Home- and Community-Based Services Experience Survey

Primary Survey

Date: March 8, 2012

Contents
Instructions For Vendor ................................................................................................................................ 3
Instructions For Interviewer .......................................................................................................................... 4
Introduction ................................................................................................................................................... 5
Identification Questions ................................................................................................................................ 6
Services And Supports From Personal Assistant And Behavioral Staff ....................................................... 8
    Getting Needed Services From Personal Assistant And Behavioral Health Staff ................................ 8
    How Well Personal Assistant And Behavioral Health Staff Communicate And Treat You .............. 11
Services And Support From Homemakers .................................................................................................. 13
    Getting Needed Services From Homemakers ..................................................................................... 13
    How Well Homemakers Communicate And Treat You ..................................................................... 14
Your Case Manager .................................................................................................................................... 16
Choosing Your Services ............................................................................................................................. 18
Transportation ............................................................................................................................................. 19
Personal Safety ............................................................................................................................................ 20
Community Inclusion And Empowerment ................................................................................................. 23
Supplemental Employment Module ............................................................................................................ 26
About You ................................................................................................................................................... 31
The scripts provided in this document use the questions from the Home- and Community-Based Services (HCBS) Experience Survey.

If you plan to add your own items to this instrument, insert them just before the “About You” section.

Response Options:
- All questions include a “REFUSED” response option. In this case, “refused” means the respondent did not provide any answer to the question.
- For response options of “never, sometimes, usually, and always”, if the respondent cannot use that scale, the alternate version of the survey should be used which uses the response options of “mostly yes and mostly no.” These response options are reserved for individuals who find the “never, sometimes, usually, always” response scale cognitively challenging.
- All questions include a “DON’T KNOW” response option. This is used when the respondent indicates that he or she does not know the answer and cannot provide a response to the question.
- All questions include an “UNCLEAR” response option. This should be used when a respondent answers, but the interviewer cannot clarify the meaning of the response even after minor probing or the response is completely unrelated to the question—for example, the response to “Do your homemakers listen carefully to what you say?” is “I like to sit by Mary.”
- Some responses have skip patterns, which are expressed as “if ‘X’ go to Q#.” That means the interviewer should skip all following questions until Q#.

Singular/Plural: Modify items such that the interviewer can use the correct form (singular or plural) of the survey item.

Program-Specific Terms: Where appropriate, add in the program-specific terms for staff (e.g., [program-specific term for these types of staff]) but allow the interviewer to modify the term based on the respondent’s choice of the word. It will be necessary to obtain information for program-specific terms. State administrative data should include the following information:

- Agency name(s)
- Titles of staff who provide care
- Names of staff who provide care
- Activities that each staff member provides (this will help with identifying appropriate skip logic)
- Hours of staff who come to the home
Please be aware that to conduct this survey, you may need approval from an Institutional Review Board (IRB). Regardless of whether you need IRB approval, you must get the respondent’s consent to participate in the survey. In addition, there may be state statutory requirements that apply to interviewers regarding reporting suspected abuse and neglect. Although information should be kept confidential, these state laws may mandate reporting in certain cases and should be reviewed prior to implementation.

**INSTRUCTIONS FOR INTERVIEWER**

- Interviewers should read aloud all text that appears in initial uppercase and lowercase letters. Text that appears in **bold, lowercase letters** should be emphasized.

- Text in *italics and in braces* will be provided by the program. However, if the interviewee provides another term, use that in place of the program-specific term wherever indicated. For example, some interviewees may refer to their case manager by another title, which should be used instead throughout the survey.

- Text in uppercase letters should **not** be read aloud. For example, “DON’T KNOW,” “REFUSED,” or “UNCLEAR RESPONSE” answer categories appear in uppercase and should not be read to the respondent, but may be used for coding a response. In addition, items that ask the interviewer to INDICATE GENDER and WHETHER SOMEONE HELPED RESPONDENT COMPLETE THIS SURVEY AND HOW should not be read aloud. Interviewer instructions appear in [UPPERCASE LETTERS ENCLOSED IN BRACKETS] and also should not be read aloud.

- Skip patterns are indicated with a ➔ [GO TO Q#].

- Record each response by selecting the box to the left of the answer.
Hello, my name is {interviewer name}. I am from {name of organization}. How are you today? Thank you again for letting me talk with you. I am very interested in hearing about your life and your experience with the people who help you. This information will be used to help improve services for people with disabilities.

Before we start, let me tell you a few things about this survey. This interview should take about 20 minutes. You can choose whether or not you want to answer each question. You can also choose if you want to be interviewed at all. The services you get will not be affected by your answers. Your services will not change whether you decide to answer a question or not.

All of your answers are completely confidential. None of the people who help you will know what you say, unless you want them in the room while we talk. {ADD STATE-SPECIFIC LANGUAGE HERE REGARDING MANDATED REPORTING, IF APPROPRIATE.}

Some people may not be able to answer a question quickly. Some people may not know the answer. This is not a test. If you don’t know the answer to a question, or can’t remember it, let me know. “I don’t remember” could be the best answer.

Also, we can take as much time as you would like to go through the survey. I am not in a hurry. Let me know if you would like me to repeat a question. We can take a break if you would like. We can also stop any time you want.

Do you have any questions before we start?

[ANSWER ANY QUESTIONS RAISED BY THE RESPONDENT, THEN GO TO QUESTION 1.]
IDENTIFICATION QUESTIONS

This survey is about the people who are paid to help you in your home and community with everyday activities. People might be paid to help you get ready in the morning, with housework, go places, or get mental health services. It also asks about the services you get.

ID-1. Our records show that you get {program specific term for personal assistance}. Is that right?
- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

ID-2. What do you call the person or people who give you {program specific term for personal assistance}? For example, do you call them {program specific term for personal assistance}, staff, personal care attendants, PCAs, workers, or something else?

ID-3. Our records show that you get {program specific term for behavioral health specialist services}. Is that right?
- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

ID-4. What do you call the person or people who give you {program specific term for behavioral health specialist services}? For example, do you call them {program-specific term for behavioral health specialists}, counselors, peer supports, recovery assistants, or something else?

ID-5. Our records show that you get {program specific term for homemaker services}. Is that right?
- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

ID-6. What do you call the person or people who give you {program specific term for homemaker services}? For example, do you call them {program-specific term for homemaker}, aides, homemakers, chore workers, or something else?
ID-7. [IF RESPONDENT REPORTS HAVING PCA AND HOMEMAKER STAFF, THEN ASK]. Do the same people who help you with everyday activities also help you to clean your home?

- YES ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS
- NO ➔ ASK PCA ITEMS AND SELECT HOMEMAKER ITEMS SEPARATELY
- DON’T KNOW ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS
- REFUSED ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS
- UNCLEAR RESPONSE ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS

ID-8. Our records show that you get {program specific term for case manager services} to help make sure that you have all the services you need, like help from {list of assistance identified previously}. Is that right?

- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

ID-9. What do you call the person who gives you {program specific term for case manager services}? For example, do you call the person a {program-specific term for case manager}, case manager, care manager, service coordinator, supports coordinator, social worker, or something else?

[RESPONDENT TITLES SHOULD BE AUTOMATICALLY ADDED INTO SECTIONS, WHEREEVER IT STATES {personal assistance/behavioral health staff}, {case manager}, or {homemaker}.]

[IF RESPONSE IS NEGATIVE TO ALL SUPPORTS, THEN GO TO CHOOSING YOUR SERVICES SECTION.]
SERVICES AND SUPPORTS FROM PERSONAL ASSISTANT AND BEHAVIORAL STAFF

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

1. First I would like to talk about the {personal assistance/behavioral health staff} who are paid to help you complete everyday activities—for example, getting dressed, using the bathroom, taking a bath or shower, or going places. How often do {personal assistance/behavioral health staff} come to work on time? Would you say . . .

☐ Never,
☐ Sometimes,
☐ Usually, or
☐ Always?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

2. How often do {personal assistance/behavioral health staff} work as long as they are supposed to? Would you say . . .

☐ Never,
☐ Sometimes,
☐ Usually, or
☐ Always?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

3. Sometimes staff cannot come to work on a day that they are scheduled. When staff cannot come to work on a day that they are scheduled, does someone let you know if {personal assistance/behavioral health staff} cannot come that day?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

4. Do you need help from {personal assistance/behavioral health staff} to get dressed or to take a shower or bath?

☐ YES
☐ NO ➔ [GO TO Q8]
☐ DON’T KNOW ➔ [GO TO Q8]
☐ REFUSED ➔ [GO TO Q8]
☐ UNCLEAR RESPONSE ➔ [GO TO Q8]
5. Do you always get dressed or take a shower or bath when you need one?
   - ☐ YES ➔ [GO TO Q7]
   - ☐ NO
   - ☐ DON’T KNOW ➔ [GO TO Q7]
   - ☐ REFUSED ➔ [GO TO Q7]
   - ☐ UNCLEAR RESPONSE ➔ [GO TO Q7]

6. Is this because there are no {personal assistance/behavioral health staff} to help you?
   - ☐ YES
   - ☐ NO
   - ☐ DON’T KNOW
   - ☐ REFUSED
   - ☐ UNCLEAR RESPONSE

7. How often do {personal assistance/behavioral health staff} make sure you have enough privacy when you get dressed or take a shower or bath? Would you say…
   - ☐ Never,
   - ☐ Sometimes,
   - ☐ Usually, or
   - ☐ Always?
   - ☐ DON’T KNOW
   - ☐ REFUSED
   - ☐ UNCLEAR RESPONSE

8. Do you need help from {personal assistance/behavioral health staff} with your meals, such as help making or cooking meals or help eating?
   - ☐ YES
   - ☐ NO ➔ [GO TO Q11]
   - ☐ DON’T KNOW ➔ [GO TO Q11]
   - ☐ REFUSED ➔ [GO TO Q11]
   - ☐ UNCLEAR RESPONSE ➔ [GO TO Q11]

9. Are you always able to get something to eat when you are hungry?
   - ☐ YES ➔ [GO TO Q11]
   - ☐ NO
   - ☐ DON’T KNOW ➔ [GO TO Q11]
   - ☐ REFUSED ➔ [GO TO Q11]
   - ☐ UNCLEAR RESPONSE ➔ [GO TO Q11]

10. Is this because there are no {personal assistance/behavioral health staff} to help you?
    - ☐ YES
    - ☐ NO
    - ☐ DON’T KNOW
    - ☐ REFUSED
    - ☐ UNCLEAR RESPONSE
11. Sometimes people need help taking their medicines, such as reminders, help pouring them, or setting up their pills. Do you need help from \{personal assistance/behavioral health staff\} to take your medicines?

☐ YES  
☐ NO ➔ [GO TO Q14]  
☐ DON’T KNOW ➔ [GO TO Q14]  
☐ REFUSED ➔ [GO TO Q14]  
☐ UNCLEAR RESPONSE ➔ [GO TO Q14]

12. Do you always take your medicine when you are supposed to?

☐ YES ➔ [GO TO Q14]  
☐ NO  
☐ DON’T KNOW ➔ [GO TO Q14]  
☐ REFUSED ➔ [GO TO Q14]  
☐ UNCLEAR RESPONSE ➔ [GO TO Q14]

13. Is this because there are no \{personal assistance/behavioral health staff\} to help you?

☐ YES  
☐ NO  
☐ DON’T KNOW  
☐ REFUSED  
☐ UNCLEAR RESPONSE

14. Help with toileting includes helping someone get on and off the toilet or helping to change disposable briefs or pads. Do you need help from \{personal assistance/behavioral health staff\} with toileting?

☐ YES  
☐ NO ➔ [GO TO Q16]  
☐ DON’T KNOW ➔ [GO TO Q16]  
☐ REFUSED ➔ [GO TO Q16]  
☐ UNCLEAR RESPONSE ➔ [GO TO Q16]

15. Do you get all the help you need with toileting from \{personal assistance/behavioral health staff\} when you need it?

☐ YES  
☐ NO  
☐ DON’T KNOW  
☐ REFUSED  
☐ UNCLEAR RESPONSE
How well personal assistant and behavioral health staff communicate and treat you.

16. How often are {personal assistance/behavioral health staff} nice and polite to you? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

17. How often are the explanations {personal assistance/behavioral health staff} give you hard to understand because of an accent or the way {personal assistance/behavioral health staff} speak English? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

18. How often do {personal assistance/behavioral health staff} treat you the way you want them to? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

19. How often do {personal assistance/behavioral health staff} explain things in a way that is easy to understand? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE
20. How often do {personal assistance/behavioral health staff} listen carefully to you?
   Would you say . . .
   □ Never,
   □ Sometimes,
   □ Usually, or
   □ Always?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

21. Do you feel {personal assistance/behavioral health staff} know what kind of help you need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

22. Do {personal assistance/behavioral health staff} encourage you to do things for yourself if you can?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

23. How would you rate the help you get from {personal assistance/behavioral health staff}?
   Would you say . . .
   □ Excellent,
   □ Very good,
   □ Good,
   □ Fair, or
   □ Poor?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

24. Would you recommend the {personal assistance/behavioral health staff} who help you to your family and friends if they needed help with everyday activities? Would you say you recommend the {personal assistance/behavioral health staff} . . .
   □ Definitely no,
   □ Probably no,
   □ Probably yes, or
   □ Definitely yes?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE
SERVICES AND SUPPORT FROM HOMEMAKERS

The next several questions are about the {homemakers}, the staff who are paid to help you do tasks around the home—such as cleaning, grocery shopping, or doing laundry.

GETTING NEEDED SERVICES FROM HOMEMAKERS

25. How often do {homemakers} come to work on time? Would you say . . .
   ☐ Never,
   ☐ Sometimes,
   ☐ Usually, or
   ☐ Always?
   ☐ DON’T KNOW
   ☐ REFUSED
   ☐ UNCLEAR RESPONSE

26. How often do {homemakers} work as long as they are supposed to? Would you say . . .
   ☐ Never,
   ☐ Sometimes,
   ☐ Usually, or
   ☐ Always?
   ☐ DON’T KNOW
   ☐ REFUSED
   ☐ UNCLEAR RESPONSE

27. Do your household tasks, like cleaning and laundry, always get done when you need them to? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]
   ☐ YES ➔ [GO TO Q29]
   ☐ NO
   ☐ DON’T KNOW NO ➔ [GO TO Q29]
   ☐ REFUSED NO ➔ [GO TO Q29]
   ☐ UNCLEAR RESPONSE ➔ [GO TO Q29]

28. Is this because there are no {homemakers} to help you? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]
   ☐ YES
   ☐ NO
   ☐ DON’T KNOW
   ☐ REFUSED
   ☐ UNCLEAR RESPONSE
HOW WELL HOMEMAKERS COMMUNICATE AND TREAT YOU

The next several questions ask about how \{homemakers\} treat you.

29. How often are \{homemakers\} nice and polite to you? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

30. How often are the explanations \{homemaker\} give you hard to understand because of an accent or the way \{homemaker\} speak English? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

31. How often do \{homemakers\} treat you the way you want them to? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

32. How often do \{homemakers\} listen carefully to you? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

33. Do you feel \{homemakers\} know what kind of help you need?
   - YES
34. How would you rate the help you get from {homemakers}? Would you say . . .

- Excellent,
- Very good,
- Good,
- Fair, or
- Poor?
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

35. Would you recommend the {homemakers} who help you to your family and friends if they needed {respondent-specific term for homemaker services}? Would you say you recommend the {homemakers} . . .

- Definitely no,
- Probably no,
- Probably yes, or
- Definitely yes?
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
YOUR CASE MANAGER

Now I would like to talk to you about your {case manager}, the person who helps make sure you have the services you need.

36. Do you know who your {case manager} is?
   - YES
   - NO ➔ [GO TO Q44]
   - DON’T KNOW ➔ [GO TO 44]
   - REFUSED ➔ [GO TO Q44]
   - UNCLEAR RESPONSE ➔ [GO TO Q44]

37. Can you contact this {case manager} when you need to?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

38. Some people need to get equipment, such as wheelchairs or grab bars, to help them, and other people need their equipment replaced or repaired. Have you asked this {case manager} for help with getting or fixing equipment?
   - YES
   - NO ➔ [GO TO Q40]
   - DON’T KNOW ➔ [GO TO Q40]
   - REFUSED ➔ [GO TO Q40]
   - UNCLEAR RESPONSE ➔ [GO TO Q40]

39. Did this {case manager} work with you when you asked for help with getting or fixing equipment?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

40. Have you asked this {case manager} for help in getting any changes to your services, such as more help from {personal assistance/behavioral health staff and/or homemakers if applicable}, or for help with getting places or finding a job?
   - YES
   - NO ➔ [GO TO 42]
   - DON’T KNOW ➔ [GO TO 42]
   - REFUSED ➔ [GO TO 42]
   - UNCLEAR RESPONSE ➔ [GO TO 42]
41. Did this *case manager* work with you when you asked for help with getting other changes to your services?

- [ ] YES
- [ ] NO
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

42. How would you rate the help you get from the *case manager*? Would you say . . .

- [ ] Excellent,
- [ ] Very good,
- [ ] Good,
- [ ] Fair, or
- [ ] Poor?
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

43. Would you recommend the *case manager* who helps you to your family and friends if they needed *respondent-specific term for case-management services*? Would you say you recommend the *case manager* . . .

- [ ] Definitely no,
- [ ] Probably no,
- [ ] Probably yes, or
- [ ] Definitely yes?
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE
44. A [program-specific term for “service plan”]—sometimes called a care plan, goals, or service plan—lists the services you need and who will provide them. Did you work with someone to develop your [program-specific term for “service plan”]?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

45. Does your [program-specific term for “service plan”] include . . .

☐ None of the things that are important to you,
☐ Some of the things that are important to you,
☐ Most of the things that are important to you, or
☐ All of the things that are important to you?
☐ DON’T KNOW ➔ [GO TO 47]
☐ REFUSED ➔ [GO TO 47]
☐ UNCLEAR RESPONSE ➔ [GO TO 47]

46. Do you feel {personal assistance/behavioral health staff} know what’s on your [program-specific term for “service plan”], including the things that are important to you?

☐ YES
☐ NO
☐ DOES NOT HAVE PERSONAL ASSISTANCE STAFF
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

47. Who would you talk to if you wanted to change your [program-specific term for “service plan”]? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

☐ CASE MANAGER
☐ OTHER STAFF
☐ FAMILY/FRIENDS
☐ OTHER
☐ I DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
TRANSPORTATION

The next questions ask about how you get to places in your community.

48. Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. How often do you have a way to get to your medical appointments? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

49. Do you use a van or some other transportation service? Do not include a van you own.
   - YES
   - NO ➔ [GO TO Q52]
   - DON’T KNOW ➔ [GO TO Q52]
   - REFUSED ➔ [GO TO Q52]
   - UNCLEAR RESPONSE ➔ [GO TO Q52]

50. Are you able to get in and out of this ride easily?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

51. How often does this ride arrive on time to pick you up? Would you say . . .
   - Never,
   - Sometimes,
   - Usually, or
   - Always?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE
PERSONAL SAFETY

The next few questions ask about your personal safety.

52. Who would you contact in case of an emergency?

☐ FAMILY MEMBER OR FRIEND
☐ CASE MANAGER
☐ AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES
☐ PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)
☐ 9–1–1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)
☐ SOMEONE ELSE, PLEASE SPECIFY ____________________
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

53. Is there a person you can talk to if someone hurts you or does something to you that you don’t like?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

The next few questions ask if anyone paid to help you now is treating you badly. This includes {personal assistance/behavioral health staff, homemakers, or your case manager}. We are asking everyone the next questions—not just you. [ADD STATE-SPECIFIC LANGUAGE HERE REGARDING MANDATED REPORTING, IF APPROPRIATE—“I want to remind you that, although your answers are confidential, I have a legal responsibility to tell {STATE} if I hear something that makes me think you are being hurt or are in danger”]

54. Do any of the {personal assistance/behavioral health staff, homemakers, or your case managers} that you have now take your money or your things without asking you first?

☐ YES
☐ NO ➔ [GO TO Q57]
☐ DON’T KNOW ➔ [GO TO Q57]
☐ REFUSED ➔ [GO TO Q57]
☐ UNCLEAR RESPONSE ➔ [GO TO Q57]

55. Is someone working with you to fix this problem?

☐ YES
☐ NO ➔ [GO TO Q57]
☐ DON’T KNOW ➔ [GO TO Q57]
☐ REFUSED ➔ [GO TO Q57]
☐ UNCLEAR RESPONSE ➔ [GO TO Q57]
56. Who is working with you to fix this problem? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]
   - FAMILY MEMBER OR FRIEND
   - CASE MANAGER
   - AGENCY
   - SOMEONE ELSE, PLEASE SPECIFY ___________________
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

57. Do any {staff} that you have now yell, swear, or curse at you?
   - YES
   - NO →[GO TO Q60]
   - DON’T KNOW →[GO TO Q60]
   - REFUSED →[GO TO Q60]
   - UNCLEAR RESPONSE →[GO TO Q60]

58. Is someone working with you to fix this problem?
   - YES
   - NO →[GO TO Q60]
   - DON’T KNOW →[GO TO Q60]
   - REFUSED →[GO TO Q60]
   - UNCLEAR RESPONSE →[GO TO Q60]

59. Who is working with you to fix this problem? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]
   - FAMILY MEMBER OR FRIEND
   - CASE MANAGER
   - AGENCY
   - SOMEONE ELSE, PLEASE SPECIFY ___________________
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

60. Do any {staff} that you have now hit you or hurt you?
   - YES
   - NO →[GO TO Q63]
   - DON’T KNOW →[GO TO Q63]
   - REFUSED →[GO TO Q63]
   - UNCLEAR RESPONSE →[GO TO Q63]
61. Is someone working with you to fix this problem?

☐ YES
☐ NO ➔ [GO TO Q63]
☐ DON’T KNOW ➔ [GO TO Q63]
☐ REFUSED ➔ [GO TO Q63]
☐ UNCLEAR RESPONSE ➔ [GO TO Q63]

62. Who is working with you to fix this problem? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

☐ FAMILY MEMBER OR FRIEND
☐ CASE MANAGER
☐ AGENCY
☐ SOMEONE ELSE, PLEASE SPECIFY ________________________
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
COMMUNITY INCLUSION AND EMPOWERMENT

Now I'd like to ask you about the things you do in your community.

63. Do you have any **family** members who live nearby? Do not include family members you live with.

- YES
- NO ➔ [GO TO Q65]
- DON’T KNOW ➔ [GO TO Q65]
- REFUSED ➔ [GO TO Q65]
- UNCLEAR RESPONSE ➔ [GO TO Q65]

64. When you want to, how often can you get together with these family members who live nearby? Would you say . . .

- Never,
- Sometimes,
- Usually, or
- Always?
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

65. Do you have any **friends** who live nearby?

- YES
- NO ➔ [GO TO Q67]
- DON’T KNOW ➔ [GO TO Q67]
- REFUSED ➔ [GO TO Q67]
- UNCLEAR RESPONSE ➔ [GO TO Q67]

66. When you want to, how often can you get together with these friends who live nearby? Would you say . . .

- Never,
- Sometimes,
- Usually, or
- Always?
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
67. When you want to, how often can you do things in the community that you like, such as shopping or going out to eat? Would you say . . .

☐ Never
☐ Sometimes
☐ Usually, or
☐ Always?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

68. Do you need more help than you get now from {personal assistance/behavioral health staff} to do things in your community?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

69. Do you take part in deciding what you do each day—for example, what you do for fun at home or in your community?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

70. Do you take part in deciding when you do things each day—for example, deciding when you get up, eat, or go to bed?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

The next few questions ask about making changes in {personal assistance/behavioral health staff, homemakers, and case manager}.

71. Have you asked for a change in {personal assistance staff, behavioral health staff, homemakers, or case manager}?

☐ YES
☐ NO ➔ [GO TO Q74]
☐ DON’T KNOW ➔ [GO TO Q74]
☐ REFUSED ➔ [GO TO Q74]
☐ UNCLEAR RESPONSE ➔ [GO TO Q74]
72. Did someone work with you when you asked to change {personal assistance/behavioral health staff, homemakers, or case manager}?

☐ YES
☐ NO ➔ [GO TO EM]
☐ DON’T KNOW ➔ [GO TO EM]
☐ REFUSED ➔ [GO TO EM]
☐ UNCLEAR RESPONSE ➔ [GO TO EM]

73. Who did you work with when you asked to change {personal assistance/behavioral health staff, homemakers, or case manager}?

☐ Family MEMBER OR FRIEND ➔ [GO TO EM OR Q75]
☐ Case MANAGER ➔ [GO TO EM OR Q75]
☐ Agency ➔ [GO TO EM OR Q75]
☐ Someone ELSE, PLEASE SPECIFY ___________________ ➔ [GO TO EM OR Q75]
☐ DON’T KNOW ➔ [GO TO EM OR Q75]
☐ REFUSED ➔ [GO TO EM OR Q75]
☐ UNCLEAR RESPONSE ➔ [GO TO EM OR Q75]

74. Do you know you can ask someone to change {personal assistance/behavioral health staff, homemakers, or case manager}?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
SUPPLEMENTAL EMPLOYMENT MODULE

EM1. Do you work for pay at a job?
☐ YES → [GO TO QEM9]
☐ NO
☐ DON’T KNOW → [GO TO Q75]
☐ REFUSED → [GO TO Q75]
☐ UNCLEAR RESPONSE → [GO TO Q75]

EM2. Do you want to work for pay at a job?
☐ YES
☐ NO → [GO TO EM4]
☐ DON’T KNOW → [GO TO Q75]
☐ REFUSED → [GO TO Q75]
☐ UNCLEAR RESPONSE → [GO TO Q75]

EM3. Sometimes people feel that something is holding them back from working when they want to. Is this true for you? If so, what is holding you back from working? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)
☐ BENEFITS → [GO TO EM5]
☐ HEALTH CONCERNS → [GO TO EM5]
☐ DON’T KNOW ABOUT JOB RESOURCES → [GO TO EM5]
☐ ADVICE FROM OTHERS → [GO TO EM5]
☐ TRAINING/EDUCATION NEED → [GO TO EM5]
☐ LOOKING AND CAN’T FIND WORK → [GO TO EM5]
☐ ISSUES WITH PREVIOUS EMPLOYMENT → [GO TO EM5]
☐ TRANSPORTATION → [GO TO EM5]
☐ CHILD CARE → [GO TO EM5]
☐ OTHER (_____________________________) → [GO TO EM5]
☐ NOTHING IS HOLDING ME BACK → [GO TO EM5]
☐ DON’T KNOW → [GO TO EM5]
☐ REFUSED → [GO TO EM5]
☐ UNCLEAR RESPONSE → [GO TO EM5]
EM4. Sometimes people would like to work for pay, but feel that something is holding them back. Is this true for you? If so, what is holding you back from wanting to work? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

☐ BENEFITS ➔ [GO TO 75]
☐ HEALTH CONCERNS ➔ [GO TO 75]
☐ DON’T KNOW ABOUT JOB RESOURCES ➔ [GO TO 75]
☐ ADVICE FROM OTHERS ➔ [GO TO 75]
☐ TRAINING/EDUCATION NEED ➔ [GO TO 75]
☐ LOOKING AND CAN’T FIND WORK ➔ [GO TO 75]
☐ ISSUES WITH PREVIOUS EMPLOYMENT ➔ [GO TO 75]
☐ TRANSPORTATION ➔ [GO TO 75]
☐ CHILD CARE ➔ [GO TO 75]
☐ OTHER (______________________________) ➔ [GO TO 75]
☐ NOTHING/DOESN’T WANT TO WORK ➔ [GO TO 75]
☐ DON’T KNOW ➔ [GO TO 75]
☐ REFUSED ➔ [GO TO 75]
☐ UNCLEAR RESPONSE ➔ [GO TO 75]

EM5. Have you asked for help in getting a job for pay?

☐ YES ➔ [GO TO EM7]
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM6. Do you know you can get help to find a job for pay?

☐ YES ➔ [GO TO Q75]
☐ NO ➔ [GO TO Q75]
☐ DON’T KNOW ➔ [GO TO Q75]
☐ REFUSED ➔ [GO TO Q75]
☐ UNCLEAR RESPONSE ➔ [GO TO Q75]

EM7. Help getting a job can include help finding a place to work or help getting the skills that you need to work. Is someone paid to help you get a job?

☐ YES
☐ NO ➔ [GO TO Q75]
☐ DON’T KNOW ➔ [GO TO Q75]
☐ REFUSED ➔ [GO TO Q75]
☐ UNCLEAR RESPONSE ➔ [GO TO Q75]
EM8. Are you getting all the help you need to find a job?

☐ YES  → [GO TO Q75]
☐ NO  → [GO TO Q75]
☐ DON’T KNOW  → [GO TO Q75]
☐ REFUSED  → [GO TO Q75]
☐ UNCLEAR RESPONSE  → [GO TO Q75]

EM9. Who helped you to find the job that you have now? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

☐ EMPLOYMENT/VOCATIONAL STAFF/JOB COACH
☐ CASE MANAGER
☐ OTHER PAID PROVIDERS
☐ OTHER CAREER SERVICES
☐ FAMILY/FRIENDS
☐ ADVERSTISEMENT
☐ SELF-EMPLOYED  → [GO TO EM11]
☐ OTHER (____________________________)
☐ NO ONE HELPED ME—I FOUND IT MYSELF  → [GO TO EM11]
☐ DON’T KNOW  → [GO TO EM11]
☐ REFUSED  → [GO TO EM11]
☐ UNCLEAR RESPONSE  → [GO TO EM11]

EM10. Did you help to choose the job you have now?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM11. Sometimes people need help from other people to work at their jobs. For example, they may need help getting to or getting around at work, help getting their work done, or help getting along with other workers. Is someone paid to help you with the job you have now?

☐ YES
☐ NO  → [GO TO Q75]
☐ DON’T KNOW  → [GO TO Q75]
☐ REFUSED  → [GO TO Q75]
☐ UNCLEAR RESPONSE  → [GO TO Q75]

EM12. What do you call this person? A job coach, peer support provider, personal assistant, or something else?


USE THIS TERM WHEREEVER IT SAYS {job coach} BELOW.
EM13. Did you hire your \textit{job coach} yourself?
- YES $\Rightarrow$ [GO TO Q75]
- NO
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM14. Is your \textit{job coach} with you all the time that you are working?
- YES
- NO
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM15. How often does your \textit{job coach} give you all the help you need? Would you say . . .
- Never,
- Sometimes,
- Usually, or
- Always?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM16. How often is your \textit{job coach} nice and polite to you? Would you say . . .
- Never,
- Sometimes,
- Usually, or
- Always?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM17. How often does your \textit{job coach} explain things in a way that is easy to understand? Would you say . . .
- Never,
- Sometimes,
- Usually, or
- Always?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM18. How often does your \textit{job coach} listen carefully to you? Would you say . . .
- Never,
Sometimes,
Usually, or
Always?
DON’T KNOW
REFUSED
UNCLEAR RESPONSE

EM19. Does your \{job coach\} encourage you to do things for yourself if you can?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM20. How would you rate the help you get from your \{job coach\}? Would you say . . .

☐ Excellent,
☐ Very good,
☐ Good,
☐ Fair, or
☐ Poor?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
Now I just have a few more questions about you.

75. In general, how would you rate your overall health? Would you say . . . (CM)
   - Excellent,
   - Very good,
   - Good,
   - Fair, or
   - Poor?

76. [IF NECESSARY, ASK, AND VERIFY IF OVER THE PHONE] Are you male or female? (CM)
   - MALE
   - FEMALE

77. What is your age? (CM)
   - 18 TO 24 YEARS ➔ [GO TO Q79]
   - 25 TO 34 YEARS ➔ [GO TO Q79]
   - 35 TO 44 YEARS ➔ [GO TO Q79]
   - 45 TO 54 YEARS ➔ [GO TO Q79]
   - 55 TO 64 YEARS ➔ [GO TO Q79]
   - 65 TO 74 YEARS ➔ [GO TO Q79]
   - 75 YEARS OR OLDER ➔ [GO TO Q79]
   - DON’T KNOW
   - REFUSED ➔ [GO TO Q79]
   - UNCLEAR RESPONSE

78. [IF NO ANSWER TO Q77, ASK] In what year were you born?
   ___________________ (YEAR)

79. Are you of Hispanic or Latino origin or descent? (CM)
   - YES, HISPANIC OR LATINO
   - NO, NOT HISPANIC OR LATINO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE
80. What is your race? You may choose one or more of the following. Would you say you are . . .
(CM)
- White
- Black or African-American
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native
- Other
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

81. Have you ever served as a member of the Armed Forces of the United States—such as the
Army, Navy, Air Force, Marines, Coast Guard—in either an active duty, guard, or reserve
capacity?
- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

82. Have you actively participated in any armed conflicts as a member of the Armed Forces? For
example, did you serve in World War two, Korea, Vietnam, Grenada, Panama, Desert Storm,
or Operation Iraqi Freedom?
- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

83. Are you currently categorized as a disabled veteran? [IF NECESSARY, ASK] Do you
receive or are able to receive any medical or dental care from the U.S. Department of
Veterans Affairs for your service related to a disability?
- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
84. **[ENGLISH VERSION]**: What language do you mainly speak at home? Would you say…
   - English, ➔ [GO TO Q85]
   - Some other language, or
   - Both English and some other language?
   - DON’T KNOW ➔ [GO TO Q85]
   - REFUSED ➔ [GO TO Q85]
   - UNCLEAR RESPONSE ➔ [GO TO Q85]

84A. What other language do you speak? ________________________________

85. **[IF NECESSARY, ASK]** Do you live with any family members?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

86. **[IF NECESSARY, ASK]** Do you live with people who are not family or are not related to you?
   - YES ➔ [GO TO Q88]
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

87. **[IF NECESSARY, ASK]** Do you live alone?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

88. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?
   - YES
   - NO
89. **WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?**
   - [ ] YES
   - [ ] NO →[END SURVEY]

90. **WHO WAS PRESENT DURING THE INTERVIEW? (MARK ALL THAT APPLY.)**
   - [ ] SOMEONE NOT PAID TO PROVIDE SUPPORT TO THE RESPONDENT
   - [ ] STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

91. **DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?**
   - [ ] YES
   - [ ] NO →[END SURVEY]

92. **HOW DID THAT PERSON HELP? (MARK ALL THAT APPLY.)**
   - [ ] ANSWERED ALL THE QUESTIONS FOR RESPONDENT
   - [ ] RESTATED THE QUESTIONS IN A DIFFERENT WAY OR REMINDED/PROMPTED THE RESPONDENT
   - [ ] TRANSLATED THE QUESTIONS OR ANSWERS INTO THE RESPONDENT’S LANGUAGE
   - [ ] HELPED WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS
   - [ ] OTHER, SPECIFY _____________________________

93. **WHO HELPED THE RESPONDENT? (MARK ALL THAT APPLY.)**
   - [ ] SOMEONE NOT PAID TO PROVIDE SUPPORT TO THE RESPONDENT
   - [ ] STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT
Home- and Community-Based Services Experience Survey

Alternate Survey

Date: March 8, 2012

Contents
Instructions For Vendor ........................................................................................................................... 36
Instructions For Interviewer .................................................................................................................... 37
Introduction ............................................................................................................................................... 38
Identification Questions ............................................................................................................................ 39
Services And Supports From Personal Assistant And Behavioral Staff .............................................. 41
  Getting Needed Services From Personal Assistant And Behavioral Health Staff ......................... 41
  How Well Personal Assistant And Behavioral Health Staff Communicate And Treat You. 44
Services And Support From Homemakers ............................................................................................. 46
  Getting Needed Services From Homemakers ............................................................................... 46
  How Well Homemakers Communicate And Treat You ................................................................. 47
Your Case Manager .................................................................................................................................. 48
Choosing Your Services ............................................................................................................................ 50
Transportation .......................................................................................................................................... 51
Personal Safety .......................................................................................................................................... 52
Community Inclusion And Empowerment ............................................................................................. 54
Supplemental Employment Module ........................................................................................................ 57
About You .................................................................................................................................................. 62
This is the alternate survey for individuals who cannot respond to the primary survey due to cognitive limitations.

The scripts provided in this document use the questions from the Home- and Community-Based Services (HCBS) Experience Survey.

If you plan to add your own items to this instrument, insert them just before the “About You” section.

Response Options:

- All questions include a “REFUSED” response option. In this case, “refused” means the respondent did not provide any answer to the question.
- This survey is used if the primary survey, which has response options of “never, sometimes, usually, and always” is found to be cognitively burdensome by the respondent.
- All questions include a “DON’T KNOW” response option. This is used when the respondent indicates that he or she does not know the answer and cannot provide a response to the question.
- All questions include an “UNCLEAR” response option. This should be used when a respondent answers, but the interviewer cannot clarify the meaning of the response even after minor probing or the response is completely unrelated to the question—for example, the response to “Do your homemakers listen carefully to what you say?” is “I like to sit by Mary.”
- Some responses have skip patterns, which are expressed as “if ‘X’ go to Q#.” That means the interviewer should skip all following questions until Q#.

Singular/Plural: Modify items such that the interviewer can use the correct form (singular or plural) of the survey item.

Program-Specific Terms: Where appropriate, add in the program-specific terms for staff (e.g., [program-specific term for these types of staff]) but allow the interviewer to modify the term based on the respondent’s choice of the word. It will be necessary to obtain information for program-specific terms. State administrative data should include the following information:

- Agency name(s)
- Titles of staff who provide care
- Names of staff who provide care
- Activities that each staff member provides (this will help with identifying appropriate skip logic)
- Hours of staff who come to the home
Please be aware that to conduct this survey, you may need approval from an Institutional Review Board (IRB). Regardless of whether you need IRB approval, you must get the respondent’s consent to participate in the survey. In addition, there may be state statutory requirements that apply to interviewers regarding reporting suspected abuse and neglect. Although information should be kept confidential, these state laws may mandate reporting in certain cases and should be reviewed prior to implementation.

**INSTRUCTIONS FOR INTERVIEWER**

- Interviewers should read aloud all text that appears in initial uppercase and lowercase letters. Text that appears in **bold, lowercase letters** should be emphasized.

- Text in *italics and in braces* will be provided by the program. However, if the interviewee provides another term, use that in place of the program-specific term wherever indicated. For example, some interviewees may refer to their case manager by another title, which should be used instead throughout the survey.

- Text in uppercase letters should **not** be read aloud. For example, “DON’T KNOW,” “REFUSED,” or “UNCLEAR RESPONSE” answer categories appear in uppercase and should not be read to the respondent, but may be used for coding a response. In addition, items that ask the interviewer to INDICATE GENDER and WHETHER SOMEONE HELPED RESPONDENT COMPLETE THIS SURVEY AND HOW should not be read aloud. Interviewer instructions appear in [UPPERCASE LETTERS ENCLOSED IN BRACKETS] and also should not be read aloud.

- Skip patterns are indicated with a ➔ [GO TO Q#].

- Record each response by selecting the box to the left of the answer.

<table>
<thead>
<tr>
<th>Title</th>
<th>Name</th>
<th>Agency</th>
<th>Roles</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCA</td>
<td>Jane Doe</td>
<td>Happy Home</td>
<td>Bathing, Dressing, Prepping meals</td>
<td># of hours</td>
</tr>
<tr>
<td>Homemaker</td>
<td>John Doe</td>
<td>Happy Home</td>
<td>Cleaning</td>
<td># of hours</td>
</tr>
</tbody>
</table>
INTRODUCTION

Hello, my name is {interviewer name}. I am from {name of organization}. How are you today? Thank you again for letting me talk with you. I am very interested in hearing about your life and your experience with the people who help you. This information will be used to help improve services for people with disabilities.

Before we start, let me tell you a few things about this survey. This interview should take about 20 minutes. You can choose whether or not you want to answer each question. You can also choose if you want to be interviewed at all. The services you get will not be affected by your answers. Your services will not change whether you decide to answer a question or not.

All of your answers are completely confidential. None of the people who help you will know what you say, unless you want them in the room while we talk. {ADD STATE-SPECIFIC LANGUAGE HERE REGARDING MANDATED REPORTING, IF APPROPRIATE.}

Some people may not be able to answer a question quickly. Some people may not know the answer. This is not a test. If you don’t know the answer to a question, or can’t remember it, let me know. “I don’t remember” could be the best answer.

Also, we can take as much time as you would like to go through the survey. I am not in a hurry. Let me know if you would like me to repeat a question. We can take a break if you would like. We can also stop any time you want.

Do you have any questions before we start?

[ANSWER ANY QUESTIONS RAISED BY THE RESPONDENT, THEN GO TO QUESTION 1.]
IDENTIFICATION QUESTIONS

This survey is about the people who are paid to help you in your home and community with everyday activities. People might be paid to help you get ready in the morning, with housework, go places, or get mental health services. It also asks about the services you get.

ID-1. Our records show that you get {program specific term for personal assistance}. Is that right?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

ID-2. What do you call the person or people who give you {program specific term for personal assistance}? For example, do you call them {program specific term for personal assistance}, staff, personal care attendants, PCAs, workers, or something else?

ID-3. Our records show that you get {program specific term for behavioral health specialist services}. Is that right?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

ID-4. What do you call the person or people who give you {program specific term for behavioral health specialist services}? For example, do you call them {program specific term for behavioral health specialists}, counselors, peer supports, recovery assistants, or something else?

ID-5. Our records show that you get {program specific term for homemaker services}. Is that right?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

ID-6. What do you call the person or people who give you {program specific term for homemaker services}? For example, do you call them {program-specific term for homemaker}, aides, homemakers, chore workers, or something else?
ID-7. [IF RESPONDENT REPORTS HAVING PCA AND HOMEMAKER STAFF, THEN ASK]. Do the same people who help you with everyday activities also help you to clean your home?

- YES ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS
- NO ➔ ASK PCA ITEMS AND SELECT HOMEMAKER ITEMS SEPARATELY
- DON’T KNOW ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS
- REFUSED ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS
- UNCLEAR RESPONSE ➔ ASK ALL PCA ITEMS AND SELECT HOMEMAKER ITEMS

ID-8. Our records show that you get {program specific term for case manager services} to help make sure that you have all the services you need, like help from {list of assistance identified previously}. Is that right?

- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

ID-9. What do you call the person who gives you {program specific term for case manager services}? For example, do you call the person a {program-specific term for case manager}, case manager, care manager, service coordinator, supports coordinator, social worker, or something else?

[RESPONDENT TITLES SHOULD BE AUTOMATICALLY ADDED INTO SECTIONS, WHEREEVER IT STATES {personal assistance/behavioral health staff}, {case manager}, or {homemaker}.]

[IF RESPONSE IS NEGATIVE TO ALL SUPPORTS, THEN GO TO CHOOSING YOUR SERVICES SECTION.]
SERVICES AND SUPPORTS FROM PERSONAL ASSISTANT AND BEHAVIORAL STAFF

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

1. First I would like to talk about the {personal assistance/behavioral health staff} who are paid to help you complete everyday activities—for example, getting dressed, using the bathroom, taking a bath or shower, or going places. Do {personal assistance/behavioral health staff} come to work on time? Would you say . . .
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

2. Do {personal assistance/behavioral health staff} work as long as they are supposed to? Would you say . . .
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

3. Sometimes staff cannot come to work on a day that they are scheduled. When staff cannot come to work on a day that they are scheduled, does someone let you know if {personal assistance/behavioral health staff} cannot come that day?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

4. Do you need help from {personal assistance/behavioral health staff} to get dressed or to take a shower or bath?
   - YES
   - NO ➔ [GO TO Q8]
   - DON’T KNOW ➔ [GO TO Q8]
   - REFUSED ➔ [GO TO Q8]
   - UNCLEAR RESPONSE ➔ [GO TO Q8]
5. Do you always get dressed or take a shower or bath when you need one?
   - YES  ➔ [GO TO Q7]
   - NO
   - DON’T KNOW  ➔ [GO TO Q7]
   - REFUSED  ➔ [GO TO Q7]
   - UNCLEAR RESPONSE  ➔ [GO TO Q7]

6. Is this because there are no {personal assistance/behavioral health staff} to help you?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

7. Do {personal assistance/behavioral health staff} make sure you have enough privacy when you get dressed or take a shower or bath? Would you say…
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

8. Do you need help from {personal assistance/behavioral health staff} with your meals, such as help making or cooking meals or help eating?
   - YES
   - NO  ➔ [GO TO Q11]
   - DON’T KNOW  ➔ [GO TO Q11]
   - REFUSED  ➔ [GO TO Q11]
   - UNCLEAR RESPONSE  ➔ [GO TO Q11]

9. Are you always able to get something to eat when you are hungry?
   - YES  ➔ [GO TO Q11]
   - NO
   - DON’T KNOW  ➔ [GO TO Q11]
   - REFUSED  ➔ [GO TO Q11]
   - UNCLEAR RESPONSE  ➔ [GO TO Q11]

10. Is this because there are no {personal assistance/behavioral health staff} to help you?
    - YES
    - NO
    - DON’T KNOW
    - REFUSED
    - UNCLEAR RESPONSE
11. Sometimes people need help taking their medicines, such as reminders, help pouring them, or setting up their pills. Do you need help from \{personal assistance/behavioral health staff\} to take your medicines?

- YES
- NO ➔ [GO TO Q14]
- DON’T KNOW ➔ [GO TO Q14]
- REFUSED ➔ [GO TO Q14]
- UNCLEAR RESPONSE ➔ [GO TO Q14]

12. Do you always take your medicine when you are supposed to?

- YES ➔ [GO TO Q14]
- NO
- DON’T KNOW ➔ [GO TO Q14]
- REFUSED ➔ [GO TO Q14]
- UNCLEAR RESPONSE ➔ [GO TO Q14]

13. Is this because there are no \{personal assistance/behavioral health staff\} to help you?

- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

14. Help with toileting includes helping someone get on and off the toilet or helping to change disposable briefs or pads. Do you need help from \{personal assistance/behavioral health staff\} with toileting?

- YES
- NO ➔ [GO TO Q16]
- DON’T KNOW ➔ [GO TO Q16]
- REFUSED ➔ [GO TO Q16]
- UNCLEAR RESPONSE ➔ [GO TO Q16]

15. Do you get all the help you need with toileting from \{personal assistance/behavioral health staff\} when you need it?

- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
HOW WELL PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF COMMUNICATE AND TREAT YOU

The next several questions ask about how {personal assistance/behavioral health staff} treat you.

16. Are {personal assistance/behavioral health staff} nice and polite to you? Would you say . . .
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

17. Are the explanations {personal assistance/behavioral health staff} give you hard to understand because of an accent or the way {personal assistance/behavioral health staff} speak English? Would you say. . .
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

18. Do {personal assistance/behavioral health staff} treat you the way you want them to? Would you say . . .
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

19. Do {personal assistance/behavioral health staff} explain things in a way that is easy to understand? Would you say . . .
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

20. Do {personal assistance/behavioral health staff} listen carefully to you? Would you say . . .
   - Mostly yes, or,
   - Mostly no?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE
21. Do you feel \{personal assistance/behavioral health staff\} know what kind of help you need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

22. Do \{personal assistance/behavioral health staff\} encourage you to do things for yourself if you can?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

23. How would you rate the help you get from \{personal assistance/behavioral health staff\}? Would you say . . .
   - Excellent,
   - Very good,
   - Good,
   - Fair, or
   - Poor?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

24. Would you recommend the \{personal assistance/behavioral health staff\} who help you to your family and friends if they needed help with everyday activities? Would you say you recommend the \{personal assistance/behavioral health staff\} . . .
   - Definitely no,
   - Probably no,
   - Probably yes, or
   - Definitely yes?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE
**SERVICES AND SUPPORT FROM HOMEMAKERS**

The next several questions are about the *homemakers*, the staff who are paid to help you do tasks around the home—such as cleaning, grocery shopping, or doing laundry.

### GETTING NEEDED SERVICES FROM HOMEMAKERS

25. Do *homemakers* come to work on time? Would you say . . .
   - [ ] Mostly yes, or,
   - [ ] Mostly no?
   - [ ] DON’T KNOW
   - [ ] REFUSED
   - [ ] UNCLEAR RESPONSE

26. Do *homemakers* work as long as they are supposed to? Would you say . . .
   - [ ] Mostly yes, or,
   - [ ] Mostly no?
   - [ ] DON’T KNOW
   - [ ] REFUSED
   - [ ] UNCLEAR RESPONSE

27. Do your household tasks, like cleaning and laundry, **always** get done when you need them to? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]
   - [ ] YES ➔ [GO TO Q29]
   - [ ] NO
   - [ ] DON’T KNOW NO ➔ [GO TO Q29]
   - [ ] REFUSED NO ➔ [GO TO Q29]
   - [ ] UNCLEAR RESPONSE ➔ [GO TO Q29]

28. Is this because there are no *homemakers* to help you? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]
   - [ ] YES
   - [ ] NO
   - [ ] DON’T KNOW
   - [ ] REFUSED
   - [ ] UNCLEAR RESPONSE
HOW WELL HOMEMAKERS COMMUNICATE AND TREAT YOU

The next several questions ask about how {homemakers} treat you.

29. Are {homemakers} nice and polite to you? Would you say . . .
   □ Mostly yes, or,
   □ Mostly no?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

30. Are the explanations {homemakers} give you hard to understand because of an accent or the way {homemakers} speak English? Would you say . . .
   □ Mostly yes, or,
   □ Mostly no?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

31. Do {homemakers} treat you the way you want them to? Would you say . . .
   □ Mostly yes, or,
   □ Mostly no?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

32. Do {homemakers} listen carefully to you? Would you say . . .
   □ Mostly yes, or,
   □ Mostly no?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

33. Do you feel {homemakers} know what kind of help you need?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

34. How would you rate the help you get from {homemakers}? Would you say . . .
   □ Excellent,
   □ Very good,
   □ Good,
35. Would you recommend the \{homemakers\} who help you to your family and friends if they needed \{respondent-specific term for homemaker services\}? Would you say you recommend the \{homemakers\} . . .

☐ Definitely no,
☐ Probably no,
☐ Probably yes, or
☐ Definitely yes?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

YOUR CASE MANAGER

Now I would like to talk to you about your \{case manager\}, the person who helps make sure you have the services you need.

36. Do you know who your \{case manager\} is?

☐ YES
☐ NO ➔[GO TO Q44]
☐ DON’T KNOW ➔[GO TO 44]
☐ REFUSED ➔[GO TO Q44]
☐ UNCLEAR RESPONSE ➔[GO TO Q44]

37. Can you contact this \{case manager\} when you need to?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

38. Some people need to get equipment, such as wheelchairs or grab bars, to help them, and other people need their equipment replaced or repaired. Have you asked this \{case manager\} for help with getting or fixing equipment?

☐ YES
☐ NO ➔[GO TO Q40]
☐ DON’T KNOW ➔[GO TO Q40]
☐ REFUSED ➔[GO TO Q40]
☐ UNCLEAR RESPONSE ➔[GO TO Q40]
39. Did this {case manager} work with you when you asked for help with getting or fixing equipment?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

40. Have you asked this {case manager} for help in getting any changes to your services, such as more help from {personal assistance/behavioral health staff and/or homemakers if applicable}, or for help with getting places or finding a job?
   - YES
   - NO [GO TO 42]
   - DON’T KNOW [GO TO 42]
   - REFUSED [GO TO 42]
   - UNCLEAR RESPONSE [GO TO 42]

41. Did this {case manager} work with you when you asked for help with getting other changes to your services?
   - YES
   - NO
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

42. How would you rate the help you get from the {case manager}? Would you say . . .
   - Excellent,
   - Very good,
   - Good,
   - Fair, or
   - Poor?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

43. Would you recommend the {case manager} who helps you to your family and friends if they needed {respondent-specific term for case-management services}? Would you say you recommend the {case manager} . . .
   - Definitely no,
   - Probably no,
   - Probably yes, or
   - Definitely yes?
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE
CHOOSING YOUR SERVICES

44. A [program-specific term for “service plan”]—sometimes called a care plan, goals, or service plan—lists the services you need and who will provide them. Did you work with someone to develop your [program-specific term for “service plan”]?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

45. Does your [program-specific term for “service plan”] include . . .

☐ None of the things that are important to you,
☐ Some of the things that are important to you,
☐ Most of the things that are important to you, or
☐ All of the things that are important to you?
☐ DON’T KNOW ➔ [GO TO 47]
☐ REFUSED ➔ [GO TO 47]
☐ UNCLEAR RESPONSE ➔ [GO TO 47]

46. Do you feel {personal assistance/behavioral health staff} know what’s on your [program-specific term for “service plan”], including the things that are important to you?

☐ YES
☐ NO
☐ DOES NOT HAVE PERSONAL ASSISTANCE STAFF
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

47. Who would you talk to if you wanted to change your [program-specific term for “service plan”]? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

☐ CASE MANAGER
☐ OTHER STAFF
☐ FAMILY/FRIENDS
☐ OTHER
☐ I DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
TRANSPORTATION

The next questions ask about how you get to places in your community.

48. Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. Do you have a way to get to your medical appointments? Would you say . . .

☐ Mostly yes, or,
☐ Mostly no?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

49. Do you use a van or some other transportation service? Do not include a van you own.

☐ YES
☐ NO [GO TO Q52]
☐ DON’T KNOW [GO TO Q52]
☐ REFUSED [GO TO Q52]
☐ UNCLEAR RESPONSE [GO TO Q52]

50. Are you able to get in and out of this ride easily?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

51. Does this ride arrive on time to pick you up? Would you say . . .

☐ Mostly yes, or,
☐ Mostly no?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
PERSONAL SAFETY

The next few questions ask about your personal safety.

52. Who would you contact in case of an emergency?
   - ☐ FAMILY MEMBER OR FRIEND
   - ☐ CASE MANAGER
   - ☐ AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES
   - ☐ PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)
   - ☐ 9–1–1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)
   - ☐ SOMEONE ELSE, PLEASE SPECIFY ___________________
   - ☐ DON’T KNOW
   - ☐ REFUSED
   - ☐ UNCLEAR RESPONSE

53. Is there a person you can talk to if someone hurts you or does something to you that you don’t like?
   - ☐ YES
   - ☐ NO
   - ☐ DON’T KNOW
   - ☐ REFUSED
   - ☐ UNCLEAR RESPONSE

The next few questions ask if anyone paid to help you now is treating you badly. This includes {personal assistance/behavioral health staff, homemakers, or your case manager}. We are asking everyone the next questions—not just you. [ADD STATE-SPECIFIC LANGUAGE HERE REGARDING MANDATED REPORTING, IF APPROPRIATE—“I want to remind you that, although your answers are confidential, I have a legal responsibility to tell {STATE} if I hear something that makes me think you are being hurt or are in danger”]

54. Do any of the {personal assistance/behavioral health staff, homemakers, or your case managers} that you have now take your money or your things without asking you first?
   - ☐ YES
   - ☐ NO ➔ [GO TO Q57]
   - ☐ DON’T KNOW ➔ [GO TO Q57]
   - ☐ REFUSED ➔ [GO TO Q57]
   - ☐ UNCLEAR RESPONSE ➔ [GO TO Q57]

55. Is someone working with you to fix this problem?
   - ☐ YES
   - ☐ NO ➔ [GO TO Q57]
   - ☐ DON’T KNOW ➔ [GO TO Q57]
   - ☐ REFUSED ➔ [GO TO Q57]
   - ☐ UNCLEAR RESPONSE ➔ [GO TO Q57]
56. Who is working with you to fix this problem? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]
   - FAMILY MEMBER OR FRIEND
   - CASE MANAGER
   - AGENCY
   - SOMEONE ELSE, PLEASE SPECIFY ___________________
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

57. Do any {staff} that you have now yell, swear, or curse at you?
   - YES
   - NO ➔ [GO TO Q60]
   - DON’T KNOW ➔ [GO TO Q60]
   - REFUSED ➔ [GO TO Q60]
   - UNCLEAR RESPONSE ➔ [GO TO Q60]

58. Is someone working with you to fix this problem?
   - YES
   - NO ➔ [GO TO Q60]
   - DON’T KNOW ➔ [GO TO Q60]
   - REFUSED ➔ [GO TO Q60]
   - UNCLEAR RESPONSE ➔ [GO TO Q60]

59. Who is working with you to fix this problem? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]
   - FAMILY MEMBER OR FRIEND
   - CASE MANAGER
   - AGENCY
   - SOMEONE ELSE, PLEASE SPECIFY ___________________
   - DON’T KNOW
   - REFUSED
   - UNCLEAR RESPONSE

60. Do any {staff} that you have now hit you or hurt you?
   - YES
   - NO ➔ [GO TO Q63]
   - DON’T KNOW ➔ [GO TO Q63]
   - REFUSED ➔ [GO TO Q63]
   - UNCLEAR RESPONSE ➔ [GO TO Q63]
61. Is someone working with you to fix this problem?
   □ YES
   □ NO  → [GO TO Q63]
   □ DON’T KNOW  → [GO TO Q63]
   □ REFUSED  → [GO TO Q63]
   □ UNCLEAR RESPONSE  → [GO TO Q63]

62. Who is working with you to fix this problem? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]
   □ FAMILY MEMBER OR FRIEND
   □ CASE MANAGER
   □ AGENCY
   □ SOMEONE ELSE, PLEASE SPECIFY ____________________
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

COMMUNITY INCLUSION AND EMPOWERMENT

Now I'd like to ask you about the things you do in your community.

63. Do you have any family members who live nearby? Do not include family members you live with.
   □ YES
   □ NO  → [GO TO Q65]
   □ DON’T KNOW  → [GO TO Q65]
   □ REFUSED  → [GO TO Q65]
   □ UNCLEAR RESPONSE  → [GO TO Q65]

64. When you want to, can you get together with these family members who live nearby? Would you say . . .
   □ Mostly yes, or,
   □ Mostly no?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

65. Do you have any friends who live nearby?
   □ YES
   □ NO  → [GO TO Q67]
   □ DON’T KNOW  → [GO TO Q67]
   □ REFUSED  → [GO TO Q67]
   □ UNCLEAR RESPONSE  → [GO TO Q67]
66. When you want to, can you get together with these friends who live nearby? Would you say . . .
   □ Mostly yes, or
   □ Mostly no?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

67. When you want to, can you do things in the community that you like, such as shopping or going out to eat? Would you say . . .
   □ Mostly yes, or
   □ Mostly no?
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

68. Do you need more help than you get now from {personal assistance/behavioral health staff} to do things in your community?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

69. Do you take part in deciding what you do each day—for example, what you do for fun at home or in your community?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

70. Do you take part in deciding when you do things each day—for example, deciding when you get up, eat, or go to bed?
   □ YES
   □ NO
   □ DON’T KNOW
   □ REFUSED
   □ UNCLEAR RESPONSE

The next few questions ask about making changes in {personal assistance/behavioral health staff, homemakers, and case manager}.

71. Have you asked for a change in {personal assistance staff, behavioral health staff, homemakers, or case manager}?
72. Did someone work with you when you asked to change {personal assistance/behavioral health staff, homemakers, or case manager}? 

☐ YES  
☐ NO ➔ [GO TO Q74]  
☐ DON’T KNOW ➔ [GO TO Q74]  
☐ REFUSED ➔ [GO TO Q74]  
☐ UNCLEAR RESPONSE ➔ [GO TO Q74]

73. Who did you work with when you asked to change {personal assistance/behavioral health staff, homemakers, or case manager}? 

☐ Family MEMBER OR FRIEND ➔ [GO TO EM OR Q75]  
☐ Case MANAGER ➔ [GO TO EM OR Q75]  
☐ Agency ➔ [GO TO EM OR Q75]  
☐ Someone ELSE, PLEASE SPECIFY ___________________ ➔ [GO TO EM OR Q75]  
☐ DON’T KNOW ➔ [GO TO EM OR Q75]  
☐ REFUSED ➔ [GO TO EM OR Q75]  
☐ UNCLEAR RESPONSE ➔ [GO TO EM OR Q75]

74. Do you know you can ask someone to change {personal assistance/behavioral health staff, homemakers, or case manager}? 

☐ YES  
☐ NO  
☐ DON’T KNOW  
☐ REFUSED  
☐ UNCLEAR RESPONSE
SUPPLEMENTAL EMPLOYMENT MODULE

EM1. Do you work for pay at a job?

☐ YES ➔ [GO TO QEM9]
☐ NO
☐ DON’T KNOW ➔ [GO TO Q75]
☐ REFUSED ➔ [GO TO Q75]
☐ UNCLEAR RESPONSE ➔ [GO TO Q75]

EM2. Do you want to work for pay at a job?

☐ YES
☐ NO ➔ [GO TO EM4]
☐ DON’T KNOW ➔ [GO TO Q75]
☐ REFUSED ➔ [GO TO Q75]
☐ UNCLEAR RESPONSE ➔ [GO TO Q75]

EM3. Sometimes people feel that something is holding them back from working when they want to. Is this true for you? If so, what is holding you back from working? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

☐ BENEFITS ➔ [GO TO EM5]
☐ HEALTH CONCERNS ➔ [GO TO EM5]
☐ DON’T KNOW ABOUT JOB RESOURCES ➔ [GO TO EM5]
☐ ADVICE FROM OTHERS ➔ [GO TO EM5]
☐ TRAINING/EDUCATION NEED ➔ [GO TO EM5]
☐ LOOKING AND CAN’T FIND WORK ➔ [GO TO EM5]
☐ ISSUES WITH PREVIOUS EMPLOYMENT ➔ [GO TO EM5]
☐ TRANSPORTATION ➔ [GO TO EM5]
☐ CHILD CARE ➔ [GO TO EM5]
☐ OTHER (_____________________________) ➔ [GO TO EM5]
☐ NOTHING IS HOLDING ME BACK ➔ [GO TO EM5]
☐ DON’T KNOW ➔ [GO TO EM5]
☐ REFUSED ➔ [GO TO EM5]
☐ UNCLEAR RESPONSE ➔ [GO TO EM5]
EM4. Sometimes people would like to work for pay, but feel that something is holding them back. Is this true for you? If so, what is holding you back from wanting to work? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

- BENEFITS ➔ [GO TO 75]
- HEALTH CONCERNS ➔ [GO TO 75]
- DON’T KNOW ABOUT JOB RESOURCES ➔ [GO TO 75]
- ADVICE FROM OTHERS ➔ [GO TO 75]
- TRAINING/EDUCATION NEED ➔ [GO TO 75]
- LOOKING AND CAN’T FIND WORK ➔ [GO TO 75]
- ISSUES WITH PREVIOUS EMPLOYMENT ➔ [GO TO 75]
- TRANSPORTATION ➔ [GO TO 75]
- CHILD CARE ➔ [GO TO 75]
- OTHER (_____________________________) ➔ [GO TO 75]
- NOTHING/DOESN’T WANT TO WORK ➔ [GO TO 75]
- DON’T KNOW ➔ [GO TO 75]
- REFUSED ➔ [GO TO 75]
- UNCLEAR RESPONSE ➔ [GO TO 75]

EM5. Have you asked for help in getting a job for pay?

- YES ➔ [GO TO EM7]
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM6. Do you know you can get help to find a job for pay?

- YES ➔ [GO TO Q75]
- NO ➔ [GO TO Q75]
- DON’T KNOW ➔ [GO TO Q75]
- REFUSED ➔ [GO TO Q75]
- UNCLEAR RESPONSE ➔ [GO TO Q75]

EM7. Help getting a job can include help finding a place to work or help getting the skills that you need to work. Is someone paid to help you get a job?

- YES
- NO ➔ [GO TO Q75]
- DON’T KNOW ➔ [GO TO Q75]
- REFUSED ➔ [GO TO Q75]
- UNCLEAR RESPONSE ➔ [GO TO Q75]
EM8. Are you getting all the help you need to find a job?

☐ YES ➔ [GO TO Q75]
☐ NO ➔ [GO TO Q75]
☐ DON’T KNOW ➔ [GO TO Q75]
☐ REFUSED ➔ [GO TO Q75]
☐ UNCLEAR RESPONSE ➔ [GO TO Q75]

EM9. Who helped you to find the job that you have now? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

☐ EMPLOYMENT/VOCATIONAL STAFF/JOB COACH
☐ CASE MANAGER
☐ OTHER PAID PROVIDERS
☐ OTHER CAREER SERVICES
☐ FAMILY/FRIENDS
☐ ADVERSTISEMENT
☐ SELF-EMPLOYED ➔ [GO TO EM11]
☐ OTHER (____________________________)
☐ NO ONE HELPED ME—I FOUND IT MYSELF ➔ [GO TO EM11]
☐ DON’T KNOW ➔ [GO TO EM11]
☐ REFUSED ➔ [GO TO EM11]
☐ UNCLEAR RESPONSE ➔ [GO TO EM11]

EM10. Did you help to choose the job you have now?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM11. Sometimes people need help from other people to work at their jobs. For example, they may need help getting to or getting around at work, help getting their work done, or help getting along with other workers. Is someone paid to help you with the job you have now?

☐ YES
☐ NO ➔ [GO TO Q75]
☐ DON’T KNOW ➔ [GO TO Q75]
☐ REFUSED ➔ [GO TO Q75]
☐ UNCLEAR RESPONSE ➔ [GO TO Q75]

EM12. What do you call this person? A job coach, peer support provider, personal assistant, or something else?

[ ]

USE THIS TERM WHEREEVER IT SAYS {job coach} BELOW.
EM13. Did you hire your {job coach} yourself?

☐ YES ➔[GO TO Q75]
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM14. Is your {job coach} with you all the time that you are working?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM15. Does your {job coach} give you all the help you need? Would you say . . .

☐ Mostly yes, or,
☐ Mostly no?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM16. Is your {job coach} nice and polite to you? Would you say . . .

☐ Mostly yes, or,
☐ Mostly no?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM17. Does your {job coach} explain things in a way that is easy to understand? Would you say . . .

☐ Mostly yes, or,
☐ Mostly no?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM18. Does your {job coach} listen carefully to you? Would you say . . .

☐ Mostly yes, or,
☐ Mostly no?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

EM19. Does your {job coach} encourage you to do things for yourself if you can?
EM20. How would you rate the help you get from your {job coach}? Would you say . . .

☐ Excellent,
☐ Very good,
☐ Good,
☐ Fair, or
☐ Poor?
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
ABOUT YOU

Now I just have a few more questions about you.

75. In general, how would you rate your overall health? Would you say . . . (CM)

☐ Excellent,
☐ Very good,
☐ Good,
☐ Fair, or
☐ Poor?

76. [IF NECESSARY, ASK, AND VERIFY IF OVER THE PHONE] Are you male or female? (CM)

☐ MALE
☐ FEMALE

77. What is your age? (CM)

☐ 18 TO 24 YEARS ➔ [GO TO Q79]
☐ 25 TO 34 YEARS ➔ [GO TO Q79]
☐ 35 TO 44 YEARS ➔ [GO TO Q79]
☐ 45 TO 54 YEARS ➔ [GO TO Q79]
☐ 55 TO 64 YEARS ➔ [GO TO Q79]
☐ 65 TO 74 YEARS ➔ [GO TO Q79]
☐ 75 YEARS OR OLDER ➔ [GO TO Q79]
☐ DON’T KNOW
☐ REFUSED ➔ [GO TO Q79]
☐ UNCLEAR RESPONSE

78. [IF NO ANSWER TO Q77, ASK] In what year were you born?

____________ (YEAR)

79. Are you of Hispanic or Latino origin or descent? (CM)

☐ YES, HISPANIC OR LATINO
☐ NO, NOT HISPANIC OR LATINO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
80. What is your race? You may choose one or more of the following. Would you say you are . . . (CM)

☐ White
☐ Black or African-American
☐ Asian
☐ Native Hawaiian or other Pacific Islander
☐ American Indian or Alaska Native
☐ Other
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

81. Have you ever served as a member of the Armed Forces of the United States—such as the Army, Navy, Air Force, Marines, Coast Guard—in either an active duty, guard, or reserve capacity?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

82. Have you actively participated in any armed conflicts as a member of the Armed Forces? For example, did you serve in World War two, Korea, Vietnam, Grenada, Panama, Desert Storm, or Operation Iraqi Freedom?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

83. Are you currently categorized as a disabled veteran? [IF NECESSARY, ASK] Do you receive or are able to receive any medical or dental care from the U.S. Department of Veterans Affairs for your service related to a disability?

☐ YES
☐ NO
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE
84. **[ENGLISH VERSION]**: What language do you mainly speak at home? Would you say…

- [ ] English. ➔ [GO TO Q85]
- [ ] Some other language, or
- [ ] Both English and some other language?
- [ ] DON’T KNOW ➔ [GO TO Q85]
- [ ] REFUSED ➔ [GO TO Q85]
- [ ] UNCLEAR RESPONSE ➔ [GO TO Q85]

84A. What other language do you speak? ________________________________

**[SPANISH VERSION]**: What language do you mainly speak at home? Would you say . . .

- [ ] English,
- [ ] Spanish,
- [ ] Both English and Spanish, or
- [ ] Some other language ➔ Which one? _____________________________
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

85. **[IF NECESSARY, ASK]** Do you live with any family members?  

- [ ] YES
- [ ] NO
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

86. **[IF NECESSARY, ASK]** Do you live with people who are not family or are not related to you?

- [ ] YES ➔ [GO TO Q88]
- [ ] NO
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

87. **[IF NECESSARY, ASK]** Do you live alone?

- [ ] YES
- [ ] NO
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

88. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

- [ ] YES
- [ ] NO
89. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?
   □ YES  
   □ NO ➔ [END SURVEY]

90. WHO WAS PRESENT DURING THE INTERVIEW? (MARK ALL THAT APPLY.)
   □ SOMEONE NOT PAID TO PROVIDE SUPPORT TO THE RESPONDENT
   □ STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

91. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?
   □ YES  
   □ NO ➔ [END SURVEY]

92. HOW DID THAT PERSON HELP? (MARK ALL THAT APPLY.)
   □ ANSWERED ALL THE QUESTIONS FOR RESPONDENT
   □ RESTATED THE QUESTIONS IN A DIFFERENT WAY OR REMINDED/PROMPTED THE RESPONDENT
   □ TRANSLATED THE QUESTIONS OR ANSWERS INTO THE RESPONDENT’S LANGUAGE
   □ HELPED WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS
   □ OTHER, SPECIFY ________________________

93. WHO HELPED THE RESPONDENT? (MARK ALL THAT APPLY.)
   □ SOMEONE NOT PAID TO PROVIDE SUPPORT TO THE RESPONDENT
   □ STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT