____ Relationship: _____

Phone: _____ Email: _____

Name(2): _____ Relationship: _____

Phone: _____ Email: _____

PS-6. Living Arrangement... Please indicate who this person lives with. (Check ONE)

- (1) lives alone
- (2) lives with parent/relatives
- (3) lives in large residential care facility
- (4) lives in shared house or apartment

PS-7. Support Staff in the Home and During the Day... If there are any people who are paid to provide supports in this person's home, please indicate their first names. If there are several workers, please list the primary staff who spend the most time with this person. Also indicate the first names of primary day and/or job support staff.

Home Support Staff: _____

Agency providing home support: _____

Day Support Staff/Job Support Staff/Coach: _____

Day support agency: _____

PS-8. Employment/Other Daily Activities... If applicable, please indicate this person's job, school or daily activity. Use term or abbreviation person is most familiar with.

Place of work: _____

School: _____

Day Program/Other Activity: _____

PS-9. 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 Up for Us, Strive)

PS-10. 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, DMR 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? (1) Yes (2) No

BACKGROUND INFORMATION

The questions in the following section are best answered by referencing agency records or obtaining information from another reliable source. 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.

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 mental retardation/intellectual disabilities (MR/ID)? (Note: we are now using the term "intellectual disabilities" to refer to "mental retardation.")

- 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 MR/ID? (Check ONE)

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

BI-10. What other disabilities are noted in this person's record? (Check ALL that apply)

- 1 Mental Illness/Psychiatric Diagnosis (e.g. Depression)
- 2 Autism Spectrum Disorder (e.g., Autism, Asperger Syndrome, Pervasive Developmental Disorder)
- 3 Cerebral Palsy
- 4 Brain Injury
- 5 Seizure Disorder/Neurological Problem
- 6 Chemical Dependency
- 7 Limited or No Vision, Legally Blind
- 8 Hearing Loss, Severe or Profound
- 9 Physical Disability
- 10 Communication Disorder
- 11 Alzheimer's Disease or other Dementia
- 12 Down Syndrome
- 13 Prader-Willi Syndrome
- 14 Other disabilities not listed
- 15 No other disabilities other than MR/ID
- 16 Don't know

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

- 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 or very good
- 2 Fairly good
- 3 Poor
- 4 Don't know

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

- 1 Yes
- 2 No
- 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 or 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-17a. Is this person edentulous? (Check ONE)

- 1 Yes
- 2 No
- 3 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-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 Yes
- 2 No
- 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 Yes
- 2 No
- 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. When was this person's last screening for cancer? (e.g. cervical, breast, prostate, colorectal cancer)

- 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 been screened for cancer
- 7 Don't know

BI-30. 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-31. 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-32 Does this person currently take medications for...

(check one column for each):

	No	Yes	Don't Know	
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3		Mood disorders? [Includes any drug prescribed to elevate or stabilize mood (reduce mood swings), e.g., to treat depression, mania, or bipolar disorder.]
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3		Anxiety? [Includes any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.]
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3		Behavior problems? [Includes any drug prescribed for a behavior modification purpose (such as a stimulant, sedative, or beta-blocker), e.g., to treat ADHD, aggression, self-injurious behavior, etc.]
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3		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.]

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 Specialized institutional facility for persons with MR/DD
- 2 Group home
- 3 Agency-operated apartment type setting
- 4 Independent home or apartment
- 5 Parent/relative's home
- 6 Foster care or host home (person lives in home of unrelated, paid caregiver)
- 7 Nursing facility
- 8 Homeless
- 9 Other (specify) _____
- 10 Don't know

BI-35. How many people (including the person receiving services) reside at this address? (If the person lives in a facility, e.g., nursing home, institution, assisted living center, etc., make sure to list the TOTAL number of residents in the entire facility)

___ ___ ___ number of people

BI-36. Of the people who reside at this address, how many of them have disabilities?

___ ___ ___ number of people with disabilities

BI-37. 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-38. 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. for possible source of information.

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

Type of activity		If yes:			
Definitions: <u>Community-based</u> setting is a place where most people do not have disabilities. <u>Facility-based</u> setting is a place where most people do have disabilities.	a) Was this person engaged in this activity during the two-week period?	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-39. Paid job in a community-based setting (e.g., competitive or supported employment, enclave, work crew)	__ 1 No __ 2 Yes __ 3 Don't know	__ __ __ hrs	\$ _____. ____	__ 1 No __ 2 Yes __ 3 Don't know	__ 1 No __ 2 Yes __ 3 Don't know
BI-40. Unpaid activity in a community-based setting (e.g., volunteer activities, skills training, community experiences)	__ 1 No __ 2 Yes __ 3 Don't know	__ __ __ hrs	N/A	__ 1 No __ 2 Yes __ 3 Don't know	__ 1 No __ 2 Yes __ 3 Don't know
BI-41. Paid work performed in a facility-based setting (e.g., workshop, activity center)	__ 1 No __ 2 Yes __ 3 Don't know	__ __ __ hrs	\$ _____. ____	N/A	N/A
BI-42. Unpaid activity in a facility-based setting (e.g., day habilitation, prevocational, seniors programs)	__ 1 No __ 2 Yes __ 3 Don't know	__ __ __ hrs	N/A	N/A	N/A

BI-43. Is integrated employment a goal in this person's service plan?

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

BI-44. Is this person enrolled in the public school system?

- 1 No
- 2 Yes

BI-45. 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 MR/DD Agency (non-waiver)
- 3 Vocational Rehabilitation Agency
- 4 ICF/MR Day Program
- 5 Other (e.g., Social Security Ticket to Work)
- 6 NOT APPLICABLE – does not receive employment supports or day services

Community Employment Only – If BI-39a above is checked "Yes," please answer BI-46 through BI-49:

BI-46. 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.)

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

BI-47. Does this person receive paid vacation and/or sick time at his/her job?

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

BI-48. How long has this person been working at his/her current job? __ mos __yrs

BI-49. What type of job does this person have? (check ONE -option that best fits)

- 1 Food preparation and food service
- 2 Building/grounds cleaning or maintenance
- 3 Personal care provider
- 4 Retail job such as sales clerk, stock person
- 5 General office and administrative support
- 6 Farming, fishing, forestry worker
- 7 Construction or repair occupation
- 8 Assembly, manufacturing, packaging
- 9 Materials handling, mail distribution
- 10 Management, business, or financial operations
- 11 Professional or technical occupation
- 12 Self-employed
- 13 Other

OTHER SUPPORTS AND SERVICES

BI-50. Does this person receive any of the following services/supports funded by the state agency? (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	Assistive Technology (supports to facilitate the use of adaptive equipment)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Clinical Services (therapies, behavior management, psychological services, etc.)
<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	Respite/Family Support
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	Other

BI-51. Does this person receive either ICF/MR or HCBS Waiver funding? (Check ONE) (PLEASE OBTAIN THIS INFORMATION FROM A STATE DATA SYSTEM/ OFFICIAL RECORD IF POSSIBLE)

- 1 Yes, ICF/MR (Intermediate Care Facility for people with Mental Retardation)
- 2 Yes, HCBS (Home and Community Based Services) Waiver Program
- 3 Don't know
- 4 No, receives other funding

BI-52. 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-53 as NOT APPLICABLE
- 2 Yes
- 3 Don't know

BI-53. 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
- 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-54. Self-injurious behavior <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>	<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-55. 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-56. 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>

General Instructions:

- Section I may only be completed by directly interviewing the person receiving services and supports.
- Do not use responses from any other person to complete this section.
- The interview must complete the last 3 questions in Section I.
- If possible, the interview should be conducted in private. Parents or guardians may be present if they insist. Others may be present if the individual requests, or if another person is needed for interpretation purposes. If staff believes that a private interview may pose risks to interviewers, then staff should be present. If others are providing assistance, interviewers should emphasize that we are trying to find out the individual's perspective.
- Do not leave any questions blank.
- 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 parentheses; you do not need to limit yourself to these suggestions.
- 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."
- Prior to the interview, interviewers should use the pre-survey form to fill in the blanks throughout the survey. Using familiar names and terms during the interview will help ensure that the person understands the questions. Questions that refer to pre-survey information are indicated with a bell symbol: 
- 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 Interviewer Feedback Sheet after each interview
- Quality of Life Interview tool and consent form are to be submitted to:
 - DHHS-Office of Quality Improvement
 - ATTN: QOL Coordinator
 - Marquardt Building 2nd Floor
 - 11 State House Station
 - Augusta, Maine 04333-0011

