

**APPENDIX A. INTERVIEWER GUIDELINES FOR ADMINISTERING
THE CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND
SYSTEMS HOME AND COMMUNITY-BASED SERVICES (HCBS
CAHPS®) SURVEY**

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This appendix to the *Technical Assistance Guide for Administration of the HCBS CAHPS Survey* presents additional information for survey vendors to conduct the interview. The appendix includes general guidance for interviewers about planning for the interview and conducting the interview, computer-assisted telephone interview (CATI) or computer-assisted personal interview (CAPI) programming instructions, and specific instructions for coding responses based on the intent of the question and other important considerations.

GENERAL GUIDANCE FOR INTERVIEWERS

A. Planning for the Interview

For interviews scheduled in the future, the survey vendor/interviewer should perform the following planning activities:

Review HCBS participant information. The interviewer should review any relevant sampled participant-specific information before the interviewer meets with or calls the HCBS participant.

Interview-specific guidance. For more information, refer to [Appendix E: Sample Introductory Scripts for the HCBS CAHPS Survey](#) and [Appendix F: Sample of Consent Form for the HCBS CAHPS Survey](#).

- **Conduct reminder calls in advance of interviews.** Call the sampled HCBS program participant a day or two in advance of the scheduled interview to remind them of the upcoming appointment. A letter or reminder postcard also can help ensure HCBS participant availability at the time of the interview.
- **Obtain consent for interviews.** Always obtain verbal consent and obtain written consent if the sponsor requires it. If in person consent is required, bring two copies of consent forms and pens. Review each section of the consent form with the participant and/or proxy.
- **If desired, bring a thank you note for respondent or email/mail a follow-up thank you note.** As determined by the sponsor, bring a thank you note to the interview or email/mail a follow-up thank you note after the interview. The note serves as a reminder to the respondent that an interview occurred and could inform family members about it. The note also provides legitimacy by listing the survey vendor's contact information.

B. Conducting the Interview

At the interview, interviewers should perform the following activities:

Introduce themselves. The interviewer should provide a self-introduction and develop a rapport with the participant. The appropriate introductory scripts (see [Appendix E: Sample Introductory Scripts for the HCBS CAHPS Survey](#)) should be read at the beginning of all interviews and should highlight key themes about the HCBS CAHPS Survey:

- The purpose of the HCBS CAHPS Survey (to learn about their experiences and determine whether the sponsor needs to make improvements to the program);
- There are no “correct” answers, and honest responses will not affect benefits;
- Responses are private and will not be shared with providers; and
- Allow time to answer any questions the HCBS participant may have before starting.

Address the presence of others. Interviewers should check with the participant to see whether the presence of any other people during the interview aligns with the participant’s wishes. Some program participants may feel more comfortable with staff or family members present. Other participants may prefer to speak in private but may need help in asking others present to give the interviewer and the HCBS participant some privacy.

You can use the following suggested language to inquire about staff presence with participants:

- This is an opportunity for us to talk about your *{program name}*, would it be possible for *{name of staff}* to leave the room while we talk about your *{program name}*?
- Are you comfortable with *{name of staff}* leaving the room while we talk?

The HCBS CAHPS Survey should be conducted privately, if possible. Many of the questions address sensitive information that federal law protects, including asking the sampled participant about staff people. No staff people should be present during the actual interview, unless the respondent specifically requests the staff person’s presence. If a staff person enters the room at any time during the interview, the interviewer should stop and wait until they leave. It will not always be possible to conduct the interview in private. If the respondent does not want to go or cannot be moved to a more private place and prefers to be interviewed with others present, try to maintain as much privacy as possible. If the sponsor or the sponsor’s institutional review board (IRB) requires it, interviewers should obtain consent from the participant for the information to be shared with those present, in accordance with the requirements of the Health Insurance Portability and Accountability Act (HIPAA) and any other applicable federal and state laws.

Consider proxies and guardians. Although the sponsor should encourage sampled HCBS participants to respond directly to the HCBS CAHPS Survey, not all participants can do so. A sponsor may decide that proxies may complete the survey for a sampled participant who is unable physically, mentally, or both to respond to the survey directly or may answer some of the questions to support the participant. The sample introductory script (see [Appendix E: Sample Introductory Scripts for the HCBS CAHPS Survey](#)) incorporates the possibility of a proxy and can be modified based on the sponsor’s and an IRB’s request(s). In the sample introductory script, the interviewer will urge the

proxy or guardian to answer the HCBS CAHPS Survey questions to reflect how the participant would respond.

The survey sponsor and survey vendor must determine whether the survey should be modified to accommodate proxies or be left as is, with the interviewer reminding the proxy to respond on behalf of the participant. The following are some examples of how an interviewer would restate questions (changes appear in all **CAPS BOLD**, with ~~DELETIONS~~ struck through):

- Q4. In the last 3 months, did ~~YOU~~ **{PARTICIPANT'S NAME}** get *{program specific term for personal assistance}* at home?
- Q28. In the last 3 months, how often did *{personal assistance/behavioral health staff}* treat ~~YOU~~ **{PARTICIPANT'S NAME}** with courtesy and respect? Would you say ...
- INTRO BEFORE Q48. Now I would like to talk to you about ~~YOUR~~ **{PARTICIPANT'S NAME}'S** *{case manager}*, the person who helps make sure ~~YOU HAVE~~ **{PARTICIPANT'S NAME}** **HAS** the services ~~YOU~~ **{THEY}** need.
- Q48 ~~Do you~~ **DOES** **{PARTICIPANT'S NAME}** know who ~~your~~ **{THEIR}** *{case manager}* is?

Obtain consent and assent, if required. As determined by the sponsor or IRB, interviewers should seek consent from participants or, in the case of participants with guardians, consent from the guardians and assent from participants to administer the HCBS CAHPS Survey. For more information, refer to [Appendix F: Sample of Consent Form for the HCBS CAHPS Survey](#). Determine with the survey sponsor whether signed consent/assent is required for in-person interviews.

Minimize distractions. Interviewers should try to minimize distractions such as cell phones, television, computers, and radios for themselves and the HCBS participant. The focus should be on the survey instrument and the HCBS participant.

Use preferred name. Some participants may want to be addressed only by the participant's first name, whereas others may find this disrespectful. Interviewers should inquire how the participant prefers to be addressed during the interview. Examples include, by first name, by last name, by Ms./Mrs./Mr., or by a nickname.

Ask the questions as they appear. This ensures that each person hears the question in a consistent manner. However, the following are some modifications that an interviewer can make when administering the HCBS CAHPS Survey:

- **Alternative questions and response options.** If a respondent does not understand the standard CAHPS question, an interviewer should ask the alternative question and response option in the HCBS CAHPS Survey;
- **Proxy respondents.** If a sponsor wants interviewers to revise questions for proxy respondents, the interviewer may change "you" to the participant's name and modify verbs and pronouns throughout; and

- **Singular/plural.** If a respondent has only a single staff person for a particular service but the question has language implying that they have many, the interviewer can change it so that it is correct.

Follow the instructions to read the survey text. The survey has formatting conventions for interviewers to know what and how to read the text, including:

- 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 UPPERCASE LETTERS should not be read aloud. For example, “DON’T KNOW” and “REFUSED” answer categories appear in uppercase and should not be read to the respondent, but they may be used to code a response. There are instructions or other information that are also in uppercase that should not be read out loud, such as, “ALTERNATE VERSION;”
- All questions include a “REFUSED” response option. In this case, “REFUSED” means that the respondent did not provide any answer to the question;
- All questions include a “DON’T KNOW” response option. The interviewer should use this option when the respondent indicates that they do not know the answer and cannot provide a response to the question; and
- All questions include an “UNCLEAR” response option. The interviewer should use this option 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.”

When to use alternative response options. Because organizations will use the HCBS CAHPS Survey across different disability groups, including individuals with intellectual or developmental disabilities, it is likely that the response options of “Never,” “Sometimes,” “Usually,” and “Always” may be cognitively challenging for some sampled participants. For sampled participants who are unable to use the “Never,” “Sometimes,” “Usually,” and “Always” response scale, the alternate response options of “Mostly yes” and “Mostly no” should be used. If the response is still unclear, the interviewer may mark “unclear response” as the response.

The interviewer can make the determination as to when to use the alternate response option using the following process. If the respondent is unable to respond using the responses “Never,” “Sometimes,” “Usually,” and “Always” as indicated by nonverbally or verbally stating, “I don’t understand,” “I am not sure of the difference,” or a similar response, the interviewer should reread the question providing the “Mostly yes” and “Mostly no” response option. For the following question, the interviewer should provide the standard responses “Never,” “Sometimes,” “Usually,” and “Always” again, providing the alternate responses of “Mostly yes” and “Mostly no” only if the respondent is unable to respond using the standard responses. After three unsuccessful attempts to use the standard response, the interviewer should switch to the alternate responses and use the alternate responses throughout the remainder of the interview.

Probe for complete answers in a neutral and professional manner. The following are neutral acknowledgment terms that interviewers can use during the course of the survey to support rapport:

- Thank you;
- Okay;
- I understand;
- I see;
- Yes, Ma'am;
- Yes, Sir; and
- Let me repeat the question/answer choices for you.

Do not leave any questions blank. If the HCBS participant does not answer, interviewers should record the appropriate response category for the type of nonresponse (e.g., REFUSED, DON'T KNOW).

When to change singular to plural. The survey assumes that more than one staff person provides each service, except for case managers. Depending on the sponsor and survey vendor decisions, the survey may be programmed to have interviewers use the correct pronouns and verbs or the interviewer may need to modify a question during the interview.

Support respondents to answer questions when respondent has multiple staff for selected service. Many participants may have multiple staff for a selected service and are unsure of how to answer some of the questions. The CAHPS Consortium¹ suggests that the participant should make the ultimate decision. The participant can choose to focus on only one of the staff or they can consider more than one when answering and give a more/less favorable response than when considering only one provider. Alternatively, if the sponsor and survey vendor agree, ask respondents to focus on the staff who was most involved in the past week as they answer questions about staff.

Be sensitive to the HCBS participant's physical and emotional state. If the participant appears tired, interviewers may want to ask whether the participant would like to continue the interview. If the HCBS participant seems tired or in pain, interviewers should offer to take a break from the questions or to continue the interview at a later time. HCBS participants always have the right to stop their participation in the interview at any time. In that case, interviewers *must* thank the participants for their time and end the interview.

Avoid biasing the responses. Interviewers should avoid assuming answers ahead of time, interpreting answers provided, or suggesting answers. Interviewers should avoid giving their opinions, even when asked. Interviewers should provide positive but neutral feedback to maintain cooperation and to show appreciation for the respondent's time and effort.

¹ Since 1995, the Agency for Healthcare Research and Quality (AHRQ) has awarded 5-year grants to private organizations to plan and conduct research for the CAHPS program. Collectively, AHRQ and these research organizations are known as the CAHPS Consortium. The Consortium is responsible for conceiving, developing, testing, and refining CAHPS surveys and conducting research on the various uses of survey data.

Amend previous answers, if appropriate. If the HCBS participant provides additional or new information later in the interview that changes a previous answer, interviewers should return to that answer and amend it. For example, if an interviewer learns or observes that the participant does require assistance with an activity of daily living, even if the participant initially states that they do not, interviewers should return to that question and follow the appropriate skip pattern. Also, if the participant later remembers additional information, such as a case manager’s name, note that information where relevant.

Close the interview. At the end of the interview, thank the HCBS participant again for their participation. As directed by the sponsor, provide contact information either by phone or in written form so that the HCBS participant can contact someone knowledgeable of the survey if they have additional questions.

CATI/CAPI PROGRAMMING INSTRUCTIONS

Keep the text as is. To keep the CAHPS brand (i.e., be able to use the CAHPS name), neither a sponsor nor a survey vendor may omit a HCBS CAHPS Survey question or change the wording of the questions, the response categories, or the order of the questions in any of the surveys, with few exceptions. For more information regarding use of the CAHPS brand and survey modifications, please see the [“Modifying and Naming your CAHPS Survey”](#) page on AHRQ.gov.

Add questions if appropriate. Sponsors may add questions to this survey before the “About You” section. A separate supplemental employment module can be added.

Provide call back information. The computer interview script does not provide scripted language for scheduling a call back, ending an interview at the request of the participant before completing the survey, and so forth. Survey vendors may use their internal scripting for such modules.

Program emphatic text. The interview is 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 and programmed. Note: Survey vendors may indicate emphasis of text in a different manner, such as underlining, highlighting, placing quotes (“”), or asterisks (**) around the text to be emphasized, if the CATI/CAPI system does not permit any of the styles indicated above.

Program administrative data. Text in *{italics and in curly brackets}* should be provided by the HCBS program’s administrative data to program into the survey. However, if the respondent provides another term, that term should be used in place of the program-specific term wherever indicated. For example, some respondents may refer to their case manager by another title, which should be used instead throughout the survey.

Allow for alternate response questions and responses. 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. Interviewers may use alternate response options only for respondents who find the “Never,” “Sometimes,” “Usually,” and “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. Interviewers may use these alternate response options only for respondents who find the numeric scale cognitively challenging.

Program skip patterns. Some responses have skip patterns, which appear as “→ GO TO Q#.” The vendor should program the survey to automatically advance the interviewer to the next appropriate item to ask the respondent. When the interviewer does not obtain a response to a screener question (“DON’T KNOW” or “REFUSED” or “UNCLEAR” are valid responses), the screener question and any questions in the skip pattern should be coded as a missing response. In this case, the telephone interviewing system should be programmed to skip the dependent question(s) and go to the next screener question.

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

Program singular/plural as needed. In most cases, the questions assume that more than one staff person supports a respondent, or it does not indicate whether more than one staff person supports a respondent. On the basis of information collected from Q4 through Q12, the interviewer may modify questions to be singular or plural as they relate to staff.

Use program- and participant-specific terms. Where appropriate, add in the program-specific terms (e.g., *{program-specific term for these types of staff}*) but allow the interviewer to modify the term on the basis of the respondent’s choice of the word. It will be necessary to obtain information for program- and participant-specific terms.

Ideally, survey sponsors will supply the following participant-specific information from state administrative data and other program sources:

- Participant name, first and last;
- Mailing address (address, city, state, and ZIP Code);
- Telephone number(s);
- Sex;
- Date of birth;
- Name and contact information of guardian (if applicable, as this would be used to contact the guardian to obtain survey participation consent);
- Services that the participant receives (e.g., personal care, behavioral health, homemaker, case management, employment) along with the program-specific name for each of the services (this information can be used to assess appropriate responses to the cognitive screener questions);

- Names for each service provider (e.g., John Smith) for each service (this information can be used to remind respondents about services the participant receives by provider name in the identification questions of the survey); and
- Preferred language (this would be used to send an appropriate pre-notification letter and conduct the interview in the language preferred).

Ahead of conducting the survey, the survey vendor should work with the sponsor to receive state data necessary to carry out the survey. The vendor should use this data, such as program name and types of services, to customize the survey. Survey sponsors should supply the vendor with the following program- or state-specific information:

- Name of the HCBS agency(ies) (vendor should use this information to tailor the pre-notification letter and to remind the participants that the survey focuses on the staff from these agencies) (see [Appendix C: Sample of Participant Pre-Notification Letters for Administration of HCBS CAHPS](#) and [Appendix D: Sample of Guardian Pre-Notification Letters for Administration of HCBS CAHPS](#));
- Name of program under which the participant receives services (this also should be linked to each respondent primarily for analysis purposes because it can be an indicator of subgroups, e.g., older adults, persons with physical disabilities, persons with intellectual or developmental disabilities, persons with acquired brain injury, and persons with mental health or substance use disorders);
- Program-specific title for each staff category (interviewers will use this information in the identification questions of the survey, e.g., personal care assistant [PCA]);
- Program-specific title for “service plan;”
- Program-specific term for “staff;” and
- State-specific language related to mandated reporting of abuse, neglect, or exploitation.

The survey vendor’s CATI/CAPI programmer will tailor the survey as noted below:

- Where the survey states, “*{program-specific term for personal assistance}*,” program in the administrative data for that term;
- Where the survey states, “*{program-specific term for behavioral health services}*,” program in the administrative data for that term;
- Where the survey states, “*{personal assistance/behavioral health staff}*,” program in the administrative data for program-specific terms for personal assistant and behavioral health staff (e.g., PCA or counselor). In addition, the program should allow for modification by the interviewer that changes the rest of the survey based on the response to Q5 and Q7. For example, if a respondent states that they call the personal assistant something else, such as “a worker” (or “my friend” or “Sally”) for Q5, the CATI/CAPI program should use “worker” (or “my friend” or “Sally”) in lieu of personal assistance staff. The survey vendor

should be instructed to program the CATI/CAPI to autofill the respondent's title wherever an item specifies "*personal assistance / behavioral health staff*;"

- Where the survey states, "{*program-specific term for homemaker services*}," program in the administrative data for that term;
- Where the survey states, "{*homemaker*}," program in the administrative data for that term. As noted in the bullet on personal assistance/behavioral health staff, allow for interviewer changes based on respondent's response to Q9 on a title for the homemaker;
- Where the survey states, "{*program-specific term for case manager services*}," program in the administrative data for that term;
- Where the survey states, "{*case manager*}," program in the administrative data for that term. As noted in the bullet on personal assistance/behavioral health staff, allow for interviewer changes based on respondent's response to Q12 on a title for the case manager;
- Where the survey states, "{*service plan*}," program in the administrative data for that term;
- Where the survey states, "{*staff*}," program in the administrative data for that term; and
- Where the survey states, [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 someone is hurting you or you are in danger" program in the language for state-specific language related to mandated reporting of abuse, neglect, or exploitation.

Suspending a call. When a respondent suspends an interview and does not resume it, the unanswered screener questions should be coded as a missing response.

If after starting the survey, the interview stops due to disconnection, or the participant requests a call-back at a later date to complete the survey, the survey vendor may resume the call where the participant left off.

Use a proxy if appropriate. In the event that a participant is unable to complete the interview, a proxy may complete the interview. For coding of whose responses to include in the disposition reports, follow this logic:

- If the interviewer contacts the participant first, answers the survey, but has a proxy answer some of the questions as noted in the question on how a proxy helped, indicate the participant in the numerator and denominator;
- If the interviewer contacts the participant first, but the participant fails one or more of the cognitive screening questions and a proxy is able to respond, include only the proxy responses in the numerator and denominator;

- If the interviewer contacts the participant first, but the participant fails one or more of the cognitive screening questions and a proxy also fails one or more of the cognitive screening questions, include the participant in the denominator only; and
- If the interviewer contacts the proxy first, include the proxy in the numerator and denominator as appropriate.

INSTRUCTIONS FOR INTERVIEWERS ON SELECT QUESTIONS AND CODING RESPONSES

This section of the appendix provides guidance by HCBS CAHPS Survey section and domain on how survey vendors should instruct interviewers to understand and code individual items. Each section begins with an explanation of the purpose of the survey section. In addition, a potential issue with the wording and guidance for addressing the issue appear after the HCBS CAHPS Survey item.

Please note that this section does not contain all questions in the HCBS CAHPS Survey. It only has questions that have been determined to need additional clarification or explanation.

A. Cognitive Screening Questions

The survey, including question wording and response sets, is accessible to as many HCBS participants as possible. However, it also is important that those using the results of the survey have confidence in the results. For this reason, the survey starts with a set of three cognitive screening questions to identify individuals who are most likely to provide reliable responses. These questions are referred to as cognitive screening questions because they generally assess a participant’s cognitive ability to participate in the survey. The questions anchor the respondent and interviewer to complete the relevant sections of the survey. The HCBS CAHPS Survey does not contain traditional cognition-related questions. The purpose of these items is to ascertain whether someone can answer the survey. All three items should be answered in a meaningful way. If participants answer all three questions adequately, the interviewer continues to administer the remainder of the survey. If fewer than three questions are answered adequately, the interviewer stops the interview with the participant and may inquire about a potential proxy respondent. If the respondent is not able to answer any of the questions, interviewers should end the interview and indicate the disposition for the case as “cannot be completed.” If the sponsor decides to include proxies in the survey, interviewers should also ask the questions to proxies.

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

¹YES

²NO → END SURVEY

⁻¹DON’T KNOW → END SURVEY

⁻²REFUSED →END SURVEY

⁻³UNCLEAR 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

⁻¹DON'T KNOW → END SURVEY

⁻²REFUSED → END SURVEY

⁻³UNCLEAR RESPONSE → END SURVEY

3. What do you call them?

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

- MY WORKER
- MY ASSISTANT
- NAMES OF STAFF (JO, DAWN, ETC.)

⁻¹DON'T KNOW → END SURVEY

⁻²REFUSED → END SURVEY

⁻³UNCLEAR 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]

B. Identification Questions

By design, this set of items confirms which portions of the HCBS CAHPS Survey should be used, as well as to customize staff titles to increase comprehension by sampled participants. There are four sets of items that ask about receipt of specific services and preferred terms for staff: for personal assistance, behavioral health, homemaker, and case management staff. All follow the pattern shown below.

The responses the interviewer enters for these items will automatically customize the CATI/CAPI tool such that the respondent's preferred titles and only relevant questions will appear on the screen.

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*"]

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

⁻¹ DON'T KNOW

⁻² REFUSED

⁻³ UNCLEAR RESPONSE

Issue: "Everyday" activities may not be clear to sampled participants. This term appears repeatedly throughout the HCBS CAHPS Survey.

Guidance: Define "everyday" activities upon first use. For example, state that "everyday activities" include getting dressed, using the bathroom, taking a bath or shower, or going places. "Everyday" activities are activities that are part of the individual's routine. Interviewers can remind survey participants of this definition upon future use if needed.

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

⁻¹ DON'T KNOW

⁻² REFUSED

⁻³ UNCLEAR RESPONSE

Issue: The definition of “help” in the context of this question is very broad.

Guidance: “Help” includes coordinating services or care that the participant has identified that they need and would like to receive.

Issue: The definition of what services were needed by the participant in the context of this question is very broad.

Guidance: Needed services include any services that the participant has identified that they need and would like to receive.

12. What do you call the person who gave 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?

[ADD RESPONSE WHEREVER IT SAYS “*case manager*”]

C. HCBS CAHPS Survey Questions by Topic

By design, this set of items elicits the experiences of sampled participants with HCBS providers. There are six sets of items in the HCBS CAHPS Survey that ask about the following aspects of the HCBS received: getting needed services, communication with providers and case managers, choice and control over services, medical transportation, personal safety, and community inclusion. See Section F. Supplemental Employment Module for additional guidance.

Select HCBS CAHPS Survey questions and potential responses appear in their entirety below. The potential issue with the wording and guidance for addressing the issue appear after the survey question.

1. Getting Needed Services

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

Issue: Sampled participants may not understand the intent of the question.

Guidance: Interviewers can explain to participants that the questions are trying to determine whether staff remains on duty for the entire shift.

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
- ² NO
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

Issue: It may not be clear to the interviewer how to code if the participant never experienced this event.

Guidance: Interviewers should code “DON'T KNOW” if HCBS participant responds that they have never experienced this event.

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

- ¹ YES
- ² NO → GO TO Q20
- ⁻¹ DON'T KNOW → GO TO Q20
- ⁻² REFUSED → GO TO Q20
- ⁻³ UNCLEAR RESPONSE → GO TO Q20

Issue: The definition of “help” in the context of this and the following questions is very broad.

Guidance: “Help” includes hands-on help, supervision, or cueing. Interviewers should listen to the respondent’s answer to determine whether staff helps complete the activity in any of these ways.

17. In the last 3 months, did you **always** get dressed, take a shower, or bathe when you needed to?
- ¹ YES → GO TO Q19
 - ² NO
 - ⁻¹ DON’T KNOW → GO TO Q19
 - ⁻² REFUSED → GO TO Q19
 - ⁻³ UNCLEAR RESPONSE → GO TO Q19

Issue: Meaning of “need” is subjective.

Guidance: The meaning of “need” will be interpreted by the HCBS participant. The appropriate criterion includes anything deemed necessary or needed by the participant.

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
 - ⁻¹ DON’T KNOW → GO TO Q23
 - ⁻² REFUSED → GO TO Q23
 - ⁻³ UNCLEAR RESPONSE → GO TO Q23

Issue: Participants may want to know if grocery shopping is included in the definition of help making meals.

Guidance: This question does not include grocery shopping or getting groceries, only preparation and consumption of meals and snacks.

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
 - ⁻¹ DON’T KNOW → GO TO Q23
 - ⁻² REFUSED → GO TO Q23
 - ⁻³ UNCLEAR RESPONSE → GO TO Q23

Issue: The meaning of “something to eat” may be unclear.

Guidance: Some participants might have particular eating habit issues, which might relate to the control of their eating. “Something to eat” refers to everyone eating when it is appropriate for their personalized care such as major meals and appropriate snacking.

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

⁻¹ DON'T KNOW → GO TO Q26

⁻² REFUSED → GO TO Q26

⁻³ UNCLEAR RESPONSE → GO TO Q26

Issue: The interviewer may wonder if picking up medications from the pharmacy should be included as part of “help taking medicines.”

Guidance: Interviewers should not include picking up medications from the pharmacy.

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

⁻¹ DON'T KNOW → GO TO Q28

⁻² REFUSED → GO TO Q28

⁻³ 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

⁻¹ DON'T KNOW

⁻² REFUSED

⁻³ UNCLEAR RESPONSE

Issue: To some participants, the word “toileting” may sound immature or uncomfortable.

Guidance: Toileting is the appropriate term for the activity. Interviewers should take note that there may be some sensitivity around the word “toileting.” In general, this would include any help using the bathroom/restroom.

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]

¹ YES → GO TO Q41

² NO

⁻¹ DON'T KNOW → GO TO Q41

⁻² REFUSED → GO TO Q41

⁻³ UNCLEAR RESPONSE → GO TO Q41

Issue: The meaning of “need” may be unclear to some participants.

Guidance: “Need” can be interpreted by the HCBS participant. Whatever they deem necessary or needed is the appropriate criterion.

2. Communication with Providers and Case Managers

29. In the last 3 months, how often were the explanations {*personal assistance/behavioral health staff*} given to 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*} given to 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

Issue: Participants may interpret “accent” as a type of American accent.

Guidance: Interviewers ask this question because paid staff may speak English as a second language or have an American accent. The intent is to determine whether language barriers cause difficulty for the participants.

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

Issue: Participants may interpret “help” in many ways. This question may prompt the participant to tell anecdotes or stories.

Guidance: Interviewers may receive anecdotes or stories. Interviewers should ask the HCBS participant “Would you say yes or no?” if they tell you a story or anecdote.

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

Issue: Participants may not want to respond negatively.

Guidance: To receive a more exact answer, interviewers should ask “If you had to choose ...”

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
 - ⁻³ UNCLEAR RESPONSE → GO TO Q56

Issue: The meaning of “know” may be unclear to some participants.

Guidance: “Know” means the participant recognizes who the case manager is either by physical appearance, name, or idea.

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

Issue: A participant may not know how to respond if they do not use equipment.

Guidance: If the HCBS participant replies that they do not use equipment, then the interviewer may code response as “NO.”

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
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
 - ² NO

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

Issue: The meaning of “work with you” may be unclear to some participants.

Guidance: This question is inquiring about whether the case manager was responsive and looked into or attempted to change the HCBS participant’s services. The case manager should not be penalized if they were not successful because of reasons beyond their control (e.g., policies, funding restraints).

3. Choice and Control Over 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

Issue: The meaning of “service plan” and “goals” may be unclear to some participants.

Guidance: The question concerning the “service plan” is trying to determine whether the service plan takes into consideration the HCBS participant’s input. The HCBS participant may refer to “things that are important to you” as “goals.” “Goals” and “things that are important to you” may be used interchangeably.

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

Issue: The intent of the question may be unclear to participants.

Guidance: The question's intent is to determine the HCBS participant's perception of staff's familiarity with the service plan and knowledge of parts of the plan that are important to the participant.

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

Issue: The participant's answer may not match any of the response options.

Guidance: It is likely the HCBS participant will specifically name the person. However, interviewers should try to most appropriately decipher and determine which category to label the specific person or persons mentioned. If necessary, the interviewer should ask the participant "what does this person do?"

4. Medical Transportation

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

Issue: The intent of the question may be unclear to the participant.

Guidance: The question is only referring to medical transportation, not nonmedical appointments.

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

Issue: Meaning of “van” may be unclear.

Guidance: Interviewers should include vans that are from paid transport services. They should not include personally owned vans.

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

Issue: It may be unclear to the interviewer how to code the participant’s response.

Guidance: If the HCBS participant responds “yes,” but mentions a need for help from a person or assistive device, the interviewer may still code the response as “yes.” The goal is to determine *accessibility*, regardless of whether the participant receives assistance.

5. Personal Safety

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

¹FAMILY MEMBER OR FRIEND

²CASE MANAGER

³AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES

⁴PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)

⁵9-1-1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)

⁶SOMEONE ELSE, PLEASE SPECIFY _____

⁻¹DON'T KNOW

⁻²REFUSED

⁻³UNCLEAR RESPONSE

Issue: The meaning of “emergency” may be unclear to the participant.

Guidance: The interviewer should not help the HCBS participant define “emergency.” The HCBS participant should define what they believe to be an emergency. If the interviewer receives a specific name, ask “How does this person relate to you?”

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?

¹YES

²NO

⁻¹DON'T KNOW

⁻²REFUSED

⁻³UNCLEAR RESPONSE

Issue: Some participants may have trouble understanding the hypothetical questions.

Guidance: If the participant does not understand, the interviewer should enter “DON'T KNOW.”

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 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 someone is hurting you or you 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

Issue: The phrase “take your money or your things without asking you” may be unclear to the participant.

Guidance: The intent of the question is to determine whether staff is stealing from the HCBS participant.

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

Issue: The intent of the question may be unclear to the participant.

Guidance: The person asked about in this question did not need to fix the problem. “Yes” is an acceptable answer if the person “worked” or tried to fix the problem.

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

Issue: It may be unclear to the interviewer how to code the participant’s response.

Guidance: The interviewer must code all that apply to the participant’s response. Interviewers may need to probe further to place named individuals in the correct category.

6. Community Inclusion

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

Issue: The meaning of “nearby” may be unclear to the participant. This question may also be sensitive for the participant.

Guidance: The HCBS participant must determine for themselves what “nearby” means to them. Also, do not include people who live with the respondent as someone who lives “nearby.”

This question along with Q76 may be emotionally impactful questions for the HCBS participant. Be prepared to be sensitive around these topics while interviewing. Also, some of the participants may live secluded lives, which might cause emotional discomfort when talking about friends and family. The participant’s friends or family may have died or moved away, so please be understanding while talking about these sensitive topics.

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

Issue: This question may be sensitive for participants.

Guidance: This question, along with Q74, may be emotionally impactful for the HCBS participant. Be prepared to be sensitive around these topics while interviewing. Also, some of the participants may live secluded lives, which might cause emotional discomfort when talking about friends and family. The participant's friends or family may have died or moved away, so please be understanding while talking about these sensitive topics.

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

Issue: The intent of the question may be unclear to the participant.

Guidance: The interviewer may need to give other examples of “community activities.” Other examples include going to parks, community functions, going to the mall or the movies, and going to church or other religious settings.

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

Issue: The intent of the question may be unclear to the participant.

Guidance: This questions is specifically asking about help in the community and not at home or elsewhere.

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

Issue: The intent of the question may be unclear to the participant.

Guidance: This question is focusing on the “what.” If necessary, say “For example, do you get to help decide the kinds of things you want to do at home? What about when you are out?”

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?

¹YES

²NO

⁻¹DON'T KNOW

⁻²REFUSED

⁻³UNCLEAR RESPONSE

Issue: The intent of the question may be unclear to the participant.

Guidance: This question is focusing on “when.” If necessary, say “For example, do you get to help decide when you get up in the morning or when you eat?”

D. Demographic Questions

This section of the HCBS CAHPS Survey asks questions about the HCBS participant. It is the last section of the survey with questions for the participant to answer. Below, interviewers can find guidance about the intent and handling of selected questions.

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 ...

¹Excellent,

²Very good,

³Good,

⁴Fair, or

⁵Poor?

⁻¹DON'T KNOW

⁻²REFUSED

⁻³UNCLEAR RESPONSE

Issue: The intent of the question may be unclear to the participant.

Guidance: This includes physical health only. There is a subsequent question that addresses mental health.

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
- ⁻³ UNCLEAR RESPONSE

Issue: The intent of the question may be unclear to the participant.

Guidance: This is an alternative question to determine the age of the HCBS participant in the event that the person's recall of birth year is better.

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

Issue: Many participants with an intellectual or developmental disability may have not followed a standard education path or had any education.

Guidance: Enter in “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

Issue: This question is long.

Guidance: Race is always self-reported. Interviewers must read all race options as they are written, however, they can repeat the options. Multiple responses may be recorded.

94. [IF NECESSARY, ASK] How many adults live at your home, including you?

- ¹ 1 [JUST THE RESPONDENT] → END SURVEY
- ² 2 TO 3
- ³ 4 OR MORE
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

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

- ¹ YES
- ² NO
- ⁻¹ DON'T KNOW
- ⁻² REFUSED
- ⁻³ UNCLEAR RESPONSE

Issue: It is unclear whether these questions should always be asked.

Guidance: The answer may appear obvious to the interviewers conducting in-person interviews. To make sure that such conclusions are correct, please ask this question for all phone and in-person interviews.

E. Questions Completed After the Interview

The last section of the HCBS CAHPS Survey instrument contains questions for the interviewer to complete. All interviewers should complete these questions.

97. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

¹ YES

² NO

Issue: It may be unclear to the interviewer how to code the participant's response.

Guidance: This is an answer that should be completed after the interview. The interviewer should use their best judgment to answer this question. Examples of valid responses include respondents being able to answer all questions, even if they needed repetition, time to answer, or used alternative response options. Examples of invalid responses include responses that did not make sense.

98. WAS ANYONE ELSE PRESENT DURING THE INTERVIEW?

¹ YES

² 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

Issue: The meaning of "who was present" may be unclear to the interviewer.

Guidance: This may be anyone present, a family member, a friend, or a paid staff.

100. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

¹ YES

² NO → END SURVEY

Issue: The meaning of "help" may be unclear to the interviewer.

Guidance: Assistance in completing the interview can range from reminding participants of experiences, translating questions and responses, helping with assistive technology, and answering items outright. If the HCBS participant had someone who was verbally prompting them, the interviewer should include that response as the participant receiving help from someone.

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 _____

Issue: It may be unclear to the interviewer when to record a response to this question.

Guidance: The interviewer should complete this question following an interview in which the participant received help answering the questions. The interviewer should use their best judgement to record what type of and how much help the participant received with answering the questions.

F. Supplemental Employment Module

The Supplemental Employment Module of the HCBS CAHPS Survey asks about programs that offer employment services, such as job coaching. This module does not cover any volunteer work. If the interviewer uses the supplemental module, the interviewer should place it just before the demographic questions (i.e., the “About You” section). Below is guidance for interviewers on select questions.

EM1. In the last 3 months, did you work for pay at a job?

- ¹ YES → GO TO EM9
- ² NO
- ⁻¹ DON'T KNOW → GO TO THE ABOUT YOU SECTION
- ⁻² REFUSED → GO TO THE ABOUT YOU SECTION
- ⁻³ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

Issue: It may be unclear to the interviewer how to code the participant’s response.

Guidance: If the HCBS participant answers, “yes, I volunteer” the appropriate code is “NO” because volunteer work is not for pay.

EM2. In the last 3 months, did you want to work for pay at a job?

- ¹ YES
- ² NO → GO TO EM4
- ⁻¹ DON’T KNOW → GO TO THE ABOUT YOU SECTION
- ⁻² REFUSED → GO TO THE ABOUT YOU SECTION
- ⁻³ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

EM3. Sometimes people feel that something is holding them back from working when they want to. In the last 3 months, was this true for you? If so, what has been holding you back from working? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

- ¹ BENEFITS → GO TO EM5
- ² HEALTH CONCERNS → GO TO EM5
- ³ DON’T KNOW ABOUT JOB RESOURCES → GO TO EM5
- ⁴ ADVICE FROM OTHERS → GO TO EM5
- ⁵ TRAINING/EDUCATION NEED → GO TO EM5
- ⁶ LOOKING FOR AND CAN’T FIND WORK → GO TO EM5
- ⁷ ISSUES WITH PREVIOUS EMPLOYMENT → GO TO EM5
- ⁸ TRANSPORTATION → GO TO EM5
- ⁹ CHILD CARE → GO TO EM5
- ¹⁰ OTHER (_____) → GO TO EM5
- ¹¹ NOTHING IS HOLDING ME BACK → GO TO EM5
- ⁻¹ DON’T KNOW → GO TO EM5
- ⁻² REFUSED → GO TO EM5
- ⁻³ UNCLEAR RESPONSE → GO TO EM5

EM4. Sometimes people would like to work for pay, but feel that something is holding them back. In the last 3 months, was this true for you? If so, what has been holding you back from wanting to work? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

- ¹ BENEFITS → GO TO THE ABOUT YOU SECTION
- ² HEALTH CONCERNS → GO TO THE ABOUT YOU SECTION
- ³ DON’T KNOW ABOUT JOB RESOURCES → GO TO THE ABOUT YOU SECTION

- ⁴ ADVICE FROM OTHERS → GO TO THE ABOUT YOU SECTION
- ⁵ TRAINING/EDUCATION NEED → GO TO THE ABOUT YOU SECTION
- ⁶ LOOKING FOR AND CAN'T FIND WORK → GO TO THE ABOUT YOU SECTION
- ⁷ ISSUES WITH PREVIOUS EMPLOYMENT → GO TO THE GO TO THE ABOUT YOU SECTION
- ⁸ TRANSPORTATION → GO TO THE GO TO THE ABOUT YOU SECTION
- ⁹ CHILD CARE → GO TO THE ABOUT YOU SECTION
- ¹⁰ OTHER (_____) → GO TO THE ABOUT YOU SECTION
- ¹¹ NOTHING/DON'T WANT TO WORK → GO TO THE ABOUT YOU SECTION
- ⁻¹ DON'T KNOW → GO TO THE ABOUT YOU SECTION
- ⁻² REFUSED → GO TO THE ABOUT YOU SECTION
- ⁻³ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

Issue: It may be unclear to the interviewer how to code the participant's response to EM2, EM3, and EM4.

Guidance: Participants will most likely answer in a story format. For example, interviewers should code the barriers from the story that the participant tells.

Issue: The intent of the EM3 and EM4 questions may be unclear to the participant.

Guidance: The interviewer should ask EM3 of people who do not work but *want* to. The interviewer should ask EM4 of people who do not work and who say they *do not want* to. EM4 explores the idea that some people don't work and say they don't want to when there are barriers to working. In both cases, the "benefits" response category can be used for concerns about a loss of public benefits such as disability and Social Security if they work. In addition, response option 11 is different in both as well. EM3 states "nothing is holding me back" and continues onto the survey, while EM4 states "NOTHING/DON'T WANT TO WORK" and ends the employment module.

EM7. Help getting a job can include help finding a place to work or help getting the skills that you need to work. In the last 3 months, did someone receive pay to help you get a job?

- ¹ YES → GO TO EM8
- ² NO → GO TO THE ABOUT YOU SECTION
- ⁻¹ DON'T KNOW → GO TO THE ABOUT YOU SECTION
- ⁻² REFUSED → GO TO THE ABOUT YOU SECTION
- ⁻³ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

Issue: The intent of the question may be unclear to the participant.

Guidance: The question is specifically asking about someone who receives pay to help the HCBS participant. This does not include volunteers or family members who do not receive pay.

EM9. Who helped you find the job that you have now? [MARK ALL THAT APPLY]

- ¹ EMPLOYMENT/VOCATIONAL STAFF/JOB COACH
- ² CASE MANAGER
- ³ OTHER PAID PROVIDERS
- ⁴ OTHER CAREER SERVICES
- ⁵ FAMILY/FRIENDS
- ⁶ ADVERTISEMENT
- ⁷ SELF-EMPLOYED → GO TO EM11
- ⁸ OTHER (_____)
- ⁹ NO ONE HELPED ME—I FOUND IT MYSELF → GO TO EM11
- ⁻¹ DON'T KNOW → GO TO EM11
- ⁻² REFUSED → GO TO EM11
- ⁻³ UNCLEAR RESPONSE → GO TO EM11

Issue: It may be unclear to the interviewer how to code the participant's response.

Guidance: The interviewer must code all options that apply.

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. In the last 3 months, did someone receive pay to help you with the job you have now?

- ¹ YES
- ² NO → GO TO THE ABOUT YOU SECTION
- ⁻¹ DON'T KNOW → GO TO THE ABOUT YOU SECTION
- ⁻² REFUSED → GO TO THE ABOUT YOU SECTION
- ⁻³ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

Issue: The intent of the question may be unclear to the participant.

Guidance: The question is not referring to coworkers, only those people hired to help the HCBS participant at their job because of their disability.

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

Issue: This question seems to duplicate what is asked in EM11.

Guidance: The interviewer will use this question to check the response to EM11 and to flag any false positive responses.