

**APPENDIX F. SAMPLE OF CONSENT FORM FOR THE CONSUMER
ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS HOME
AND COMMUNITY-BASED SERVICES (HCBS CAHPS®) SURVEY**

Instructions

- The following page is a template for the consent form that can be used for phone or in-person consent for the HCBS CAHPS Survey.
- There is the option to collect verbal consent to minimize the amount of identifiable information a vendor needs to collect and secure. If the survey sponsor requires a written signature indicating consent to participate in the survey, then there is an option for written consent.
- Text that sponsors may need to tailor is indicated in brackets.
- Some sponsors may have an institutional review board (IRB) that may require changes in the language, for example, from “survey” to “research study” at first mention. These are indicated in *italics* and in brackets.

Consent Form for the HCBS CAHPS Survey

We are asking you to *[answer a survey/be in a research study]*.

You do not have to *[answer the survey/be in the research study]*.

If you say yes, you can quit at any time.

Please take as much time as you need to make your choice.

Your services and supports will not change in any way if you say no.

Why are you doing this *{survey/research study}*?

[Sponsor name] wants to learn more about how to help people with disabilities who receive services in their homes. This *{survey/research study}* will help [sponsor name] learn more about these services and improve home and community-based services.

What happens if I say yes, I want to answer the questions?

If you say yes, I will:

- Ask about the people paid to help you, your case manager, your personal safety, your transportation services, things you do in the community, and about working at a job; and
- Read the questions out loud and enter your answers into a computer.

There are no right or wrong answers to these questions. You can skip any question you do not want to answer.

How long will the *{survey/research study}* take?

The *{survey/research study}* will take about 30 minutes of your time.

What happens if I say no, I do not want to answer the survey?

No one will treat you differently. You will not be penalized. The services and supports you get will not change.

What happens if I say yes, but change my mind later?

You can stop answering the questions at any time. You will not be penalized. The services and supports you get will not change.

Who will see my answers?

The only people allowed to see your answers will be the people who work on the *{survey/research study}* and people who make sure we run our *{survey/research study}* the right way.

Your personal information will be removed, and your answers may be used for future research studies without asking your permission again.

None of the people who help you will know what you say, unless you want them in the room while you answer the questions. Your answers will be grouped together with other people's responses and will be reported with no identifying information.

Will it cost me anything to answer the questions?

No.

Will answering these questions help me in any way?

Answering the questions will not help you right now, but may help people with disabilities in the future.

Is there any way answering the questions could be bad for me?

There is a chance that the questions could make you sad or upset.

What if I have questions?

Please call the [sponsor] contact person at [insert phone #] if you have any questions about the *{survey/research study}*.

[INSTITUTIONAL REVIEW BOARD (IRB) ONLY] You can also call [name of IRB] at [insert phone #], if you:

- Have questions about your rights as someone answering the questions in this *{survey/research study}*; or
- Feel you have been injured in any way by being in this study.

Do I have to give consent?

No. You only give your consent if you want to answer the questions.

What should I do if I want to answer the questions?

By agreeing and signing the consent form you are saying:

- You agree to *{take the survey/be in the research study}* and answer the questions; and
- We talked with you about the *{survey/research study}* information and answered all your questions.

What if I want to answer the questions but need help from someone such as a proxy?

You may identify a proxy respondent to provide the input on your behalf. The interviewer will help you decide who is allowed and not allowed as proxy respondents. In general, a person who is familiar with the services and supports that you receive and has regular, ongoing contact with you is more likely to be a good proxy respondent. Unpaid family members, friends, or neighbors may meet these criteria. Anyone who is paid to provide care or services to you should not be used as a proxy.

You know that:

- You can skip questions you do not want to answer;
- You can stop answering our questions at any time and nothing will happen to you; and
- You can call [sponsor’s name, contact name, and phone number] if you have any questions about the survey.

[You may either obtain verbal consent or written consent if the sponsor requires it.]

Verbal consent:

Do you agree to participate and have your answers included in this research?

Written consent:

Signature

Date

Authorization of this consent form expires one year from the date of signature.