APPENDIX E. SAMPLE OF INTRODUCTORY SCRIPTS TO USE WITH PARTICIPANTS OR THEIR PROXIES FOR THE CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS HOME AND COMMUNITY-BASED SERVICES (HCBS CAHPS[®]) SURVEY

Appendix E. Sample of introductory scripts for the HCBS CAHPS Survey

Instructions

The interviewer can use the introduction and recruitment script as a basic approach to introduce the HCBS CAHPS Survey to the participant. This document provides the following basic templates that can be tailored by the survey sponsor:

- <u>Interviewer and Computer-Assisted Interview Programmer Formatting Conventions</u> (E-3);
- Introducing Participants to the Survey and Recruiting Participants (E-4);
- <u>Continuing and Setting Up the Phone Interview</u> (E-8);
- <u>Setting Up In-Person Interview</u> (E-9); and
- <u>Greeting Participant During the Face-to-Face Interview</u> (E-9)

It is expected that survey sponsors will tailor the introductory script to suit their populations' unique needs, to implement decisions regarding the inclusion of proxies, and to comply with institutional review board (IRB) requirements. Similarly, the interviewer can use the sample greeting script for face-to-face interviews as a basic approach. Survey sponsors should tailor the sample script using the following guidelines as appropriate:

- Institutional review board requirements. An IRB may require changes in the language, for example, from "survey" to "research study" at first mention. Such potential changes appear in italics and brackets. An IRB may have other requirements that could alter the introductory script. Such IRB requirements have precedence over the sample script;
- **Proxy respondents**. A proxy is someone who answers on behalf of the intended respondent. At the end of the HCBS CAHPS Survey instrument, the interviewer reports any assistance another person—such as a proxy—provided to the respondent during the survey. Sponsors will need to make decisions about including proxy respondents, following the guidelines set out in the *Technical Assistance Guide for Administration of the HCBS CAHPS Survey* Section IV.J. Decisions Regarding Proxy Respondents, and these decisions will affect the script. The sample script assumes that proxies will be allowed. Some prompts are provided for where such decisions should be taken into account in tailoring the script. Because different approaches may be taken, it is envisioned that sponsors will use this sample script as a starting point for developing a script that reflects their decisions regarding proxy respondents. Examples of user considerations related to proxy respondents that affect the script include:
 - Whether to allow proxy respondents if a participant is otherwise unable to participate in the survey;
 - Whether to require guardian (e.g., legal representative, legal guardian) consent for a proxy respondent in the event that an IRB does not stipulate consent;
 - The criterion to apply to who can be a proxy respondent;

- Whether to allow a guardian (any or only certain individuals, such as only those who have an active role in the participant's care) to be the participant's proxy respondent;
- Whether to require participant assent in addition to guardian consent in the event that an IRB does not stipulate assent;
- Whether to require participant assent to have a proxy respondent, and determination of *who* will be the proxy respondent. From a person-centered perspective, users should consider not allowing a proxy to respond if the participant does not agree to it. Likewise, users should consider not allowing a particular person to be the proxy if the participant does not agree to that person;
- Whether and how to explore the possibility of having a proxy respondent, if the participant or guardian has not requested one; and
- **Mode.** The survey allows for two modes—telephone and in-person. The sponsor will need to make a decision as to which mode to use and how to proceed with the modes. For example, a sponsor may wish to randomly assign respondents to one or the other mode or may let the participant choose. The script will need to be modified according to which mode(s) the sponsor selects.

Interviewer and Computer-Assisted Interview Programmer Formatting Conventions

The following formatting conventions are used only for the purposes of this document. Survey vendors may use their own formatting conventions if they differ from those presented here as long as the intended results are the same (e.g., the interviewer reads the same text aloud, the interviewer emphasizes the same words, the vendor implements the same programming instructions) and the vendor consistently applies the conventions throughout the script.

- Computer-assisted telephone interview (CATI) programmer instructions should be removed from the electronic interviewing system screens. These may appear in <ENGLISH UPPERCASE LETTERS ENCLOSED IN ANGLE BRACKETS>. Many responses include an arrow with a question number to go to, for example"→ GO TO INTRO1." These show programming instructions that must not actually appear on electronic interviewing system screens;
- Text in {*italics and in braces*} ideally would be provided by the sponsor's administrative data or the vendor's data (e.g., name of survey vendor). Initial information should be programmed by the CATI programmer;
- 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; and
- The purpose of the introduction and recruitment script is to protect the privacy of the sampled respondent. The interviewer does not provide details about the survey until he or she is speaking with the sampled respondent. Therefore, the interviewer first asks to speak to the participant before stating the nature of the call. For proxies and/or guardians, the interviewer again first asks for a proxy or the guardian before discussing the nature of the interview.

Sample Introduction and Recruitment Script for Participants

1. Hello, may I please speak to {*participant respondent's name*}?

□YES, PARTICIPANT → GO TO Q2 □YES, REQUEST FOR ASSISTANCE → GO TO Q3 □YES, REQUEST FOR GUARDIAN OR PROXY → GO TO Q4 □NOT AVAILABLE RIGHT NOW → SCHEDULE CALLBACK NO/REFUSAL → CODE AS REFUSAL □[IF PROXIES ARE ALLOWED] PERSON ANSWERING PHONE INDICATES RESPONDENT MENTALLY/PHYSICALLY UNABLE TO RESPOND → GO TO Q6

□[IF PROXIES ARE NOT ALLOWED] MENTALLY/PHYSICALLY UNABLE \rightarrow END SURVEY

IF ASKED WHO IS CALLING: I'm calling to follow up on a letter from {*name of signatory on letter*} from {*sponsor name*}.

2. Hello, my name is {*interviewer name*} calling from {*survey vendor*} on behalf of {*sponsor name*} to ask you about your experiences in the last 3 months with the people who are paid to help you in your home and community with everyday activities. You may remember receiving a letter about the {*survey/research study*}. Your answers are very important and will be used to help improve home and community-based services. It is your choice to answer the survey and your choice will not affect any of the services you get. The interview should take about 30 minutes to complete. The only people allowed to hear or see your answers will be the people who are doing the survey, like me, and anyone you want to listen. Your answers will be grouped with others and reported with no identifying information. Can I ask you some questions about the services you receive? We could do this now or at another time that is convenient for you, either over the phone or in person.

 \Box YES, OVER THE PHONE \rightarrow GO TO PHONE 1

 \Box YES, FACE-TO-FACE \rightarrow GO TO F2F 1

 \Box YES, AND PARTICIPANT RESPONDENT REQUESTS ASSISTANCE \rightarrow GO TO Q3

 \Box REFUSE \rightarrow END SURVEY

3. What kind of assistance would you like?

□REQUEST FOR GUARDIAN TO RESPOND \rightarrow "We can contact *{guardian name}* and ask them the questions. Thank you and have a good day." \rightarrow USE GUARDIAN CONTACT INFORMATION AND GO TO Q7

 \Box REQUEST FOR PROXY TO RESPOND \rightarrow GO TO Q4

□ REQUEST FOR PROXY OR PROMPTER TO BE NEAR PARTICIPANT WHEN RESPONDING TO HELP THEM \rightarrow GO TO Q5

□TRANSLATE QUESTIONS OR ANSWERS INTO THE RESPONDENT'S LANGUAGE → STATE THAT YOU WILL CALL THE PARTICIPANT BACK IN THE LANGUAGE PREFERRED. FOLLOW PROTOCOL TO CONDUCT INTERVIEW IN ANOTHER LANGUAGE.

□ HELP WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS → "What kind of help do you need? Just to let you know, I or someone else will ask you the questions, so if it is reading assistance, you shouldn't need that." IDENTIFY RESPONDENT NEEDS AND MAKE ARRANGEMENTS.

OTHER, SPECIFY _____

4. If you like, we can interview someone else to answer on your behalf. This person needs to be someone who knows you well. Also, this person should be someone who is **not** paid to help you. This could be an unpaid family member, friend, or neighbor you are close with. Is there someone not paid to help you who could answer these questions for you?

□YES. GET CONTACT INFORMATION AND GO TO Q7

NAME:

ADDRESS:

PHONE NUMBER:

5. If you like, we can contact the person to set up a joint in-person interview where they can help you to answer questions. This person needs to be someone who knows you well. Also, this person should be someone who is **not** paid to help you. This might be an unpaid family member, friend, or neighbor. Is there someone not paid to help you who could help you answer these questions?

□YES. GET CONTACT INFORMATION AND GO TO Q9

NAME:_____

ADDRESS: _____

PHONE NUMBER: _____

6. Thank you for letting me know. We would like to interview someone else to answer on {*participant's name's*} behalf. This person needs to be someone who knows {*participant's name*} well. Also, this person should be someone who is not paid to help {*participant's name*}. Is there someone not paid to help {*participant's name's*} who could answer these questions for them?

 \Box YES. PERSON ON PHONE CAN \rightarrow GO TO Q8

 \Box YES, ANOTHER PERSON. GET CONTACT INFORMATION AND GO TO Q7

ADDRESS:

PHONE NUMBER: _____

NAME:

 \Box REFUSE \rightarrow END SURVEY

7. <FOR PROXY ALONE INTERVIEWS> Hello, may I please speak to {guardian/proxy respondent's name}?

 \Box YES, GUARDIAN/PROXY \rightarrow GO TO Q8

 \Box NOT AVAILABLE RIGHT NOW \rightarrow SCHEDULE CALLBACK

 $\Box \text{NO/REFUSAL} \rightarrow \text{CODE AS REFUSAL}$

IF ASKED WHO IS CALLING: I'm calling to follow up on a letter from {*name of signatory on letter*} from {*sponsor name*}.

8. <FOR PROXY ALONE INTERVIEWS> Hello, my name is {*interviewer name*} calling from {*survey vendor*} on behalf of {*sponsor name*}. We recently sent a letter to the {*participant's name*} about a survey the sponsor is conducting. We would like to get feedback about their experience with the people who are paid to help {*participant's name*} in their home and community with everyday activities. {*Participant's name*} requested that you answer on their behalf.

Your answers are very important and will be used to help improve home and communitybased services. It is your choice to answer the survey and your choice will not affect **any of the services that** {*participant's name*} gets. The only people allowed to hear or see your answers will be the people who are doing the survey, like me. Your answers will be grouped with others and reported with no identifying information. The interview should take about 30 minutes to complete.

As you answer the survey questions, please remember that you are answering the questions for {*participant's name*} and that all survey questions refer to their experiences with the {*HCBS program name*}. Please do not consider your own experiences or information in the answers you provide. Can I ask you some questions about the services {*participant's name*} receives? We could do this now or at another time that is convenient for you, either over the phone or in person.

□YES, OVER THE PHONE, NOW → GO TO Q11 □YES, OVER THE PHONE, LATER → GO TO Q11 THEN GO TO PHONE1 □YES, FACE-TO-FACE → GO TO Q11 THEN GO TO F2F 1 □REFUSE → END SURVEY

9. <FOR JOINT INTERVIEWS> Hello, may I please speak to {guardian/proxy respondent's name}?

□YES, GUARDIAN/PROXY → GO TO Q10 □NOT AVAILABLE RIGHT NOW → SCHEDULE CALLBACK □NO/REFUSAL → CODE AS REFUSAL

- IF ASKED WHO IS CALLING: I'm calling to follow up on a letter from {*name of signatory on letter*} from {*sponsor name*}.
- 10. <FOR JOINT INTERVIEWS> Hello, my name is {*interviewer name*} calling from {*survey vendor*} on behalf of {*sponsor name*}. We recently sent a letter to the {*participant's name*} about a survey the sponsor is conducting. We would like to interview both of you about {*participant's name*} experience with the people who are paid to help {*participant's name*} in their home and community with everyday activities. {*participant's name*} gave me your contact information and requested that you help them answer the survey.

{*Participant's name*}'s answers are very important and will be used to help improve home and community-based services. It is your choice to answer the survey, and your choice will not affect any of the services that {*participant's name*} gets. The only people allowed to hear or see {*participant's name*}'s and your answers will be the people who are doing the survey, like me. Your answers will be grouped with others and reported with no identifying information. The interview should take about 30 minutes to complete. As you help {*participant's name*} answer the survey questions, please remember that all survey questions refer to their experiences with the {*HCBS program name*}. Please do not consider your own experiences or information when you help {*participant's name*}. Can I ask both of you some questions about the services {*participant's name*} receives? We could do this now or at another time that is convenient for both of you, either over the phone or in person.

 \Box YES, OVER THE PHONE, NOW \rightarrow GO TO Q11

 \Box YES, OVER THE PHONE, LATER \rightarrow GO TO Q11 THEN GO TO PHONE3

 \Box YES, FACE-TO-FACE \rightarrow GO TO Q11 THEN GO TO F2F 1

 \Box REFUSE \rightarrow END SURVEY

11. What is your relationship to {*participant's name*}? Are you...? MARK ALL THAT APPLY.

 \Box Someone paid to provide home and community-based services to the participant? \rightarrow END SURVEY

A relative of the participant (not paid to provide HCBS services to the participant),

 \Box Someone who lives with the participant (not paid to provide HCBS services to the participant),

 \Box The legal guardian of the participant, or

□OTHER RELATIONSHIP: SPECIFY_____

FOR SCHEDULING:

PROXY/GUARDIAN APPOINTMENTS \rightarrow GO TO PHONE1 JOINT PHONE APPOINTMENTS WITH A PROXY \rightarrow GO TO PHONE3 FOR FACE TO FACE INTERVIEWS \rightarrow GO TO F2F1.

Script for Continuing or Setting Up Phone Interview

PHONE 1 <FOR TELEPHONE INTERVIEWS ONLY> Is this a good time to answer a few questions?

 \Box YES, CONTINUE \rightarrow GO TO Q1 OF HCBS SURVEY

ANSWER ANY QUESTIONS, THEN GO TO QUESTION 1 IN THE HCBS CAHPS SURVEY.

IF RESPONDENT AND/OR PROXY DOES NOT HAVE TIME TO PARTICIPATE IN INTERVIEW NOW, GO TO PHONE 2.

PHONE 2 When would be a convenient time to call back?

□RECORD CALLBACK TIME ON CALL RECORD

PHONE 3 <FOR JOINT TELEPHONE INTERVIEWS ONLY> Is this a good time for both of you to answer a few questions?

 \Box YES, CONTINUE \rightarrow CONFIRM BOTH THE PROXY AND PARTICIPANT ARE ON THE PHONE AND GO TO Q1 OF HCBS SURVEY ANSWER ANY QUESTIONS. THEN GO TO QUESTION 1 IN THE HCBS

ANSWER ANY QUESTIONS, THEN GO TO QUESTION 1 IN THE HCBS CAHPS SURVEY.

IF RESPONDENT AND/OR PROXY DOES NOT HAVE TIME TO PARTICIPATE IN INTERVIEW NOW, GO TO PHONE 4.

PHONE 4 When would be a convenient time to call {proxy name and participant name/you} back?

□RECORD CALLBACK TIME ON CALL RECORD.

IF NECESSARY, IDENTIFY MULTIPLE DATES AND TIMES AND CONTACT PROXY OR PARTICIPANT TO DETERMINE FINAL DATE AND TIME.

Script for Setting Up In-Person Interview

- F2F 1 <FOR F2F INTERVIEWS ONLY>. I would like to set up a date and time to interview you in person. When would be a convenient time to interview you?
 □RECORD DATE AND TIME TO INTERVIEW PARTICIPANT OR PROXY IF PARTICIPANT WOULD LIKE PROXY WITH HIM, OR IDENTIFY MULTIPLE DATES AND TIMES AND CONTACT PROXY TO DETERMINE FINAL DATE AND TIME.
- F2F 2 <FOR F2F INTERVIEWS ONLY>. And I would like to confirm the address and how to get there. We have {address, city, state}. Is that correct? Is there anything I should know about driving to the location?
 □RECORD DIFFERENT ADDRESS IF NECESSARY. RECORD INFORMATION ABOUT HOW TO GET TO THE LOCATION
- END SURVEY <FOR ENDING A SURVEY> Those are all of the questions I have for you. Thank you for your time. Your answers will be very helpful for improving home and community-based services.

Sample Greeting Script for Face-To-Face Participant Interview

- F2F 3 <TO BE USED AT IN-PERSON INTERVIEWS ONLY> Hello, may I please speak to {*participant's name*}?
- F2F 4 ONCE INTERVIEWER IS WITH PARTICIPANT. My name is *{interviewer name}* from *{survey vendor}* on behalf of *{name of sponsor}*. I am here to ask you about your experiences with the people who are paid to help you in your home and community with everyday activities. Do you remember that? Great.

IF REMINDER NEEDED: You may remember receiving a letter about the {*survey/research study*}. Someone from {*survey vendor*} on behalf of {*sponsor name*} called to set up a time to ask you about your experiences in the last 3 months with the people who are paid to help you in your home and community with everyday activities.

ALLOW TIME FOR THE TWO OF YOU TO SIT DOWN.

IF THERE ARE PAID PROVIDERS PRESENT: This is an opportunity for us to talk about the services you get. Would it be possible for your staff to leave the room while we talk about the services you get?

IF NECESSARY: Are you comfortable with your staff leaving the room while we talk?

F2F 5 You may remember receiving a letter about the {survey/research study}. Your answers are very important and will be used to help improve home and community-based services. {If required by sponsor, discuss the consent form.} It is your choice to answer the survey, and your choice will not affect any of the services you get. The interview should take about 30 minutes to complete. The only people allowed to hear or see your answers will be the people who are doing the survey, like me, and anyone you want to listen. Your answers will be grouped with others and reported with no identifying information.

IF REQUIRED BY SPONSOR, PROVIDE WRITTEN CONSENT FORM AND REQUEST THAT THEY REVIEW AND SIGN IT.

Shall we begin? < GO TO Q1 OF THE HCBS CAHPS SURVEY>