MONEY FOLLOWS THE PERSON QUALITY OF LIFE SURVEY

The Money Follows the Person Quality of Life Survey (QoL) was designed to measure quality of life in seven domains: living situation, choice and control, access to personal care, respect/dignity, community integration/inclusion, overall life satisfaction, and health status. The target population for the survey includes people with disabilities and long-term illnesses who are transitioning from institutionalized care to a care setting in the community. The survey is to be administered to all participants at three points in time—just prior to transition, about 11 months after transition, and about 24 months after transition.

The QoL takes approximately 15 to 20 minutes to complete. A few questions are asked only before or after the transition, although most are asked at all three interviews. The survey is intended to be administered by an interviewer, in person, and in a private setting (e.g., an office in a nursing facility). Depending on the individual circumstances and the abilities of the participant, however, a proxy respondent or an assisted interview may be necessary. A proxy respondent is a person who answers the survey questions on the participant’s behalf. In an assisted interview, a third person is present to help the participant answer questions. This survey also has been translated into Spanish.

The development of the QoL survey was funded by the Centers for Medicare and Medicaid Services (CMS) under contract HHSM-500-2005-00025I (0002). The majority of questions are based on the Participant Experience Survey (Version 1.0 of Mental Retardation/Developmental Disabilities 2003, MEDSTAT Group, Inc.), although a few items are drawn from other instruments (ASK ME!, Cash and Counseling, National Core Indicator Survey (NCI), Quality of Life Enjoyment and Satisfaction Questionnaire—Short Form, and the Nursing Home Consumer Assessment of Health Plans Survey (NH CAHPS)).

The survey is free and available for use by the public; no one can use the survey for monetary purposes. Users are expected to include the following citation:

MFP QUALITY OF LIFE SURVEY

RESPONDENT INFORMATION

Respondent Name: ______________________________________

Respondent Street Address: ______________________________________

Respondent City: ______________________________________

Respondent State: ______________________________________

Respondent ZIP Code: ______________________________________

Medicaid ID number: ______________________________________

☐ Check here if the Sample Member is deceased and record date of death:

[_____] [_____] [_____] 
Month Day Year

⇒ GO TO END
Hello, my name is _______ and I am from ________. I’m here to ask for your help with an important study of Medicaid beneficiaries in the state of __________. The Quality of Life Survey, sponsored by the Centers for Medicare & Medicaid Services (CMS) and the state of __________, is an essential part of an evaluation of the Money Follows the Person Program, a program designed to help Medicaid beneficiaries transition out of institutional care into the community. I’d like to ask you some questions about your housing, access to care, community involvement, and your health and well-being. Results from the study will help CMS and the state of __________ evaluate how well its programs are meeting the needs of Medicaid beneficiaries like you.

Before we begin, let me assure you that all information collected will be kept strictly confidential and will not be reported in any way that identifies you personally. Your answers will be combined with the answers of others and reported in such a way that no single individual could ever be identified. Further, the information collected will not be used by anyone to determine your continuing eligibility for Medicaid benefits. We are collecting this information for research purposes only. However, I may be required to report any instances of abuse or neglect that you tell me about to authorities. Your participation is completely voluntary and if we come to any question you prefer not to answer, just tell me and we’ll move on to the next one.

If you have any questions, please stop me and ask me. Also, please let me know if you do not understand a question or if you would like me to repeat it.

MODULE 1: LIVING SITUATION

1. I’m going to ask you a few questions about the place you live. About how long have you lived (here/in your home)?

   Probe: Your best estimate is fine.

   Interviewer: If respondent indicates less than 1 month, enter 1 month.

   [_________]  [_________]  ✔ GO TO QUESTION 2

   DON’T KNOW ........................................ DK
   REFUSED ............................................. R

1a. Would you say you have lived here more than five years?

   Yes ............................................................... 01
   No................................................................. 02
   Don’t Know ................................................... DK
   Refused ......................................................... R

2. Interviewer: Does sample member live in a group home or nursing facility?

   Yes ................................................................. 01
   No........................................................................ 02
   Don’t Know ..................................................... DK
   Refused ........................................................... R
3. Do you like where you live?

Yes ........................................................ 01
No .......................................................... 02
Sometimes ............................................ 03
DON’T KNOW ........................................ DK
REFUSED ............................................... R

4. Did you help pick (this/that) place to live?

Yes ........................................................ 01
No .......................................................... 02
DON’T KNOW ........................................ DK
REFUSED ............................................... R

5. Do you feel safe living (here/there)?

Yes ........................................................ 01
No .......................................................... 02
DON’T KNOW ........................................ DK
REFUSED ............................................... R

5a. How often do you feel unsafe living (here/there)?

Sometimes ................................................... 01
Most of the Time .......................................... 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

6. Can you get the sleep you need without noises or other disturbances where you live?

Yes ........................................................ 01
No .......................................................... 02
Sometimes ............................................ 03
DON’T KNOW ........................................ DK
REFUSED ............................................... R

MODULE 2: CHOICE AND CONTROL

7. Can you go to bed when you want?

Yes ........................................................ 01
No .......................................................... 02
Sometimes .............................................. 03
DON’T KNOW ......................................... DK
REFUSED ................................................ R
8. Can you be by yourself when you want to?

Yes ........................................................ 01
No............................................................ 02
Sometimes ............................................ 03
DON’T KNOW .................................... DK
REFUSED ............................................. R

9. When you are at home, can you eat when you want to?

Yes ........................................................ 01
No............................................................ 02
Sometimes ............................................ 03
DON’T KNOW .................................... DK
REFUSED ............................................. R

10. Can you choose the foods that you eat?

Yes ........................................................ 01
No............................................................ 02
Sometimes ............................................ 03
DON’T KNOW .................................... DK
REFUSED ............................................. R

11. Can you talk on the telephone without someone listening in?

Yes ........................................................ 01
No............................................................ 02
Sometimes ............................................ 03
No access to telephone ......................... 04
DON’T KNOW .................................... DK
REFUSED ............................................. R

12. Can you watch TV when you want to?

Yes ........................................................ 01
No............................................................ 02
Sometimes ............................................ 03
No access to TV .................................... 04
DON’T KNOW .................................... DK
REFUSED ............................................. R
13. **[AFTER TRANSITION ONLY]** Some people get an allowance from the state to pay for the help or equipment they need. Do you get an allowance like this?

Yes ........................................................ 01
No.......................................................... 02 ➤ GO TO QUESTION 14
DON’T KNOW ......................................... DK ➤ GO TO QUESTION 14
REFUSED ................................................. R ➤ GO TO QUESTION 14

13a. **[AFTER TRANSITION ONLY]** In the last 12 months, what help or equipment did you buy with this allowance?

[Code all that apply]

- Modified Home ............................................. 01
- Modified Car ................................................. 02
- Special Equipment ......................................... 03
- Paid Help ...................................................... 04
- Transportation .............................................. 05
- Household Goods ......................................... 06
- Security Deposit ........................................... 07
- Other ............................................................. 08
- DON’T KNOW .............................................. DK
- REFUSED .................................................... R

**MODULE 3: ACCESS TO PERSONAL CARE**

14. Now I’d like to ask you about some everyday activities, like getting dressed or taking a bath. Some people have no problem doing these things by themselves. Other people need somebody to help them. First, does anyone help you with things like bathing, dressing, or preparing meals?

Probe: Please include any help received by another person, including cueing or standby assistance.

Yes ........................................................ 01
No.......................................................... 02 ➤ GO TO QUESTION 15
DON’T KNOW ......................................... DK ➤ GO TO QUESTION 15
REFUSED ................................................. R ➤ GO TO QUESTION 15

14a. Do any of these people get paid to help you?

Yes ................................................................. 01
No............................................................ 02 ➤ GO TO QUESTION 15
Don’t Know .................................................. DK ➤ GO TO QUESTION 15
Refused ....................................................... R ➤ GO TO QUESTION 15
14b. Do you pick the people who are paid to help you?

Yes ............................................................... 01
No ................................................................. 02
Don't Know .................................................. DK
Refused ......................................................... R

15. Do you ever go without a bath or shower when you need one?

Yes ............................................................... 01
No ................................................................. 02
DON'T KNOW .............................................. DK
REFUSED ......................................................... R

15a. How often do you go without a bath or shower when you need one? Would you say only sometimes or most of the time?

Sometimes ................................................... 01
Most of the time ............................................. 02
DON'T KNOW .............................................. DK
REFUSED ......................................................... R

15b. Is this because there is no one there to help you?

Probe: Please include any help received by another person, including cueing or standby assistance.

Yes ............................................................... 01
No ................................................................. 02
DON'T KNOW .............................................. DK
REFUSED ......................................................... R

16. Do you ever go without a meal when you need one?

Yes ............................................................... 01
No ................................................................. 02
DON'T KNOW .............................................. DK
REFUSED ......................................................... R

16a. How often do you go without a meal when you need one? Would you say only sometimes or most of the time?

Sometimes ................................................... 01
Most of the Time ............................................. 02
DON'T KNOW .............................................. DK
REFUSED ......................................................... R
16b. Is this because there is no one there to help you?

Probe: Please include any help received by another person, including cueing or standby assistance.

Yes ............................................................... 01
No........................................................................... 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

17. Do you ever go without taking your medicine when you need it?

Probes: Medicines are pills or liquids that are given to you by a doctor to help you feel better.

Yes ........................................................ 01
No .......................................................... 02  ➔ GO TO QUESTION 18
DON’T KNOW ....................................... DK  ➔ GO TO QUESTION 18
REFUSED ............................................. R  ➔ GO TO QUESTION 18

17a. How often do you go without taking your medicine when you need it? Would you say only sometimes or most of the time?

Sometimes ................................................... 01
Most of the Time............................................. 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

17b. Is this because there is no one there to help you?

Probe: Please include any help received by another person, including cueing or standby assistance.

Yes ............................................................... 01
No........................................................................... 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

18. Are you ever unable to use the bathroom when you need to?

Yes ........................................................ 01
No........................................................................... 02  ➔ GO TO QUESTION 19
DON’T KNOW ....................................... DK  ➔ GO TO QUESTION 19
REFUSED ............................................. R  ➔ GO TO QUESTION 19

18a. How often are you unable to use the bathroom when you need to? Would you say only sometimes or most of the time?

Sometimes ................................................... 01
Most of the Time .......................................... 02
DON’T KNOW ............................................... DK
REFUSED .................................................... R

18b. Is this because there is no one there to help you?

Probe: Please include any help received by another person, including cueing or standby assistance.

Yes ......................................................... 01
No ........................................................... 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

19. [AFTER TRANSITION ONLY] Have you ever talked with a case manager or support coordinator about any special equipment or changes to your home that might make your life easier?

Probe: Equipment means things like wheelchairs, canes, vans with lifts, and automatic door opener.

Yes ......................................................... 01
No ........................................................... 02 ➔ GO TO QUESTION 20
DON’T KNOW .............................................. DK ➔ GO TO QUESTION 20
Not Applicable ........................................... N/A ➔ GO TO QUESTION 20
REFUSED .................................................... R ➔ GO TO QUESTION 20

19a. [AFTER TRANSITION ONLY] What equipment or changes did you talk about?

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________

DON’T KNOW .............................................. DK
REFUSED .................................................... R

19b. [AFTER TRANSITION ONLY] Did you get the equipment or make the changes you needed?

Yes ......................................................... 01
No ........................................................... 02
In Process ................................................... 03
DON’T KNOW .............................................. DK
REFUSED .................................................... R

20. [AFTER TRANSITION ONLY] Please think about all the help you received during the last week around the house like cooking or cleaning. Do you need more help with things around the house than you are now receiving?

Yes ......................................................... 01
No ........................................................... 02
21. **[AFTER TRANSITION ONLY]** During the last week, did any family member or friends help you with things around the house?

Yes ........................................................ 01
No .......................................................... 02 ➤ **GO TO QUESTION 22**
DON’T KNOW ....................................... DK ➤ **GO TO QUESTION 22**
REFUSED ............................................. R ➤ **GO TO QUESTION 22**

21a. **[AFTER TRANSITION ONLY]** Please think about all the family members and friends who help you. About how many hours did they spend helping you yesterday?

Probe: Your best estimate is fine.

*Interviewer: if less than one hour, enter 1 hour.*

[_________] Hours

DON’T KNOW .............................................. DK
REFUSED .................................................... R

**MODULE 4: RESPECT AND DIGNITY**

Note: If Q14 = No, DK or R ➤ **GO TO QUESTION 27**

*Interviewer: For questions in this module, refer to your state’s policy on reporting any suspected incidents of abuse and neglect. For this survey, record only reports of current abuse.*

22. You said that you have people who help you. Do the people who help you treat you the way you want them to?

Yes ........................................................ 01 ➤ **GO TO QUESTION 23**
No .......................................................... 02 ➤ **GO TO QUESTION 23**
DON’T KNOW ....................................... DK ➤ **GO TO QUESTION 23**
REFUSED ............................................. R ➤ **GO TO QUESTION 23**

22a. How often do they not treat you the way you want them to? Would you say only sometimes or most of the time?

Sometimes ................................................... 01
Most of the Time .......................................... 02
DON’T KNOW ....................................... DK
REFUSED ............................................. R
23. Do the people who help you listen carefully to what you ask them to do?

Yes ........................................................ 01     ➤ GO TO QUESTION 24
No .................................................................. 02
DON’T KNOW ........................................ DK     ➤ GO TO QUESTION 24
REFUSED .................................................. R     ➤ GO TO QUESTION 24

23a. How often do they not listen to you? Would you say only sometimes or most of the time?

Sometimes ................................................... 01
Most of the time ............................................ 02
DON’T KNOW ........................................ DK
REFUSED .................................................. R

24. [Optional] Have you ever been physically hurt by any of the people who help you now?

Probe: Physically hurt means someone could have pushed, kicked, or slapped you.

Yes ........................................................ 01     ➤ GO TO QUESTION 25
No .......................................................... 02     ➤ GO TO QUESTION 25
DON’T KNOW ........................................ DK     ➤ GO TO QUESTION 25
REFUSED .................................................. R     ➤ GO TO QUESTION 25

24a. [Optional] What happened when the people who help you now physically hurt you?

DON’T KNOW ........................................ DK
REFUSED .................................................. R

24b. [Optional] How many times have you been physically hurt by the people who help you now?

Probe: Your best guess is fine.

[_________] Times

DON’T KNOW ........................................ DK
REFUSED .................................................. R

25. [Optional] Are any of the people who help you now mean to you or do they yell at you?

Probe: Do they treat you in a way that makes you feel bad or do they hurt your feelings?
25a. **[Optional]** How often are they mean to you? Would you say only sometimes or most of the time?

- Sometimes ................................................... 01
- Most of the Time........................................... 02
- DON’T KNOW .............................................. DK
- REFUSED .................................................... R

26. **[Optional]** Have any of the people who help you now ever taken your money or things without asking first?

- Yes ........................................................ 01
- No .......................................................... 02
- DON’T KNOW .............................................. DK
- REFUSED .................................................... R

26a. **[Optional]** How many times have they taken your money or things without asking first?

Probe: Your best guess is fine.

[_________] Times

- DON’T KNOW .............................................. DK
- REFUSED .................................................... R

**MODULE 5: COMMUNITY INTEGRATION AND INCLUSION**

27. I’d like to ask you a few questions about things you do. Can you see your friends and family when you want to see them?

*Interviewer: Code “yes” if respondent indicates that they have either gone to see friends or family or that friends and family have come to visit them.*

- Yes ........................................................ 01
- No .......................................................... 02
- DON’T KNOW .............................................. DK
- REFUSED .................................................... R

27a. How often do you see your friends and family when you want to see them? Would you say only sometimes or most of the time?

- Sometimes ................................................... 01
- Most of the Time .......................................... 02
28. Can you get to the places you need to go, like work, shopping, or the doctor’s office?

Yes ........................................................ 01
No .......................................................... 02 ➤ GO TO QUESTION 29
DON’T KNOW .............................................. DK ➤ GO TO QUESTION 29
REFUSED .................................................... R ➤ GO TO QUESTION 29

28a. How often do you get to the places you need to go, like work, shopping, or the doctor’s office? Would you say only sometimes or most of the time?

Sometimes ................................................... 01
Most of the Time .......................................... 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

29. Is there anything you want to do outside [the facility/your home] that you can’t do now?

Yes ........................................................ 01
No .......................................................... 02 ➤ GO TO QUESTION 30
DON’T KNOW .............................................. DK ➤ GO TO QUESTION 30
REFUSED .................................................... R ➤ GO TO QUESTION 30

29a. What would you like to do that you don’t do now?

______________________________________________

______________________________________________

______________________________________________

DON’T KNOW .............................................. DK
REFUSED .................................................... R

29b. What do you need to do these things?

______________________________________________

______________________________________________

______________________________________________

______________________________________________

DON’T KNOW .............................................. DK
REFUSED .................................................... R
30. When you go out, can you go by yourself or do you need help?

Go out Independently............................ 01 ➤ GO TO QUESTION 31
Need Help ............................................. 02
DON’T KNOW ....................................... DK ➤ GO TO QUESTION 31
REFUSED ............................................. R ➤ GO TO QUESTION 31

30a. Please think about all the help you received during the last week with getting around the community, such as shopping and going to a doctor’s appointment, do you need more help getting around than you are receiving?

Yes ............................................................... 01
No ................................................................. 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

31. [AFTER TRANSITION ONLY] Are you working for pay right now?

Probe: Do you get any money for doing work?

Yes ........................................................ 01 ➤ GO TO QUESTION 32
No .......................................................... 02
DON’T KNOW ........................................ DK ➤ GO TO QUESTION 32
REFUSED ............................................. R ➤ GO TO QUESTION 32

31a. [AFTER TRANSITION ONLY] Do you want to work for pay?

Yes ............................................................... 01
No ................................................................. 02
DON’T KNOW .............................................. DK
REFUSED .................................................... R

32. [AFTER TRANSITION ONLY] Are you doing volunteer work or working without getting paid?

Probe: Are you doing work but not getting any money for it?

Yes ................................................................. 01 ➤ GO TO QUESTION 33
No ................................................................. 02
DON’T KNOW .............................................. DK ➤ GO TO QUESTION 33
REFUSED .................................................... R ➤ GO TO QUESTION 33
32a. **[AFTER TRANSITION ONLY]** Would you like to do volunteer work or work without getting paid?

Probe: would you like to do work without getting paid for it?

Yes ............................................................... 01  
No ................................................................. 02  
DON’T KNOW .............................................. DK  
REFUSED .................................................... R

33. I’d like to ask you a few questions about how you get around. Do you go out to do fun things in your community?

Probe: These are things that you enjoy such as going to church, the movies or shopping?

Yes ........................................................ 01  
No .......................................................... 02  
DON’T KNOW ....................................... DK  
REFUSED ............................................. R

34. When you want to go somewhere, can you just go, do you have to make some arrangements, or do you have to plan many days ahead and ask people for help?

Decide and Go ...................................... 01  
Plan Some ............................................ 02  
Plan Many Days Ahead ......................... 03  
DON’T KNOW ....................................... DK  
REFUSED ............................................. R  
N/A…………………………………………NA

35. Do you miss things or have to change plans because you don’t have a way to get around easily?

Probe: Do you have to miss things because it is hard for you to get there?

Yes ........................................................ 01  
No .......................................................... 02  
Sometimes ............................................ 03  
DON’T KNOW ....................................... DK  
REFUSED ............................................. R

36. Is there any medical care, such as a medical treatment or doctor’s visits, which you have not received or could not get to within the past month?

Probe: The medical care includes doctor visits or medical treatments that you may need.

Yes ........................................................ 01  
No .......................................................... 02  
DON’T KNOW ....................................... DK  
REFUSED ............................................. R
MODULE 6: SATISFACTION

37. Taking everything into consideration, during the past week have you been happy or unhappy with the help you get with things around the house or getting around your community?

Happy .................................................... 01 ➤ GO TO QUESTION 37a
Unhappy ................................................ 02 ➤ GO TO QUESTION 37b
DON’T KNOW .................................... DK ➤ GO TO QUESTION 38
REFUSED .......................................... R ➤ GO TO QUESTION 38

37a Would you say you are a little happy or very happy?

A little happy ................................................. 01 ➤ GO TO QUESTION 38
Very happy .................................................. 02 ➤ GO TO QUESTION 38
Don’t Know ................................................... DK ➤ GO TO QUESTION 38
Refused ........................................................ R ➤ GO TO QUESTION 38

37b Would you say you are a little unhappy or very unhappy?

A little unhappy ............................................. 01
Very unhappy ............................................... 02
Don’t Know ................................................... DK
Refused ........................................................ R

38. Taking everything into consideration, during the past week have you been happy or unhappy with the way you live your life?

Happy .................................................... 01 ➤ GO TO QUESTION 38a
Unhappy ................................................ 02 ➤ GO TO QUESTION 38b
DON’T KNOW .................................... DK ➤ GO TO QUESTION 39
REFUSED .......................................... R ➤ GO TO QUESTION 39

38a. Would you say you are a little happy or very happy?

A little happy ................................................. 01 ➤ GO TO QUESTION 39
Very happy .................................................. 02 ➤ GO TO QUESTION 39
Don’t Know ................................................... DK ➤ GO TO QUESTION 39
Refused ........................................................ R ➤ GO TO QUESTION 39

38b. Would you say you are a little unhappy or very unhappy?

A little unhappy ............................................. 01
Very unhappy ............................................... 02
Don’t Know ................................................... DK
Refused ........................................................ R
MODULE 7: HEALTH STATUS

39. During the past week have you felt sad or blue?

   Yes ........................................................ 01
   No .......................................................... 02 ➤ GO TO QUESTION 40
   DON’T KNOW ........................................ DK ➤ GO TO QUESTION 40
   REFUSED .................................................. R ➤ GO TO QUESTION 40

39a. How often have you felt sad and blue? Would you say only sometimes or most of the time?

   Sometimes ................................................... 01
   Most of the Time ........................................... 02
   DON’T KNOW .............................................. DK
   REFUSED .................................................... R

40. During the past week have you felt irritable?

   Yes ........................................................ 01
   No .......................................................... 02 ➤ GO TO QUESTION 41
   DON’T KNOW ........................................ DK ➤ GO TO QUESTION 41
   REFUSED .................................................. R ➤ GO TO QUESTION 41

40a. How often have you felt irritable? Would you say only sometimes or most of the time?

   Probe: Irritable means grumpy or easily upset about things in your life.

   Sometimes ................................................... 01
   Most of the Time .......................................... 02
   DON’T KNOW .............................................. DK
   REFUSED .................................................... R

41. During the past week have you had aches and pains?

   Yes ........................................................ 01
   No .......................................................... 02 ➤ GO TO QUESTION 42
   DON’T KNOW ........................................ DK ➤ GO TO QUESTION 42
   REFUSED .................................................. R ➤ GO TO QUESTION 42

41a. How often do you have aches and pain? Would you say only sometimes or most of the time?

   Sometimes ................................................... 01
   Most of the Time ........................................... 02
   DON’T KNOW .............................................. DK
   REFUSED .................................................... R
Transportation

1. Not including medical appointments, can you get to the places that you want to go?
   Probe: Places such as the grocery store, church, and locations where you do fun things.
   Yes (1)
   No (2) **IF NO, GO TO QUESTION 1a.**
   Don’t Know (3)
   Refused (4)
   1a. If no, is it because transportation is not available?
   Yes (1)
   No (2)
   Don’t Know (3)
   Refused (4)
   Not Applicable (5)

Living Situation

2. Do you currently live with family or friends? *(Note: Do not include other residents/roommates as friends unless they intentionally moved in to a home together)*
   Yes (1)
   No (2)
   Don’t Know (3)
   Refused (4)

Contact with Family and Friends

3. Earlier we asked if you can see your friends and family when you want to. Would you say that you are able to communicate with friends or family when you want to? Probe: Communication could include phone calls, texts, emails, in-person visits, video conferencing, or other communication methods? *(Note: If unable to communicate using these methods, mark “Don’t Know.”)*
   Yes (1)
   No (2)
   Don’t Know (3)
   Refused (4)

Diet

4. We asked questions about choosing when and what you eat. Are there restrictions or requirements which affect your ability to eat what you want?
   Probe: Restrictions or requirements could include a diabetic diet, liquid nutrition or restrictions due to intolerances.
   Yes (1)
   No (2)
Don’t Know (3)
Refused (4)

**Housing Clarification**

5a. How would you describe your current living arrangement? *After the respondent provides a description, confirm the response fits into one of the categories below:*

- Skilled Nursing Facility, Nursing Home, or Hospital (1)
- Host Home (2)
- Group or personal care home of 4 or less individuals (not to include host home, could be a community living arrangement) (3)
- Group or personal care home of 5 or more individuals (Probe: could also be an assisted living community) (4)
- An apartment (5)
- A house (or condominium) (6)
- Other: (7) _______________________
- Don’t Know (8)
- Refused (9)

5b. Is this where you want to live?
- Yes (1)
- No (2) **IF NO, GO TO QUESTION 5b1.**
- Don’t Know (3)
- Refused (4)

5b1. If no, where do you want to live?
- Skilled Nursing Facility, Nursing Home, or Hospital (1)
- Host Home (2)
- Group or personal care home of 4 or less individuals (not to include host home, could be a community living arrangement) (3)
- Group or personal care home of 5 or more individuals (Probe: could also be an assisted living community) (4)
- An apartment (5)
- A house (or condominium) (6)
- Other: (7) _______________________
- Don’t Know (8)
- Refused (9)
- Not Applicable (10)

**Proxy Relationship**
6. If the respondent is a proxy, what is their relationship to the participant?
   - Family (1)
   - Friend (2)
   - Service/Care Provider (3)
   - Not Applicable (4)
   - Don’t Know (5)
   - Refused (6)

   **Health Status**

7. In general, would you say your health is:
   - Excellent (1)
   - Good (2)
   - Fair (3)
   - Poor (4)
   - Don’t Know (5)
   - Refused (6)

8. Do you have a doctor or clinic that you go to regularly?
   - Yes (1)
   - No (2) **IF NO, GO TO QUESTION 8a.**
   - Don’t Know (3)
   - Refused (4)

8a. Why? (Probe: Please describe the barriers you’ve experienced). *(Interviewer: write down participant/proxy responses)*

___________________________________________________________________
___________________________________________________________________

**Assistive technology devices and durable medical equipment**

9. What would you say is your primary disability or limitation: ______________________________
   Probe: What diagnosis or condition keeps you from doing things independently?

   After the respondent provides a primary disability, confirm that the response fits into one of the categories below:
   - Cognitive/Language [Developmental Disability, Traumatic Brain Injury (TBI)] (1)
   - Hearing [Deaf, hard of hearing, hearing loss] (2)
   - Mental/Emotional [Severe and Persistent Mental Illness (SPMI)] (3)
   - Physical [Mobility loss, dexterity, or stamina] (4)
   - Vision [Blind, low vision, vision loss] (5)
   - Not Applicable (6)
   - Don't Know (7)
   - Refused (8)
10. Is there an area of your life at home where you would like to increase your independence?
   YES (1) If YES, go to 10a.
   No (2)
   Not Applicable (3)
   Don’t Know (4)
   Refused (5)

10a. What area? ______________________________ (Prompts – getting around inside your home, bathing, dressing, toileting, communicating, preparing meals.)

11. I would like to talk with you about any devices or special equipment you might use. Assistive devices include any item, piece of equipment, or technology that helps people live more easily in their homes or do things for themselves. Are there any devices or special equipment that could assist you to remain as independent as possible in your home?
   YES (1) If YES, go to 11a.
   No (2)
   Not Applicable (3)
   Don’t Know (4)
   Refused (5)

11a. What type of device or special equipment: __________________________(Number)_______

   **Code response based on the following categories of assistive devices or special equipment:**
   
   | 1. home modifications, such as entrance ramps, wide doorways, raised toilet seat, roll-in shower, grab bars, etc. |
   | 2. mobility devices, such as walker, cane, wheelchair, scooter, Hoyer lift, stair lift, etc. |
   | 3. computer access aids, such as touch screens, trackball mouse, speech to text software, adjustable workstations, etc. |
   | 4. communication aids, such as communication boards, speech output devices, switches to control devices, voice activated telephones, etc. |
   | 5. devices for people who are deaf or hard of hearing, such as TDD, TTY, phone re |
   | 6. devices for people who are blind, legally blind or have low vision, such as Braille translation software, large button telephone, magnification, CCTV, etc. |
   | 7. environmental controls to control items in your environment by voice or switch activation, such as lights or lamps, room temperature, TV, door opener/closer, etc. |
   | 8. Lifeline or a 24 hour life alert system |
   | 9. Transportation aids, such as a van lift or ramp, adaptive driving controls, etc. |
   | 10. Other devices or equipment (describe): |

**Employment**

12. **ASK ONLY IF ANSWERED YES TO WANTING TO WORK OR VOLUNTEER in either Question 31a. OR 32a.**
   Earlier in the survey you were asked about your interest in working for pay or doing volunteer
work. What keeps you from working for pay or doing volunteer work? (*Interviewer: write down participant/proxy responses*)

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

**VERIFY THE ADDRESS WHERE THE PARTICIPANT RESIDES**

CLOSEOUT

42. Those are all the questions I have you now. We would like to talk with you in about a year or so to find out how you are doing. In case we have trouble reaching you, what is the name, address, and phone number of a close relative or friend who is not living with you and is likely to know your location in the future? For example, a mother, father, brother, sister, aunt, uncle, or close friend.

No Contact Available............................ 01
Contact Available ..................................... 02

GO TO QUESTION 43

42a. Contact Name: _____________________________

42b. Contact Street Address: _____________________________

42c. Contact City: _____________________________

42d. Contact State: _____________________________

42e. Contact ZIP: _____________________________

42f. Contact Phone: _____________________________

43. *Interviewer: Did you complete the interview with the sample member alone, the sample member who was assisted by another, or with a proxy?*

Sample Member Alone................................. 01
Sample Member with Assistance .................. 02
Proxy .................................................. 03

44. *Interviewer: Record date the interview was completed:*

[_____] [_____] [_____] Month Day Year

END INTERVIEW