Questions for Interviewer(s):

I-1. Where is the interview being held? (Check ALL that apply)

- 1 Person's home
- 2 Person's workplace
- 3 Provider agency
- 4 Public place
- 5 Other _____

I-2. What is your job title/relationship to the state agency? (If there is more than one interviewer, check ALL that apply. If an interviewer 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 interviewers are conducting the survey with this person?

- 1 One
- 2 Two
- 3 Three
- 4 Four or more

I-5. Date of Interview: (mm/dd/yyyy) ___ / ___ / _____

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 Maine 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.”

“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.”

Review the consent form.

SECTION I

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 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.



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 & 6 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 have staff who help you at your job?

 PS-7 (Does _____ help you at your job?)

- 8 **NOT APPLICABLE** – no job in the community
- 2 Yes
- 0 No
- 9 Don't know, no response, unclear response

6) Are the staff who help you at your job nice and polite to you? (*Do they treat you with respect?*)

- 8 **NOT APPLICABLE** no job in the community or no job staff
- 2 Yes
- 1 Sometimes or some staff
- 0 No
- 9 Don't know, no response, unclear response

7) Do you go to a day program or do some other activity during the day? It does not include a job in the community.

 PS-8 (Do you go to _____?)

- 2 Yes
- 0 No -code Questions 8 & 11 as NOT APPLICABLE
- 9 Don't know, no response, unclear response

8) 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

9) 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

10) Do you have staff who help you at your day program or other activity?



PS-7 (Does _____ help you at your day program or other activity?)

- 8 **NOT APPLICABLE** – no day program or other activity
- 2 Yes
- 0 No -code Question 11 as NOT APPLICABLE
- 9 Don't know, no response, unclear response

11) Are the staff at your day program/other activity nice and polite to you? (*Do they treat you with respect?*)

- 8 **NOT APPLICABLE** - no day program/other activity or no staff
- 2 Yes
- 1 Sometimes or some staff
- 0 No
- 9 Don't know, no response, unclear response

12) Do you do any volunteer work?

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

HOME

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

13) 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

14) Would you like to live somewhere else?

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

15) Do you like your neighborhood?

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

16) 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

17) Do you have any staff who help you where you live?

 PS-7 Does _____ help you at home?

- 2 Yes
- 0 No - code Question 18 as NOT APPLICABLE
- 9 Don't know, no response, unclear response

18) Are they nice and polite to you? (*Do they treat you with respect?*)

- 8 **NOT APPLICABLE** – no home support staff
- 2 Yes
- 1 Sometimes or some staff
- 0 No
- 9 Don't know, no response, unclear response

19) 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

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

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

☞ If person lives alone, code Question 21 as NOT APPLICABLE. (PS-6)

21) Do you have enough privacy at home?
(*Can you have time to yourself?*)

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 AND HEALTH

Now I'm going to ask you some personal questions about your safety and health.

22) 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

23) 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

24) 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

☞ If the person responds "Yes" or "Sometimes" to Questions 22, 23, or 24, **ask Question 25**. Otherwise, code Question 25 as NOT APPLICABLE.

25) If you feel afraid, is there someone you can go to for help?

- 8 **NOT APPLICABLE** – does not feel afraid
- 2 Yes
- 1 Maybe, not sure
- 0 No
- 9 Don't know, no response, unclear response

26) Are you able to go to the doctor when you need to?

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

FRIENDS AND FAMILY

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

27) 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

28) Do you have a best friend, or someone you are really close to? (*Is there someone you can talk to about personal things?*)

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

☞ If the person responds NO TO **BOTH QUESTIONS 27 AND 28**, code Questions **29** as NOT APPLICABLE.

29) 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

30) 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

31) 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

32) 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

33) 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

34) Do you get to help other people?
(Do you get to teach things to other people?)

- 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 35-37 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.

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

 PS-3 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

36) 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

37) 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
- 2 Calls back right away
- 1 In-between
- 0 Takes a long time to call back
- 9 Don't know, no response, unclear response

38) How do you usually get places you need to go?

- 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

39) 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 40-47 ONLY IF PERSON USES A SELF-DIRECTED SUPPORTS OPTION (SEE PS-10 and QUESTION BI-52).

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

For those who are using self-directed supports, the interviewer 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-10 for terms the person may be familiar with.

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

 PS-10 Does someone talk with you about your _____?

- 8 **NOT APPLICABLE**
- 2 Yes
- 1 Maybe, not sure
- 0 No- code Questions 41-45 as NOT APPLICABLE
- 9 Don't know, no response, unclear response

41) 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

42) 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

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

- 8 **NOT APPLICABLE**
- 2 [Yes] – need more help
- 1 Maybe, not sure
- 0 [No] – have enough help
- 9 Don't know, no response, unclear response

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

 PS-10 Do you get information from _____ (financial -management service)?

- 8 **NOT APPLICABLE**
- 2 Yes
- 1 Maybe, not sure
- 0 No - code Question 45 as NOT APPLICABLE
- 9 Don't know, no response, unclear response

45) 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

46) Do your support workers come when they are supposed to?

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

47) Do you get the help you need to work out any problems you have with your support workers?

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



Interviewers must answer the following questions on page 31 before continuing with Section II of the interview

48) Interviewer: 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

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

- 8 **NOT APPLICABLE** – did not complete
- 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

50) Interviewer: 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
- 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 48-50**, then determine now if s/he is willing to answer more questions. If you answered no to any of the above questions, another respondent is to be interviewed for Section II of the survey. With consent, other respondents who may contribute to the interview may include guardians, other staff, family, friends etc.

If the individual is not willing to continue, or if you believe comprehension or consistency was a problem, then say:

“Thank you for your help. It’s been very nice talking to you. You’ve been very helpful.”

Otherwise, continue with the consumer as the respondent to questions in the next section.

SECTION II

STOP - Please review Section 1 questions #48-50. Please make sure you have answered those questions before proceeding.

Interview the person receiving services if possible. If you are unable to interview the person, other respondents may be interviewed (family, advocate, staff; however *not* the case manager or service coordinator). As an interviewer, you should not be a respondent.

Respondents must be knowledgeable in the areas below (they should know the person well and have frequent contact with him/her).

- If the person receiving services has completed Section I, but has become tired or does not wish to continue with this section, you may interview other persons.
- Use alternate wording when questioning other respondents.
- If both the individual and another 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 another respondent, you may need to ask follow up questions to determine the most valid response.
- Check only one box to indicate whose response was used.

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). Try to rule out non-integrated activities (where only people with disabilities are participating). If the person answers 'yes', you may ask for an example to verify that the person understood the question.

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

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 (did this person) usually go with?
(Check ALL that apply)

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

52) In the past month, did you (did this person) go out on errands or appointments? (Examples: bank, post office, hair dressers/barber)

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 (did this person) usually go with?
(Check ALL that apply)

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

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

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 (did this person) usually go with?
(Check ALL that apply)

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

54) In the past month, did you (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

54a) If yes, how many times in the past month?
__ __ times in past month

54b) If yes, who did you (did this person) usually go with?
(Check ALL that apply)

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

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

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

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

55a) If yes, how many times in the past month?
__ __ times in past month

55b) If yes, who did you (did this person) usually go with?
(Check ALL that apply)

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

56) In the past month, did you (did this person) go out for exercise?
(*Examples: jogging, swimming, riding bike, YMCA, gym/health club*)

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

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

56a) If yes, how many times in the past month?
__ __ times in past month

56b) If yes, who did you (did this person) usually go with?

(Check ALL that apply)

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

57) In the past year, did you (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

57a) If yes, how many times in the past year?

__ __ times in past year

57b) If yes, who did you (did this person) usually go with?

(Check ALL that apply)

- 1 Alone
- 2 Friends or family
- 3 House-mates
- 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” only if you can convince yourself that 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 you think the person had some input in making the decision. Choices made with spouses/partners should be coded as “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. There is a code for indicating that someone else made the decision.

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 Other 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.

58) 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?)

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

- 2 Person made the choice
- 1 Person had some input
- 0 Someone else chose
- 9 Don't know, no response, unclear response

59) How many places did you visit before moving here?

(Other respondent – How many places did s/he look at before moving in?)

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

- 2 Looked at more than one place
- 1 Visited one place only (current home)
- 0 Did not visit before moving in (or always lived there)
- 9 Don't know, no response, unclear response, can't remember – too long ago

60) 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?)

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

- 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

61) Do you choose (or pick) who helps you at home? (*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 residential staff?)

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

- 8 **NOT APPLICABLE** no staff in the home
- 2 Yes, person choose staff
- 1 Staff are assigned but s/he can request a change if not satisfied
- 0 No, someone else chose
- 9 Don't know, no response, unclear response

62) 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

63) 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

64) 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

65) How many places did you visit before working there?
(**Other respondent** – *How many places did s/he look at before working there?*)

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

- __ 8 **NOT APPLICABLE** – no job in the community
- __ 2 Looked at more than one place
- __ 1 Visited one place only (current job)
- __ 0 Did not visit beforehand
- __ 9 Don't know, no response, unclear response, can't remember – too long ago

66) Do you choose (or pick) who helps you at your job? (*Do you get to interview them? Was someone assigned to you? Could you request someone different?*)

 PS-7 Did you choose _____ to help you at your job?
(**Other respondent** – *Does this person choose his/her job staff?*)

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

- __ 8 **NOT APPLICABLE** – no community job or job staff
- __ 2 Yes, person chose staff
- __ 1 Some staff, or staff are assigned but s/he can request someone different
- __ 0 No, someone else chose staff
- __ 9 Don't know, no response, unclear response

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



PS-8 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

68) How many places did you visit before going there? (**Other respondent** – *How many places did s/he look at before going there?*)

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

- 8 **NOT APPLICABLE** – no day program or other activity
- 2 Looked at more than one place
- 1 Visited one place only (current day activity)
- 0 Did not visit beforehand
- 9 Don't know, no response, unclear response, can't remember – too long ago

69) Do you choose (or pick) who helps you during the day? (*Do you get to interview them? Was someone assigned to you? Could you request someone different?*)



PS-7 Did you choose _____ to help you during the day?

(Other respondent – *Does this person choose his/her day activity staff?*)

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

- 8 **NOT APPLICABLE** no day program or other activity
- 2 Yes, person chose staff
- 1 Some staff, or staff are assigned but s/he can request someone different
- 0 No, someone else chose staff
- 9 Don't know, no response, unclear response

70) 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

71) 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 s/he
can request a change if not satisfied
- 0 No, someone else chose case manager/service coordinator
- 9 Don't know, no response, unclear response

RIGHTS

72) 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

73) 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
- 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

74) 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

75) Have you ever participated in a self-advocacy group meeting, conference, or event? (*A self advocacy group is where people 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.*)



PS-9 (*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

76) 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
- 1 Sometimes, or doesn't get enough of the services needed
- 0 No - code Question 76a as NOT APPLICABLE
- 9 Don't know, no response, unclear response

76a) 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 Transportation
- 2 Assistance finding or changing jobs
- 3 Education or training
- 4 Health care
- 5 Dental care
- 6 Assistance finding or changing housing
- 7 Social/relationship issues, meeting people
- 8 Communication technology
- 9 Environmental adaptations/home modifications
- 10 Benefits/insurance information
- 11 Other

77) Interviewer: 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

Instructions to interviewers:

Please take a few minutes to complete a feedback sheet after each interview you complete.

1. How long did it take to complete the direct interview(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 interviews, 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.

Question: Problem/Suggestions:

Other Comments:

