CAHPS® Home- and Community-Based Services Survey

Version: 1.0
Population: Adult
Language: English

File name: CAHPSHcbs01192017SurvEng508
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Instructions for Vendor

- The interview is intended as an interviewer-administered survey; thus all text that appears in initial uppercase and lowercase letters should be read aloud. Text that appears in **bold, lowercase letters** should be emphasized.

- Text in `{italics and in braces}` will be provided by the HCBS program’s administrative data. However, if the interviewee provides another term, that term should be used 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.

- For response options of “never,” “sometimes,” “usually,” and “always,” if the respondent cannot use that scale, the alternate version of the survey with response options of “mostly yes” and “mostly no” should be used. These alternate response options are reserved for respondents who find the “never,” “sometimes,” “usually,” “always” response scale cognitively challenging.

- For response options of 0 to 10, if the respondent cannot use that scale, the alternate version of the survey with response options of “excellent,” “very good,” “good,” “fair,” or “poor” should be used. These alternate response options are reserved for respondents who find the numeric scale cognitively challenging.

- All questions include a “REFUSED” response option. In this case, “refused” means the respondent did not provide any answer to the question.

  - 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, (e.g., the response to “In the last 3 months, how often did your homemakers listen carefully to what you say?” is “I like to sit by Mary”).

  - Some responses have skip patterns, which are expressed as “→ GO TO Q#.” The interviewer should be advanced to the next appropriate item to ask the respondent.

  - Not all respondents receive all home and community-based services asked about in this instrument. Items Q4 through Q12 help to confirm which services a respondent receives. The table after it summarizes the logic of which items should be used.

  - Survey users may add questions to this survey before the “About You” section. A separate supplemental employment module can be added.

- Use singular/plural as needed. In most cases, questions are written assuming there is more than one staff person supporting a respondent or it is written without an indication of whether there is more than one staff person. Based on information
collected from Q4 through Q12, it is possible to modify questions to be singular or plural as they relate to staff.

- Use 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
COGNITIVE SCREENING QUESTIONS

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

1. Does someone come into your home to help you?

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

2. How do they help you?

   [EXAMPLES OF CORRECT RESPONSES INCLUDE]
   - HELPS ME GET READY EVERY DAY
   - CLEANS MY HOME
   - WORKS WITH ME AT MY JOB
   - HELPS ME DO THINGS
   - DRIVES ME AROUND

   - [ ] DON’T KNOW → END SURVEY
   - [ ] REFUSED → END SURVEY
   - [ ] UNCLEAR RESPONSE → END SURVEY

3. What do you call them?

   [EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]
   - MY WORKER
   - MY ASSISTANT
   - NAMES OF STAFF (JO, DAWN, ETC.)

   - [ ] DON’T KNOW → END SURVEY
   - [ ] REFUSED → END SURVEY
   - [ ] UNCLEAR RESPONSE → END SURVEY
CSQPASS.

[IF ALL 3 QUESTIONS WERE ANSWERED CORRECTLY, ENTER 1 TO CONTINUE.]
1 PASS - ALL 3 QUESTIONS WERE ANSWERED CORRECTLY → GO TO Q4
2 FAIL - AT LEAST 1 QUESTION WAS NOT ANSWERED CORRECTLY → GO TO SURVEND

SURVEND.
Thank you for your time. Those are all the questions we have.
Have a nice day/evening. [ENTER 1 TO EXIT SURVEY]

IDENTIFICATION QUESTIONS

Now I would like to ask you some more questions about the types of people who come to your home.

4. In the last 3 months, did you get {program specific term for personal assistance} at home?
   
   1\[YES\] 2\[NO → GO TO Q6\]
   -1\[DON'T KNOW → GO TO Q6\]
   -2\[REFUSED → GO TO Q6\]
   -3\[UNCLEAR RESPONSE → GO TO Q6\]

5. What do you call the person or people who gave 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?

   [ADD RESPONSE WHEREVER IT SAYS “personal assistance/behavioral health staff”]

6. In the last 3 months, did you get {program specific term for behavioral health specialist services} at home?

   1\[YES\] 2\[NO → GO TO Q8\]
   -1\[DON'T KNOW → GO TO Q8\]
   -2\[REFUSED → GO TO Q8\]
   -3\[UNCLEAR RESPONSE → GO TO Q8\]

7. What do you call the person or people who gave 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?
8. In the last 3 months, did you get {program specific term for homemaker services} at home?

1. YES
2. NO ➔ GO TO Q11
3. DON’T KNOW ➔ GO TO Q11
4. REFUSED ➔ GO TO Q11
5. UNCLEAR RESPONSE ➔ GO TO Q11

9. What do you call the person or people who gave 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?

[ADD RESPONSE WHEREVER IT SAYS “homemaker”]

10.  [IF (Q4 OR Q6) AND Q8 = YES, ASK] In the last 3 months, did the same people who help you with everyday activities also help you clean your home?

1. YES
2. NO
3. DON’T KNOW
4. REFUSED
5. UNCLEAR RESPONSE

11. In the last 3 months, did you get help from {program specific term for case manager services} to help make sure that you had all the services you needed?

1. YES
2. NO
3. DON’T KNOW
4. REFUSED
5. UNCLEAR RESPONSE
12. What do you call the person who gave you \textit{program specific term for case manager services}? For example, do you call the person a \textit{program-specific term for case manager}, case manager, care manager, service coordinator, supports coordinator, social worker, or something else?

________________________________________________________________________

[ADD RESPONSE WHEREVER IT SAYS “case manager”]

BELOW ARE INSTRUCTIONS FOR WHICH QUESTIONS TO ASK FOR EACH RESPONSE ABOVE.

<table>
<thead>
<tr>
<th>ITEM AND RESPONSE—FOLLOW ALL ROWS THAT APPLY</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES), AND Q8 = NO, DON’T KNOW, REFUSE, UNCLEAR (HOMEMAKER SERVICES)</td>
<td>ASK Q13–Q36, AND Q48 ONWARD</td>
</tr>
<tr>
<td>IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES), AND Q8 = YES (HOMEMAKER SERVICES)</td>
<td>ASK Q13 ONWARD</td>
</tr>
<tr>
<td>IF Q4 AND Q6 = NO (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES)</td>
<td>SKIP Q13–36, Q57 AND Q79</td>
</tr>
<tr>
<td>IF Q8 = YES (HOMEMAKER SERVICES)</td>
<td>ASK Q37 ONWARD</td>
</tr>
<tr>
<td>IF Q10 = YES (HOMEMAKER AND PERSONAL ASSISTANCE STAFF SAME)</td>
<td>ASK Q13–Q36, Q39, Q40, AND Q48 ONWARD</td>
</tr>
<tr>
<td>IF Q11 = ANY RESPONSE (CASE MANAGER)</td>
<td>ASK Q48 ONWARD</td>
</tr>
</tbody>
</table>

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

13. First I would like to talk about the \textit{personal assistance/behavioral health staff} who are paid to help you with everyday activities—for example, getting dressed, using the bathroom, taking a bath or shower, or going places. In the last 3 months, how often did \{personal assistance/behavioral health staff\} come to work on time? Would you say . . .

1□ Never,
2 Sometimes,  
3 Usually, or  
4 Always?  
-1 DON'T KNOW  
-2 REFUSED  
-3 UNCLEAR RESPONSE  

ALTERNATE VERSION: First I would like to talk about the {personal assistance/behavioral health staff} who are paid to help you with everyday activities—for example, getting dressed, using the bathroom, taking a bath or shower, or going places. In the last 3 months, did {personal assistance/behavioral health staff} come to work on time? Would you say . . .

1 Mostly yes or  
2 Mostly no?  
-1 DON'T KNOW  
-2 REFUSED  
-3 UNCLEAR RESPONSE  

14. In the last 3 months, how often did {personal assistance/behavioral health staff} work as long as they were supposed to? Would you say . . .

1 Never,  
2 Sometimes,  
3 Usually, or  
4 Always?  
-1 DON'T KNOW  
-2 REFUSED  
-3 UNCLEAR RESPONSE  

ALTERNATE VERSION: In the last 3 months, did {personal assistance/behavioral health staff} work as long as they were supposed to? Would you say . . .

1 Mostly yes or  
2 Mostly no?  
-1 DON'T KNOW  
-2 REFUSED  
-3 UNCLEAR RESPONSE  

15. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that {personal assistance/behavioral health staff} could not come that day?  

1 YES
16. In the last 3 months, did you need help from \textit{personal assistance/behavioral health staff} to get dressed, take a shower, or bathe?

1. YES
2. NO → GO TO Q20
3. DON’T KNOW → GO TO Q20
4. REFUSED → GO TO Q20
5. UNCLEAR RESPONSE → GO TO Q20

17. In the last 3 months, did you \textbf{always} get dressed, take a shower, or bathe when you needed to?

1. YES → GO TO Q19
2. NO
3. DON’T KNOW → GO TO Q19
4. REFUSED → GO TO Q19
5. UNCLEAR RESPONSE → GO TO Q19

18. In the last 3 months, was this because there were no \textit{personal assistance/behavioral health staff} to help you?

1. YES
2. NO
3. DON’T KNOW
4. REFUSED
5. UNCLEAR RESPONSE

19. In the last 3 months, how often did \textit{personal assistance/behavioral health staff} make sure you had enough personal privacy when you dressed, took a shower, or bathed? Would you say.

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
5. DON’T KNOW
6. REFUSED
7. UNCLEAR RESPONSE
ALTERNATE VERSION: In the last 3 months, did {personal assistance/behavioral health staff} make sure you had enough personal privacy when you dressed, took a shower, or bathed? Would you say . . .

1. Mostly yes or
2. Mostly no?
3. DON'T KNOW
4. REFUSED
5. UNCLEAR RESPONSE

20. In the last 3 months, did you need help from {personal assistance/behavioral health staff} with your meals, such as help making or cooking meals or help eating?

1. YES □
2. NO □ → GO TO Q23
3. DON'T KNOW □ → GO TO Q23
4. REFUSED □ → GO TO Q23
5. UNCLEAR RESPONSE □ → GO TO Q23

21. In the last 3 months, were you always able to get something to eat when you were hungry?

1. YES □ → GO TO Q23
2. NO □
3. DON'T KNOW □ → GO TO Q23
4. REFUSED □ → GO TO Q23
5. UNCLEAR RESPONSE □ → GO TO Q23

22. In the last 3 months, was this because there were no {personal assistance/behavioral health staff} to help you?

1. YES □
2. NO □
3. DON'T KNOW □ → GO TO Q23
4. REFUSED □ → GO TO Q23
5. UNCLEAR RESPONSE □ → GO TO Q23

23. Sometimes people need help taking their medicines, such as reminders to take a medicine, help pouring them, or setting up their pills. In the last 3 months, did you need help from {personal assistance/behavioral health staff} to take your medicines?

1. YES □
2. NO □ → GO TO Q26
3. DON'T KNOW □ → GO TO Q26
4. REFUSED □ → GO TO Q26
5. UNCLEAR RESPONSE □ → GO TO Q26
24. In the last 3 months, did you **always** take your medicine when you were supposed to?

1. YES  →  GO TO Q26  
2. NO  
3. DON'T KNOW  →  GO TO Q26  
4. REFUSED  →  GO TO Q26  
5. UNCLEAR RESPONSE  →  GO TO Q26

25. In the last 3 months, was this because there were no {personal assistance/behavioral health staff} to help you?

1. YES  
2. NO  
3. DON'T KNOW  
4. REFUSED  
5. UNCLEAR RESPONSE

26. Help with toileting includes helping someone get on and off the toilet or help changing disposable briefs or pads. In the last 3 months, did you need help from {personal assistance/behavioral health staff} with toileting?

1. YES  
2. NO  →  GO TO Q28  
3. DON'T KNOW  →  GO TO Q28  
4. REFUSED  →  GO TO Q28  
5. UNCLEAR RESPONSE  →  GO TO Q28

27. In the last 3 months, did you get all the help you needed with toileting from {personal assistance/behavioral health staff} when you needed it?

1. YES  
2. NO  
3. DON'T KNOW  
4. REFUSED  
5. UNCLEAR RESPONSE

**HOW WELL PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF COMMUNICATE WITH AND TREAT YOU**

The next several questions ask about how {personal assistance/behavioral health staff} treat you.
28. In the last 3 months, how often did \{personal assistance/behavioral health staff\} treat you with courtesy and respect? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did \{personal assistance/behavioral health staff\} treat you with courtesy and respect? Would you say . . .

1. Mostly yes or
2. Mostly no?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

29. In the last 3 months, how often were the explanations \{personal assistance/behavioral health staff\} gave you hard to understand because of an accent or the way \{personal assistance/behavioral health staff\} spoke English? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, were the explanations \{personal assistance/behavioral health staff\} gave you hard to understand because of an accent or the way \{personal assistance/behavioral health staff\} spoke English? Would you say . . .

1. Mostly yes or
2. Mostly no?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

30. In the last 3 months, how often did \{personal assistance/behavioral health staff\} treat you the way you wanted them to? Would you say . . .
31. In the last 3 months, how often did {personal assistance/behavioral health staff} explain things in a way that was easy to understand? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {personal assistance/behavioral health staff} treat you the way you wanted them to? Would you say . . .

1. Mostly yes or
2. Mostly no?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

32. In the last 3 months, how often did {personal assistance/behavioral health staff} listen carefully to you? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
33. In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?

1. YES
2. NO
1. DON’T KNOW
2. REFUSED
3. UNCLEAR RESPONSE

34. In the last 3 months, did {personal assistance/behavioral health staff} encourage you to do things for yourself if you could?

1. YES
2. NO
1. DON’T KNOW
2. REFUSED
3. UNCLEAR RESPONSE

35. Using any number from 0 to 10, where 0 is the worst help from {personal assistance/behavioral health staff} possible and 10 is the best help from {personal assistance/behavioral health staff} possible, what number would you use to rate the help you get from {personal assistance/behavioral health staff}?

__0 TO 10
1. DON’T KNOW
2. REFUSED
3. UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from {personal assistance/behavioral health staff}? Would you say . . .
36. 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 would recommend the \{personal assistance/behavioral health staff\} . . .

1. **Definitely no,**
2. **Probably no,**
3. **Probably yes, or**
4. **Definitely yes?**
-1. **DON’T KNOW**
-2. **REFUSED**
-3. **UNCLEAR RESPONSE**

**GETTING NEEDED SERVICES 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.

37. In the last 3 months, how often did \{homemakers\} come to work on time? Would you say . . .

1. **Never,**
2. **Sometimes,**
3. **Usually, or**
4. **Always?**
-1. **DON’T KNOW**
-2. **REFUSED**
-3. **UNCLEAR RESPONSE**

**ALTERNATE VERSION:** In the last 3 months, did \{homemakers\} come to work on time? Would you say . . .

1. **Mostly yes or**
2. **Mostly no?**
-1. **DON’T KNOW**
38. In the last 3 months, how often did {homemakers} work as long as they were supposed to? Would you say . . .

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

ALTERNATE VERSION: In the last 3 months, did {homemakers} work as long as they were supposed to? Would you say . . .

- □ Mostly yes or
- □ Mostly no?
- □ DON’T KNOW
- □ REFUSED
- □ UNCLEAR RESPONSE

39. In the last 3 months, did your household tasks, like cleaning and laundry, always get done when you needed them to? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]

- □ YES  →  GO TO Q41
- □ NO  →  GO TO Q41
- □ DON’T KNOW  →  GO TO Q41
- □ REFUSED  →  GO TO Q41
- □ UNCLEAR RESPONSE  →  GO TO Q41

40. In the last 3 months, was this because there were 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 WITH AND TREAT YOU

The next several questions ask about how {homemakers} treat you.
41. In the last 3 months, how often did {homemakers} treat you with courtesy and respect? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {homemakers} treat you with courtesy and respect? Would you say . . .

1. Mostly yes or
2. Mostly no?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

42. In the last 3 months, how often were the explanations {homemakers} gave you hard to understand because of an accent or the way the {homemakers} spoke English? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, were the explanations {homemakers} gave you hard to understand because of an accent or the way {homemakers} spoke English? Would you say . . .

1. Mostly yes or
2. Mostly no?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

43. In the last 3 months, how often did {homemakers} treat you the way you wanted them to? Would you say . . .
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1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON'T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {homemakers} treat you the way you wanted them to? Would you say . . .

1. Mostly yes or
2. Mostly no?
-1. DON'T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

44. In the last 3 months, how often did {homemakers} listen carefully to you? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON'T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did {homemakers} listen carefully to you? Would you say . . .

1. Mostly yes or
2. Mostly no?
-1. DON'T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

45. In the last 3 months, did you feel {homemakers} knew what kind of help you needed?

1. YES
2. NO
-1. DON'T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE
46. Using any number from 0 to 10, where 0 is the worst help from {homemakers} possible and 10 is the best help from {homemakers} possible, what number would you use to rate the help you get from {homemakers}?

   0 TO 10
   -1 DON'T KNOW
   -2 REFUSED
   -3 UNCLEAR RESPONSE

   ALTERNATE VERSION: How would you rate the help you get from {homemakers}?
   Would you say . . .

   1 Excellent,
   2 Very good,
   3 Good,
   4 Fair, or
   5 Poor?

   -1 DON'T KNOW
   -2 REFUSED
   -3 UNCLEAR RESPONSE

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

   1 Definitely no,
   2 Probably no,
   3 Probably yes, or
   4 Definitely yes?

   -1 DON'T KNOW
   -2 REFUSED
   -3 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.

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

   1 YES
   2 NO → GO TO Q56
   -1 DON'T KNOW → GO TO Q56
   -2 REFUSED → GO TO Q56
49. In the last 3 months, could you contact this {case manager} when you needed to?

1 □ YES
2 □ NO
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

→ GO TO Q56

50. Some people need to get equipment to help them, like wheelchairs or walkers, and other people need their equipment replaced or fixed. In the last 3 months, did you ask this {case manager} for help with getting or fixing equipment?

1 □ YES
2 □ NO → GO TO Q52
3 □ DON’T NEED → GO TO Q52
-1 □ DON’T KNOW → GO TO Q52
-2 □ REFUSED → GO TO Q52
-3 □ UNCLEAR RESPONSE → GO TO Q52

51. In the last 3 months, did this {case manager} work with you when you asked for help with getting or fixing equipment?

1 □ YES
2 □ NO
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

52. In the last 3 months, did you ask 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?

1 □ YES
2 □ NO → GO TO 54
3 □ DON’T NEED → GO TO Q54
-1 □ DON’T KNOW → GO TO Q54
-2 □ REFUSED → GO TO Q54
-3 □ UNCLEAR RESPONSE → GO TO Q54

53. In the last 3 months, did this {case manager} work with you when you asked for help with getting other changes to your services?

1 □ YES
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54. Using any number from 0 to 10, where 0 is the worst help from {case manager} possible and 10 is the best help from {case manager} possible, what number would you use to rate the help you get from {case manager}?

\[0 \text{ TO } 10\]

-1 DON’T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from the {case manager}? Would you say . . .

1 Excellent,
2 Very good,
3 Good,
4 Fair, or
5 Poor?
-1 DON’T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

55. Would you recommend the {case manager} who helps you to your family and friends if they needed {program-specific term for case-management services}? Would you say you would recommend the {case manager} . . .

1 Definitely no,
2 Probably no,
3 Probably yes, or
4 Definitely yes?
-1 DON’T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

CHOOSING YOUR SERVICES

56. In the last 3 months, did your \[program-specific term for “service plan”\] include . . .

1 None of the things that are important to you,
2 Some of the things that are important to you,
3. Most of the things that are important to you, or
4. All of the things that are important to you?
-1. DON’T KNOW → GO TO Q58
-2. REFUSED → GO TO Q58
-3. UNCLEAR RESPONSE → GO TO Q58

57. In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what’s on your [program-specific term for “service plan”], including the things that are important to you?

1. YES
2. NO
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

58. In the last 3 months, who would you have talked to if you wanted to change your [program-specific term for “service plan”]? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

1. CASE MANAGER
2. OTHER STAFF
3. FAMILY/FRIENDS
4. SOMEONE ELSE, PLEASE SPECIFY ____________________
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

TRANSPORTATION

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

59. Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. In the last 3 months, how often did you have a way to get to your medical appointments? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE
ALTERNATE VERSION: Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. In the last 3 months, did you have a way to get to your medical appointments? Would you say . . .

1 □ Mostly yes or
2 □ Mostly no?
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

60. In the last 3 months, did you use a van or some other transportation service? Do not include a van you own.

1 □ YES
2 □ NO → GO TO Q63
-1 □ DON’T KNOW → GO TO Q63
-2 □ REFUSED → GO TO Q63
-3 □ UNCLEAR RESPONSE → GO TO Q63

61. In the last 3 months, were you able to get in and out of this ride easily?

1 □ YES
2 □ NO
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

62. In the last 3 months, how often did this ride arrive on time to pick you up? Would you say . . .

1 □ Never,
2 □ Sometimes,
3 □ Usually, or
4 □ Always?
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did this ride arrive on time to pick you up? Would you say . . .

1 □ Mostly yes or
2 □ Mostly no?
-1 □ DON’T KNOW
-2 □ REFUSED
The next few questions ask about your personal safety.

63. Who would you contact in case of an emergency? [INTERVIEWER MARKS ALL THAT APPLY]

1. FAMILY MEMBER OR FRIEND
2. CASE MANAGER
3. AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES
4. PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)
5. 9–1–1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)
6. SOMEONE ELSE, PLEASE SPECIFY ____________________

-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

64. In the last 3 months, was there a person you could talk to if someone hurt you or did something to you that you didn’t like?

1. YES
2. NO

-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

The next few questions ask if anyone paid to help you treated you badly in the last 3 months. This includes {personal assistance/behavioral health staff, homemakers, or your case managers}. 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.”]

65. In the last 3 months, did any {personal assistance/behavioral health staff, homemakers, or your case managers} take your money or your things without asking you first?

1. YES
2. NO → GO TO Q68

-1. DON’T KNOW → GO TO Q68
-2. REFUSED → GO TO Q68
-3. UNCLEAR RESPONSE → GO TO Q68
66. In the last 3 months, did someone work with you to fix this problem?
1. YES
2. NO → GO TO Q68
-1. DON’T KNOW → GO TO Q68
-2. REFUSED → GO TO Q68
-3. UNCLEAR RESPONSE → GO TO Q68

67. In the last 3 months, who has been working with you to fix this problem? Anyone else?
[INTERVIEWER MARKS ALL THAT APPLY]
1. FAMILY MEMBER OR FRIEND
2. CASE MANAGER
3. AGENCY
4. SOMEONE ELSE, PLEASE SPECIFY ______________________
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

68. In the last 3 months, did any {staff} yell, swear, or curse at you?
1. YES
2. NO → GO TO Q71
-1. DON’T KNOW → GO TO Q71
-2. REFUSED → GO TO Q71
-3. UNCLEAR RESPONSE → GO TO Q71

69. In the last 3 months, did someone work with you to fix this problem?
1. YES
2. NO → GO TO Q71
-1. DON’T KNOW → GO TO Q71
-2. REFUSED → GO TO Q71
-3. UNCLEAR RESPONSE → GO TO Q71

70. In the last 3 months, who has been working with you to fix this problem? Anyone else?
[INTERVIEWER MARKS ALL THAT APPLY]
1. FAMILY MEMBER OR FRIEND
2. CASE MANAGER
3. AGENCY
4. SOMEONE ELSE, PLEASE SPECIFY ______________________
-1. DON’T KNOW
-2. REFUSED
71. In the last 3 months, did any {staff} hit you or hurt you?

1. YES
2. NO  →  GO TO Q74
-1. DON’T KNOW  →  GO TO Q74
-2. REFUSED  →  GO TO Q74
-3. UNCLEAR RESPONSE  →  GO TO Q74

72. In the last 3 months, did someone work with you to fix this problem?

1. YES
2. NO  →  GO TO Q74
-1. DON’T KNOW  →  GO TO Q74
-2. REFUSED  →  GO TO Q74
-3. UNCLEAR RESPONSE  →  GO TO Q74

73. In the last 3 months, who has been working with you to fix this problem? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

1. FAMILY MEMBER OR FRIEND
2. CASE MANAGER
3. AGENCY
4. SOMEONE ELSE, PLEASE SPECIFY ___________________
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

COMMUNITY INCLUSION AND EMPOWERMENT

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

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

1. YES
2. NO  →  GO TO Q76
-1. DON’T KNOW  →  GO TO Q76
-2. REFUSED  →  GO TO Q76
-3. UNCLEAR RESPONSE  →  GO TO Q76

75. In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby? Would you say . . .
1. Never,  
2. Sometimes,  
3. Usually, or  
4. Always?  
-1. DON'T KNOW  
-2. REFUSED  
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these family members who live nearby? Would you say . . .  
1. Mostly yes or  
2. Mostly no?  
-1. DON'T KNOW  
-2. REFUSED  
-3. UNCLEAR RESPONSE

76. Do you have any friends who live nearby?  
1. YES  
2. NO → GO TO Q78  
-1. DON'T KNOW → GO TO Q78  
-2. REFUSED → GO TO Q78  
-3. UNCLEAR RESPONSE → GO TO Q78

77. In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby? Would you say . . .  
1. Never,  
2. Sometimes,  
3. Usually, or  
4. Always?  
-1. DON'T KNOW  
-2. REFUSED  
-3. UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these friends who live nearby? Would you say . . .  
1. Mostly yes or  
2. Mostly no?  
-1. DON'T KNOW  
-2. REFUSED  
-3. UNCLEAR RESPONSE
78. In the last 3 months, when you wanted to, how often could you do things in the community that you like? Would you say . . .

1 □ Never,
2 □ Sometimes,
3 □ Usually, or
4 □ Always?
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you do things in the community that you like? Would you say . . .

1 □ Mostly yes or
2 □ Mostly no?
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

79. In the last 3 months, did you need more help than you get from {personal assistance/behavioral health staff} to do things in your community?

1 □ YES
2 □ NO
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

80. In the last 3 months, did you take part in deciding what you do with your time each day?

1 □ YES
2 □ NO
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

81. In the last 3 months, did you take part in deciding when you do things each day—for example, deciding when you get up, eat, or go to bed?

1 □ YES
2 □ NO
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE
ABOUT YOU

Now I just have a few more questions about you.

82. In general, how would you rate your overall health? Would you say . . .
   1 □ Excellent,
   2 □ Very good,
   3 □ Good,
   4 □ Fair, or
   5 □ Poor?
   -1 □ DON’T KNOW
   -2 □ REFUSED
   -3 □ UNCLEAR RESPONSE

83. In general, how would you rate your overall mental or emotional health? Would you say . . .
   1 □ Excellent,
   2 □ Very good,
   3 □ Good,
   4 □ Fair, or
   5 □ Poor?
   -1 □ DON’T KNOW
   -2 □ REFUSED
   -3 □ UNCLEAR RESPONSE

84. What is your age?
   1 □ 18 TO 24 YEARS
   2 □ 25 TO 34 YEARS
   3 □ 35 TO 44 YEARS
   4 □ 45 TO 54 YEARS
   5 □ 55 TO 64 YEARS
   6 □ 65 TO 74 YEARS
   7 □ 75 YEARS OR OLDER
   -1 □ DON’T KNOW
   -2 □ REFUSED
   -3 □ UNCLEAR RESPONSE

   ALTERNATE VERSION: In what year were you born?
   ____________ (YEAR)
   -1 □ DON’T KNOW
   -2 □ REFUSED
85. [IF NECESSARY, ASK, AND VERIFY IF OVER THE PHONE] Are you male or female?

1 □ MALE
2 □ FEMALE
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

86. What is the highest grade or level of school that you have completed?

1 □ 8th grade or less
2 □ Some high school, but did not graduate
3 □ High school graduate or GED
4 □ Some college or 2-year degree
5 □ 4-year college graduate
6 □ More than 4-year college degree
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

87. Are you of Hispanic, Latino, or Spanish origin?

1 □ YES, HISPANIC, LATINO, OR SPANISH
2 □ NO, NOT HISPANIC, LATINO, OR SPANISH → GO TO Q89
-1 □ DON’T KNOW → GO TO Q89
-2 □ REFUSED → GO TO Q89
-3 □ UNCLEAR RESPONSE → GO TO Q89

88. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

1 □ Mexican, Mexican American, Chicano, Chicana
2 □ Puerto Rican
3 □ Cuban
4 □ Another Hispanic, Latino, or Spanish origin
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

89. What is your race? You may choose one or more of the following. Would you say you are...

1 □ White → GO TO Q92
2 □ Black or African-American → GO TO Q92
3. Asian → GO TO Q90
4. Native Hawaiian or other Pacific Islander → GO TO Q91
5. American Indian or Alaska Native → GO TO Q92
6. OTHER → GO TO Q92
-1 DON'T KNOW → GO TO Q92
-2 REFUSED → GO TO Q92
-3 UNCLEAR RESPONSE → GO TO Q92

90. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

1. Asian Indian → GO TO Q92
2. Chinese → GO TO Q92
3. Filipino → GO TO Q92
4. Japanese → GO TO Q92
5. Korean → GO TO Q92
6. Vietnamese → GO TO Q92
7. Other Asian → GO TO Q92
-1 DON'T KNOW → GO TO Q92
-2 REFUSED → GO TO Q92
-3 UNCLEAR RESPONSE → GO TO Q92

91. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

1. Native Hawaiian
2. Guamanian or Chamorro
3. Samoan
4. Other Pacific Islander
-1 DON'T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

92. Do you speak a language other than English at home?

1. YES
2. NO → GO TO Q94
-1 DON'T KNOW → GO TO Q94
-2 REFUSED → GO TO Q94
-3 UNCLEAR RESPONSE → GO TO Q94

93. What is the language you speak at home?

1. Spanish,
2. Some other language → Which one? _____________________
-1 DON'T KNOW
94.  [IF NECESSARY, ASK] How many adults live at your home, including you?

- □ 1 [JUST THE RESPONDENT] ➔ END SURVEY
- □ 2 TO 3
- □ 4 OR MORE
- □ DON’T KNOW
- □ REFUSED
- □ UNCLEAR RESPONSE

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

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

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

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

INTERVIEWER QUESTIONS

THE FOLLOWING QUESTIONS SHOULD BE ANSWERED AFTER THE INTERVIEW IS CONDUCTED.

97.  WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

- □ YES
- □ NO

98.  WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

- □ YES
- □ NO ➔ END SURVEY

99.  WHO WAS PRESENT DURING THE INTERVIEW? (MARK ALL THAT APPLY.)
1. **SOMEONE NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
2. STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

100. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

1. **YES**
2. **NO** → END SURVEY

101. HOW DID THAT PERSON HELP? [MARK ALL THAT APPLY.]

1. **ANSWERED ALL** THE QUESTIONS FOR RESPONDENT
2. **ANSWERED SOME** OF THE QUESTIONS FOR THE RESPONDENT
3. **RESTATED THE QUESTIONS IN A DIFFERENT WAY OR REMINDED/PROMPTED THE RESPONDENT**
4. **TRANSLATED** THE QUESTIONS OR ANSWERS INTO THE RESPONDENT’S LANGUAGE
5. **HELPED WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT** SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS
6. **HELPED THE RESPONDENT IN ANOTHER WAY,**
   SPECIFY ____________________________

102. WHO HELPED THE RESPONDENT? (MARK ALL THAT APPLY.)

1. **SOMEONE NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
2. STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT