



HCBS Experience of Care Survey

Field Test Results for Connecticut

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Introduction

Background and Purpose of This Report

As part of the Testing Experience and Functional Tools (TEFT) Demonstration, the Centers for Medicare & Medicaid Services (CMS) funded a field test of the cross-disability Home and Community-Based Services (HCBS) Experience of Care (EoC) survey in nine TEFT grantee states during 2014–2015.¹ The survey was designed to ask Medicaid beneficiaries provided with home and community-based services about their experiences with paid staff who support and/or provide their care. In contrast to many other experience or satisfaction surveys that are disability-specific, the HCBS EoC survey was designed so that individuals with different types of disabilities (e.g., physical, cognitive, intellectual, behavioral) could respond to the same questionnaire, thus enabling comparisons across programs and disability groups within a state.² An earlier version of the survey was piloted with two states in spring 2014 under the auspices of the CMS-funded National Quality Enterprise.³

CMS provided funds for Truven Health Analytics to contract with survey vendors to conduct in-person and telephone interviews for both the pilot and field tests. Many of the participating states saw this as an opportunity to contribute to the validation of the survey while simultaneously gaining access to beneficiary input on their programs without having to fund the survey effort themselves. They also saw this as an occasion to compare beneficiary assessment of program performance across the various HCBS programs using the very same survey instrument. States could now compare HCBS programs serving diverse populations with disability (e.g., aged/disabled, persons with intellectual disability, those with brain injury, persons with severe mental illness) with a new cross-disability tool.

As a participant in the TEFT Experience of Care Field Test, Connecticut provided Truven with a sample of members to survey from the following programs: the Acquired Brain Injury Waiver (ABI), Connecticut Home Care Program for Elders (CHCPE), and Working for Support and Empowerment Waiver (WISE). This report highlights results specific to each of these programs with the goal of providing you with information that Connecticut can use to better understand how well these HCBS programs are meeting the needs of beneficiaries and to identify priorities for improving their support, care, and community integration. In addition, aggregated survey results from all states and programs participating in either the pilot study or the field test appear in Appendix A to enable your state to compare its results to other states. .

¹ TEFT demonstration states included AZ, CO, CT, GA, KY, LA, MD, MN, and NH.

² Examples of disability-specific surveys include the Participant Experience Survey for the aged and disabled (A/D) populations, and the Core Indicators surveys for the Intellectually Disabled and Developmentally Disabled (ID/DD) and A/D populations, respectively.

³ TN and LA participated in the pilot study. LA also participated in the field test as part of the TEFT demonstration; LA provided beneficiaries from different HCBS programs for the pilot and field tests.

Overview of the Survey

The HCBS EoC survey asks HCBS program participants to report on their experiences with different aspects of their HCBS program, including the staff, case manager, transportation services, and their ability to engage in community life. The field test survey included 95 questions about the beneficiary's experience of care, including:

- A few preliminary screening questions to assess whether the individual was capable of responding to the survey.
- Reports on the individual's experience with the HCBS program, typically to say whether something happened, and its frequency.
- Ratings of the individual's overall experience with the HCBS program ("Global Ratings").
- Whether the individual would recommend his or her provider (referred to as "Recommendations").
- Self-descriptions such as age, gender, race, health status, level of education, and employment status (referred to as "Respondent Characteristics").

Many of these questions have an alternative response option that may be easier to understand for those who are cognitively challenged. Respondents who had difficulty answering questions with the response options of *"never," "sometimes," "usually,"* and *"always"* received more basic response options of *"mostly yes"* and *"mostly no."*

Methods

Development of the Survey

The HCBS EoC survey tested in the pilot and field tests was developed following the Consumer Assessment of Healthcare Providers and Systems® (CAHPS®) process. This included conducting a literature review of survey questions from other applicable surveys, interviews with adults representing varying kinds of disabilities who receive home and community-based services, as well as guidance from a Technical Expert Panel. In the interviews, beneficiaries were asked about what was important to them in their receipt of home and community-based services. A draft version of the survey was developed iteratively, and underwent four rounds of cognitive testing with individuals with different types of disabilities to ensure that the questions and response options were understood as intended, and were easy to answer.⁴

The pilot and field tests of the HCBS EoC survey were conducted to evaluate the reliability and validity of the instrument. This included assessing the measurement properties of the survey, individual survey questions, and composite measures. It also included testing the equivalence of these measurement properties across response options and mode of administration. In the study, response options that are used for CAHPS surveys (*never, sometimes, usually, and always*) were compared with alternative response options (*mostly yes and mostly no*). A comparison of in-person interview responses with telephone survey responses was also conducted. Our analyses found that there were no statistically significant differences by mode of administration or by response option. Although it would have been ideal to also test for differences in responses for surveys conducted in English and Spanish, the number of interviews conducted in Spanish was insufficient to allow a comparison. Results of psychometric testing will inform revisions to the survey.

Collection of Survey Data

The survey was administered from 9/15/2014 through 1/17/2015. Eligible participants included adults 18 years old or older who received at least care coordination services. A random sample of all eligible potential respondents was selected to participate. The University of Connecticut collected the survey data in Connecticut; the majority of interviews were conducted in person, mostly in the beneficiary's home, with the remainder conducted by telephone. Table 1 presents the response rates for Connecticut.

⁴ J. Seibert, E. Frentzel, C. Mallery, T. Whitworth, *Interim Report on the Development of the HCBS Experience of Care Survey and Lessons Learned from the Pilot Field Study*, Truven Health Analytics, April 11, 2014.

Table 1. Connecticut response rate by program and all programs combined

Program	Number of Surveys	Response Rate
Acquired Brain Injury Waiver	113	29.7%
Connecticut Home Care Program for Elders	174	34.2%
Working for Support and Empowerment Waiver	79	34.5%
Programs Combined	366	32.8%

Before initiation of data collection, a letter notifying eligible respondents was sent alerting them to expect a telephone call about the interview, and assuring the sampled members that the survey was sponsored by CMS and endorsed by the state. This was followed by survey vendors making initial telephone contact with HCBS program participants to introduce the survey, explain its purpose, and upon receipt of verbal consent, schedule the interview date, place, and time.

Proxy responses were collected for a portion of the field test. Proxy refers to any help the respondent received in completing the survey; such help ranges from answering all questions for the respondent to providing prompts, translation, or help with assistive technology. Although not allowed consistently during the overall TEFT data collection period, proxy responses were accepted later in the process due to data collection difficulties for some HCBS populations. To the extent that state data collection was ongoing when this approach started, proxy responses that met other criteria for completed surveys are included in the reported results.

Case Mix Adjustment

To compare each HCBS program’s results to those of other programs fairly, we adjusted the results for differences in respondent characteristics across programs. These characteristics could change the way someone responds to the survey, regardless of his or her experience. They include demographics (e.g., respondent age) as well as other characteristics, including mental health status, survey mode, and survey response option. For example, older individuals have tended to rate their experiences higher than younger individuals. The adjusted results are those we would expect for each program if they had similar respondents. An in-depth guide on how to apply case mix adjustment is available from the Agency for Healthcare Research and Quality (AHRQ) CAHPS Web site.⁵

⁵ This resource is available at:
https://cahps.ahrq.gov/surveys-guidance/survey4.0-docs/2015_instructions_for_analyzing_data.pdf

How to Interpret Your Results

The following types of data are presented in tables by each state program, with an average across participating programs for comparison:

- 1. Respondent characteristics (e.g., age, sex, race, types of home and community-based services).**
- 2. Composite measures.** These are scores derived by combining groups of similar questions. The response for each item is first put on a 0 to 100 scale by transforming *never/sometimes/usually/always* to 0/33/66/100, and transforming *mostly no/mostly yes* to 0/100. To calculate the mean score for each composite measure, the means for each of the questions included in the composite measure were added up and divided by the total number of questions in the composite measure.
- 3. Global ratings and recommendation questions.** These questions ask how respondents rate their staff, and whether they would recommend their staff to family and friends who need that type of help. The initial rating was based on a measurement scale of 0 to 10, with 0 being the worst provider and 10 being the best. These items were transformed to a 0 to 100 scale (by multiplying the response by 10) to be consistent with the presentation of other results.

Confidentiality. To protect the confidentiality of participating beneficiaries, if there are less than 10 respondents for an item, the results are not presented for that question.

Statistical Significance. For this report, we tested the statistical significance of the difference in results between each of Connecticut's HCBS programs and the average of all programs combined. Levels of statistical significance are set at $p \leq .05$, indicating that the difference would occur by chance less than 5 out of 100 times. If a statistical difference exists between a given program's score and the average score (across all participating programs in your state) *and* the program's score is higher, this is reported with a green "up" arrow (▲). Similarly, if the difference is statistically significant, but the program's score is lower than the average score, a red "down" arrow (▼) is used to indicate the direction of the difference. A statistically significant different result may not be considered a substantively significant result, however; program administrators and other stakeholders can determine best whether differences are meaningful for a given program.

Most of the survey questions are written where a positive response (e.g., "yes" or "always") indicates good care. For example, an "always" response to "how often are staff nice and polite to you?" is a positive response. In some cases, the questions are written such that a negative response indicates good quality. For example, a "never" response to "how often are the explanations staff give you hard to understand because of an accent, or the way he or she speaks English?" is a positive response. In these cases, negatively worded questions were changed so that when you read them in this report, a positive response indicates higher quality.

Generalizability of Results. Samples were drawn from each program in each participating state so that *in combination* they would provide a large enough sample to conduct validity and reliability analyses of the survey across the various program types. The sample was not drawn to be representative of any one program in any one state. In general, the sample size associated with a given program is not large enough to be considered representative, and caution is urged when drawing any conclusions about program performance or generalizing to the program as a whole.

Comparison to Other States' Programs (Cross-State Results). Tables in Appendix A to this report include information that will enable you to compare the scores of your HCBS programs with similar programs also participating in the HCBS EoC pilot and field tests. Tables in Appendix A closely parallel those in the body of this report but, rather than provide scores for each individual program, they provide scores by program type across states; that is, scores are presented separately for programs serving:

- The elderly and those with physical disabilities
- Persons with intellectual and developmental disabilities
- Individuals with traumatic brain injury
- Persons with severe mental illness

In addition, each table provides overall scores for all programs and states participating in the study.

Results

Survey Respondent Characteristics

Table 2 below presents demographic characteristics for all respondents.

Table 2. Connecticut respondent characteristics (n=366)

Respondent Characteristics	ABI % (n)	CHCPE % (n)	WISE % (n)	Programs Combined % (n)
Types of Services Received				
Personal assistance/behavioral health	57.1% (64)	66.7% (116)	88.6% (70)	68.5% (250)
Homemaker services	43.8% (49)	89.1% (49)	53.9% (42)	67.6% (246)
Case manager	93.8% (90)	93.0% (147)	98.7% (74)	94.5% (311)
Job coach	74.4% (32)	0.0% (0)	0.0%(0)	74.4% (32)
Overall Health				
Excellent	25.0% (28)	†	†	12.7% (46)
Very good	22.3% (25)	10.6% (18)	13.9% (11)	15.0% (54)
Good	33.0% (37)	25.9% (44)	21.5% (17)	27.2% (98)
Fair	14.3% (16)	40.6% (69)	36.7% (29)	31.6% (114)
Poor	†	17.7% (30)	16.5% (13)	13.6% (49)
Overall Mental or Emotional Health				
Excellent	25.2% (28)	17.0% (29)	†	18.1% (65)
Very good	31.5% (35)	18.1% (31)	24.7% (19)	23.7% (85)
Good	28.8% (32)	39.2% (67)	33.8% (26)	34.8% (125)
Fair	11.7% (13)	20.5% (35)	28.6% (22)	19.5% (70)
Poor	†	†	†	3.9% (14)
Age				
18 to 24	†	†	†	†
25 to 34	16.2% (18)	†	†	6.9% (25)
35 to 44	14.4% (16)	†	†	5.8% (21)
45 to 54	30.6% (34)	†	30.8% (24)	16.1% (58)
55 to 64	28.8% (32)	†	43.6% (34)	18.3% (66)
65 to 74	†	41.9% (72)	10.3% (8)	24.4% (88)
75 or older	†	58.1% (100)	†	24.7% (100)
Sex				
Female	40.7% (46)	78.2% (136)	60.8% (48)	62.8% (230)
Male	59.3% (67)	21.8% (38)	39.2% (31)	37.2% (136)
Race (respondents could answer more				

Respondent Characteristics	ABI % (n)	CHCPE % (n)	WISE % (n)	Programs Combined % (n)
than one category)				
Black or African-American	10.7% (12)	19.5% (34)	17.7% (14)	16.4% (44)
White	83.9% (94)	60.9% (106)	72.2% (57)	70.4% (257)
Other	9.8% (11)	23.6% (41)	16.5% (13)	17.8% (65)
Hispanic, Latino, or Spanish Ethnicity				
Yes	†	20.8% (36)	†	14.3% (52)
No	92.9% (105)	79.2% (137)	89.9% (71)	85.8% (313)
Main Language Spoken at Home				
English	91.2% (103)	73.6% (128)	81.0% (64)	80.6% (295)
Spanish	†	20.7% (36)	†	13.4% (49)
Other	†	†	†	6.0% (22)
Living Arrangements				
Lives alone	65.2% (73)	72.2% (122)	85.9% (67)	73.0% (262)
Lives with family member(s)	19.6% (22)	24.9% (42)	†	19.8% (71)
Lives with others	15.2% (17)	†	†	7.2% (26)
Military Service				
Served in Armed Forces	†	9.3% (16)	†	8.2% (30)
Served in armed conflict	†	†	†	†
Disabled veteran	†	†	†	†
Population				
Aged / Physically disabled	0.0% (0)	100.0% (174)	0.0% (0)	47.5% (174)
Intellectual Disability, Developmental Disability	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Traumatic Brain Injury	100.0% (113)	†	†	30.9% (113)
Severely Mentally Ill	†	†	100.0% (79)	21.6% (79)

NOTE: Percentages may not add up to 100% because of rounding.

† The number of responses to this question was 10 or less and therefore not included for confidentiality purposes.

Composite Measures

Responses to individual survey questions were combined to form composite measures of beneficiaries' experiences with their home and community-based services. As part of following the CAHPS process, composite measures are developed for reporting back to the public. Composite measures are useful for the public reporting of survey results because they efficiently summarize what would otherwise be a large amount of data. This approach makes it easier for users to understand and interpret the data display. These scores are presented on a 0 to 100 point scale. Table 3 shows composite scores for each program, followed by the average for all programs in the state that participated in the survey. The

table also indicates whether a given composite result was significantly greater than or less than the average of all programs participating in the survey.

Table 3. Connecticut mean scores for composite measures by program and all programs combined

Composite Measure	ABI		CHCPE		WISE		Programs Combined	
	Score	n	Score	n	Score	n	Score	n
Getting Needed Services From Staff	91.4	111	▲95.8	169	90.6	76	92.6	356
How Well Staff Communicate and Treat You	93.0	111	94.4	169	94.4	76	93.9	356
Case Management	92.0	89	88.9	133	93.4	73	91.4	295
Choosing Your Services	▼78.6	106	▲89.9	154	88.3	75	85.6	335
Transportation	▲95.7	113	▼85.5	173	88.7	78	90.0	364
Personal Safety	98.8	113	▼94.8	174	98.8	78	97.5	365
Community Inclusion and Empowerment	81.8	113	82.4	174	77.7	78	80.7	365

▲ This program’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Global Ratings and Recommendations

Table 4 shows the performance for each HCBS program on the global rating items, as well as the average for all participating programs in the state; the global ratings score is on a scale of 0 to 10, with 0 being the worst, and 10 being the best. Table 5 provides the same information for the questions asking whether a respondent would recommend a particular staff member to family or friends who need those services. The numbering of items matches their placement in the survey. These scores are presented on a 0 to 100 point scale, with 0 being the worst, and 10 being the best. The tables also report whether a program’s score was significantly greater than or less than the average of all participating programs.

Table 4. Connecticut global ratings scores by program and all programs combined

Ratings	ABI		CHCPE		WISE		Programs Combined	
	Score	n	Score	n	Score	n	Score	n
23. Personal assistance and behavioral health staff	90.4	93	90.4	99	88.5	65	89.8	257
34. Homemaker	89.4	40	89.4	129	91.9	37	90.3	206
42. Case manager	87.9	71	87.6	109	89.5	65	88.3	245
EM20. Job coach	☼	☼	☼	☼	☼	☼	☼	☼

▲ This program’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

☼ Scores were unable to be produced for this question due to low sample size or low variation in responses.

Table 5. Connecticut scores for whether respondents would recommend staff members by program and all programs combined

Recommendations	ABI		CHCPE		WISE		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
24. Personal assistance and behavioral health staff	88.5	104	▲93.4	106	87.4	71	89.8	281
35. Homemaker	†	†	▲94.2	83	†	†	86.7	88
43. Case manager	88.1	90	90.1	129	87.0	72	88.4	291
EM21. Job coach	91.4	31	†	†	†	†	91.4	31

▲ This program’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

† The number of responses to this question was 10 or less and therefore not included for confidentiality purposes.

Individual Questions

Tables 6 through 13 depict each program’s performance on individual items and composite measures, as well as the average for each of these items for all participating programs in the state. The scores associated with each item are presented on a 0 to 100 point scale. The numbering of items matches their placement in the survey. The full text of all survey questions, by number, appears in Appendix B. The tables also include whether a program’s performance was significantly greater than or less than the average of all programs participating in the survey.

Table 6. Connecticut scores for individual questions for the *Getting Needed Services from Staff* composite by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Getting Needed Services From Staff	91.4	111	▲95.8	169	90.6	76	92.6	356
1. Staff come to work on time	91.4	109	▲96.7	114	▼88.0	74	92.0	297
2. Staff work as long as they are supposed to	93.6	110	94.9	115	94.8	74	94.5	299
3. Someone tells you if staff cannot come	84.8	104	▲100.0	107	▼78.6	75	88.1	286
7. Staff make sure you have enough privacy for dressing, showering, bathing	95.8	33	91.3	78	94.7	20	93.9	131
25. Homemakers come to work on time	89.5	49	▲96.7	148	92.1	43	92.8	240
26. Homemakers work as long as they are supposed to	93.4	49	94.2	149	95.1	43	94.2	241

▲ This program's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Table 7. Connecticut scores for individual questions for the *How Well Staff Communicate and Treat You* composite by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	n	Score	n	Score	n	Score	n
How Well Personal Assistant and Behavioral Health Staff Communicate and Treat You	93.0	111	94.4	169	94.4	76	93.9	356
16. Staff are nice and polite	▼89.3	109	▲100.0	115	95.2	73	96.0	297
17. Staff explanations are easy to understand*	91.5	106	87.7	112	93.6	75	90.9	293
18. Staff treat you the way you want them to	▼91.6	109	▲100.0	114	▼89.9	74	94.8	297
19. Staff explain things in a way that is easy to understand	96.0	109	94.4	113	92.6	74	94.3	296
20. Staff listen carefully to you	90.7	109	94.1	115	88.8	75	91.2	299
21. Staff know what kind of help you need with everyday activities	91.2	107	93.4	109	96.3	70	93.6	286
29. Homemakers are nice and polite	94.5	49	97.7	148	▲99.7	42	97.3	239
30. Homemaker explanations are easy to understand*	92.1	48	▼83.8	145	93.2	43	89.7	236
31. Homemakers treat you the way you want them to	93.9	49	97.2	147	93.1	42	94.7	238
32. Homemakers listen carefully	95.1	48	92.8	147	96.1	43	94.7	238
33. Homemakers know what kind of help you need	97.3	48	▼91.3	142	99.9	42	96.2	232

▲ This program's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

* The original question was written negatively, but we are reporting it positively to support comparing the questions.

Table 8. Connecticut scores for individual questions for the *Your Case Manager* composite by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	n	Score	n	Score	n	Score	n
Your Case Manager	92.0	89	88.9	133	93.4	73	91.4	295
37. Able to contact this case manager when needed	91.7	89	▼85.8	132	94.5	73	90.7	294
39. Case manager helped when asked for help with getting or fixing equipment	91.7	89	85.8	132	94.5	73	☼	294
41. Case manager helped when asked for help with getting other changes to services	92.2	44	91.9	44	92.3	41	92.1	129

▲ This program’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

☼ Scores were unable to be produced for this question due either a low sample size or a low variation in responses.

Table 9. Connecticut scores for individual questions for the *Choosing Your Services* composite by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	n	Score	n	Score	n	Score	n
Choosing Your Services	▼78.6	106	▲89.9	154	88.3	75	85.6	335
45. Person-centered service plan included all of the things that are important	▼69.4	106	▲86.2	154	80.3	75	78.6	335
46. Case manager knows what’s on the service plan, including the things that are important	▼87.8	99	93.7	141	96.3	68	92.6	308

▲ This program’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Table 10. Connecticut scores for individual questions for the *Transportation* composite by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Transportation	▲95.7	113	▼85.5	173	88.7	78	90.0	364
48. Always have a way to get to your medical appointments	97.4	113	94.2	172	95.3	78	95.6	363
50. Able to get in and out of this ride easily	▲100.0	30	▼81.1	78	88.7	41	91.0	149
51. Ride arrives on time to pick you up	86.4	30	81.1	77	82.1	41	83.2	148

▲ This program’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Table 11. Connecticut scores for individual questions for the *Personal Safety* composite by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Personal Safety	98.8	113	▼94.8	174	98.8	78	97.5	365
53. Have someone to talk to if someone hurts you or does something to you that you don’t like	97.1	105	▼88.0	166	97.1	76	94.0	347
54. None of the staff take money or things without asking*	▲100.0	111	99.5	174	98.3	76	99.4	361
57. None of the staff yell, swear, or curse*	98.8	113	▼97.0	174	▲100.0	78	99.0	365

▲ This program’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

* The original question was written negatively, but we are reporting it positively to support comparing the questions.

Table 12. Connecticut scores for individual questions for the *Community Inclusion and Empowerment* composite by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Community Inclusion and Empowerment	81.8	113	82.4	174	77.7	78	80.7	365
64. Can get together with nearby family	77.8	84	▲89.2	131	▼64.7	48	77.2	263
66. Can get together with nearby friends	72.7	65	75.3	103	76.6	49	74.9	217
67. Can do things in community	▲69.7	109	▼55.3	171	60.6	75	61.9	355
68. Needs more help to do things in community	82.7	110	74.6	167	72.8	69	76.7	346
69. Takes part in deciding what to do with their time	▼90.1	110	▲100.0	163	▼92.0	78	95.5	351
70. Takes part in deciding when they do things each day	97.9	107	95.9	170	▲99.7	75	97.8	352

▲ This program's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Table 13. Connecticut scores for the employment-related questions by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	n	Score	n	Score	n	Score	n
EM1. Work for pay at a job	▲ 37.1	112	†	†	▼ 1.3	78	19.2	190
EM2. Want to work for pay at a job	55.9	66	†	†	53.0	74	54.5	140
EM5. Asked for help in getting a job for pay	68.8	37	†	†	51.4	38	60.1	75
EM6. Aware of help to find a job for pay	85.7	12	†	†	76.6	17	81.1	29
EM7. Has paid help to get a job	49.6	24	†	†	47.8	19	48.7	43
EM8. Getting all the help needed to find a job	72.1	11	†	†	†	†	79.8	20
EM10. Respondent helped chose the job he/she has	60.0	30	†	†	†	†	60.0	30
EM11. Has a paid job coach	74.4	43	†	†	†	†	74.4	43
EM13. Respondent hired job coach	3.1	32	†	†	†	†	3.1	32
EM14. Job coach is available the entire time while working	74.2	31	†	†	†	†	74.2	31
EM15. Job coach gives needed help	84.4	30	†	†	†	†	84.4	30
EM16. Job coach is nice and polite	93.5	31	†	†	†	†	93.5	31
EM17. Job coach explains things in a way that is easy to understand	93.5	31	†	†	†	†	93.5	31
EM18. Job coach listens carefully	92.5	31	†	†	†	†	92.5	31
EM19. Job coach encourages respondent to do things for himself	100.0	31	†	†	†	†	100.0	31

▲ This program's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

† The number of responses to this question was 10 or less and therefore not included for confidentiality purposes.

Table 14. Connecticut scores for other questions by program and all programs combined

Question	ABI		CHCPE		WISE		Programs Combined	
	Score	n	Score	n	Score	n	Score	n
6. There are no staff to help dress, shower, or bathe	†	†	†	†	†	†	†	†
10. Sufficient staff to help you with meals*	†	†	†	†	†	†	†	†
13. Sufficient staff to help you with medications*	†	†	†	†	†	†	74.2	18
15. Sufficient staff to help you with toileting*	100.0	16	100.0	15	†	†	100.0	31
28. Sufficient homemakers to help you with household tasks	†	†	†	†	†	†	75.0	12
22. Staff encourage you to do things for yourself if you can	84.9	110	▲96.0	113	84.4	75	88.4	298
44. Worked with someone to develop person-centered service plan	73.0	91	▼64.9	144	▲94.8	72	77.6	307
55. Someone is helping if staff take money or things	☼	☼	☼	☼	☼	☼	☼	☼
58. Someone is helping if staff yell, swear, or curse	†	†	†	†	†	†	†	†
60. None of the staff hit or hurt*	▲100.0	113	99.6	174	98.7	78	99.6	365
61. Someone is helping if staff yell, swear, or curse	☼	☼	☼	☼	☼	☼	☼	☼
72. Worked with someone when asked to change staff	76.1	34	95.4	30	86.4	27	86.0	91
74. Knew that they can ask someone to change staff	▼83.8	73	▲99.7	140	85.8	51	89.8	264
36. Case manager is known	▼80.4	108	87.2	165	▲92.8	78	86.8	351

▲ This program's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

† The number of responses to this question was 10 or less and therefore not included for confidentiality purposes.

* The original question was written negatively, but we are reporting it positively to support comparing the questions.

☼ Scores were unable to be produced for this question due either a low sample size or a low variation in responses.

For More Information

Please contact Susan Raetzman, M.S.P.H., TEFT Technical Assistance (TA) Lead for the Experience of Care Survey and Senior Research Leader of Truven Health Analytics.

Information About CAHPS® Surveys and Quality Improvement

This survey was sponsored by the Centers for Medicare & Medicaid Services. The development of this survey followed the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) development process. For more information on the CAHPS surveys and family of products, go to <https://cahps.ahrq.gov/>. On this Web site, you can learn about the CAHPS program, including survey instrument development, using survey results for quality improvement, and reporting results.

The CAHPS Consortium has created a guide for using survey results for quality improvement. For more information, go to <https://cahps.ahrq.gov/quality-improvement/index.html>.

Appendix A.

Cross-State Performance Scores by Program Type (Combined Pilot and Field Test Data for All Participating States)

The tables included in this appendix may be used to compare your state's results to those of the 10 states and their programs participating in the pilot and field tests.

These parallel those in the body of the report, but rather than providing scores for each program, the appendix provides scores by program type; that is, scores are presented separately for programs serving the:

- Aged and physically disabled (A/D)
- Persons with intellectual and developmental disabilities (ID/DD)
- Individuals with traumatic brain injury (TBI)
- Persons with severe mental illness (SMI)

In addition, each table provides overall scores for all programs in the 10 states participating in the study (Programs Combined).

Exhibit A1. Cross-state mean scores for composite measures by program type and combined (for all programs in the pilot and field test states)

Composite Measure	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	n	Score	n	Score	n	Score	n	Score	n
Getting Needed Services From Staff	▲ 94.6	1925	94.7	321	92.0	217	92.6	291	93.5	2754
How Well Staff Communicate and Treat You	93.9	1935	93.3	325	▼ 91.5	215	94.4	292	93.3	2767
Case Management	▲ 92.7	1764	88.3	350	87.5	211	90.9	268	89.9	2593
Choosing Your Services	▲ 89.0	1741	▲ 90.1	356	▼ 81.9	225	84.7	273	86.4	2595
Transportation	▼ 87.9	2038	▲ 92.7	376	92.1	255	89.1	307	90.4	2976
Personal Safety	97.2	2049	98.2	385	96.7	255	▲ 98.5	307	97.6	2996
Community Inclusion and Empowerment	82.1	2049	81.5	385	81.7	254	▼ 79.3	307	81.2	2995

▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Exhibit A2. Cross-state global ratings scores by program type and combined (for all programs in the pilot and field test states)

Ratings	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	n	Score	n	Score	n	Score	n	Score	n
23. Personal assistance and behavioral health staff	▲ 91.5	1551	90.4	233	88.2	173	88.4	245	89.6	2202
34. Homemaker	▲ 92.7	634	91.4	85	▼ 85.1	83	89.6	114	89.7	916
42. Case manager	▲ 88.3	1470	85.6	263	▼ 81.9	172	86.3	233	85.5	2138
EM20. Job coach	☼	☼	☼	☼	☼	☼	☼	☼	☼	☼

▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

☼ Scores were unable to be produced for this question due either a low sample size or a low variation in responses.

Exhibit A3. Cross-state scores for whether respondents would recommend staff members by program type and combined (for all programs in the pilot and field test states)

Recommendations	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
24. Personal assistance and behavioral health staff	89.2	1765	▲91.9	275	88.0	199	88.6	282	89.4	2521
35. Homemaker	▲91.0	620	82.5	53	81.3	70	89.0	128	86.0	871
43. Case manager	86.4	1723	86.6	340	84.1	208	85.1	266	85.6	2537
EM21. Job coach	†	†	85.2	50	84.6	44	†	†	86.8	102

▲ This program type’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

† The number of responses to this question was 10 or less and therefore not included for confidentiality purposes.

Exhibit A4. Cross-state scores for individual questions for the *Getting Needed Services from Staff* composite by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Getting Needed Services from Staff	▲ 94.6	1925	94.7	321	92.0	217	92.6	291	93.5	2754
1. Staff come to work on time	▲ 93.0	1801	92.8	300	90.7	209	89.1	284	91.4	2594
2. Staff work as long as they are supposed to	▲ 96.1	1802	95.2	293	93.7	210	93.0	286	94.5	2591
3. Someone tells you if staff cannot come	92.8	1,694	▲ 94.6	276	89.6	191	▼ 87.7	274	91.2	2,435
7. Staff make sure you have enough privacy for dressing, showering, bathing	94.7	1365	96.8	158	94.4	80	▲ 98.0	142	96.0	1745
25. Homemakers come to work on time	93.5	728	93.7	103	89.7	102	93.2	134	92.5	1067
26. Homemakers work as long as they are supposed to	▲ 97.2	729	95.1	104	94.0	104	94.6	134	95.2	1071

▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Exhibit A5. Cross-state scores for individual questions for the *How Well Staff Communicate and Treat You* composite by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	n	Score	n	Score	n	Score	n	Score	n
How Well Personal Assistant and Behavioral Health Staff Communicate and Treat You	93.9	1935	93.3	325	▼91.5	215	94.4	292	93.3	2767
16. Staff are nice and polite	▲97.4	1810	96.7	294	▼93.5	209	97.1	286	96.2	2599
17. Staff explanations are easy to understand*	▼82.2	1800	82.8	286	86.7	207	▲92.7	287	86.1	2580
18. Staff treat you the way you want them to	96.1	1812	▲97.9	293	93.3	209	93.8	288	95.3	2602
19. Staff explain things in a way that is easy to understand	95.2	1798	95.8	289	93.5	209	93.9	285	94.6	2581
20. Staff listen carefully to you	93.7	1804	▲94.8	293	▼89.8	208	91.7	289	92.5	2594
21. Staff know what kind of help you need with everyday activities	▲96.6	1788	96.0	280	93.5	206	93.1	279	94.8	2,553
29. Homemakers are nice and polite	▲98.2	735	96.7	105	▼93.3	101	▲99.2	132	96.8	1073
30. Homemaker explanations are easy to understand*	85.2	730	▼79.4	105	85.3	101	▲91.4	134	85.3	1070
31. Homemakers treat you the way you want them to	▲98.0	735	▲97.9	105	▼92.0	101	94.3	133	95.5	1074
32. Homemakers listen carefully	94.3	733	93.0	104	89.8	99	94.0	134	92.8	1070
33. Homemakers know what kind of help you need	96.1	733	94.9	112	95.7	99	96.9	130	95.9	1074

▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

* The original question was written negatively, but we are reporting it positively to support comparing the questions.

Exhibit A6. Cross-state scores for individual questions for the *Your Case Manager* composite by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Your Case Manager	▲ 92.7	1764	88.3	350	87.5	211	90.9	268	89.9	2593
37. Able to contact this case manager when needed	▲ 97.2	1754	▲ 97.1	348	▼ 89.8	209	93.5	267	94.4	2578
39. Case manager helped when asked for help with getting or fixing equipment	▲ 91.9	856	82.1	92	84.3	59	90.6	105	87.2	1112
41. Case manager helped when asked for help with getting other changes to services	89.2	737	85.7	194	88.5	100	88.6	148	88.0	1179

▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Exhibit A7. Cross-state scores for individual questions for the *Choosing Your Services* composite by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Choosing Your Services	▲ 89.0	1741	▲ 90.1	356	▼ 81.9	225	84.7	273	86.4	2595
45. Person-centered service plan included all of the things that are important	▲ 84.3	1741	▲ 85.0	356	▼ 74.0	225	79.0	273	80.6	2595
46. Case manager knows what's on the service plan, including the things that are important	93.8	1616	▲ 95.1	318	89.9	201	90.4	255	92.3	2390

▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Exhibit A8. Cross-state scores for individual questions for the *Transportation* composite by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Transportation	▼ 87.9	2038	▲ 92.7	376	92.1	255	89.1	307	90.4	2976
48. Always have a way to get to your medical appointments	93.9	2029	▲ 96.4	370	95.4	254	▼ 91.2	307	94.2	2960
50. Able to get in and out of this ride easily	▼ 89.0	894	92.1	123	▲ 95.2	113	90.6	162	91.7	1292
51. Ride arrives on time to pick you up	▼ 80.7	878	▲ 89.6	117	85.8	112	85.3	163	85.4	1270

▲ This program type’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Exhibit A9. Cross-state scores for individual questions for the *Personal Safety* composite by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Personal Safety	97.2	2049	98.2	385	96.7	255	▲ 98.5	307	97.6	2996
53. Have someone to talk to if someone hurts you or does something to you that you don’t like	95.4	1994	96.1	365	93.6	246	95.8	303	95.2	2908
54. None of the staff take money or things without asking*	▼ 98.0	2045	99.2	381	99.2	251	99.6	304	99.0	2981
57. None of the staff yell, swear, or curse*	98.2	2042	99.2	378	97.2	255	▲ 100.0	307	98.6	2982

▲ This program type’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

* The original question was written negatively, but we are reporting it positively to support comparing the questions.

Exhibit A10. Cross-state scores for individual questions for the *Community Inclusion and Empowerment* composite by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
Community Inclusion and Empowerment	82.1	2049	81.5	385	81.7	254	▼ 79.3	307	81.2	2995
64. Can get together with nearby family	▲ 83.9	1579	82.9	276	81.7	177	▼ 71.4	194	80.0	2226
66. Can get together with nearby friends	80.1	1381	80.1	248	76.0	137	78.6	179	78.7	1945
67. Can do things in community	▼ 64.9	2002	▲ 76.0	365	71.4	245	▼ 60.5	296	68.2	2908
68. Needs more help to do things in community	72.4	1976	69.7	378	73.9	249	67.5	283	70.9	2886
69. Takes part in deciding what to do with their time	95.4	2003	▼ 91.2	376	92.6	250	▲ 98.4	306	94.4	2935
70. Takes part in deciding when they do things each day	95.7	2027	▼ 89.0	382	94.8	247	▲ 99.6	303	94.8	2959

▲ This program type’s score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type’s score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

Exhibit A11. Cross-state scores for the employment related questions by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>	Score	<i>n</i>
EM1. Work for pay at a job	▼ 5.2	919	▲ 29.9	382	▲ 27.2	252	▼ 10.5	304	18.2	1857
EM2. Want to work for pay at a job	45.5	869	▼ 33.2	245	▲ 50.2	175	42.8	265	43.0	1554
EM5. Asked for help in getting a job for pay	▼ 27.6	273	▲ 63.3	107	54.7	86	43.9	117	47.4	583
EM6. Aware of help to find a job for pay	▼ 61.9	202	▲ 89.2	35	66.1	38	70.9	62	72.0	337
EM7. Has paid help to get a job	▼ 23.0	60	▲ 59.6	71	53.9	43	43.7	50	45.1	224
EM8. Getting all the help needed to find a job	†	†	75.1	40	82.0	22	86.8	21	73.7	93
EM10. Respondent helped chose the job he/she has	72.5	13	82.0	99	▼ 67.1	53	▲ 99.7	16	80.3	99
EM11. Has a paid job coach	▼ 17.9	28	▲ 52.0	117	▲ 69.8	69	▼ 16.3	31	39.0	245
EM13. Respondent hired job coach	†	†	15.2	62	5.3	46	†	†	15.3	118
EM14. Job coach is available the entire time while working	†	†	56.8	54	79.0	44	†	†	68.9	106
EM15. Job coach gives needed help	†	†	93.4	51	83.6	43	†	†	87.0	101
EM16. Job coach is nice and polite	†	†	94.5	50	94.1	44	†	†	95.8	102
EM17. Job coach explain things in a way that is easy to understand	†	†	91.3	51	93.8	44	†	†	92.2	103
EM18. Job coach listens carefully	†	†	93.3	50	92.1	44	†	†	91.7	102
EM19. Job coach encourages respondent to do things for himself	†	†	100.0	53	99.0	44	†	†	99.4	105

▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).

† The number of responses to this question was 10 or less and therefore not included for confidentiality purposes.

Exhibit A12. Cross-state scores for other questions by program type and combined (for all programs in the pilot and field test states)

Question	A/D		ID/DD		TBI		SMI		Programs Combined	
	Score	n	Score	n	Score	n	Score	n	Score	n
6. There are no staff to help dress, shower, or bathe	43.1	76	†	†	†	†	27.1	19	39.4	107
10. Sufficient staff to help you with meals*	32.4	45	†	†	†	†	▼17.1	19	40.5	74
13. Sufficient staff to help you with medications*	68.3	79	†	†	†	†	54.6	19	65.0	114
15. Sufficient staff to help you with toileting*	96.3	834	▲99.9	114	98.2	51	93.4	46	97.0	1045
28. Sufficient homemakers to help you with household tasks	52.4	74	58.4	11	52.3	12	39.6	14	50.7	111
22. Staff encourage you to do things for yourself if you can	91.2	1749	▲96.8	285	92.2	208	90.7	281	92.7	2523
44. Worked with someone to develop person-centered service plan	82.9	1810	▲90.5	369	▼76.2	221	▲89.7	278	84.8	2678
55. Someone is helping if staff take money or things	44.1	30	†	†	†	†	†	†	46.7	38
58. Someone is helping if staff yell, swear, or curse	40.0	23	†	†	†	†	†	†	46.4	35
60. None of the staff hit or hurt*	99.7	2047	▲100.0	384	99.6	255	99.6	307	99.8	2993
61. Someone is helping if staff yell, swear, or curse	†	†	†	†	†	†	†	†	†	†
72. Worked with someone when asked to change staff	82.9	419	▲88.1	84	74.7	60	81.5	77	81.8	640
74. Knew that they can ask someone to change staff	▲92.9	1579	88.7	286	▼78.1	181	86.6	219	86.6	2265
36. Case manager is known	▲92.9	1950	91.8	377	▼86.0	246	91.0	300	90.4	2873

- ▲ This program type's score is **above** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).
- ▼ This program type's score is **below** the average score for all HCBS programs (statistically significant at the $p \leq 0.05$ level).
- * The original question was written negatively, but we are reporting it positively to support comparing the questions.
- † The number of responses to this question was 10 or less and therefore not included for confidentiality purposes.

Appendix B.

Home and Community-Based Experience of Care Field Test Survey Instrument

Home and Community Based Services Experience Survey

The Centers for Medicare & Medicaid Services (CMS) has supported Truven Health Analytics and its subcontractor AIR, to develop and pilot the Home and Community Based Services (HCBS) Experience Survey. The goal of the survey is to measure experiences of services and care by individuals—across disabilities—who received HCBS.

The following is a copy of the draft field test version of the HCBS Experience Survey. Please note that this tool has not undergone field testing and should not be considered final. States and other interested parties are **asked to coordinate with CMS on any potential use of this survey.** For more information, please contact Kerry Lida (kerry.lida@cms.hhs.gov), Susan Raetzman (susan.raetzman@truvenhealth.com) or Beth Jackson (beth.jackson@truvenhealth.com).

Public reporting burden for this collection of information is estimated to average 30 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: CMS

Home and Community Based Services Experience Survey

Version: English

Mode: Interviewer administered (CAPI/CATI)

Date: 6/19/13

Home and Community Based Services Experience Survey

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INFORMATION ON READING THE INTERVIEW INSTRUMENT

This survey includes all of the questions for review.

- 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. 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 should be used which uses the response options of “mostly yes and mostly no.” These response options are reserved for individuals who find the “never, sometimes, usually, always” response scale cognitively challenging.
- All questions include a “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—for example, the response to “Do your homemakers listen carefully to what you say?” is “I like to sit by Mary.”
- Some responses have skip patterns, which are expressed as “→ [GO TO Q#].” The interviewer will be automatically skipped to the next correct item.

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.

CT1. 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]

CT2. 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 TO DO THINGS
- DRIVES ME AROUND

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

CT3. 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.

(INT: IF ALL 4 QUESTIONS ANSWERED CORRECTLY, ENTER 1 TO CONTINUE.)

1 PASS - ALL 3 QUESTIONS WERE ANSWERED CORRECTLY → GO TO ID1

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.

(INT: ENTER 1 TO EXIT SURVEY)

IDENTIFICATION QUESTIONS

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

ID-1. Do you get *{program specific term for personal assistance}* at home?

- YES
- NO → Go to ID3
- DON'T KNOW → Go to ID3
- REFUSED → Go to ID3
- UNCLEAR RESPONSE → Go to ID?

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

ID-3. Do you get *{program specific term for behavioral health specialist services}* at home?

- YES
- NO → Go to ID5
- DON'T KNOW → Go to ID5
- REFUSED → Go to ID5
- UNCLEAR RESPONSE → Go to ID5

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

ID-5. Do you get *{program specific term for homemaker services}* at home?

- YES
- NO → GO to ID8
- DON'T KNOW → Go to ID7 (or Go to ID8 if Negative response to ID1, ID3, and ID5)
- REFUSED → Go to ID8
- UNCLEAR RESPONSE → Go to ID8

ID-6. What do you call the person or people who give you *{program specific term for homemaker services}*? For example, do you call them *{program-specific term for homemaker}*, aides, homemakers, chore workers, or something else? →IF ID1=YES, GO TO ID7

ID-7. [IF ID1 = YES AND ID5 = YES, ASK]. Do the same people who help you with everyday activities also help you to clean your home?

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

ID-8. Do you get help from {*program specific term for case manager services*} to help make sure that you have all the services you need. Is that right?

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

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

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

[IF RESPONSE IS NEGATIVE TO ALL SUPPORTS, THEN GO TO ABOUT YOU SECTION.]

SERVICES AND SUPPORTS FROM PERSONAL ASSISTANT AND BEHAVIORAL STAFF

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

1. First I would like to talk about the *{personal assistance/behavioral health staff}* who are paid to help you with everyday activities—for example, getting dressed, using the bathroom, taking a bath or shower, or going places. How often do *{personal assistance/behavioral health staff}* come to work on time? Would you say . . .
 - Never,
 - Sometimes,
 - Usually, or
 - Always?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
 - i. 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. Do *{personal assistance/behavioral health staff}* come to work on time? Would you say...
 - Mostly yes, or,
 - Mostly no?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
2. How often do *{personal assistance/behavioral health staff}* work as long as they are supposed to? Would you say . . .
 - Never,
 - Sometimes,
 - Usually, or
 - Always?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
 - i. Alternate Version: Do *{personal assistance/behavioral health staff}* work as long as they are supposed to? Would you say . . .
 - Mostly yes, or,
 - Mostly no?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

3. Sometimes staff cannot come to work on a day that they are scheduled. When staff cannot come to work on a day that they are scheduled, does someone let you know if {*personal assistance/behavioral health staff*} cannot come that day?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
4. Do you need help from {*personal assistance/behavioral health staff*} to get dressed, take a shower, or bathe?
- YES
 - NO →[GO TO Q8]
 - DON'T KNOW →[GO TO Q8]
 - REFUSED →[GO TO Q8]
 - UNCLEAR RESPONSE →[GO TO Q8]
5. Do you **always** get dressed, take a shower, or bathe when you need to?
- YES →[GO TO Q7]
 - NO
 - DON'T KNOW →[GO TO Q7]
 - REFUSED →[GO TO Q7]
 - UNCLEAR RESPONSE →[GO TO Q7]
6. Is this because there are no {*personal assistance/behavioral health staff*} to help you?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
7. How often do {*personal assistance/behavioral health staff*} make sure you have enough personal privacy when you dress, take a shower, or bathe? Would you say...
- Never,
 - Sometimes,
 - Usually, or
 - Always?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
- i. Alternate Version: Do {*personal assistance/behavioral health staff*} make sure you have enough personal privacy when you dress, take a shower, or bathe? Would you say...
- Mostly yes, or,
 - Mostly no?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

8. Do you need help from {*personal assistance/behavioral health staff*} with your meals, such as help making or cooking meals or help eating?
- YES
 - NO →[GO TO Q11]
 - DON'T KNOW →[GO TO Q11]
 - REFUSED →[GO TO Q11]
 - UNCLEAR RESPONSE →[GO TO Q11]
9. Are you **always** able to get something to eat when you are hungry?
- YES →[GO TO Q11]
 - NO
 - DON'T KNOW →[GO TO Q11]
 - REFUSED →[GO TO Q11]
 - UNCLEAR RESPONSE →[GO TO Q11]
10. Is this because there are no {*personal assistance/behavioral health staff*} to help you?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
11. Sometimes people need help taking their medicines, such as reminders to take a medicine, help pouring them, or setting up their pills. Do you need help from {*personal assistance/behavioral health staff*} to take your medicines?
- YES
 - NO →[GO TO Q14]
 - DON'T KNOW →[GO TO Q14]
 - REFUSED →[GO TO Q14]
 - UNCLEAR RESPONSE →[GO TO Q14]
12. Do you **always** take your medicine when you are supposed to?
- YES →[GO TO Q14]
 - NO
 - DON'T KNOW →[GO TO Q14]
 - REFUSED →[GO TO Q14]
 - UNCLEAR RESPONSE →[GO TO Q14]
13. Is this because there are no {*personal assistance/behavioral health staff*} to help you?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

14. Help with toileting includes helping someone get on and off the toilet or helping to change disposable briefs or pads. Do you need help from {*personal assistance/behavioral health staff*} with toileting?
- YES
 - NO →[GO TO Q16]
 - DON'T KNOW →[GO TO Q16]
 - REFUSED →[GO TO Q16]
 - UNCLEAR RESPONSE →[GO TO Q16]
15. Do you get all the help you need with toileting from {*personal assistance/behavioral health staff*} when you need it?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

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

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

16. How often are {*personal assistance/behavioral health staff*} nice and polite to you? Would you say . . .
- Never,
 - Sometimes,
 - Usually, or
 - Always?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
- i. Alternate Version: Are {*personal assistance/behavioral health staff*} nice and polite to you? Would you say . . .
- Mostly yes, or,
 - Mostly no?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

17. How often are the explanations {*personal assistance/behavioral health staff*} gives you hard to understand because of an accent or the way he or she speaks English? Would you say ...

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

i. Alternate Version: Are the explanations {*personal assistance/behavioral health staff*} give you hard to understand because of an accent or the way {*personal assistance/behavioral health staff*} speaks English? Would you say. . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

18. How often do {*personal assistance/behavioral health staff*} treat you the way you want them to? Would you say . . .

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

i. Alternate Version: Do {*personal assistance/behavioral health staff*} treat you the way you want them to? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

19. How often do {*personal assistance/behavioral health staff*} explain things in a way that is easy to understand? Would you say . . .

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

- i. Alternate Version: Do *{personal assistance/behavioral health staff}* explain things in a way that is easy to understand? Would you say . . .

- Mostly yes, or,
 Mostly no?
 DON'T KNOW
 REFUSED
 UNCLEAR RESPONSE

20. How often do *{personal assistance/behavioral health staff}* listen carefully to you? Would you say . . .

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

- i. Alternate Version: Do *{personal assistance/behavioral health staff}* listen carefully to you? Would you say . . .

- Mostly yes, or,
 Mostly no?
 DON'T KNOW
 REFUSED
 UNCLEAR RESPONSE

21. Do you feel *{personal assistance/behavioral health staff}* know what kind of help **you** need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?

- YES
 NO
 DON'T KNOW
 REFUSED
 UNCLEAR RESPONSE

22. Do *{personal assistance/behavioral health staff}* encourage you to do things for yourself if you can?

- YES
 NO
 DON'T KNOW
 REFUSED
 UNCLEAR RESPONSE

23. 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

- DON'T KNOW →GO TO ALTERNATE VERSION
- REFUSED
- UNCLEAR RESPONSE →GO TO ALTERNATE VERSION

- i. Alternate version: How would you rate the help you get from {*personal assistance/behavioral health staff*}? Would you say . . .

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

24. Would you recommend the {*personal assistance/behavioral health staff*} who help you to your family and friends if they needed help with everyday activities? Would you say you recommend the {*personal assistance/behavioral health staff*} . . .

- Definitely no,
- Probably no,
- Probably yes, or
- Definitely yes?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

SERVICES AND SUPPORT FROM HOMEMAKERS

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

GETTING NEEDED SERVICES FROM HOMEMAKERS

25. How often do {*homemakers*} come to work on time? Would you say . . .

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

i. Alternate Version: Do {*homemakers*} come to work on time? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

26. How often do {*homemakers*} work as long as they are supposed to? Would you say . . .

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

i. Alternate Version: Do {*homemakers*} work as long as they are supposed to? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

27. Do your household tasks, like cleaning and laundry, **always** get done when you need them to? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]
- YES →[GO TO Q29]
 - NO
 - DON'T KNOW NO →[GO TO Q29]
 - REFUSED NO →[GO TO Q29]
 - UNCLEAR RESPONSE →[GO TO Q29]
28. Is this because there are no {homemakers} to help you? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

HOW WELL HOMEMAKERS COMMUNICATE AND TREAT YOU

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

29. How often are {homemakers} nice and polite to you? Would you say . . .
- Never,
 - Sometimes,
 - Usually, or
 - Always?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
- i. Alternate Version: Are {homemakers} nice and polite to you? Would you say ...
- Mostly yes, or,
 - Mostly no?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
30. How often are the explanations {homemaker} gives you hard to understand because of an accent or the way the provider speaks English? Would you say . . .
- Never,
 - Sometimes,
 - Usually, or
 - Always?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

- i. Alternate Version: Are the explanations {*homemakers*} give you hard to understand because of an accent or the way {*homemakers*} speaks English? Would you say. . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

31. How often do {*homemakers*} treat you the way you want them to? Would you say . . .

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

- i. Alternate Version: Do {*homemakers*} treat you the way you want them to? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

32. How often do {*homemakers*} listen carefully to you? Would you say . . .

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

- i. Alternate Version: Do {*homemakers*} listen carefully to you? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

33. Do you feel {homemakers} know what kind of help you need?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
34. 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
- DON'T KNOW → ALTERNATE VERSION
 - REFUSED
 - UNCLEAR RESPONSE → ALTERNATE VERSION
- i. Alternate version: How would you rate the help you get from {homemakers}? Would you say . . .
- Excellent,
 - Very good,
 - Good,
 - Fair, or
 - Poor?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
35. Would you recommend the {homemakers} who help you to your family and friends if they needed {program-specific term for homemaker services}? Would you say you recommend the {homemakers} . . .
- Definitely no,
 - Probably no,
 - Probably yes, or
 - Definitely yes?
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

YOUR CASE MANAGER

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

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

- YES
- NO →[GO TO Q44]
- DON'T KNOW →[GO TO 44]
- REFUSED →[GO TO Q44]
- UNCLEAR RESPONSE →[GO TO Q44]

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

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

38. Some people need to get equipment to help them, like wheelchairs or walkers, and other people need their equipment replaced or fixed. Have you asked this {*case manager*} for help with getting or fixing equipment?

- YES
- NO →[GO TO Q40]
- DON'T NEED →[GO TO Q40]
- DON'T KNOW →[GO TO Q40]
- REFUSED →[GO TO Q40]
- UNCLEAR RESPONSE →[GO TO Q40]

39. Did this {*case manager*} work with you when you asked for help with getting or fixing equipment?

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

40. Have you asked this {*case manager*} for help in getting any changes to your services, such as more help from {*personal assistance/behavioral health staff and/or homemakers if applicable*}, or for help with getting places or finding a job?

- YES
- NO →[GO TO 42]
- DON'T NEED →[GO TO Q42]
- DON'T KNOW →[GO TO 42]
- REFUSED →[GO TO 42]
- UNCLEAR RESPONSE →[GO TO 42]

41. Did this {*case manager*} work with you when you asked for help with getting other changes to your services?

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

42. 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 TO 10

- DON'T KNOW → ALTERNATE VERSION
- REFUSED
- UNCLEAR RESPONSE → ALTERNATE VERSION

i. Alternate version: How would you rate the help you get from the {*case manager*}? Would you say . . .

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

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

- Definitely no,
- Probably no,
- Probably yes, or
- Definitely yes?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

CHOOSING YOUR SERVICES

44. A [*program-specific term for “service plan”*]*—sometimes called a care plan, goals, or service plan—lists the services you need and who will provide them. Did you work with someone to develop your [*program-specific term for “service plan”*]*?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
45. Does your [*program-specific term for “service plan”*] include . . .
- None** of the things that are important to you,
 - Some** of the things that are important to you,
 - Most** of the things that are important to you, or
 - All** of the things that are important to you?
 - DON'T KNOW →[GO TO 47]
 - REFUSED →[GO TO 47]
 - UNCLEAR RESPONSE →[GO TO 47]
46. Do you feel {*personal assistance/behavioral health staff*} know what's on your [*program-specific term for “service plan”*], including the things that are important to you?
- YES
 - NO
 - DOES NOT HAVE PERSONAL ASSISTANCE STAFF
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
47. Who would you talk to if you wanted to change your [*program-specific term for “service plan”*]? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]
- CASE MANAGER
 - OTHER STAFF
 - FAMILY/FRIENDS
 - OTHER
 - I DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

TRANSPORTATION

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

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

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

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

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

- YES
- NO →[GO TO Q52]
- DON'T KNOW →[GO TO Q52]
- REFUSED →[GO TO Q52]
- UNCLEAR RESPONSE →[GO TO Q52]

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

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

51. How often does this ride arrive on time to pick you up? Would you say . . .

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

i. Alternate Version: Does this ride arrive on time to pick you up? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

PERSONAL SAFETY

The next few questions ask about your personal safety.

52. Who would you contact in case of an emergency?
- FAMILY MEMBER OR FRIEND
 - CASE MANAGER
 - AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES
 - PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)
 - 9-1-1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)
 - SOMEONE ELSE, PLEASE SPECIFY _____
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE
53. Is there a person you can talk to if someone hurts you or does something to you that you don't like?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

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

54. Do **any** of the {*personal assistance/behavioral health staff, homemakers, or your case managers*} that you have **now** take your money or your things without asking you first?
- YES
 - NO →[GO TO Q57]
 - DON'T KNOW →[GO TO Q57]
 - REFUSED →[GO TO Q57]
 - UNCLEAR RESPONSE →[GO TO Q57]
55. Is someone working with you to fix this problem?
- YES
 - NO →[GO TO Q57]
 - DON'T KNOW →[GO TO Q57]
 - REFUSED →[GO TO Q57]
 - UNCLEAR RESPONSE →[GO TO Q57]

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

- FAMILY MEMBER OR FRIEND
- CASE MANAGER
- AGENCY
- SOMEONE ELSE, PLEASE SPECIFY _____
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

57. Do any {staff} that you have now yell, swear, or curse at you?

- YES
- NO →[GO TO Q60]
- DON'T KNOW →[GO TO Q60]
- REFUSED →[GO TO Q60]
- UNCLEAR RESPONSE →[GO TO Q60]

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

- YES
- NO →[GO TO Q60]
- DON'T KNOW →[GO TO Q60]
- REFUSED →[GO TO Q60]
- UNCLEAR RESPONSE →[GO TO Q60]

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

- FAMILY MEMBER OR FRIEND
- CASE MANAGER
- AGENCY
- SOMEONE ELSE, PLEASE SPECIFY _____
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

60. Do any {staff} that you have now hit you or hurt you?

- YES
- NO →[GO TO Q63]
- DON'T KNOW →[GO TO Q63]
- REFUSED →[GO TO Q63]
- UNCLEAR RESPONSE →[GO TO Q63]

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

- YES
- NO →[GO TO Q63]
- DON'T KNOW →[GO TO Q63]
- REFUSED →[GO TO Q63]
- UNCLEAR RESPONSE →[GO TO Q63]

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

- FAMILY MEMBER OR FRIEND
- CASE MANAGER
- AGENCY
- SOMEONE ELSE, PLEASE SPECIFY _____
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

DRAFT

COMMUNITY INCLUSION AND EMPOWERMENT

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

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

- YES
- NO →[GO TO Q65]
- DON'T KNOW →[GO TO Q65]
- REFUSED →[GO TO Q65]
- UNCLEAR RESPONSE →[GO TO Q65]

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

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

i. Alternate Version: When you want to, can you get together with these family members who live nearby? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

- YES
- NO →[GO TO Q67]
- DON'T KNOW →[GO TO Q67]
- REFUSED →[GO TO Q67]
- UNCLEAR RESPONSE →[GO TO Q67]

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

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

- i. Alternate Version: When you want to, can you get together with these friends who live nearby? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

67. When you want to, how often can you do things in the community that you like?

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

- i. Alternate Version: When you want to, can you do things in the community that you like? Would you say . . .

- Mostly yes, or
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

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

69. Do you take part in deciding **what** you do with your time each day?

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

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

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

71. Have you asked for a change in {personal assistance staff, behavioral health staff, homemakers, or case manager}?
- YES
 - NO →[GO TO Q74]
 - DON'T KNOW →[GO TO Q74]
 - REFUSED →[GO TO Q74]
 - UNCLEAR RESPONSE →[GO TO Q74]
72. Did someone work with you when you asked to change {personal assistance/behavioral health staff, homemakers, or case manager}?
- YES
 - NO →[GO TO EM]
 - DON'T KNOW →[GO TO EM]
 - REFUSED →[GO TO EM]
 - UNCLEAR RESPONSE →[GO TO EM]
73. Who did you work with when you asked to change {personal assistance/behavioral health staff, homemakers, or case manager} [RECORD ALL THAT APPLY]
- Family MEMBER OR FRIEND →[IF ASKING EM, GO TO EM; IF NOT, GO TO Q75]
 - Case MANAGER →[GO TO EM OR Q75]
 - Agency →[GO TO EM OR Q75]
 - Someone ELSE, PLEASE SPECIFY _____ →[GO TO EM OR Q75]
 - DON'T KNOW →[GO TO EM OR Q75]
 - REFUSED →[GO TO EM OR Q75]
 - UNCLEAR RESPONSE →[GO TO EM OR Q75]
74. Do you know you can ask someone to change {personal assistance/behavioral health staff, homemakers, or case manager}?
- YES
 - NO
 - DON'T KNOW
 - REFUSED
 - UNCLEAR RESPONSE

SUPPLEMENTAL EMPLOYMENT MODULE

EM1. Do you work for pay at a job?

- YES →[GO TO EM9]
- NO
- DON'T KNOW →[GO TO Q75]
- REFUSED →[GO TO Q75]
- UNCLEAR RESPONSE →[GO TO Q75]

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

- YES
- NO →[GO TO EM4]
- DON'T KNOW →[GO TO Q75]
- REFUSED →[GO TO Q75]
- UNCLEAR RESPONSE →[GO TO Q75]

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

- BENEFITS →[GO TO EM5]
- HEALTH CONCERNS →[GO TO EM5]
- DON'T KNOW ABOUT JOB RESOURCES →[GO TO EM5]
- ADVICE FROM OTHERS →[GO TO EM5]
- TRAINING/EDUCATION NEED →[GO TO EM5]
- LOOKING AND CAN'T FIND WORK →[GO TO EM5]
- ISSUES WITH PREVIOUS EMPLOYMENT →[GO TO EM5]
- TRANSPORTATION →[GO TO EM5]
- CHILD CARE →[GO TO EM5]
- OTHER (_____) →[GO TO EM5]
- NOTHING IS HOLDING ME BACK → [GO TO EM5]
- DON'T KNOW →[GO TO EM5]
- REFUSED →[GO TO EM5]
- UNCLEAR RESPONSE →[GO TO EM5]

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

- BENEFITS →[GO TO Q75]
- HEALTH CONCERNS →[GO TO Q75]
- DON'T KNOW ABOUT JOB RESOURCES →[GO TO Q75]
- ADVICE FROM OTHERS →[GO TO Q75]
- TRAINING/EDUCATION NEED →[GO TO Q75]
- LOOKING AND CAN'T FIND WORK →[GO TO Q75]
- ISSUES WITH PREVIOUS EMPLOYMENT →[GO TO Q75]
- TRANSPORTATION →[GO TO Q75]
- CHILD CARE →[GO TO Q75]
- OTHER (_____) →[GO TO Q75]
- NOTHING/DOESN'T WANT TO WORK →[GO TO Q75]
- DON'T KNOW →[GO TO Q75]
- REFUSED →[GO TO Q75]
- UNCLEAR RESPONSE →[GO TO Q75]

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

- YES →[GO TO EM7]
- NO
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

- YES →[GO TO Q75]
- NO →[GO TO Q75]
- DON'T KNOW →[GO TO Q75]
- REFUSED →[GO TO Q75]
- UNCLEAR RESPONSE →[GO TO Q75]

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

- YES → [GO TO EM8]
- NO →[GO TO Q75]
- DON'T KNOW →[GO TO Q75]
- REFUSED →[GO TO Q75]
- UNCLEAR RESPONSE →[GO TO Q75]

EM8. Are you getting all the help you need to find a job?

- YES →[GO TO Q75]
- NO →[GO TO Q75]
- DON'T KNOW →[GO TO Q75]
- REFUSED →[GO TO Q75]
- UNCLEAR RESPONSE →[GO TO Q75]

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

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

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

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

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

- YES
- NO →[GO TO Q75]
- DON'T KNOW →[GO TO Q75]
- REFUSED →[GO TO Q75]
- UNCLEAR RESPONSE →[GO TO Q75]

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

USE THIS TERM WHEREVER IT SAYS {job coach} BELOW.

EM13. Did you hire your {*job coach*} yourself?

- YES →[GO TO Q75]
- NO
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

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

EM15. How often does your {*job coach*} give you all the help you need? Would you say . . .

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

i. Alternate Version: Does your {*job coach*} give you all the help you need? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM16. How often is your {*job coach*} nice and polite to you? Would you say . . .

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

i. Alternate Version: Is your {*job coach*} nice and polite to you? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

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

i. Alternate Version: Does your {*job coach*} explain things in a way that is easy to understand? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

EM18. How often does your {*job coach*} listen carefully to you? Would you say . . .

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

- i. Alternate Version: Does your {*job coach*} listen carefully to you? Would you say . . .

- Mostly yes, or,
- Mostly no?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

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

EM20. Using any number from 0 to 10, where 0 is the worst help from {*job coach*} possible and 10 is the best help from {*job coach*} possible, what number would you use to rate the help you get from {*job coach*}?

__0 TO 10

- DON'T KNOW → ALTERNATE VERSION
- REFUSED
- UNCLEAR RESPONSE → ALTERNATE VERSION

- i. Alternate version: How would you rate the help you get from your {*job coach*}? Would you say . . .

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

EM21. Would you recommend the {*job coach*} who helps you to your family and friends if they needed {*program-specific term for employment services*}? Would you say you recommend the {*job coach*} . . .

- Definitely no,
- Probably no,
- Probably yes, or
- Definitely yes?
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

ABOUT YOU

Now I just have a few more questions about you.

75. In general, how would you rate your overall health? Would you say . . .
- Excellent,
 - Very good,
 - Good,
 - Fair, or
 - Poor?
- 8 Don't know
-9 Refused
76. In general, how would you rate your overall mental or emotional health? Would you say . . .
- Excellent,
 - Very good,
 - Good,
 - Fair, or
 - Poor?
- 8 Don't know
-9 Refused
77. What is your age?
- 18 TO 24 YEARS →[GO TO Q79]
 - 25 TO 34 YEARS →[GO TO Q79]
 - 35 TO 44 YEARS →[GO TO Q79]
 - 45 TO 54 YEARS →[GO TO Q79]
 - 55 TO 64 YEARS →[GO TO Q79]
 - 65 TO 74 YEARS →[GO TO Q79]
 - 75 YEARS OR OLDER →[GO TO Q79]
 - DON'T KNOW
 - REFUSED →[GO TO Q79]
 - UNCLEAR RESPONSE
78. **[IF NO ANSWER TO Q77, ASK]** In what year were you born?
- _____ (YEAR)
- 8 Don't know
-9 Refused
79. **[IF NECESSARY, ASK, AND VERIFY IF OVER THE PHONE]** Are you male or female?
- MALE
 - FEMALE

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

- YES, HISPANIC, LATINO, OR SPANISH
- NO, NOT HISPANIC, LATINO, OR SPANISH → [GO TO Q82]
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

81. Which group best describes you? {READ ALL ANSWER CHOICES}

- Mexican, Mexican, American, Chicano
- Puerto Rican
- Cuban
- Another Hispanic, Latino, or Spanish origin
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

- White **GO TO 83**
- Black or African-American **GO TO 83**
- Asian **GO TO 82A**
- Native Hawaiian or other Pacific Islander **GO TO 83**
- American Indian or Alaska Native **GO TO 82B**
- OTHER **GO TO 83**
- DON'T KNOW **GO TO 83**
- REFUSED **GO TO 83**
- UNCLEAR RESPONSE **GO TO 83**

82A Which group best describes you? READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.

- Asian Indian **GO TO 83**
- Chinese **GO TO 83**
- Filipino **GO TO 83**
- Japanese **GO TO 83**
- Korean **GO TO 83**
- Vietnamese **GO TO 83**
- OTHER ASIAN **GO TO 83**
- DON'T KNOW **GO TO 83**
- REFUSED **GO TO 83**
- UNCLEAR RESPONSE **GO TO 83**

82B Which group best describes you? READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.

- Native Hawaiian **GO TO 83**
- Guamanian or Chamorro **GO TO 83**
- Samoan **GO TO 83**
- OTHER PACIFIC Islander **GO TO 83**
- DON'T KNOW **GO TO 83**
- REFUSED **GO TO 83**
- UNCLEAR RESPONSE **GO TO 83**

83. [ENGLISH VERSION]: Do you speak a language other than English at home? READ CHOICES ONLY IF NEEDED...

- Yes
- No[GO TO Q84]
- DON'T KNOW →[GO TO Q84]
- REFUSED →[GO TO Q84]
- UNCLEAR RESPONSE →[GO TO Q84]

83A. What is the language you speak at home ? _____

- SPANISH,
- CHINESE
- KOREAN
- RUSSIAN
- VIETNAMESE
- Some other language → Which one? _____
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

- 1 [JUST THE RESPONDENT] →[GO TO Q87]
- 2 TO 3
- 4 OR MORE
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

- YES →[GO TO Q87]
- NO
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

INTERVIEWER QUESTIONS

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

90. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

- YES
- NO

91. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

- YES
- NO → [END SURVEY]

92. WHO WAS PRESENT DURING THE INTERVIEW? (MARK ALL THAT APPLY.)

- SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

93. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

- YES
- NO → [END SURVEY]

94. HOW DID THAT PERSON HELP? (MARK ALL THAT APPLY.)

- ANSWERED ALL THE QUESTIONS FOR RESPONDENT
- RESTATED THE QUESTIONS IN A DIFFERENT WAY OR REMINDED/
PROMPTED THE RESPONDENT
- TRANSLATED THE QUESTIONS OR ANSWERS INTO THE RESPONDENT'S
LANGUAGE
- HELPED WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT
SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS
- OTHER, SPECIFY _____

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

- SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT