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, over 30 States and sub-State entities participate in NCI. This survey is intended to measure performance indicators identified by the NCI Operations Committee (formerly known as the NCI Steering 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 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.
The Pre-Survey Form is intended to provide interviewers with the information they will need to schedule and conduct interviews. The State should review this form and decide what information will be provided to interviewers in advance (e.g., name, phone number, communication needs, etc.), how the information will be gathered (e.g., service coordinators, databases, etc.), and determine the administrative procedures (including informed consent) that must be followed when arranging interviews.

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.

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 interviewers during training.

Additional instructions regarding your state’s specific administrative procedures may be noted below:
A. Person completing this Pre-Survey form:

Name: ____________________________________________

Date: _____ / _____ / ________

B. Person to be interviewed:

Individual Name: ____________________________________________

Gender: _____ Male _____ Female

Age: ______

Phone: _______ - __________________________

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. If required in your state, please answer the following questions and/or attach copy of signed consent form.

Did individual/legal guardian give verbal consent for interviewer to contact him/her? ___ Yes ___ No

Is the signature of a legal guardian required for this individual to consent to participation in this study? ___ Yes ___ No

Did individual/legal guardian give written consent to be interviewed? ___ Yes ___ No

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: ___________________________

Daytime Phone: ____________________ Evening Phone: _______________________

Cell Phone: ________________________ E-mail address: ________________________

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.

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

___ Yes ___ No

If yes, please explain:

__________________________________________________________________________
__________________________________________________________________________

NCI Adult Consumer Survey 2009-10
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.

________________________________________________________________________

________________________________________________________________________

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. **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: ___________________________  E-mail address: __________________

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.

Name: ___________________________  Relationship: ___________________

Daytime Phone: ___________________  Evening Phone: ________________

Cell Phone: _______________________  E-mail address: __________________

Name: ___________________________  Relationship: ___________________

Daytime Phone: ___________________  Evening Phone: ________________

Cell 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

If applicable, provide first names of roommates or housemates:

____________________________________________________________________

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: _________________________________________________

Day Support Staff/Job Support Staff/Coach: _____________________________

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 for Ourselves.)

____________________________________________________________________

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?

___ 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).

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

The questions in this section are best 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 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?**

- 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?)

- __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?**

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>Excellent or very good</td>
</tr>
<tr>
<td>2</td>
<td>Fairly good</td>
</tr>
<tr>
<td>3</td>
<td>Poor</td>
</tr>
<tr>
<td>4</td>
<td>Don’t know</td>
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</table>

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

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<tbody>
<tr>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

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)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>1</td>
<td>In the past year (anytime less than 12 months ago)</td>
</tr>
<tr>
<td>2</td>
<td>One year ago or more</td>
</tr>
<tr>
<td>3</td>
<td>Don’t know</td>
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</table>

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

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<tbody>
<tr>
<td>1</td>
<td>Within the last six months (anytime less than 6 months ago)</td>
</tr>
<tr>
<td>2</td>
<td>Within the past year (6 months but less than 12 months ago)</td>
</tr>
<tr>
<td>3</td>
<td>One year ago or more</td>
</tr>
<tr>
<td>4</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

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

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<tbody>
<tr>
<td>1</td>
<td>Within the past year (anytime less than 12 months ago)</td>
</tr>
<tr>
<td>2</td>
<td>Within the past 2 years (1 year but less than 2 years ago)</td>
</tr>
<tr>
<td>3</td>
<td>Within the past 3 years (2 years but less than 3 years ago)</td>
</tr>
<tr>
<td>4</td>
<td>Within the past 5 years (3 years but less than 5 years ago)</td>
</tr>
<tr>
<td>5</td>
<td>5 or more years ago</td>
</tr>
<tr>
<td>6</td>
<td>Has never had a vision screening</td>
</tr>
<tr>
<td>7</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

BI-19. **When was the last time this person had a hearing test?**

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<table>
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<tbody>
<tr>
<td>1</td>
<td>Within the past 5 years (anytime less than 5 years ago)</td>
</tr>
<tr>
<td>2</td>
<td>5 years ago or more</td>
</tr>
<tr>
<td>3</td>
<td>Has never had a hearing test</td>
</tr>
<tr>
<td>4</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>
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  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. 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)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td><strong>NOT APPLICABLE</strong> – INDIVIDUAL IS MALE</td>
</tr>
<tr>
<td>1</td>
<td>Within the past year (anytime less than 12 months ago)</td>
</tr>
<tr>
<td>2</td>
<td>Within the past 2 years (1 year but less than 2 years ago)</td>
</tr>
<tr>
<td>3</td>
<td>Within the past 3 years (2 years but less than 3 years ago)</td>
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<tr>
<td>4</td>
<td>Within the past 5 years (3 years but less than 5 years ago)</td>
</tr>
<tr>
<td>5</td>
<td>5 or more years ago</td>
</tr>
<tr>
<td>6</td>
<td>Has never had a Pap test</td>
</tr>
<tr>
<td>7</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

**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)

<table>
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<tr>
<th>Code</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>0</td>
<td><strong>NOT APPLICABLE</strong> – INDIVIDUAL IS MALE</td>
</tr>
<tr>
<td>1</td>
<td>Within the past year (anytime less than 12 months ago)</td>
</tr>
<tr>
<td>2</td>
<td>Within the past 2 years (1 year but less than 2 years ago)</td>
</tr>
<tr>
<td>3</td>
<td>Within the past 3 years (2 years but less than 3 years ago)</td>
</tr>
<tr>
<td>4</td>
<td>Within the past 5 years (3 years but less than 5 years ago)</td>
</tr>
<tr>
<td>5</td>
<td>5 or more years ago</td>
</tr>
<tr>
<td>6</td>
<td>Has never had a mammogram</td>
</tr>
<tr>
<td>7</td>
<td>Don’t know</td>
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</table>

**BI-28. If male, when was his last PSA test?** A PSA or prostate-specific antigen test is a blood test used to check men for prostate cancer. (Check ONE) (Will be reported for males age 50 and over)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>0</td>
<td><strong>NOT APPLICABLE</strong> – INDIVIDUAL IS FEMALE</td>
</tr>
<tr>
<td>1</td>
<td>Within the past year (anytime less than 12 months ago)</td>
</tr>
<tr>
<td>2</td>
<td>Within the past 2 years (1 year but less than 2 years ago)</td>
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<tr>
<td>3</td>
<td>Within the past 3 years (2 years but less than 3 years ago)</td>
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<tr>
<td>4</td>
<td>Within the past 5 years (3 years but less than 5 years ago)</td>
</tr>
<tr>
<td>5</td>
<td>5 or more years ago</td>
</tr>
<tr>
<td>6</td>
<td>Has never had a PSA test</td>
</tr>
<tr>
<td>7</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>
BI-29. 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)

__ 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-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 to treat...

(Check one column for each):

<table>
<thead>
<tr>
<th></th>
<th>Don't</th>
<th>No</th>
<th>Yes</th>
<th>Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood disorders?</td>
<td>__ 1</td>
<td>__ 2</td>
<td>__ 3</td>
<td></td>
</tr>
<tr>
<td>Anxiety?</td>
<td>__ 1</td>
<td>__ 2</td>
<td>__ 3</td>
<td></td>
</tr>
<tr>
<td>Behavior problems?</td>
<td>__ 1</td>
<td>__ 2</td>
<td>__ 3</td>
<td></td>
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<tr>
<td>Psychotic disorders?</td>
<td>__ 1</td>
<td>__ 2</td>
<td>__ 3</td>
<td></td>
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</tbody>
</table>

Mood disorders? [Includes any drug prescribed to elevate or stabilize mood (reduce mood swings), e.g., to treat depression, mania, or bipolar disorder.]

Anxiety? [Includes any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.]

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.]

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

### Type of activity

<table>
<thead>
<tr>
<th>BI-39. Paid job in a community-based setting (e.g., competitive or supported employment, enclave, work crew)</th>
<th>a) Was this person engaged in this activity during the two-week period?</th>
<th>b) Number of hours worked or spent at this activity during the two-week period:</th>
<th>c) Total gross wages (before taxes or deductions) earned at this activity during the two-week period:</th>
<th>d) Does this person get publicly-funded services or supports to participate in this activity?</th>
<th>e) Is the job or activity done primarily by a group of people with disabilities?</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>1</em> No</td>
<td></td>
<td></td>
<td></td>
<td><em>1</em> No</td>
<td><em>1</em> No</td>
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<tr>
<td><em>2</em> Yes</td>
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<td><em>2</em> Yes</td>
<td><em>2</em> Yes</td>
</tr>
<tr>
<td><em>3</em> Don’t know</td>
<td></td>
<td></td>
<td></td>
<td><em>3</em> Don’t know</td>
<td><em>3</em> Don’t know</td>
</tr>
</tbody>
</table>

### BI-40. Unpaid activity in a community-based setting (e.g., volunteer activities, skills training, community experiences)

| _1_ No |  |  |  | _1_ No | _1_ No |
| _2_ Yes |  |  |  | _2_ Yes | _2_ Yes |
| _3_ Don’t know |  |  |  | _3_ Don’t know | _3_ Don’t know |

### BI-41. Paid work performed in a facility-based setting (e.g., workshop, activity center)

| _1_ No |  |  |  | _1_ No | _1_ No |
| _2_ Yes |  |  |  | _2_ Yes | _2_ Yes |
| _3_ Don’t know |  |  |  | _3_ Don’t know | _3_ Don’t know |

### BI-42. Unpaid activity in a facility-based setting (e.g., day habilitation, prevocational, seniors programs)

| _1_ No |  |  |  | _1_ No | _1_ No |
| _2_ Yes |  |  |  | _2_ Yes | _2_ Yes |
| _3_ Don’t know |  |  |  | _3_ Don’t know | _3_ Don’t know |
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 or County 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

<table>
<thead>
<tr>
<th>Community Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>BI-46. <strong>Did this person work 10 out of the last 12 months in a community job?</strong> (Person may have changed jobs or had periods of unemployment/transition.)</td>
</tr>
<tr>
<td>___ 1   No</td>
</tr>
<tr>
<td>___ 2   Yes</td>
</tr>
<tr>
<td>___ 3   Don’t Know</td>
</tr>
</tbody>
</table>

| 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?** (If multiple jobs, pick the job the person has worked at the longest). |
| ___ ___ years |
| ___ ___ months |

| BI-49. **What type of job does this person have?** (check ONE - option that best fits) |
| ___ 1   Food preparation and food service |
| ___ 2   Building and grounds cleaning or maintenance |
| ___ 3   Personal care provider |
| ___ 4   Retail job such as sales clerk or stock person |
| ___ 5   General office and administrative support |
| ___ 6   Farming, fishing, forestry worker |
| ___ 7   Construction or repair occupation |
| ___ 8   Assembly, manufacturing, or packaging |
| ___ 9   Materials handling, mail distribution |
| ___ 10   Management, business, or financial operations |
| ___ 11   Professional or technical occupation |
| ___ 12   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 (or County agency if applicable)?

(Check one column for each service):  

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>No</td>
<td>Yes</td>
<td>Know</td>
<td></td>
</tr>
<tr>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>Service Coordination/Case Management</td>
</tr>
<tr>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>Assistive Technology (supports to facilitate the use of adaptive equipment)</td>
</tr>
<tr>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>Clinical Services (PT, OT, Speech, and other therapies, behavior management, psychological services, etc.)</td>
</tr>
<tr>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>Transportation</td>
</tr>
<tr>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>Respite/Family Support</td>
</tr>
<tr>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>Other</td>
</tr>
</tbody>
</table>

**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)

<p>| | | |</p>
<table>
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<tbody>
<tr>
<td>__1</td>
<td>Yes, ICF/MR (Intermediate Care Facility for people with Mental Retardation)</td>
<td></td>
</tr>
<tr>
<td>__2</td>
<td>Yes, HCBS (Home and Community-Based Services) Waiver Program</td>
<td></td>
</tr>
<tr>
<td>__3</td>
<td>Don't know</td>
<td></td>
</tr>
<tr>
<td>__4</td>
<td>No, receives other funding</td>
<td></td>
</tr>
</tbody>
</table>

**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.

<p>| | |</p>
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<tbody>
<tr>
<td>__1</td>
<td>No → code BI-53 and 43-50 as NOT APPLICABLE</td>
</tr>
<tr>
<td>__2</td>
<td>Yes</td>
</tr>
<tr>
<td>__3</td>
<td>Don’t know → code BI-53 and 43-50 as NOT APPLICABLE</td>
</tr>
</tbody>
</table>

**BI-53.** If yes, who employs this person’s support workers?

<p>| | |</p>
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<tbody>
<tr>
<td>__8</td>
<td>NOT APPLICABLE – not using self-directed/participant-directed supports</td>
</tr>
<tr>
<td>__1</td>
<td>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.</td>
</tr>
<tr>
<td>__2</td>
<td>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).</td>
</tr>
<tr>
<td>__3</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>
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.

<table>
<thead>
<tr>
<th>Does person need support to manage:</th>
<th>Level of Support Needed (Check ONE)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BI-54. Self-injurious behavior</strong></td>
<td>___1 No support needed</td>
</tr>
<tr>
<td>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.</td>
<td>___2 Some support needed; requires only occasional assistance or monitoring</td>
</tr>
<tr>
<td></td>
<td>___3 Extensive support needed; frequent or severe enough to require regular assistance</td>
</tr>
<tr>
<td></td>
<td>___9 Don’t Know</td>
</tr>
</tbody>
</table>

| **BI-55. Disruptive behavior** | ___1 No support needed               |
| 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. | ___2 Some support needed; requires only occasional assistance or monitoring |
| | ___3 Extensive support needed; frequent or severe enough to require regular assistance |
| | ___9 Don’t Know |

| **BI-56. Destructive behavior** | ___1 No support needed               |
| Refers broadly to externally-directed, defiant behavior, for example, taking other people’s property, property destruction, stealing, or assaults and injuries to others. | ___2 Some support needed; requires only occasional assistance or monitoring |
| | ___3 Extensive support needed; frequent or severe enough to require regular assistance |
| | ___9 Don’t Know |
SECTION I: Direct Interview with Person Receiving Services and Supports

General Instructions:

✧ This section 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.

✧ 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 believe 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 italics - 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.
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 (or County agency if applicable)? (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? (This includes “shadow interviewers” or other silent observers)

__ 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 _____ (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.”

(If applicable): Ask respondent to sign consent form before proceeding with interview.
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. 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 3-6 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?** *(Does __________________________ help you at your job?)*

- 8 NOT APPLICABLE – no job in the community
- 2 Yes
- 0 No \(\rightarrow\) code Question 6 as NOT APPLICABLE
- 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?** *(This does not include a job in the community.)*

- 2 Yes
- 0 No \(\rightarrow\) 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

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?

<table>
<thead>
<tr>
<th>Code</th>
<th>Response</th>
</tr>
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<tbody>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>0</td>
<td>No → code Question 18 as NOT APPLICABLE</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Code</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – no home support staff</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td>Sometimes or some staff</td>
</tr>
<tr>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Code</th>
<th>Response</th>
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<tbody>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td>Sometimes</td>
</tr>
<tr>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

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

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<tr>
<th>Code</th>
<th>Response</th>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td>Sometimes</td>
</tr>
<tr>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>
21) **Do you have enough privacy at home?** *(Can you have time to yourself?)* If person lives alone, code Q21 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 AND HEALTH**

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

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
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? (Can you go to the doctor when you get hurt or sick?)

__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 help other people?** *(Do you show other people how to do things?)*

- **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 and 38-40 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?**

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

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<thead>
<tr>
<th>Code</th>
<th>Response</th>
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<tbody>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td>Maybe, not sure</td>
</tr>
<tr>
<td>0</td>
<td>No → code Question 37 as NOT APPLICABLE</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

37) **If yes, did you help make your service plan?** *(If yes, did you help decide which services are on the list?)*

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<tr>
<th>Code</th>
<th>Response</th>
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<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – does not have service plan</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td>Maybe, not sure</td>
</tr>
<tr>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
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</table>

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

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<th>Code</th>
<th>Response</th>
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<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – does not have case manager/service coordinator</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td>Sometimes</td>
</tr>
<tr>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

39) **If you ask for something, does your case manager/service coordinator help you get what you need?**

<table>
<thead>
<tr>
<th>Code</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – does not have case manager/service coordinator, or does not ask for help</td>
</tr>
<tr>
<td>2</td>
<td>Yes, does help</td>
</tr>
<tr>
<td>1</td>
<td>Sometimes helps</td>
</tr>
<tr>
<td>0</td>
<td>No, does not help</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>
40) 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

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

41) How do you usually get 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
42) 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 43-50 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.

43) 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 44-48 as NOT APPLICABLE
__9 Don’t know, no response, unclear response

44) 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
45) 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

46) 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

47) 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 48 as NOT APPLICABLE
- 9 Don’t know, no response, unclear response

48) 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
49) **Do your support workers come when they are supposed to?**

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>_8</td>
<td>NOT APPLICABLE</td>
</tr>
<tr>
<td>_2</td>
<td>Yes</td>
</tr>
<tr>
<td>_1</td>
<td>Maybe, not sure</td>
</tr>
<tr>
<td>_0</td>
<td>No</td>
</tr>
<tr>
<td>_9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>_8</td>
<td>NOT APPLICABLE</td>
</tr>
<tr>
<td>_2</td>
<td>Yes</td>
</tr>
<tr>
<td>_1</td>
<td>Maybe, not sure</td>
</tr>
<tr>
<td>_0</td>
<td>No</td>
</tr>
<tr>
<td>_9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>
51) **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

52) **Interviewer:** 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

53) **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 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 51-53, 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.
STOP - Please review Section 1 questions #51-53. 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). 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.

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

<table>
<thead>
<tr>
<th>Respondent: ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

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 on errands or appointments?** *(Examples: bank, post office, hair dressers/barber)*

<table>
<thead>
<tr>
<th>Respondent: ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

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 entertainment? (Examples: movies, plays, concerts, attend sporting events)

<table>
<thead>
<tr>
<th>Respondent:</th>
<th>( ) 1-individual</th>
<th>( ) 2-family/friend</th>
<th>( ) 3-staff</th>
<th>( ) 4-other</th>
</tr>
</thead>
</table>
__ 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 month, did you (did this person) go out to a restaurant or coffee shop?

<table>
<thead>
<tr>
<th>Respondent:</th>
<th>( ) 1-individual</th>
<th>( ) 2-family/friend</th>
<th>( ) 3-staff</th>
<th>( ) 4-other</th>
</tr>
</thead>
</table>
__ 2  Yes
__ 0  No
__ 9  Don’t know, no response, unclear response

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

__ __ times in past month
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

58) 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

58a) If yes, how many times in the past month?
__ __ times in past month

58b) 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

59) 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

59a) If yes, how many times in the past month?
__ __ times in past month
59b) **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

60) **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

60a) **If yes, how many times in the past year?**

- __ __ times in past year

60b) **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
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.
Section II

61) 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?)

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<tr>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>Person made the choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Person had some input</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Someone else chose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
<td></td>
<td></td>
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</table>

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

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

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<th></th>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>Looked at more than one place</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Visited one place only (current home)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Did not visit before moving in (or always lived there)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response, can’t remember – too long ago</td>
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</tbody>
</table>

63) 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?)

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<tbody>
<tr>
<td>2</td>
<td>Yes, chose people s/he lives with, or chose to live alone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Chose some people or had some input</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>No, someone else chose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
64) **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?*)

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</tr>
</tbody>
</table>

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

65) **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?*)

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</tr>
</tbody>
</table>

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

66) **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?*)

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</tr>
</tbody>
</table>

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
Questions 67-69 refer to choices made concerning paid work in the community.

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

<table>
<thead>
<tr>
<th>PS-8</th>
<th>Did you choose to work at ____________________________?</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Respondent: ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – no job in the community</td>
</tr>
<tr>
<td>2</td>
<td>Person made the choice</td>
</tr>
<tr>
<td>1</td>
<td>Person had some input</td>
</tr>
<tr>
<td>0</td>
<td>Someone else chose</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

### 68) How many places did you visit before working there?

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

<table>
<thead>
<tr>
<th></th>
<th>Respondent: ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – no job in the community</td>
</tr>
<tr>
<td>2</td>
<td>Looked at more than one place</td>
</tr>
<tr>
<td>1</td>
<td>Visited one place only (current job)</td>
</tr>
<tr>
<td>0</td>
<td>Did not visit beforehand</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response, can’t remember – too long ago</td>
</tr>
</tbody>
</table>
69) **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?)*

<table>
<thead>
<tr>
<th>Respondent: ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>__8</td>
</tr>
<tr>
<td>__2</td>
</tr>
<tr>
<td>__1</td>
</tr>
<tr>
<td>__0</td>
</tr>
<tr>
<td>__9</td>
</tr>
</tbody>
</table>

Questions 70-72 refer to choices made concerning day programs or other activities during the day.

70) **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?)*

<table>
<thead>
<tr>
<th>Respondent: ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>__8</td>
</tr>
<tr>
<td>__2</td>
</tr>
<tr>
<td>__1</td>
</tr>
<tr>
<td>__0</td>
</tr>
<tr>
<td>__9</td>
</tr>
</tbody>
</table>
71) 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

72) 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/other activity or day 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
73) **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?*)

<table>
<thead>
<tr>
<th>Respondent:</th>
<th>1-individual</th>
<th>2-family/friend</th>
<th>3-staff</th>
<th>4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>__2</td>
<td>Person chooses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>__1</td>
<td>Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>__0</td>
<td>Someone else chooses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>__9</td>
<td>Don’t know, no response, unclear response</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th>Respondent:</th>
<th>1-individual</th>
<th>2-family/friend</th>
<th>3-staff</th>
<th>4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>__8</td>
<td>NOT APPLICABLE - no case manager/service coordinator</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>__2</td>
<td>Yes, chose case manager/service coordinator</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>__1</td>
<td>Case manager/service coordinator was assigned but s/he can request a change if not satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>__0</td>
<td>No, someone else chose case manager/service coordinator</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>__9</td>
<td>Don’t know, no response, unclear response</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
RIGHTS

75) **Do people read your mail or email without asking you first?**

*(Other respondent – Does anyone read this person’s mail or email without permission?)*

<table>
<thead>
<tr>
<th>Response</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE - does not get mail/email</td>
</tr>
<tr>
<td>2</td>
<td>[Yes] – mail/email is read without permission</td>
</tr>
<tr>
<td>0</td>
<td>[No] – person reads own mail/email or others read with permission</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

76) **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?)*

<table>
<thead>
<tr>
<th>Response</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – no friends or visitors, or no friends visit your home</td>
</tr>
<tr>
<td>2</td>
<td>Can be alone with friends or visitors</td>
</tr>
<tr>
<td>0</td>
<td>There are rules against being alone with friends or visitors</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>
77) **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?)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE - doesn’t have access or unable to use phone/internet</td>
</tr>
<tr>
<td>2</td>
<td>Yes, can use anytime, either independently or with assistance</td>
</tr>
<tr>
<td>0</td>
<td>No, there are rules/restrictions on use of phone/internet</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

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

78) **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.)*

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

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

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>NOT APPLICABLE – there is no self-advocacy group in the area</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td>Had the opportunity but chose not to participate</td>
</tr>
<tr>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

**Respondent:** ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other
ACCESS TO NEEDED SERVICES

79) Do you get the services you need?

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

<table>
<thead>
<tr>
<th>Respondent: ( ) 1-individual ( ) 2-family/friend ( ) 3-staff ( ) 4-other</th>
</tr>
</thead>
<tbody>
<tr>
<td>__2  Yes → code Question 79a as NOT APPLICABLE</td>
</tr>
<tr>
<td>__1  Sometimes, or doesn’t get enough of the services needed</td>
</tr>
<tr>
<td>__0  No</td>
</tr>
<tr>
<td>__9  Don’t know, no response, unclear response</td>
</tr>
</tbody>
</table>

79a) 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                                                    |

80) Do you feel your support staff have the right training to meet your needs?

| __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                 |
81) **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
**INTERVIEWER FEEDBACK SHEET**

**Instructions to interviewers:**
Please take a few minutes to complete a feedback sheet after each interview you complete.

**Interviewer’s Initials or Code** (optional):______________

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:**

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

NCI Adult Consumer Survey 2009-10