2022 Annual Report:
Consumer Assessment of Health Provider Systems
Home and Community-Based Services
(HCBS CAHPS) Survey Results:
Connecticut HCBS programs*

*Access agencies De-Identified

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I. Introduction

The Consumer Assessment of Health Provider Systems Home and Community-Based Services (HCBS CAHPS®) survey is a standardized, cross-disability tool to assess and improve HCBS program quality. The survey underwent rigorous reliability and validity testing and gained approval from the national Consumer Assessment of Health Provider Systems (CAHPS®) consortium and endorsement by the National Quality Forum.

Unlike surveys that assess satisfaction with services, the HCBS CAHPS survey elicits program participant feedback on his/her daily experience with HCBS. Reporting actual experiences across multiple domains is more conducive for measuring quality than satisfaction alone. The HCBS CAHPS survey also allows for the comparison of various HCBS programs and case management providers, as individuals with different disabilities respond to the same questions. The HCBS CAHPS survey provides Connecticut with one consistent approach to reward quality and facilitate reporting across waiver programs and care management provider agencies. Another benefit of the HCBS CAHPS survey is its increased accessibility. Participants can choose to do the survey by telephone or in-person, and a Spanish version is available. If a participant cannot answer the questions on his/her own, an unpaid person can either assist the consumer or complete the survey by proxy. Another advantage of the HCBS CAHPS is its integration of alternately worded questions and responses, making the survey more accessible for persons with cognitive or speech challenges. These more inclusive approaches mean that Connecticut’s data includes all participants’ perspectives, regardless of disability.

Connecticut is in its fifth year of HCBS CAHPS survey administration, using the survey to inform quality measurement in seven of its Medicaid programs: Connecticut Home Care Program (CHCP) Categories 3 and 5, Personal Care Assistance (PCA), Acquired Brain Injury I and II (ABI), Autism, and Katie Beckett (KBW) waivers. This is the third year of use with the Mental Health waiver (MHW). This report presents results from these waivers and programs. Connecticut also uses the HCBS CAHPS survey with Money Follows the Person and Community First Choice participants.

II. Methods

A. HCBS CAHPS Survey

The HCBC CAHPS survey is composed of eleven sections: cognitive screen, identification of paid services, personal assistance and/or behavioral health staff services, homemaking services, case manager, choosing your services, transportation, personal safety, community inclusion and empowerment, demographics, and employment. The Department of Mental Health and Addiction services (DMHAS) added a separate set of questions for MHW participants. To tailor the survey to the participant and waiver program, waiver specific services and terms are integrated directly into the survey. For example, only ABI participants are asked about Independent Living Training Specialists (ILSTs). All participants are asked how they refer to their paid staff; these responses are then used throughout that individual’s survey. A participant’s waiver program determines which services to ask about and what terms to use to refer to these services (see Table 1). The full HCBS CAHPS surveys are attached in Appendix B (CHCP, PCA, ABI, Autism, KBW) and Appendix C (MHW).
Table 1. Program Services

<table>
<thead>
<tr>
<th>Service</th>
<th>CHCP</th>
<th>PCA</th>
<th>ABI</th>
<th>Autism</th>
<th>KBW</th>
<th>MHW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care assistance</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral health services</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recovery assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Homemaker/companion or Homemaking services</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case manager or Clinical Case Manager</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Job coach</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Service Provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

*Independent Living Skills Training (ILST)
**Life skills coach or community mentor

B. Survey Administration

Contracted case management agencies, or Access Agencies, are required to complete surveys for the CHCP, PCA, and ABI waivers. Connecticut Department of Social Services (DSS) staff are responsible for completing surveys for the Katie Beckett and Autism waivers. DMHAS uses quality assurance staff from one of its case management provider agencies, as well as research staff from the University of Connecticut at Storrs to complete their surveys (hereafter collectively referred to as MHW quality assurance staff). Using client enrollment numbers as of 7/1/2021, DSS determined the target number of surveys for each Access Agency, DSS, and DMHAS to complete between July 1, 2021 to June 30, 2022 (Fiscal Year [FY] 2022) in order to reach their representative sample sizes.

Using random sampling, Access Agency, DSS, and MHW quality assurance staff contact waiver participants from their client lists and invite them to do the survey. If there is a legal guardian or conservator of person, the quality assurance staff contact them first before contacting the waiver participant.

Waiver participants are encouraged to complete the survey on their own or with assistance if needed. If the participant cannot take part in the survey process at all, then the survey is completed by a proxy on behalf of the participant. Proxies can be a family member, legal representative, or friend who knows the participant well, but not a paid staff person.

As the training and technical assistance provider, UConn Center on Aging (UConn) provides ongoing training for the quality assurance staff from all four Access Agencies, DSS, and DMHAS. Using role playing, hands-on practice, and didactic teaching, the training covers the purpose of the HCBS CAHPS survey, a question by question survey review, participant recruitment, survey administration, and use of the online survey site. UConn provides and manages a secure online HCBS CAHPS platform with program specific surveys, including programming to insert program and participant specific terms. Computer assisted telephone-personal interviewing programming is used to direct the interviewer to the correct question and accurately follow the skip patterns for each type of survey.

C. Measures

Key results are presented using established HCBS CAHPS composite and other key measures (see Table 2). Individual items not covered by these measures are included in specific program results.

Each composite scale comprises three to twelve individual questions (see Appendix A). Most of these questions have four response options: never, sometimes, usually, always. Each response is coded with a number from one to four, with one indicating the most negative and four the most positive response. A composite’s final score is generated by combining the answers from each question, producing one number ranging from one to four. All scores were rounded to the second decimal point.
For global ratings, participants are asked to rate the help they get from each type of staff based on a scale from 0 to 10, or alternatively, using a worded scale from poor to excellent. These responses are grouped to form a five point rating scale with scores ranging from one to five, with the higher the number, the more positive the rating. Recommendations are based on a four point scale derived from asking if the participant would recommend the person using one of the following responses: definitely no, probably no, probably yes, or definitely yes (range 1 to 4; higher numbers indicate more positive recommendation).

To determine if there is any unmet need for personal care, a stem question asks if the participant gets assistance for that activity, and if so, did this activity always happen when needed. Unmet need is defined as the activity not occurring when needed because there were no staff to assist the participant, and scored as either yes, an unmet need is present, or no, it was not. One item was used to determine physical safety: “In the past 3 months, did any [staff] hit you or hurt you?” using a yes or no response.

Following CAHPS protocol, this report presents the composites, global ratings, and recommendations in two ways: the mean or average score, and the percentage with the highest score. The latter is especially helpful when comparing services or providers, as it highlights which providers are delivering the highest quality service. To produce the highest composite scores, responses are divided into two groups: the most positive (scores of 4 only) and all other responses (scores of 1, 2, or 3). Each item is scored individually, and the mean across the items in that composite is used. Highest recommendation was determined similarly – only “definitely yes” was given the highest score, while the other three responses were grouped together. Likewise, each global rating was categorized as the highest score (rating of a 5), versus all other responses (any number less than five). This report displays the percentage of participants who gave the most positive or highest score, rating, or recommendation.

Table 2. Key Measures

| Composites                                      | Staff are reliable and helpful |
|                                                | Staff listen and communicate well |
|                                                | Case manager is helpful |
|                                                | Choosing services that matter to you |
|                                                | Transportation to medical appointments |
|                                                | Personal safety and respect |
|                                                | Planning your time and activities |

| Global ratings                                  | Personal care/Recovery assistance/Behavioral health staff |
|                                                | Homemaker/Companion |
|                                                | Case manager |
|                                                | Job coach |
|                                                | Community Service Provider |

| Recommendations                                  | Personal care/Recovery assistance/Behavioral health staff |
|                                                | Homemaker/Companion |
|                                                | Case manager |
|                                                | Job coach |
|                                                | Community Service Provider |

| Unmet need                                      | Personal care |
|                                                | Meals |
|                                                | Medications |
|                                                | Toileting |
|                                                | Household tasks |

| Physical safety                                | Did any staff hit or hurt you |
III. Results

After overall respondent sample and demographics, results are presented as follows: Key results by program, Performance benchmarks by agency, Additional findings by program, and Comparisons by agency for each program.

A. Respondent Sample

HCBS CAHPS surveys were completed for each of the mandated waiver programs: CHCP program Categories 3 and 5, and the PCA, ABI 1 and 2, Autism, Katie Beckett, and MH waivers. For purposes of analysis, the CHCP data includes all completed CHCP surveys, and the ABI analysis combines all completed ABI surveys. Table 3 shows the number of program participants, representative sample, completed surveys, and percent of representative sample reached by program.

All the Access Agencies met or exceeded their respective representative samples for the CHCP programs, the PCA waiver, and the ABI waivers.

The other 3 waiver programs did not reach their representative sample sizes. The Autism program came the closest, completing 75% of their representative sample (78% in 2021). KBW completed 35% of their representative sample this year, compared to 40% in 2021. MHW numbers fell as well; only 29 MHW surveys were completed from July 1, 2021 to May 31, 2022, equaling just 13% of the MHW representative sample, compared to 18% (n=42 surveys) in FY 2021. DMHAS revised its Annual HCBS CAHPS survey in June, 2022, and the 8 surveys completed in June, 2022 will be analyzed with next year’s data. This report still presents the results for these three programs to show program trends.

Table 3. Representative Sample and Completed Surveys by Program

<table>
<thead>
<tr>
<th>Total number of waiver participants (N)</th>
<th>Representative sample (N)</th>
<th>Completed surveys (N)</th>
<th>Percentage of representative sample completed (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHCP programs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHCP Category 3</td>
<td>12256</td>
<td>374</td>
<td>388</td>
</tr>
<tr>
<td>CHCP Category 5</td>
<td>311</td>
<td>173</td>
<td>175</td>
</tr>
<tr>
<td>Total CHCP Surveys</td>
<td>12567</td>
<td>547</td>
<td>563</td>
</tr>
<tr>
<td>PCA</td>
<td>1011</td>
<td>279</td>
<td>286</td>
</tr>
<tr>
<td>ABI waivers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABI 1</td>
<td>328</td>
<td>178</td>
<td>184</td>
</tr>
<tr>
<td>ABI 2</td>
<td>229</td>
<td>144</td>
<td>151</td>
</tr>
<tr>
<td>Total ABI Surveys</td>
<td>557</td>
<td>322</td>
<td>335</td>
</tr>
<tr>
<td>Autism</td>
<td>127</td>
<td>96</td>
<td>72</td>
</tr>
<tr>
<td>Katie Beckett</td>
<td>323</td>
<td>176</td>
<td>61</td>
</tr>
<tr>
<td>MHW</td>
<td>568</td>
<td>230</td>
<td>29*</td>
</tr>
<tr>
<td>Total surveys completed, any program</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1346</td>
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</table>

*Surveys completed from 7/1/2021 to 5/31/2022. DMHAS revised its Annual HCBS CAHPS survey in June, 2022. The 8 surveys completed in June, 2022 will be analyzed with next year’s data.
With the exception of KBW and Autism, most surveys were completed by the consumer or the consumer with assistance (Table 4). Forty-two percent of all ABI surveys were also completed by someone other than the consumer (by proxy). For assisted interviews, the person assisting most often helped with translation, answering, or restating some of the questions, or prompting the consumer. The majority of proxy respondents were related to the consumer (87%). All but two of the surveys were completed by telephone, and 8% were completed in Spanish.

Table 4. Survey Respondents

<table>
<thead>
<tr>
<th></th>
<th>CHCP n (%)</th>
<th>PCA n (%)</th>
<th>ABI n (%)</th>
<th>Autism n (%)</th>
<th>KBW n (%)</th>
<th>MHW n (%)</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>By self</td>
<td>434 (77.1)</td>
<td>230 (80.4)</td>
<td>175 (52.2)</td>
<td>23 (31.9)</td>
<td>0 (0)</td>
<td>29 (100)</td>
<td>891 (66.2)</td>
</tr>
<tr>
<td>With assistance</td>
<td>45 (8.0)</td>
<td>4 (1.4)</td>
<td>20 (6.0)</td>
<td>3 (4.2)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>72 (5.4)</td>
</tr>
<tr>
<td>By proxy</td>
<td>84 (14.9)</td>
<td>52 (18.2)</td>
<td>140 (41.8)</td>
<td>46 (63.9)</td>
<td>61 (100)</td>
<td>0 (0)</td>
<td>383 (28.5)</td>
</tr>
</tbody>
</table>

**B. Consumer Demographics**

Consumer demographics by program are presented in Table 5.

Table 5. Consumer Demographics*  

<table>
<thead>
<tr>
<th></th>
<th>CHCP %</th>
<th>PCA %</th>
<th>ABI %</th>
<th>Autism %</th>
<th>KBW %**</th>
<th>MHW %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>&lt;18</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>6.9</td>
<td>73.8</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>18-24</td>
<td>0.0</td>
<td>1.0</td>
<td>1.8</td>
<td>15.3</td>
<td>26.2</td>
<td>0.0</td>
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<tr>
<td>25-34</td>
<td>0.0</td>
<td>8.7</td>
<td>10.4</td>
<td>38.9</td>
<td>0.0</td>
<td>3.4</td>
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<tr>
<td>35-44</td>
<td>0.0</td>
<td>11.2</td>
<td>21.5</td>
<td>30.6</td>
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<td>45-54</td>
<td>0.0</td>
<td>26.2</td>
<td>24.8</td>
<td>2.8</td>
<td>0.0</td>
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<tr>
<td>55-64</td>
<td>0.0</td>
<td>51.7</td>
<td>28.4</td>
<td>5.6</td>
<td>0.0</td>
<td>44.8</td>
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<tr>
<td>65-74</td>
<td>32.1</td>
<td>1.0</td>
<td>12.2</td>
<td>0.0</td>
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<td>20.7</td>
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<tr>
<td>75+</td>
<td>67.9</td>
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<td>&lt;1.0</td>
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<tr>
<td>Language</td>
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</tr>
<tr>
<td>English</td>
<td>61.2</td>
<td>71.0</td>
<td>78.8</td>
<td>100</td>
<td>77.0</td>
<td>89.3</td>
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<td>Spanish only</td>
<td>15.4</td>
<td>1.4</td>
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<td>0.0</td>
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<tr>
<td>Multi-lingual</td>
<td>23.4</td>
<td>27.6</td>
<td>21.2</td>
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<td>23.0</td>
<td>7.1</td>
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<tr>
<td>Race</td>
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<td></td>
</tr>
<tr>
<td>White</td>
<td>64.3</td>
<td>66.5</td>
<td>80.9</td>
<td>87.1</td>
<td>81.0</td>
<td>80.8</td>
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<tr>
<td>Black</td>
<td>20.7</td>
<td>29.9</td>
<td>15.3</td>
<td>7.1</td>
<td>6.9</td>
<td>19.2</td>
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<tr>
<td>Other</td>
<td>15.0</td>
<td>3.6</td>
<td>3.8</td>
<td>5.7</td>
<td>12.1</td>
<td>0.0</td>
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<tr>
<td>Ethnicity</td>
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<td>Non-Hispanic</td>
<td>75.8</td>
<td>83.2</td>
<td>93.6</td>
<td>91.7</td>
<td>80.7</td>
<td>96.2</td>
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<tr>
<td>Hispanic</td>
<td>24.2</td>
<td>16.8</td>
<td>6.4</td>
<td>8.3</td>
<td>19.3</td>
<td>3.8</td>
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<tr>
<td>Education</td>
<td></td>
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</tr>
<tr>
<td>&lt; 8th Grade</td>
<td>24.9</td>
<td>4.2</td>
<td>2.2</td>
<td>2.8</td>
<td>52.9</td>
<td>3.7</td>
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<tr>
<td>Some high school</td>
<td>13.8</td>
<td>12.3</td>
<td>11.3</td>
<td>9.7</td>
<td>35.3</td>
<td>7.4</td>
<td></td>
</tr>
<tr>
<td>High school degree</td>
<td>27.5</td>
<td>40.4</td>
<td>51.6</td>
<td>52.8</td>
<td>7.8</td>
<td>51.9</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>19.5</td>
<td>35.4</td>
<td>29.2</td>
<td>23.6</td>
<td>3.9</td>
<td>14.8</td>
<td></td>
</tr>
<tr>
<td>4-year college</td>
<td>9.1</td>
<td>5.6</td>
<td>4.7</td>
<td>8.3</td>
<td>0.0</td>
<td>11.1</td>
<td></td>
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<tr>
<td>&gt; 4 year college</td>
<td>5.3</td>
<td>2.1</td>
<td>&lt;1.0</td>
<td>2.8</td>
<td>0.0</td>
<td>11.1</td>
<td></td>
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<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
<td>21.8</td>
<td>46.5</td>
<td>65.4</td>
<td>80.6</td>
<td>62.7</td>
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<tr>
<td>Female</td>
<td>78.2</td>
<td>53.5</td>
<td>34.6</td>
<td>19.4</td>
<td>37.3</td>
<td>71.4</td>
<td></td>
</tr>
</tbody>
</table>

*Percentages listed for each item are based on the total number of valid responses to that question (N)

**Missing data not reported
C. Service Use by Program

Participants reported using a variety of program services in the three months prior to completing the survey (see Table 6). Use of PCA services by CHCP and PCA program participants, and use of ILST services by ABI participants increased in FY 2022. This year 50% of CHCP and 95% of PCA respondents reported using PCA services in the last 3 months, compared to 32% CHCP and 83% PCA last year. This year 90% of ABI respondents recently used ILSTs, compared to 79% in 2021. This may be an effect of the lessening of the COVID-19 pandemic, as participants and their family members became more comfortable receiving services at home and going out into the community. On the other hand, there was a large drop in the percentage of PCA and ABI respondents reporting use of homemaking services. While over 80% of PCA participants used homemaking services in FY 2021, only 27% reported doing so this year, and homemaking service use by ABI participants fell from 34% to 14%. PCAs in particular are often used for both homemaking and personal care assistance. Perhaps with the lessening of the COVID-19 pandemic, participants became more comfortable using dual-role direct support staff for personal care or activities other than helping with household tasks.

Table 6. Program Service Use

<table>
<thead>
<tr>
<th>Service</th>
<th>CHCP n (%)</th>
<th>PCA n (%)</th>
<th>ABI n (%)</th>
<th>Autism n (%)</th>
<th>KBW n (%)</th>
<th>MHW n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care assistance</td>
<td>277 (49.5)</td>
<td>272 (95.4)</td>
<td>177 (52.8)</td>
<td>5 (6.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral health services</td>
<td></td>
<td>291 (89.5)*</td>
<td>53 (74.7)**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recovery assistance (RA)</td>
<td>429 (76.5)</td>
<td>78 (27.3)</td>
<td>47 (14.2)</td>
<td>1 (1.4)</td>
<td>21 (72.4)</td>
<td></td>
</tr>
<tr>
<td>Homemaker/companion or Homemaking services</td>
<td>516 (95.6)</td>
<td>263 (92.3)</td>
<td>327 (98.5)</td>
<td>64 (88.9)</td>
<td>18 (31.0)</td>
<td>20 (74.1)</td>
</tr>
<tr>
<td>Case manager or Clinical case manager</td>
<td>38 (11.3)</td>
<td>9 (12.5)</td>
<td></td>
<td></td>
<td></td>
<td>17 (60.7)</td>
</tr>
</tbody>
</table>

*Independent Living Skills Training (ILST) services
**Life skills coach or community mentor services

D. HCBS CAHPS Key Results by Program

Composite measures, global ratings, and recommendations by program are displayed two ways: the mean score and the percentage reporting the highest score.

i. Composite measures by program

Figure 1 shows mean scores for the 7 composite measures by program. Overall, mean scores for five of the seven composite measures were high for CHCP, PCA, ABI, and Autism programs waiver. As seen in previous years, participants across all programs reported lower scores for items regarding choice of services and ability to plan one’s time and activities. Both of these composites speak to consumer choice and control and represent areas which could use more support across all programs. Similar to FY 2021, KBW and MHW participants reported the lowest scores across most composite measures.
Figure 1. Composite Measures by Program: Mean Scores (Range 1-4)*

*In Figures 1 and 2, “Staff” combines all PCA, ILST, recovery assistant, community service provider, homemaking, companion, life skills coach, and community mentor staff.
Figure 2 shows the percentage of participants in each program who gave the most positive answer for each composite item. This method highlights any program differences more clearly. For example, the differences among the 3 largest waivers for both staff composites are more pronounced with this method. Using mean scores for the composite staff are reliable and helpful, mean scores for these waivers ranged from 3.75 (ABI) to 3.87 (CHCP). By using the percentage highest scores, the differences are more apparent – 92% of CHCP participants gave this composite item the highest scores, compared to 78% of ABI participants. The lower scores given by KBW participants to their case managers is more apparent as well – 63% of KBW participants gave their case managers the highest score, compared to 86% to 98% of the other programs. This method also highlights the need to improve transportation to medical appointments, especially for Autism and KBW participants.

Figure 2. Composite Measures by Program: Percentage with Highest Score
ii. **Staff global ratings by program**

Using a scale from 1 to 5, mean global rating scores varied across programs for all types of staff (Figure 3). With the exception of homemaking services, mean scores for the majority of programs were 4.5 or higher for most program staff and case managers. Noticeably lower scores were given to PCA, ABI, and Autism homemaking services and KBW case managers.

Figure 4 presents the percentage of participants in each program who gave their staff or case managers the highest rating possible, a 9 or 10 (range 0-10). When shown this way, the differences among programs in the ratings of personal assistance/behavioral health staff become more apparent. For example, only 66% of ABI respondents gave their personal assistance/behavioral health staff the highest rating, compared to 81-87% of the other waivers. CHCP respondents in particular gave their case managers high ratings – 84% of CHCP case managers received a score of 9 or 10. One CHCP consumer who gave their care manager a high score, remarked that the care manager was quick to respond to their calls.

Figure 3. Staff Global Ratings by Program: Mean Score (Range 1-5)*

*In Figures 3, 4, 5 and 6, “Personal assistance & behavioral health staff” combines all PCA, ILST, recovery assistant, life skills coach, and community mentor staff.
Staff recommendations were based on a four point scale, asking if the participant would recommend their staff from “Definitely No” (score 1) to “Definitely Yes” (score 4). Figure 5 shows the mean recommendation score, while Figure 6 shows the percentage of respondents who would “definitely” recommend their staff or services. Recommendation scores varied among waivers and types of staff with few identifiable trends. Overall, CHCP participants gave all their types of waiver staff, especially PCAs and case managers high recommendation scores. On the other hand, ABI participants were much less likely to recommend their PCAs/ILSTs, homemaking staff, or case managers. This becomes very apparent when one considers the percentage of respondents who would “definitely” recommend their staff, shown in Figure 6.
Figure 5. Staff Recommendations by Program: Mean Score (Range 1-4)

Figure 6. Staff Recommendations by Program: Percentage Who “Definitely” Recommend Staff
iv. Unmet needs by program

CHCP, PCA, ABI, Autism, and MHW participants who reported receiving some type of personal care assistance were asked if they needed help from their personal assistants with four everyday activities (Table 7). Almost all PCA and 91% of CHCP participants needed assistance with dressing or bathing; the majority of PCA, CHCP, and ABI participants reported receiving assistance with meals. The percentage of CHCP consumers receiving assistance with meals may be underrepresented, as many CHCP participants receive this assistance from their homemakers, not PCAs.

To determine unmet need, participants who received personal care assistance were asked if an activity did not occur because they had no staff to assist them. Seven CHCP, 3 PCA, 2 ABI, and 1 Autism participant reported any unmet need, most frequently with dressing/bathing or toileting (data not shown in a table). Note that this describes unmet needs for consumers who reported using these services; it is possible that consumers who do not have these services also need, but do not have, assistance in these areas.

Table 7. Self-reported Assistance with Everyday Activities

<table>
<thead>
<tr>
<th>Needs assistance with:</th>
<th>CHCP n (%)</th>
<th>PCA n (%)</th>
<th>ABI n (%)</th>
<th>Autism n (%)</th>
<th>MHW n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing or bathing</td>
<td>256 (92.8)</td>
<td>266 (98.2)</td>
<td>157 (51.5)</td>
<td>6 (11.1)</td>
<td>2 (10.0)</td>
</tr>
<tr>
<td>Meals or eating</td>
<td>238 (86.2)</td>
<td>265 (97.4)</td>
<td>250 (81.7)</td>
<td>23 (42.6)</td>
<td>14 (73.7)</td>
</tr>
<tr>
<td>Taking medications</td>
<td>173 (62.7)</td>
<td>206 (76.0)</td>
<td>224 (73.0)</td>
<td>12 (22.2)</td>
<td>6 (31.6)</td>
</tr>
<tr>
<td>Toileting</td>
<td>125 (45.3)</td>
<td>171 (63.1)</td>
<td>86 (28.3)</td>
<td>1 (1.9)</td>
<td>1 (5.3)</td>
</tr>
</tbody>
</table>

v. Physical safety by program

No participant from any program reported that a staff person had hit them or hurt them in the past three months.

E. CHCP, PCA, and ABI Performance Benchmarks by Agency

The HCBS CAHPS provides DSS with a standard instrument to measure quality and performance among the Access Agencies which provide DSS waiver case management: AASCC, CCC, SWCAA, and WCAA. All four agencies provide case management services for the CHCP and PCA waivers; all but one provide ABI waiver case management.

Five HCBS CAHPS measures were chosen to examine case management services: case manager global rating, case manager recommendation, and three composites (case manager is helpful, choosing the services which matter to you, and personal safety and respect). These five items measure HCBS participant experiences which a case manager could directly impact. More positive scores on these measures indicates higher quality case management. DSS established mean scores required to meet the performance benchmarks in each of the five measures based on CHCP data from initial survey testing: 3.5 for each composite measure (range 1-4), 4.5 for case manager global rating (range 1-5), and 3.5 for case manager recommendation (range 1-4). In each of the following figures, the performance benchmark score is indicated by the bold black line.
i. CHCP programs

At the beginning of the fiscal year, DSS determines the number of surveys each Access Agency must complete in order to reach a representative sample size for each program which they provide case management. This number is based on the number of clients each agency serves in that program at the beginning of the fiscal year.

Table 8 shows the representative sample size for CHCP Categories 3 and 5 by Agency, the number of surveys completed, and the percentage of the representative sample which was completed. In FY 2021, all Access Agencies met or exceeded their required sample sizes for both CHCP Categories 3 and 5.

Table 8. CHCP Program: Completed Surveys and Representative Sample Size by Agency

<table>
<thead>
<tr>
<th>Program</th>
<th>Agency &amp; Region</th>
<th>Representative sample size</th>
<th>Completed surveys</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHCP Category 3</td>
<td>AASCC</td>
<td>66</td>
<td>69</td>
<td>(&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - E</td>
<td>33</td>
<td>34</td>
<td>(&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>142</td>
<td>147</td>
<td>(&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>38</td>
<td>42</td>
<td>(&gt;100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>68</td>
<td>69</td>
<td>(&gt;100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>27</td>
<td>27</td>
<td>(100.0)</td>
</tr>
<tr>
<td>CHCP Category 5</td>
<td>AASCC</td>
<td>32</td>
<td>32</td>
<td>(100.0)</td>
</tr>
<tr>
<td></td>
<td>CCC - E</td>
<td>8</td>
<td>8</td>
<td>(100.0)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>100</td>
<td>101</td>
<td>(&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>14</td>
<td>14</td>
<td>(100.0)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>11</td>
<td>11</td>
<td>(100.0)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>9</td>
<td>9</td>
<td>(100.0)</td>
</tr>
</tbody>
</table>

All four Access Agencies met or exceeded the benchmark 3.5 mean score for two of the three composites: “Choosing the services that matter to you” and “Personal safety and respect.” Three of the four agencies also met the benchmark score for the composite “Case manager is helpful” (Figure 7). One Access Agency’s score was slightly under this performance benchmark (3.48 vs. 3.5). All Access Agencies also met and exceeded the performance benchmark score for CHCP case manager global rating (mean score 4.5) as well as the CHCP case manager recommendation benchmark mean score (3.5) (Figures 8 and 9).
Figure 7. CHCP Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)

- **Care manager is helpful**
  - Agency M: 3.48
  - Agency G: 3.93
  - Agency Y: 3.85
  - Agency R: 3.90

- **Choosing the services that matter to you**
  - Agency M: 3.64
  - Agency G: 3.75
  - Agency Y: 3.88
  - Agency R: 3.97

- **Personal safety and respect**
  - Agency M: 3.97
  - Agency G: 3.97
  - Agency Y: 3.90
  - Agency R: 3.81
Figure 8. CHCP Performance Benchmarks by Agency: Care Manager Global Rating (Mean Score, Range 1-5)

Figure 9. CHCP Performance Benchmarks by Agency: Care Manager Recommendation (Mean Score, Range 1-4)
ii. PCA waiver

Similar to the CHCP programs, all Access Agencies met or exceeded the number of completed surveys required to meet their PCA waiver representative sample size (Table 9).

Table 9. PCA Waiver: Completed Surveys and Representative Sample Size by Agency

<table>
<thead>
<tr>
<th>Program</th>
<th>Agency &amp; Region</th>
<th>Representative sample size</th>
<th>Completed surveys N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCA</td>
<td>AASCC</td>
<td>73</td>
<td>73 (100.0)</td>
</tr>
<tr>
<td></td>
<td>CCC - E</td>
<td>33</td>
<td>33 (100.0)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>85</td>
<td>85 (100.0)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>30</td>
<td>31 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>41</td>
<td>47 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>17</td>
<td>17 (100.0)</td>
</tr>
</tbody>
</table>

Performance benchmark measures for the PCA waiver are shown in Figures 10, 11, and 12. Figure 10 shows that all four Access Agencies met or exceeded the benchmark mean score for all three PCA composite measures. All four Access Agencies also met and exceeded the benchmarks for PCA case manager global rating (Figure 11) and case manager recommendation (Figure 12).
Figure 10. PCA Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)

PCA Performance Benchmarks by Agency: Composite Measures
(Mean Score, Range 1-4)

- Care manager is helpful
  - Agency M: 3.93
  - Agency G: 3.95
  - Agency Y: 3.88
  - Agency R: 3.63

- Choosing the services that matter to you
  - Agency M: 3.91
  - Agency G: 3.69
  - Agency Y: 3.61
  - Agency R: 3.97

- Personal safety and respect
  - Agency M: 4.00
  - Agency G: 3.97
  - Agency Y: 3.87
  - Agency R: 4.00
Figure 11. PCA Performance Benchmarks by Agency: Care Manager Global Rating (Mean Score, Range 1-5)

PCA Performance Benchmarks by Agency: Care Manager Global Rating (Mean Score, Range 1-5)

Agency M: 4.70
Agency G: 4.64
Agency Y: 4.58
Agency R: 4.81

Figure 12. PCA Performance Benchmarks by Agency: Care Manager Recommendation (Mean Score, Range 1-4)

PCA Performance Benchmarks by Agency: Care Manager Recommendation (Mean Score, Range 1-4)

Agency M: 3.80
Agency G: 3.71
Agency Y: 3.56
Agency R: 3.81
iii. ABI waivers

Table 10 shows that each Access Agency also completed enough ABI I and ABI II surveys to meet or exceed the representative samples in both ABI waivers.

Table 10. ABI Waivers: Completed Surveys and Representative Sample Size by Agency

<table>
<thead>
<tr>
<th>Program</th>
<th>Agency &amp; Region</th>
<th>Representative sample size</th>
<th>Completed surveys N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABI 1</td>
<td>CCC - E</td>
<td>34</td>
<td>35 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>54</td>
<td>55 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>34</td>
<td>38 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>39</td>
<td>40 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>16</td>
<td>16 (100.0)</td>
</tr>
<tr>
<td>ABI 2</td>
<td>CCC - E</td>
<td>19</td>
<td>19 (100.0)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>50</td>
<td>52 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>21</td>
<td>22 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>47</td>
<td>50 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>8</td>
<td>8 (100.0)</td>
</tr>
</tbody>
</table>

Figures 13, 14, and 15 show the ABI performance benchmark measures. Three Access Agencies provide case management for the ABI waiver: CCC, SWCAA, and WCAAA. Similar to CHCP benchmarks, all three Access Agencies met or exceeded a 3.5 mean score for two of the three composites: “Choosing the services that matter to you” and “Personal safety and respect.” Two of the three agencies met the benchmark score of 3.5 for the third composite “Case manager is helpful;” one agency scored a 3.11. All three Access Agencies met or exceeded the 4.5 benchmark score for case manager global rating (Figure 14). Two of the three Access Agencies met or exceeded the 3.5 benchmark score for case manager recommendation, while the third Access Agency scored a 3.36 (Figure 15).
Figure 13. ABI Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)
Figure 14. ABI Performance Benchmarks by Agency: Care Manager Global Rating (Mean Score, Range 1-5)

Figure 15. ABI Performance Benchmarks by Agency: Case Manager Recommendation (Mean Score, Range 1-4)
F. Additional Findings by Program

i. Additional staff, case manager, and care plan measures by program

Participants with personal care, behavioral health, homemaking, or CSP services were asked, “Did [staff] encourage you to do things for yourself if you could?” As shown in Figure 16, the majority of participants from all waivers reported their staff encouraged them in this way.

[It’s] very happy with the caregivers. They are very patient and understanding with [consumer]. They try to encourage him as much as possible and take him out often into the community. ABI

Figure 16. Staff Encourage You to Do Things for Yourself - Percentage Positive Responses*

*“Personal assistance & behavioral health staff” combines all PCA, ILST, recovery assistant, life skills coach, and community mentor staff.

Although many participants in each program knew who their care manager was, there were definite differences among the programs (Figure 17). Autism, ABI, and PCA participants (95-99%) were the most knowledgeable of their care manager. The percentage of both ABI and PCA participants who know their care manager increased substantially this year, from 77% (PCA) and 87% (ABI) in 2021 to 95% (PCA) and 99% (ABI) in 2022. Meanwhile, just 57% of KBW respondents knew who their care manager was. One KBW respondent remarked that without care managers at DSS, she had no one to call. Commented another KBW respondent:
We were never made aware that the third-party vendor was a care manager, and that we could reach out to her regarding services. When we did express interest in feeding therapy, that was never followed up on. KBW

Figure 17. Knows Who Care Manager Is – Percentage Positive Responses

![Bar chart showing percentage of respondents who knows who their care manager is, with different colors for each group: CHCP, PCA, ABI, Autism, Katie Beckett, and MHW.]

Figure 18 shows how often respondents asked their care manager for help with changing services or with equipment. A greater percentage of ABI participants asked for assistance with changing services this year – 59% did so this year, compared to 26% last year. Comments indicated that some service change requests focused on getting a totally new HCBS provider, which was not always possible. ABI participants were more likely this year to ask their care manager for help with equipment – 59% did this year, compared to 24% last year. MHW respondents (67%) were once again the most likely to ask for help with getting or fixing equipment. There were very few comments across any of the programs describing what type of equipment was needed or acquired.

We are just working with [care manager] to get [consumer] a new cognitive behavior therapist so we can work to get [consumer] new assistive technology. ABI

Estoy satisfecha pero aunque la trabajadora no me pudo conseguir un andador mas grande, y lo necesito porque el que tengo es muy pequeno y incomodo para mi, soy una mujer grande [I am satisfied, although the worker could not get me a bigger walker, and I need it because the one I have is very small and uncomfortable for me, I am a big woman.] CHCP

Although not specifically asked about, a couple of comments mentioned about home modifications, such as the PCA participant who commented, “I wish the process for getting modifications could be streamlined.”
Participants were asked the open-ended question, “In the last 3 months, who would you have talked to if you wanted to change your care plan/service plan?” Figure 19 shows that the great majority of participants in all but the KBW program reported they knew who they would talk to about changing their care plan. When asked to name the person they would talk to, most participants reported they would talk to their case manager (Table 11). Although not shown on the table, 30% of KBW respondents would talk to their doctor or other health care provider to change their care plan. Again, not everyone knew whom they would talk to or that they had a case manager:

Estoy satisfecha con los servicios. No tengo una trabajadora asignada y por ende no sabría con quien comunicarme. [I am satisfied with the services. I do not have an assigned worker and therefore I would not know who to communicate with.] CHCP
Table 11. Who Would You Talk to if You Wanted to Change Your Care Plan?*

<table>
<thead>
<tr>
<th></th>
<th>CHCP N=541</th>
<th>PCA N=283</th>
<th>ABI N=333</th>
<th>Autism N=72</th>
<th>KBW N=54</th>
<th>MHW N=28</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Case manager or social worker</td>
<td>471 (87.1)</td>
<td>271 (95.8)</td>
<td>295 (88.6)</td>
<td>63 (87.5)</td>
<td>34 (63.0)</td>
<td>19 (67.9)</td>
</tr>
<tr>
<td>Other staff or home care agency/provider</td>
<td>47 (8.7)</td>
<td>4 (1.4)</td>
<td>35 (10.5)</td>
<td>21 (29.2)</td>
<td>5 (9.3)</td>
<td>2 (7.1)</td>
</tr>
<tr>
<td>Family/friends</td>
<td>118 (21.8)</td>
<td>30 (10.6)</td>
<td>58 (17.4)</td>
<td>3 (4.2)</td>
<td>3 (5.6)</td>
<td>3 (10.7)</td>
</tr>
<tr>
<td>Someone else</td>
<td>24 (4.4)</td>
<td>8 (2.8)</td>
<td>9 (2.7)</td>
<td>2 (2.8)</td>
<td>24 (44.4)</td>
<td>8 (28.6)</td>
</tr>
<tr>
<td>Do not know who to talk to</td>
<td>20 (3.7)</td>
<td>1 (0.4)</td>
<td>2 (0.6)</td>
<td>0 (0)</td>
<td>6 (11.1)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

*Multiple choice

ii. Living situation and social support

Similar to previous years, the majority of MHW participants (82%) lived alone or without other adults, as did 64% of CHCP, 63% of ABI, and 57% of PCA participants (Table 12). Participants in the MHW also had considerably fewer family or friends who live nearby compared to all other waivers. Looking at all programs, between 55% (Autism) to 77% (CHCP) of participants said they “usually” or “always” could see their nearby family when they want to. Overall, these percentages are greater than last year’s, which reflect the lessening of the pandemic.

Table 12. Living Situation and Social Support*

<table>
<thead>
<tr>
<th></th>
<th>CHCP %</th>
<th>PCA %</th>
<th>ABI %</th>
<th>Autism %</th>
<th>KBW %</th>
<th>MHW %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of adults living in household</td>
<td>N=559</td>
<td>N=286</td>
<td>N=325</td>
<td>N=72</td>
<td>N=61</td>
<td>N=28</td>
</tr>
<tr>
<td>1</td>
<td>64.0</td>
<td>57.0</td>
<td>62.8</td>
<td>22.2</td>
<td>8.2</td>
<td>82.1</td>
</tr>
<tr>
<td>2-3</td>
<td>34.7</td>
<td>41.3</td>
<td>33.5</td>
<td>54.2</td>
<td>77.1</td>
<td>17.9</td>
</tr>
<tr>
<td>4+</td>
<td>1.3</td>
<td>1.8</td>
<td>3.7</td>
<td>23.6</td>
<td>14.8</td>
<td>0</td>
</tr>
<tr>
<td>Lives with family</td>
<td>N=201</td>
<td>N=123</td>
<td>N=122</td>
<td>N=56</td>
<td>N=56</td>
<td>N=5</td>
</tr>
<tr>
<td>Yes</td>
<td>80.1</td>
<td>85.4</td>
<td>59.8</td>
<td>89.3</td>
<td>85.7</td>
<td>60.0</td>
</tr>
<tr>
<td>No</td>
<td>19.9</td>
<td>14.6</td>
<td>40.2</td>
<td>10.7</td>
<td>14.3</td>
<td>40.0</td>
</tr>
<tr>
<td>Lives with non-family</td>
<td>N=201</td>
<td>N=123</td>
<td>N=122</td>
<td>N=56</td>
<td>N=56</td>
<td>N=5</td>
</tr>
<tr>
<td>Yes</td>
<td>19.4</td>
<td>18.7</td>
<td>42.6</td>
<td>10.4</td>
<td>1.8</td>
<td>20.0</td>
</tr>
<tr>
<td>No</td>
<td>80.6</td>
<td>81.3</td>
<td>57.4</td>
<td>89.6</td>
<td>98.2</td>
<td>80.0</td>
</tr>
<tr>
<td>Family live nearby</td>
<td>N=561</td>
<td>N=286</td>
<td>N=333</td>
<td>N=71</td>
<td>N=61</td>
<td>N=29</td>
</tr>
<tr>
<td>Yes</td>
<td>80.4</td>
<td>78.7</td>
<td>79.0</td>
<td>74.7</td>
<td>85.3</td>
<td>44.8</td>
</tr>
<tr>
<td>No</td>
<td>19.6</td>
<td>21.3</td>
<td>21.0</td>
<td>25.4</td>
<td>14.8</td>
<td>55.2</td>
</tr>
<tr>
<td>Friend/s live nearby</td>
<td>N=554</td>
<td>N=286</td>
<td>N=331</td>
<td>N=70</td>
<td>N=61</td>
<td>N=29</td>
</tr>
<tr>
<td>Yes</td>
<td>65.2</td>
<td>75.2</td>
<td>59.5</td>
<td>47.1</td>
<td>77.0</td>
<td>31.0</td>
</tr>
<tr>
<td>No</td>
<td>34.8</td>
<td>24.8</td>
<td>40.5</td>
<td>52.9</td>
<td>23.0</td>
<td>69.0</td>
</tr>
</tbody>
</table>

*Percentages listed for each item are based on the total number of valid responses to that question (N).
iii. Physical and mental health

In two separate questions, respondents were asked to rate their physical health and mental or emotional health with response choices from Excellent to Poor. Once again PCA participants reported the worst physical health overall; 58% rated their health as fair or poor (Figure 20). As in previous years, CHCP and MHW participants also reported worse health than the remaining programs.

Figure 20. Self-Reported Physical Health*

![Self-Reported Physical Health](image)

*KBW not shown due to missing data

Unexpectedly, PCA participants reported the worst mental health this year, with 37% reporting fair to poor mental or emotional health (Figure 21). MHW also had some unexpected results showing better mental health, but the limited number of participants this year makes it too difficult to identify this as a trend. CHCP reported better mental health than last year – 31% of CHCP reported very good to excellent mental health, compared to 23% last year. One CHCP participant commented that he was going to be in his town’s Memorial Day parade driving his classic car. Meanwhile, the self-reported mental health of Autism respondents appeared to decline – just 26% reported very good to excellent mental health, compared to 44% last year. Once again, Autism consumers in particular mentioned that the COVID-19 pandemic prevented them from doing their regular community or job activities, which may be part of these participants’ reported decline in mental health.

Comments indicated the effect of services, transportation, accessibility, and living situation on community participation and mental health. One father of an ABI participant remarked that he wanted his son to get out into the community more often, even if his son’s ABI disability made this difficult at times. Two comments mentioned the role of pets, and a few mentioned the role of COVID in limiting their community activities.

*My son* has not been able to do as much as he would like in the community due to COVID.

*Autism*

I *would like a pet. ABI*

[Consumer is] living in an apartment that isn’t wheelchair friendly, so she hasn’t left home in many days since leg amputation. *MHW*
iv. Transportation service, home-delivered meals, and day program use

CHCP use of van or transportation service increased dramatically – 28% of CHCP participants reported using a van service this year, compared to 12% in FY 2021 (Table 13). PCA and ABI transportation service use increased, adding between 4-5% more users. Meanwhile, KBW consumer use of transportation service declined this year. Although most respondents (81%) said the van picked them up on time “usually” or “always,” comments indicated that there is a need for improved wheelchair accessible transportation and lack of nonmedical transportation limits community involvement.

"The transportation service I received is bad, never on time. I have to wait on average 1 hour each time I need the service." MHW

I'm upset because it's unfair that my PCA can’t take me to my doctors who are more than 10 miles away now. And they cannot take me and my animals to the vet anymore. CHCP

There needs to be more transportation availability in his area. [The ride service] will only stop at bus stops. There are no transportation services in [town name]. Autism

Someone needs to investigate and do something about the State Transportation for the elderly and disabled. In the last three months I've made eight reservations and the transportation has only shown up four times! The State is paying an awful lot of money for unreliable service. CHCP

Table 13. Use of Van or Transportation Service

<table>
<thead>
<tr>
<th></th>
<th>CHCP</th>
<th>PCA</th>
<th>ABI</th>
<th>Autism</th>
<th>KBW</th>
<th>MHW</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>N=562</td>
<td>N=286</td>
<td>N=333</td>
<td>N=72</td>
<td>N=61</td>
<td>N=29</td>
</tr>
<tr>
<td>Yes</td>
<td>27.8</td>
<td>43.4</td>
<td>19.2</td>
<td>5.6</td>
<td>8.2</td>
<td>41.4</td>
</tr>
<tr>
<td>No</td>
<td>72.2</td>
<td>56.6</td>
<td>80.8</td>
<td>94.4</td>
<td>91.8</td>
<td>58.6</td>
</tr>
</tbody>
</table>
A total of 209 participants rated their home delivered meal service, including 37% of CHCP participants (Figure 22). While most participants rated their meal service as “good” or better, substantial percentages in each program rated their home delivered meal service as either fair or poor, ranging from 22% MHW to 35% PCA participants. One consumer commented that despite multiple calls to the meal provider, she cannot get her meals as they continue to be delivered to the wrong door.

Figure 22. Experience with Home Delivered Meal Service

Another 108 participants rated their day program services, including 10% of CHCP and 12% of ABI participants. Similar to last year, ABI consumers were less satisfied with their day programs when compared to either CHCP or PCA consumers (Figure 23).
v. Personal safety and respect follow-up

Eleven participants (less than 1% of all participants) said that one of their staff had taken their money or things without permission: 5 ABI, 4 PCA, and 2 CHCP. Six of these participants said someone was working with them to fix the problem, most often either the HCBS provider agency or the care manager. Although the numbers are small, it is notable that only 1 of the 5 ABI participants who were stolen from was working with someone to fix the problem. Eleven of all participants (<1%) said that one of their staff had yelled or cursed at them: 7 CHCP, 2 PCA, and 1 each ABI and Autism. Nine of them said someone was working with them to fix the problem, most often either the HCBS provider or a family member, friend. One PCA consumer who had been stolen from had some specific recommendations for DSS:

* Make the background checks of aides better as many [clients] get robbed from aides that get hired. Offer some kind of alarm – surveillance – security systems. PCA*

vi. Emergency contact

Another open-ended question asked consumes who they would contact in case of an emergency (Table 14). Neither the survey nor the interviewers defined what “emergency” meant, and participants could identify more than one person. Responses show that family and friends play a large role in consumer emergency plans. With the exception of KBW, the majority of participants in each program would
contact their family or friends in case of an emergency, followed by 911. For KBW this was reversed – the majority would call 911. Over one-third (36%) of KBW respondents would call a member of their medical team, while a common “someone else” response for ABI respondents was conservator or lawyer.

Table 14. Who would you contact in case of an emergency?*

<table>
<thead>
<tr>
<th></th>
<th>CHCP N=563</th>
<th>PCA N=286</th>
<th>ABI N=335</th>
<th>Autism N=72</th>
<th>KBW N=61</th>
<th>MHW N=29</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Family/friend</td>
<td>65.5</td>
<td>83.9</td>
<td>71.0</td>
<td>93.1</td>
<td>59.0</td>
<td>69.0</td>
</tr>
<tr>
<td>Case manager</td>
<td>3.6</td>
<td>1.1</td>
<td>2.4</td>
<td>2.8</td>
<td>3.3</td>
<td>24.1</td>
</tr>
<tr>
<td>Home care agency or staff</td>
<td>3.2</td>
<td>4.2</td>
<td>11.3</td>
<td>5.6</td>
<td>0</td>
<td>6.9</td>
</tr>
<tr>
<td>PERS/Lifeline</td>
<td>32.5</td>
<td>6.3</td>
<td>2.7</td>
<td>0</td>
<td>0</td>
<td>6.9</td>
</tr>
<tr>
<td>911</td>
<td>48.1</td>
<td>39.9</td>
<td>18.8</td>
<td>18.1</td>
<td>73.8</td>
<td>31.0</td>
</tr>
<tr>
<td>Someone else</td>
<td>4.3</td>
<td>2.5</td>
<td>7.5</td>
<td>4.2</td>
<td>37.7</td>
<td>13.8</td>
</tr>
</tbody>
</table>

*Respondents could select more than one category. The percentages listed for each item are based on the total number of valid responses for that category (N).

vii. Self-directed employment of paid assistants

To measure use of consumer employer self-direction, consumers were asked if their caregivers come from an agency or if they or a family member find and hire their caregivers. Not surprisingly, 87% of PCA participants hired their own staff, compared to 8% of CHCP (Table 15). These self-directing consumers were then asked if they employed family members as staff. Although fewer CHCP participants self-directed their services, those who did were more likely to hire family members, followed by PCA participants. Consumers most frequently employed adult children, siblings, or parents as staff.

Table 15. Self-Direction

<table>
<thead>
<tr>
<th></th>
<th>CHCP N=563</th>
<th>PCA N=286</th>
<th>ABI N=335</th>
<th>Autism N=72</th>
<th>KBW N=61</th>
<th>MHW N=29</th>
</tr>
</thead>
<tbody>
<tr>
<td>How hire staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agency</td>
<td>92.3</td>
<td>13.2</td>
<td>78.2</td>
<td>75.4</td>
<td>29.2</td>
<td>95.7</td>
</tr>
<tr>
<td>Self-hire</td>
<td>7.7</td>
<td>86.8</td>
<td>21.8</td>
<td>24.6</td>
<td>70.8</td>
<td>4.3</td>
</tr>
<tr>
<td>Employs family members</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>46.3</td>
<td>40.3</td>
<td>24.2</td>
<td>18.8</td>
<td>35.3</td>
<td>0</td>
</tr>
<tr>
<td>No</td>
<td>53.7</td>
<td>59.7</td>
<td>75.8</td>
<td>81.3</td>
<td>64.7</td>
<td>100</td>
</tr>
</tbody>
</table>

G. Employment

All but CHCP and KBW participants answered the employment module, which covered work status, goals, and assistance finding a job.

i. Employment status

Figures 24 and 25 show employment status and goals. Similar to previous years, there was a striking difference with respect to rate of employment – none of MHW and less than 5% of PCA participants were working, compared to 23% of ABI and 39% of Autism participants. Both ABI and Autism waivers showed a large increase in participant employment over the past year (ABI 16% 2021, 23% 2022) (Autism 33% 2021, 39% 2022), which might reflect the lessening of the pandemic. Commented one ABI participant parent, “We are very happy with his services he gets, and he is very happy at his job working.” It is notable that 51% of unemployed Autism participants would like to work, compared to 18-27% of MHW, ABI, and PCA participants. One parent of an Autism waiver participant would like the
waiver participant to receive group supported employment, remarking that this would allow the waiver participant to work in a group and receive continual supervision and support.

For unemployed respondents who wanted to work, physical or mental health and disability related concerns were the most frequently reported reason for not working, most notably for PCA, MHW, and ABI participants (Table 16). Almost one-third (32%) of the 22 unemployed Autism participants who wanted to work said they for looking for but could not find employment. Overall COVID was less of a barrier to working this year across all programs, as it was only mentioned by 5 respondents who wanted to work and 4 who did not. One parent respondent commented on how staffing can impact working at a job for pay:

*The job [consumer] got help finding lasted three days. [Consumer] had no on the job support. He received help from [his] community mentor, but I was not aware the community mentor would not be able to go to the job with [him]. The community mentor did drive [him] to the workplace.*

Between 26% (PCA) to 64% (ABI) of participants who did not want a job reported that nothing was holding them back from working. Physical or mental health and disability was also frequently mentioned by participants who did not want to work, especially by PCA respondents.

Table 16. Most Common Reasons for Not Working*

<table>
<thead>
<tr>
<th>Participants who would like to work</th>
<th>PCA (N=72)</th>
<th>ABI (N=57)</th>
<th>MHW (N=5)</th>
<th>Autism (N=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits</td>
<td>2 (2.8%)</td>
<td>1 (1.8%)</td>
<td>2 (40.0%)</td>
<td>1 (4.6%)</td>
</tr>
<tr>
<td>Physical or mental health/disability</td>
<td>62 (86.1%)</td>
<td>26 (45.6%)</td>
<td>3 (60.0%)</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>Training/education</td>
<td>2 (2.8%)</td>
<td>3 (5.3%)</td>
<td>0 (0%)</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>Transportation</td>
<td>2 (2.8%)</td>
<td>4 (7.0%)</td>
<td>0 (0%)</td>
<td>1 (4.5%)</td>
</tr>
<tr>
<td>Looking for but cannot find work</td>
<td>7 (9.7%)</td>
<td>6 (10.5%)</td>
<td>0 (0%)</td>
<td>7 (31.8%)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (5.6%)</td>
<td>12 (21.1%)</td>
<td>0 (0%)</td>
<td>11 (50.0%)</td>
</tr>
<tr>
<td>Nothing is holding me back</td>
<td>0 (0%)</td>
<td>6 (10.5%)</td>
<td>0 (0%)</td>
<td>2 (9.1%)</td>
</tr>
</tbody>
</table>
Overall, a small number of unemployed participants had asked for assistance with finding a job (Figure 26). Unemployed Autism participants were much more likely to ask for employment assistance than participants in other programs. The vast majority of unemployed participants knew that help finding a job was available, although most of them did not seek it out (Figure 27). Some consumers commented on the effect of the COVID-19 pandemic on receiving job services, or that they had pursued job assistance in the past, but found it was not as helpful as they thought it would be.

### ii. ABI and Autism Employment Experiences

The ABI, Autism, and MHW waivers provide various employment specific services for employed participants. When asked who helped them find their job, both ABI and Autism participants most often found their jobs using waiver/vocational staff or family/friends.

*We [family members] helped [consumer] find the job he has now. BRS has not been able to find [consumer] a job before he finds one on his own, and they are not able to send a job coach after he finds his own employment. [Consumer] has not really needed on the job support because the employer has stepped in and has helped him. Autism*
**ABI Job Coach**

Fifty-one percent (n=38) of employed ABI participants said someone was paid to help them with their job; 35 answered job coach questions. All of these participants said that their job coaches encouraged them to do things for themselves; the great majority reported positive experiences with their job support staff (Figure 28). As reported earlier in Figures 3 and 5, ABI participants as a whole gave their job coaches very good ratings (mean score 4.60, out of 1-5) and recommendations (mean score 3.57, out of 1-4).

**Autism Job Coach**

Thirty-nine percent (n=28) of Autism respondents were employed. Nine of them (32%) reported someone was paid to help them with their job; 8 answered job coach questions. Seven of the eight (participants said their job coach “usually” or “always” gives them all the help they need. All 8 participants said their job coach “always” treats them with courtesy and respect, explains things in a way that is easy to understand, and listens carefully. All eight participants also said their job coach encouraged them to do things for themselves if they could. As reported in Figures 3 and 5, these Autism participants gave their job coaches high ratings (mean 4.5, range 1-5) and recommendations (mean 3.71, range 1-4).

**Mental Health Waiver Participant Questions**

MHW participants were asked to what extent their MHW services have affected their lives in five key areas (Figure 29). As in the previous years, participants gave positive responses – 79% or more either agreed or strongly agreed with each statement. In particular, all MHW respondents agreed or strongly agreed that they are in better control of their lives because of their MHW services, and 92% felt their MHW services helped them stay in the community.
I'm really blessed with the caregivers I have. I have strong, smart, beautiful women in my circle, and that helps me stay sober and safe. ... I'm grateful for the services. They really keep me going. It's made a difference in my life. The stability of having an apartment really is huge. MHW

Figure 29. Mental Health Waiver Participant Experience

I. CHCP, PCA, and ABI Additional Data by Agency

This section presents CHCP, PCA, and ABI key results by each Access Agency. Figures show the percentage of participants who gave the most positive answer for the composite measures, staff global ratings, and staff recommendations. Note that the Access Agencies provide care management only. The scores for the global ratings or recommendations of other types of staff, as well as for most of the composites, may not reflect the agency providing the case management. Other things to consider include the area or town where the participant lives, the number of homecare agencies and staff, transportation choices and cost, and the number of PCAs for self-directed consumers.

i. CHCP programs

Many of the CHCP composite scores showed wide variation among the agencies without any real identifiable trends (Figure 30). Percentage of CHCP participants who gave the highest scores for the composite case manager is helpful showed the greatest agency variation, ranging from 79% (AGENCY M) to 95% (AGENCY G). Scores for choosing services which matter to you also varied widely, from 81% (AGENCY G) to 94% (AGENCY R). All agencies had low scores for planning your time and activities and relatively low scores for medical transportation, indicating areas for program improvement.

Global ratings for CHCP personal assistants, homemakers, and case managers showed striking differences among agencies (Figure 31). For example, the percentage of care managers who received a 9 or 10 varied from 75% (AGENCY Y) to 97% (AGENCY R).

The percentage of CHCP participants from each agency who “definitely” recommended their PCA or homemaker/companion staff also varied among agencies (Figure 32). Less variation was seen this year
for care manager recommendation. Between 82% (AGENCY Y) to 87% (AGENCY G) of CHCP participants would “definitely” recommend their care managers.

Figure 30. CHCP Composite Measures by Agency: Percentage with Highest Score

<table>
<thead>
<tr>
<th>Measure</th>
<th>Agency M</th>
<th>Agency G</th>
<th>Agency Y</th>
<th>Agency R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff are reliable and helpful</td>
<td>87.14</td>
<td>91.08</td>
<td>94.44</td>
<td>93.10</td>
</tr>
<tr>
<td>Staff listen and communicate well</td>
<td>88.52</td>
<td>94.81</td>
<td>93.94</td>
<td>94.44</td>
</tr>
<tr>
<td>Case manager is helpful</td>
<td>84.72</td>
<td>93.10</td>
<td>93.07</td>
<td>93.10</td>
</tr>
<tr>
<td>Choosing the services that matter to you</td>
<td>80.76</td>
<td>94.44</td>
<td>99.01</td>
<td>95.00</td>
</tr>
<tr>
<td>Transportation to medical appointments</td>
<td>75.14</td>
<td>70.51</td>
<td>80.56</td>
<td>84.72</td>
</tr>
<tr>
<td>Personal safety and respect</td>
<td>65.35</td>
<td>64.10</td>
<td>58.33</td>
<td>64.10</td>
</tr>
<tr>
<td>Planning your time and activities</td>
<td>63.29</td>
<td>60.40</td>
<td>64.10</td>
<td>60.40</td>
</tr>
</tbody>
</table>

CHCP Composite Measures by Agency: Percentage with Highest Score
Figure 31. CHCP Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”

![CHCP Global Rating by Agency: Percentage Who Rate Their Staff a "9" or "10"](image)

Figure 32. CHCP Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff

![CHCP Recommendations by Agency: Percentage Who "Definitely" Recommend Their Staff](image)
ii. PCA waiver

Between 94% to 97% of PCA participants from any agency gave the highest scores to the composite case manager is helpful. Scores for 5 of the remaining composites showed wide variation across agencies. For example, participants giving the highest score to the composite choosing the services that matter to you ranged from 76% (Agency G) to 100% (Agency R). Even the low scores for the composite planning your time and activities varied from 53% (Agency R) to 64% (Agency Y). Global ratings and recommendations for PCA waiver staff and case managers also showed agency variation (Figures 34 and 35). Percentage of PCA participants who would definitely recommend their case manager ranged from 72% (Agency Y) to 84% (Agency R).

Figure 33. PCA Composite Measures by Agency: Percentage with Highest Score
Figure 34. PCA Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”*

*Only 11 consumers across all agencies had homemaking staff who did not provide personal care

Figure 35. PCA Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff*

*Only 11 consumers across all agencies had homemaking staff who did not provide personal care
iii. **ABI waivers**

All ABI composite scores, staff global ratings, and staff recommendations showed wide variation across the 3 care management agencies without any identifiable trends (Figures 36, 37, and 38). The percentage of ABI participants who gave the highest scores to the composite care manager is helpful ranged from 77% (AGENCY H) to 100% (AGENCY A), while medical transportation scores ranged from 73% (AGENCY Q) to 96% (AGENCY H). Compared to the other waivers, choice of services was not rated as highly by ABI participants; scores ranged from 69% (AGENCY Q) to 83% (AGENCY H). The percentage of ABI participants who rated their case managers a 9 or 10 ranged from 60% (AGENCY A) to 78% (AGENCY Q), while between 43% (AGENCY A) and 91% (AGENCY H) of ABI participants would definitely recommend their case manager.

Figure 36. ABI Composite Measures by Agency: Percentage with Highest Score
Figure 37. ABI Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”*

Figure 38. ABI Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff*
IV. Conclusions

This is the fifth year Connecticut has used the HCBS CAHPS survey to inform quality measurement in seven of its Medicaid programs (CHCP Categories 3 and 5, PCA, ABI I and II, Autism, and KBW), and the third year in the MHW program. As a standardized, cross-disability survey, the HCBS CAHPS provides Connecticut with the ability to compare participant experiences in the same domains across different waivers. The HCBS CAHPS survey is also part of quality and performance assessment for the Access Agencies contracted to provide CHCP, PCA, and ABI case management services. This report presents results from surveys conducted in FY 2022, from July 1, 2021 to June 30, 2022.

A. Survey Completion Rates

As in the past 4 years, in FY 2022 each Access Agency met or exceeded their respective representative samples for each of the programs they case manage.

As in previous years, the other 3 waiver programs did not reach their representative sample sizes – Autism completed 75% (n=72), KBW 35% (n=61), and MHW 13% (n=29) of their respective sample sizes. KBW and MHW completed surveys fell noticeably over the past two years – In FY 2020, KBW met 72% and MHW met 35% of their respective representative sample size. This report still presents the results for these three programs to show program trends.

Reaching the statistically derived representative sample, or close to this number, allows for a more accurate assessment of participants’ experiences across waivers. It is likely that KBW and Autism will need a different survey strategy to improve their survey numbers. As the training and technical assistance provider, the UConn Health Center on Aging (UConn) is available to support these programs, for example, by developing a personalized recruitment strategy for each of those programs.

In an effort to increase the number of completed MHW surveys, DMHAS revised its Annual HCBS CAHPS survey and process with the assistance of UConn in June, 2022. Only a subset of HCBS CAHPS questions was included in the new MHW survey, and self-administration using paper or online was added. This new process and survey will be described in more detail in the FY 2023 report. The 8 surveys completed in June, 2022 with the new survey will be analyzed with next year’s data.

B. Key Results by Program

Composite measures

The composite item scores varied among the composites and the programs. Choosing the services that matter to you showed the greatest variation this year, with CHCP and PCA reporting much higher scores than the other four programs. Care manager is helpful also exhibited much variation among programs, with PCA, ABI, and CHCP reporting much higher scores than Autism, MHW, or KBW. All programs reported low scores for planning your time and activities and high scores for personal safety and respect. Overall, KBW, Autism, and MHW participants reported the lowest scores in most composite items compared to the other programs.

• Planning your time and activities

The items in the composite “Planning your time and activities” assess the participant’s ability to choose and control their social interactions, community engagement, and daily activities (see Appendix A). As in previous years, consumers in all waiver programs gave this composite the lowest score compared to the other composites. While COVID-19 likely disrupted some participants’ social and community activities, this does not explain this composite’s historically low scores. Meaningful community involvement, social engagement, and choice and control are all important elements of successful community living, and these areas represent an opportunity for improvement across all programs.
• **Choosing the services that matter to you**

Choosing the services that matter to you asks if the consumer’s care/service plan includes the things that are important to the consumer and if their staff know what is on their care plan. These items speak to choice, control, and person-centered care. Similar to last year, CHCP and PCA had higher scores in this composite compared to other programs. Developing methods to elicit from each individual what is important to them, incorporating these into their care plan, and effectively communicating this to their staff, would improve services for all waiver participants.

• **Transportation to medical appointments**

When compared by percentage given the highest score, transportation to medical appointments was also given lower scores by most programs. Commented one MHW participant, “VEYO bus service is not good! It left me stranded for 2 hours once and went to the wrong location 3 times. I have trouble getting in and out of vans, and they’re not very helpful on that front.”

**Case Manager Items**

Once again CHCP participants gave their case managers the highest ratings and recommendations among all the programs. Eighty-four percent of CHCP participants gave their case manager the highest rating, followed by PCA (77%) and MHW participants (76%). While 86% of CHCP and 85% of MHW participants would definitely recommend their care manager, only 70% of Autism and 68% of ABI participants would do so. Remarks indicated that consumers highly valued care managers who responded to their calls in a timely manner, as well as care managers who listened empathetically and made an effort to understand and not dismiss their concerns.

Comments also indicated that there is still room for improvement, especially with respect to responsiveness, communication, and staffing changes. Communication issues often happened when care managers changed, as the consumer did not always know who the new care manager was or how to reach them. Several Spanish speaking consumers expressed this in particular.

> Hasta el momento todo bien. No se quien es mi trabajador - ahora cambian mucho. No se mme han llamado. [Up to now, everything is fine. I don’t know who my social worker is – now they change a lot. I don’t know. They’ve called me.] CHCP

> Tengo mas de un mes sin personal que me ayude, llame a la agencia, y aun no tengo quein me ayude no se quien es mi trabajador no tengo una asignada. [I have had no staff to help me for more than a month. I called the agency, and I still don’t have anyone to help me. I don’t know who my social worker is. I don’t have one assigned.] CHCP

Autism, ABI, PCA, and CHCP participants (88-99%) were the most knowledgeable of who their case manager was, compared to just 57% of KBW participants. Most participants in each program said they would contact their care manager if they wanted to change their service or care plan. Comments indicated that KBW parents in particular could use increased case manager support. KBW care management is currently provided by various home care agencies which confused some respondents and left others feeling they were not getting the care management support they needed. Commented one KBW respondent:

> We don’t feel supported. We worry if something happens to us, we have nothing to do [for] [consumer]. ... It’s terrible that DSS no longer has case managers. I have no one to call. KBW

In addition to providing a timely and empathetic response, Access Agencies and waiver program staff could improve communication and consumer outreach whenever there is a change in care managers, especially for non-English speaking consumers. KBW consumers in particular would benefit from DSS effectively communicating the specific case management and other services provided by the waiver, such as the parent who commented:
We needed care for [consumer] while I was hospitalized, but it was refused. I would like to speak with someone about specifics of what can be covered under Katie Becket. KBW

Additional care manager comments included:

I gave the case manager an 8 rating only because [case manager] is dismissive of my concerns sometimes and minimizes my concerns. Also, sometimes [case manager] is not as responsive as [case manager] should be when working with the Autism Spectrum Disorder population. Autism

He reports being very pleased with his Care Manager and how quickly she responds to his calls. PCA

[Consumer] reports that she is very pleased with [case manager] for helping her find a good companion/homemaker. CHCP

I emailed [case manager] twice ... regarding equipment and mileage and have not heard a response or had the issue resolved. There were disconnects regarding the budget. Autism

There are services that were requested as part of his individual plan of care but has yet to receive it. The family has asked for transportation assistance and still no help. The family has not received any help to resolve this issue from DSS. Autism

Staff Ratings and Recommendations

CHCP, MHW, Autism, and PCA participants were much more likely than ABI participants to highly rate and recommend their personal/behavioral staff. For example, 90% of CHCP participants would definitely recommend their personal assistance staff, compared to just 61% of ABI participants. CHCP respondents in particular also expressed that they appreciated the program and the services it provides.

Consumers from various programs expressed that sometimes they had to change agencies or ask for different staff in order to find agencies and staff they were happy with. Positive comments about various types of HCBS staff included:

I can't say enough about how wonderful [my homemaker-companion] is, and I'm grateful for her services. CHCP

"[I have a] really good and solid team right now. Had some terrible times with the services a few months ago, but they were very responsive to concerns, and the whole team is excellent. MHW

The aides are wonderful. They've helped make a difference with my mother. CHCP

My aide lights up my life! CHCP

She enjoys the program overall experience, but she has needed to change her [service provider] in the past due to being unhappy with specific providers only. MHW

- Staffing issues

Although most consumers had good experiences with their services, comments also pointed to more HCBS systemic issues such as staff shortages and staff turnover. Participants mentioned difficulties with consistency, reliability, and quality of staff, not enough available HCBS staff, difficulties finding staff on weekends, and a need for disability-specific training. Staff turnover and having different staff come in and out was mentioned often. Having reliable, consistent staff can be very important for individuals who cannot express themselves, who have medical concerns, or who need specialized care. It can take time for a staff person to learn about the individual and how to best assist them. Commented one family member of a CHCP participant, “We have a routine [which] we like. [Consumer] is unable to communicate well due to her dementia and often needs reminders to eat.” A couple of respondents reported a need for Spanish speaking staff. More than one consumer suggested that PCAs or ILSTs get paid more. Remarks reflecting staffing challenges as well as suggestions for improvements include:
It’s very hard to find aides and PCAs and to keep them. CHCP

Having caregivers that speak English and Spanish can be hard to find. PCA

Quiere una sola persona que la ayude no una hoy y otra al otro día. necesita ayuda con eso. de lo demás satisfecha. [She wants only one person to help her, not one today and a different one tomorrow. She needs help with that. She is satisfied with everything else.] CHCP

It’s hard to find people to work with [consumer] that are appropriate and available. Autism

It’s very difficult to hire PCAs for the amount of money that Allied can offer them. Several people are finding this same issue. Workers don’t want to take the job because they can get more pay elsewhere. It’s making it very hard to hire staff when we can’t pay them as much as other places. PCA

The company that sends [the aides] needs to do more about training and observe their employees. Make sure they can do the job that they are hired to do. CHCP

Both self-directing consumers and those using agency-based services expressed the need for a better trained and qualified workforce, including working with diverse disabilities. Stated one CHCP participant, “I’m in the state of flux and have no steady caregivers just [name]. I find with different disabilities people aren’t taught how to care for a blind person. We all need assistance.” Another CHCP participant remarked, “I would like [caregivers with] more advanced cooking skills and a better understanding of persons with mental health and physical disabilities. And the elderly in general.” Increasing workforce training opportunities for agency-based and self-employed HCBS staff would also help those working in this field to expand their skill set or gain specialized skills.

In addition, some participants from all waivers expressed a need for additional services or hours not provided in their care plan, such as an “extra day a week” or more help with driving or other household tasks. Comments indicated the real physical or psychological effects of not having enough or the right paid supports, such as the CHCP respondent who stated, “It would help to have someone who can drive when I am housebound.” Another CHCP respondent said he needed some hours on the weekend so he “could get around.” Remarks like these indicate a need for the state to focus on workforce development – building a quality, multi-lingual, and well-staffed workforce – as well as focusing on improving person-centered care at the state and HCBS agency level.

• Self-Direction

Not surprisingly, 87% of PCA participants hired their own caregivers, followed by 71% of KBW, while nearly all CHCP and MHW participants, as well as the majority of ABI and Autism participants, used an agency to provide staff. Although only 8% of CHCP participants hired their own staff, self-directing CHCP participants were the most likely to employ family members, followed by PCA. One consumer commented on a benefit of hiring family members remarking, “We have family that are his caregivers because he has no short-term memory, and our family understands his needs.” Unfortunately, as indicated in the previous section, finding the right person is not always easy even when hiring your own staff. Benefits of self-direction include the ability to choose who works with you, determine the hours and tasks to be provided, manage staff directly, and hire family members. In addition, self-directing one’s paid caregivers can build self-efficacy and self-empowerment. However, not everyone was aware that they could possibly hire their own staff.

The PCAs are unfit and cannot safely help my child. I’d like to be able to hire my own caregiver. The state should coordinate with nursing or therapy schools to use students as caregivers for these risky children. KBW

Parents should be allowed to become paid aides, mentors, or coaches under the Autism waiver. Because siblings are allowed, parents should be allowed too. Autism
Once again self-directed consumers remarked on their difficulties working with Allied, including struggles getting their staff paid on time or getting reimbursed for covered items, or reaching someone at Allied to address questions or concerns. This challenge to self-direction has been expressed every year and indicates the need for the state to address concerns about Allied or find a new DSS fiscal intermediary for self-directed consumers. With any fiscal intermediary, it is suggested that measurable, quality metrics be written in the contract such as responsiveness, consumer experience, and the fiscal intermediary’s internal quality assurance practices.

Make it easier for caregivers to get paid. PCA

The only thing I would want is Allied has not been paying for holidays. ABI

[Staff name] gets paid through Allied, and it is awful to get through to Allied due to the system of payment. It is easier to email then it is to call. I wish someone else has to do the payment. Autism

C. CHCP, PCA, and ABI Performance Benchmarks

Five HCBS CAHPS composites or items which a case manager could directly impact were chosen to examine CHCP, PCA, and ABI Access Agency case management performance: case manager global rating, case manager recommendation, and three composites – case manager is helpful, choosing services that matter to you, and personal safety and respect. Access Agencies must also meet their representative sample of surveys for that waiver (Tables 8, 9, 10). Performance Benchmarks for all three waivers were determined using the CHCP data from initial survey testing:

- Case manager is helpful composite: Mean score 3.5 (range 1-4)
- Choosing the service which matter to you composite: Mean score 3.5 (range 1-4)
- Personal safety and respect composite: Mean score 3.5 (range 1-4)
- Case manager global rating: Mean score 4.5 (range 1-5)
- Case manager recommendation: Mean score 3.5 (range 1-4)

CHCP programs

All four Access Agencies met or exceeded the CHCP performance benchmark for two of the three composites (choosing services that matter to you and personal safety and respect). Three of the four agencies met the benchmark score for the composite case manager is helpful. Agency R’s score was slightly under this performance benchmark (3.48 vs. 3.5). All Access Agencies also met and exceeded the performance benchmarks for CHCP case manager global rating and recommendation. The CHCP performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.48 to 3.93
- Choosing the service which matter to you composite: 3.64 to 3.88
- Personal safety and respect composite: 3.81 to 3.97
- Case manager global rating: 4.62 to 4.93
- Case manager recommendation: 3.77 to 3.86

PCA waiver

All four Access Agencies met or exceeded all 5 PCA performance benchmarks. The PCA performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.63 to 3.95
- Choosing the service which matter to you composite: 3.61 to 3.97
- Personal safety and respect composite: 3.87 to 4.0
- Case manager global rating: 4.58 to 4.81
- Case manager recommendation: 3.56 to 3.81
ABI waiver

All three access agencies met the ABI performance benchmarks for two composite measures – choosing the services that matter to you and personal safety and respect. Two of the three agencies met the ABI performance benchmark for the third composite, case manager is helpful. Agency Q scored a 3.11 for this composite (benchmark is 3.5). All three Access Agencies met or exceeded the performance benchmark for case manager global rating. Two of the three met the performance benchmark for case manager recommendation. Agency A received a score of 3.36 for this measure (benchmark is 3.5). The ABI performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.11 to 4.00
- Choosing the service which matter to you composite: 3.56 to 3.67
- Personal safety and respect composite: 3.58 to 3.96
- Case manager global rating: 4.51 to 4.67
- Case manager recommendation: 3.36 to 3.91

D. Impact of COVID-19

Some comments specifically referred to COVID-19 and its effect on their community activities, services, and employment. Some participants intentionally stayed in their homes and limited their time out in the community to prevent themselves from getting COVID-19. Participants reported that COVID-19 made it harder to have services as not as many caregivers, either agency-based or self-hiring, were available. These comments indicated that COVID-19 can be especially difficult for those who live alone or rely on others for assistance, such as those receiving HCBS. COVID-19 was also a factor in some consumers’ employment status and goals. Similar to last year, Autism consumers in particular mentioned that COVID prevented them from doing activities out in the community including working.

I was left without an RA for 10 days when [the RA] got COVID. They never got a replacement.
MHW

I did not want anyone in the home that was not vaccinated due to the coronavirus. There were health concerns with [consumer]. The agencies were not able to tell whether or not employees were vaccinated. It is not the Autism waiver program’s problem; it was the pandemic problem.
Autism

[Consumer] has not had services since the pandemic. [He] had [provider] who backed out of services due to COVID. We do not want any services in the home at this time due to COVID.
Autism

E. Mental and Emotional Health

Similar to previous years, mental health is an area of concern for all 5 waiver programs – between 25% (Autism) to 37% (PCA) of respondents in each waiver program reported fair or poor mental or emotional health. Still, compared to last year, larger percentages of CHCP and MHW respondents reported very good to excellent mental health; meanwhile self-reported mental health of Autism respondents declined from last year. It is possible that the continued effect of the COVID-19 pandemic expressed by Autism respondents played a role in the decline in self-reported mental health. Comments indicated the effect of services, transportation, accessibility, and living situation on community participation and mental health.

The majority of MHW, CHCP, ABI, and PCA participants lived alone or without other adults. Waiver sponsored volunteer programs across the state could be one way to increase social connections and at the same time expand employment skills. Another way to increase social engagement might be to strengthen organized peer supports, drawing upon experienced self-advocates and other stakeholders.
to help facilitate. One recommendation is for DSS to reach out directly to waiver participants and ask what would be helpful for them to increase their community engagement and socialization.

F. Employment

Autism respondents were the most likely to be employed, especially compared to MHW and PCA participants. In addition, unemployed Autism respondents were much more likely to want to work compared to unemployed respondents in the other waivers. Similar to previous years, unemployed respondents who wanted to work most often reported that physical or mental health issues and disability related concerns prevented them from working. Still, both ABI and Autism waivers showed a large increase in participant employment over the past year (ABI 16% 2021, 23% 2022) (Autism 33% 2021, 39% 2022), which might reflect the lessening of the pandemic effects. Working for pay can increase both social and financial well-being. The state could explore ways to encourage participant employment, such as learning from the experiences of other waiver participants who are successfully employed.

G. Mental Health Waiver Participant Experience

MHW participants were asked to what extent their MHW services have affected their lives in five key areas. As in the previous years, participants gave positive responses – 79% or more either agreed or strongly agreed with each statement. In particular, all MHW respondents agreed or strongly agreed that they are in better control of their lives because of their MHW services, and 92% felt their MHW services helped them stay in the community. Once again, the area given the lowest rating was the MHW effect on the item, “I do better in social situations.” Working with MHW participants on their social skills and social connections represents a potential opportunity for improvement.

H. CHCP, PCA, ABI Additional Data by Agency

CHCP, PCA, and ABI composites, staff ratings, and staff recommendations were shown by care management agency using the percentage of participants who gave the highest or most positive score. Except for care manager related items, the ratings and recommendations of other staff and composite scores may be more reflective of the area or town where the participant lives, and not the agency providing the case management.

Scores for the CHCP case manager composite and care manager global ratings showed much interagency variation. For example, the percentage of CHCP care managers who received a 9 or 10 varied from 75% to 97%. Meanwhile CHCP care manager recommendation scores were grouped more tightly: 82-87% of CHCP participants from any Access Agency would definitely recommend their case managers.

Between 94% to 97% of PCA participants from any agency gave the highest scores to the composite case manager is helpful. Meanwhile, case manager global ratings and recommendations showed greater interagency variation. For example, the percentage of PCA participants who would definitely recommend their case manager ranged from 72% to 84%.

All ABI composite scores, staff global ratings, and staff recommendations showed wide variation across the 3 care management agencies. For example, between 77-100% of respondents from different agencies gave the highest score for the composite case manager is helpful, and the percentage of respondents who would definitely recommend their case manager ranged from 43-91%.

All agencies had low scores for planning your time and activities and relatively low scores for medical transportation, indicating areas for program improvement.

I. Final thoughts

Quality assurance staff from the Access Agencies, DSS, and DMHAS are currently completing HCBS CAHPS surveys for the CHCP, PCA, ABI, Autism, Katie Beckett, and Mental Health waivers. UConn Health
Center on Aging continues to provide technical assistance, including survey site administration, training, and other support. In final comments, respondents also expressed appreciation for the waiver services and commented on the impact of the waiver programs on their lives.

I appreciate the services I’ve been getting all these years. CHCP

Our family is thankful for this program. The services and supports have been very helpful to our family. KBW

I’m grateful for the program because I could not stay in my home without it. CHCP

I am very happy with everything and all the help I get. CHCP

I am doing a lot better and keep working on my independence. ABI

I am very lucky to have the help and son I have, and to have the staff I have helping me. CHCP

I appreciate all the help I get and wish I can repay it in some way. CHCP
V. Appendices

Appendix A. Composite Measures Items

Appendix B. CAHPS® Home and Community-Based Services Survey (CHCP, PCA, ABI, Autism, KBW) – Connecticut version 2019

Appendix C. CAHPS® Home and Community-Based Services Survey (Mental Health Waiver) – Connecticut version 2019
### Appendix A. Composite Measures Items

<table>
<thead>
<tr>
<th><strong>Staff are reliable and helpful</strong></th>
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<tbody>
<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} come to work on time?</td>
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<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} work as long as they were supposed to?</td>
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<tr>
<td>In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that {personal assistance/behavioral health staff} could not come that day?</td>
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<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} make sure you had enough personal privacy when you dressed, took a shower, or bathed?</td>
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<tr>
<td>In the last 3 months, how often did {homemakers} come to work on time?</td>
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<tr>
<td>In the last 3 months, how often did {homemakers} work as long as they were supposed to?</td>
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<tr>
<td>In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that {homemakers} could not come that day?</td>
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<tr>
<th><strong>Staff listen and communicate well</strong></th>
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<tbody>
<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} treat you with courtesy and respect?</td>
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<tr>
<td>In the last 3 months, how often were the explanations {personal assistance/behavioral health staff} gave you hard to understand because of an accent or the way {personal assistance/behavioral health staff} spoke English?</td>
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<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} treat you the way you wanted them to?</td>
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<td>In the last 3 months, how often did {personal assistance/behavioral health staff} explain things in a way that was easy to understand?</td>
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<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} listen carefully to you?</td>
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<tr>
<td>In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?</td>
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<tr>
<td>In the last 3 months, how often did {homemakers} treat you with courtesy and respect?</td>
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<tr>
<td>In the last 3 months, how often were the explanations {homemakers} gave you hard to understand because of an accent or the way the {homemakers} spoke English?</td>
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<td>In the last 3 months, how often did {homemakers} treat you the way you wanted them to?</td>
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<thead>
<tr>
<th><strong>Case manager is helpful</strong></th>
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<tr>
<td>In the last 3 months, could you contact this {case manager} when you needed to?</td>
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<tr>
<td>In the last 3 months, did this {case manager} work with you when you asked for help with getting or fixing equipment?</td>
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<tr>
<td>In the last 3 months, did this {case manager} work with you when you asked for help with getting other changes to your services?</td>
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</table>
### Choosing services that matter to you

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

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

### Transportation to medical appointments

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

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

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

### Personal safety and respect

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

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

In the last 3 months, did any [staff] yell, swear, or curse at you?

### Planning your time and activities

In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby?

In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby?

In the last 3 months, when you wanted to, how often could you do things in the community that you like?

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

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

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

* Question added by Connecticut
Appendix B. CAHPS® Home and Community-Based Services Survey – Connecticut version

Waivers-Programs:

– Acquired Brain Injury Waivers
– Autism Waiver
– Connecticut Home Care Program
– Katie Beckett Waiver
– Personal Care Assistance Waiver
CAHPS® Home- and Community-Based Services Survey

Version: 1.0
Population: Adult
Language: English

Connecticut version – 2019

Waivers-Programs
- Acquired Brain Injury Waivers
- Autism Waiver
- Community First Choice
- Connecticut Home Care Program
- Katie Beckett Waiver
- Personal care Assistance Waiver
Instructions for Vendor

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

- Text in *italics and in braces* will be provided by the HCBS program’s administrative data. However, if the interviewee provides another term, that term should be used in place of the program-specific term wherever indicated. For example, some interviewees may refer to their case manager by another title, which should be used instead throughout the survey.

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

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

- All questions include a “REFUSED” response option. In this case, “refused” means the respondent did not provide any answer to the question.
- All questions include a “DON’T KNOW” response option. This is used when the respondent indicates that he or she does not know the answer and cannot provide a response to the question.
- All questions include an “UNCLEAR” response option. This should be used when a respondent answers, but the interviewer cannot clarify the meaning of the response even after minor probing or the response is completely unrelated to the question, (e.g., the response to “In the last 3 months, how often did your homemakers listen carefully to what you say?” is “I like to sit by Mary”).
- Some responses have skip patterns, which are expressed as “→ GO TO Q#.” The interviewer should be advanced to the next appropriate item to ask the respondent.
- Not all respondents receive all home and community-based services asked about in this instrument. Items Q4 through Q12 help to confirm which services a respondent receives. The table after it summarizes the logic of which items should be used.
- Survey users may add questions to this survey before the “About You” section. A separate supplemental employment module can be added.

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

- Use program-specific terms. Where appropriate, add in the program-specific terms for staff (e.g., [program-specific term for these types of staff]) but allow the interviewer to modify the term based on the respondent’s choice of the word. It will be necessary to obtain information for program-specific terms. State administrative data should include the following information:
  - Agency name(s)
  - Titles of staff who provide care
COGNITIVE SCREENING QUESTIONS

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

1. Does someone come into your home to help you?
   - 1 YES
   - 2 NO → END SURVEY
   - -1 DON’T KNOW → END SURVEY
   - -2 REFUSED → END SURVEY
   - -3 UNCLEAR RESPONSE → END SURVEY

2. How do they help you?

   [EXAMPLES OF CORRECT RESPONSES INCLUDE]
   - HELPS ME GET READY EVERY DAY
   - CLEANS MY HOME
   - WORKS WITH ME AT MY JOB
   - HELPS ME DO THINGS
   - DRIVES ME AROUND
   - -1 DON’T KNOW → END SURVEY
   - -2 REFUSED → END SURVEY
   - -3 UNCLEAR RESPONSE → END SURVEY

3. What do you call them?

   [EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]
   - MY WORKER
   - MY ASSISTANT
   - NAMES OF STAFF (JO, DAWN, ETC.)
   - -1 DON’T KNOW → END SURVEY
   - -2 REFUSED → END SURVEY
   - -3 UNCLEAR RESPONSE → END SURVEY
[Interviewer - Screening Failed]

☐ Continue Anyhow → GO TO Q4
☐ End Survey → Thank you for your time. Those are all the questions we have.

IDENTIFICATION QUESTIONS

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

4. In the last 3 months, did you get {program specific term for personal assistance} at home?

☐ 1 YES
☐ 2 NO → GO TO Q6
☐ -1 DON’T KNOW → GO TO Q6
☐ -2 REFUSED → GO TO Q6
☐ -3 UNCLEAR RESPONSE → GO TO Q6

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

________________________________________________________________________

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

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

☐ 1 YES
☐ 2 NO → GO TO Q8
☐ -1 DON’T KNOW → GO TO Q8
☐ -2 REFUSED → GO TO Q8
☐ -3 UNCLEAR RESPONSE → GO TO Q8

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

________________________________________________________________________

[ADD RESPONSE WHEREVER IT SAYS “personal assistance/behavioral health staff.” IF Q4 ALSO = YES, LIST BOTH TITLES]

8. In the last 3 months, did you get {program specific term for homemaker services} at
9. What do you call the person or people who gave you \{program specific term for homemaker services\}? For example, do you call them \{program-specific term for homemaker\}, aides, homemakers, chore workers, or something else?

________________________________________________________________________

[ADD RESPONSE WHEREVER IT SAYS “homemaker”]

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

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

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

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

________________________________________________________________________

[ADD RESPONSE WHEREVER IT SAYS “case manager”]

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

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

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

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

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

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

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

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

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

1 □ Mostly yes or
2 □ Mostly no?
-1 □ DON’T KNOW
15. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that {personal assistance/behavioral health staff} could not come that day?

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

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

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

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

1 □ YES → GO TO Q19
2 □ NO
-1 □ DON’T KNOW → GO TO Q19
-2 □ REFUSED → GO TO Q19
-3 □ UNCLEAR RESPONSE → GO TO Q19

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

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

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

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

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

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

1. YES
2. NO → GO TO Q23
-1. DON’T KNOW → GO TO Q23
-2. REFUSED → GO TO Q23
-3. UNCLEAR RESPONSE → GO TO Q23

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

1. YES → GO TO Q23
2. NO
-1. DON’T KNOW → GO TO Q23
-2. REFUSED → GO TO Q23
-3. UNCLEAR RESPONSE → GO TO Q23

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

1. YES
2. NO
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE
23. Sometimes people need help taking their medicines, such as reminders to take a medicine, help pouring them, or setting up their pills. In the last 3 months, did you need help from {personal assistance/behavioral health staff} to take your medicines?

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

24. In the last 3 months, did you always take your medicine when you were supposed to?

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

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

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

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

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

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

1. YES
2. NO
-1. DON'T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE
HOW WELL PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF COMMUNICATE WITH AND TREAT YOU

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

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

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

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

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

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

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

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

   1 □ Mostly yes or
   2 □ Mostly no?
   -1 □ DON’T KNOW
30. In the last 3 months, how often did {personal assistance/behavioral health staff} treat you the way you wanted them to? Would you say . . .

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

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

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

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

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

ALTERNATE VERSION: In the last 3 months, did {personal assistance/behavioral health staff} explain things in a way that was easy to understand? Would you say . . .

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

32. In the last 3 months, how often did {personal assistance/behavioral health staff} listen carefully to you? Would you say . . .
Never,
Sometimes,
Usually, or
Always?

DON'T KNOW
REFUSED
UNCLEAR RESPONSE

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

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

33. In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?

YES
NO
DON'T KNOW
REFUSED
UNCLEAR RESPONSE

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

YES
NO
DON'T KNOW
REFUSED
UNCLEAR RESPONSE

35. Using any number from 0 to 10, where 0 is the worst help from {personal assistance/behavioral health staff} possible and 10 is the best help from {personal assistance/behavioral health staff} possible, what number would you use to rate the help you get from {personal assistance/behavioral health staff}? __0 TO 10

DON'T KNOW
REFUSED
36. Would you recommend the \{personal assistance/behavioral health staff\} who help you to your family and friends if they needed help with everyday activities? Would you say you would recommend the \{personal assistance/behavioral health staff\} . . .

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

**GETTING NEEDED SERVICES FROM HOMEMAKERS**

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

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

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

**ALTERNATE VERSION:** In the last 3 months, did \{homemakers\} come to work on time? Would you say . . .
38. In the last 3 months, how often did {hometakers} work as long as they were supposed to? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?

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

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

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

38a. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that {personal assistance/behavioral health staff} could not come that day?

1. YES
2. NO

-1. DON'T KNOW
-2. REFUSED
3. UNCLEAR RESPONSE OR NOT APPLICABLE

38b. In the last 3 months, how often did {personal assistance/behavioral health staff} explain things in a way that was easy to understand? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
ALTERNATE VERSION: In the last 3 months, did {personal assistance/behavioral health staff} explain things in a way that was easy to understand? Would you say . . .

1. Mostly yes or
2. Mostly no?
3. DON’T KNOW
4. REFUSED
5. UNCLEAR RESPONSE OR NOT APPLICABLE

38c. In the last 3 months, did {personal assistance/behavioral health staff} encourage you to do things for yourself if you could?

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

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

1. YES → GO TO Q41
2. NO
3. DON’T KNOW → GO TO Q41
4. REFUSED → GO TO Q41
5. UNCLEAR RESPONSE → GO TO Q41

40. In the last 3 months, was this because there were no {homemakers} to help you? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]

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

HOW WELL HOMEMAKERS COMMUNICATE WITH AND TREAT YOU

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

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

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

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

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

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

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

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

43. In the last 3 months, how often did \{homemakers\} treat you the way you wanted them to? Would you say . . .
1. Never,
2. Sometimes,
3. Usually, or
4. Always?

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

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

1 Mostly yes or
2 Mostly no?

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

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

1. Never,
2. Sometimes,
3. Usually, or
4. Always?

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

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

1 Mostly yes or
2 Mostly no?

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

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

1 YES
2 NO

-1 DON’T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE
46. Using any number from 0 to 10, where 0 is the worst help from \{homemakers\} possible and 10 is the best help from \{homemakers\} possible, what number would you use to rate the help you get from \{homemakers\}?

0 TO 10

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

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

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

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

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

YOUR CASE MANAGER

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

48. Do you know who your \{case manager\} at \{case management agency\} is?

1 YES
2 NO → GO TO Q55a
-1 DON’T KNOW → GO TO Q55a
-2 REFUSED → GO TO Q55a
49. In the last 3 months, could you contact this {case manager} when you needed to?

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

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

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

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

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

52. In the last 3 months, did you ask this {case manager} for help in getting any changes to your services, such as more help from {personal assistance/behavioral health staff and/or homemakers if applicable}, or for help with getting places or finding a job?

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

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

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

\_0 TO 10

\_DON’T KNOW
\_REFUSED
\_UNCLEAR RESPONSE

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

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

\_DON’T KNOW
\_REFUSED
\_UNCLEAR RESPONSE

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

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

\_DON’T KNOW
\_REFUSED
\_UNCLEAR RESPONSE

HOME-DELIVERED MEALS, ADULT DAY PROGRAM

The next questions ask about home-delivered meals and adult day programs.

55a. In the last 3 months, how would you rate your overall experience with Meals on Wheels or a home-delivered meal service? Would you say . . .
1. Excellent,
2. Very good,
3. Good,
4. Fair, or
5. Poor?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE OR DID NOT USE A HOME-DELIVERED MEALS SERVICE

55b. In the last 3 months, how would you rate your adult day program? Would you say . . .
1. Excellent,
2. Very good,
3. Good,
4. Fair, or
5. Poor?
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE OR DID NOT USE AN ADULT DAY PROGRAM

CHOOSING YOUR SERVICES

56. In the last 3 months, did your [program-specific term for “service plan”] include . . .
1. None of the things that are important to you,
2. Some of the things that are important to you,
3. Most of the things that are important to you, or
4. All of the things that are important to you?
-1. DON’T KNOW → GO TO Q57a
-2. REFUSED → GO TO Q57a
-3. UNCLEAR RESPONSE → GO TO Q57a

57. In the last 3 months, did you feel [personal assistance/behavioral health staff] knew what’s on your [program-specific term for “service plan”], including the things that are important to you?
1. YES
2. NO
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE
57a. I would like to ask you about how you find and hire your paid caregivers or aides. Does a homecare agency provide them? Or, do you or a family member find and hire your aides, and do you sign and send in their timesheets?

Probes (Use only if respondent is unclear or does not know):
- How do you hire and pay your aides or caregivers?
- Do you work with Allied, Sunset Shores, or Advanced Behavioral Health/ABH to pay your aides?

1 □ AGENCY → GO TO Q58
2 □ SELF-HIRE
3 □ BOTH AGENCY AND SELF-HIRE
-1 □ DON’T KNOW → GO TO Q58
-2 □ REFUSED → GO TO Q58
-3 □ UNCLEAR RESPONSE → GO TO Q58
-4 □ NOT APPLICABLE → GO TO Q58

57b. Are any of your family members paid to help you?

1 □ YES, Please specify relationship/s: _______________________
2 □ NO
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE

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

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

TRANSPORTATION

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

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

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

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

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

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

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

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

1 [ ] Never,
2 [ ] Sometimes,
3 [ ] Usually, or
4 [ ] Always?
-1 [ ] DON’T KNOW
-2 [ ] REFUSED
-3 [ ] UNCLEAR RESPONSE
ALTERNATE VERSION: In the last 3 months, did this ride arrive on time to pick you up? Would you say . . .

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

PERSONAL SAFETY

The next few questions ask about your personal safety.

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

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

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

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

1. YES
2. NO

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

The next few questions ask if anyone paid to help you treated you badly in the last 3 months. This includes {personal assistance/behavioral health staff, homemakers, or your case manager}. We are asking everyone the next questions—not just you. I want to remind you that, although your answers are confidential, I have a responsibility to tell my supervisor if I see or hear something that makes me think you are being hurt or are in danger.

65. In the last 3 months, did any {personal assistance/behavioral health staff, homemakers, or your case managers} take your money or your things without asking you first?
66. In the last 3 months, did someone work with you to fix this problem?

<table>
<thead>
<tr>
<th>Response</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 YES</td>
<td></td>
</tr>
<tr>
<td>2 NO → GO TO Q68</td>
<td></td>
</tr>
<tr>
<td>-1 DON'T KNOW → GO TO Q68</td>
<td></td>
</tr>
<tr>
<td>-2 REFUSED → GO TO Q68</td>
<td></td>
</tr>
<tr>
<td>-3 UNCLEAR RESPONSE → GO TO Q68</td>
<td></td>
</tr>
</tbody>
</table>

67. In the last 3 months, who has been working with you to fix this problem? Anyone else?  
[Interviewer marks all that apply]

<table>
<thead>
<tr>
<th>Response</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 FAMILY MEMBER OR FRIEND</td>
<td></td>
</tr>
<tr>
<td>2 CASE MANAGER</td>
<td></td>
</tr>
<tr>
<td>3 AGENCY</td>
<td></td>
</tr>
<tr>
<td>4 SOMEONE ELSE, PLEASE SPECIFY ____________________</td>
<td></td>
</tr>
<tr>
<td>-1 DON'T KNOW</td>
<td></td>
</tr>
<tr>
<td>-2 REFUSED</td>
<td></td>
</tr>
<tr>
<td>-3 UNCLEAR RESPONSE</td>
<td></td>
</tr>
</tbody>
</table>

68. In the last 3 months, did any \( \textit{staff} \) yell, swear, or curse at you?

<table>
<thead>
<tr>
<th>Response</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 YES</td>
<td></td>
</tr>
<tr>
<td>2 NO → GO TO Q71</td>
<td></td>
</tr>
<tr>
<td>-1 DON'T KNOW → GO TO Q71</td>
<td></td>
</tr>
<tr>
<td>-2 REFUSED → GO TO Q71</td>
<td></td>
</tr>
<tr>
<td>-3 UNCLEAR RESPONSE → GO TO Q71</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Response</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 YES</td>
<td></td>
</tr>
<tr>
<td>2 NO → GO TO Q71</td>
<td></td>
</tr>
<tr>
<td>-1 DON'T KNOW → GO TO Q71</td>
<td></td>
</tr>
<tr>
<td>-2 REFUSED → GO TO Q71</td>
<td></td>
</tr>
<tr>
<td>-3 UNCLEAR RESPONSE → GO TO Q71</td>
<td></td>
</tr>
</tbody>
</table>

70. In the last 3 months, who has been working with you to fix this problem? Anyone else?  
[Interviewer marks all that apply]

<table>
<thead>
<tr>
<th>Response</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 FAMILY MEMBER OR FRIEND</td>
<td></td>
</tr>
</tbody>
</table>
71. In the last 3 months, did any {staff} hit you or hurt you?

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

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

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

73. In the last 3 months, who has been working with you to fix this problem? Anyone else?

[Interviewer marks all that apply]

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

COMMUNITY INCLUSION AND EMPOWERMENT

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

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

1. YES
2. NO → GO TO Q76
-1. DON’T KNOW → GO TO Q76
75. In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?

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

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these family members who live nearby? Would you say . . .

1. Mostly yes or
2. Mostly no?

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

76. Do you have any friends who live nearby?

1. YES
2. NO → GO TO Q78

-1. DON’T KNOW → GO TO Q78
-2. REFUSED → GO TO Q78
-3. UNCLEAR RESPONSE → GO TO Q78

77. In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?

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

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these friends who live nearby? Would you say . . .

1. Mostly yes or
2. Mostly no?
78. In the last 3 months, when you wanted to, how often could you do things in the community that you like? Would you say . . .

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

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

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

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

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

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

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

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

1. YES
2. NO
ABI, Autism, and PCA: Ask Employment Module

CHCP & Katie Beckett: Skip to ABOUT YOU

EMPLOYMENT MODULE (ABI, Autism & PCA)

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

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

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

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

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

1. BENEFITS → GO TO EM5
2. HEALTH CONCERNS → GO TO EM5
3. DON’T KNOW ABOUT JOB RESOURCES → GO TO EM5
4. ADVICE FROM OTHERS → GO TO EM5
5. TRAINING/EDUCATION NEED → GO TO EM5
6. LOOKING FOR AND CAN’T FIND WORK → GO TO EM5
7. ISSUES WITH PREVIOUS EMPLOYMENT → GO TO EM5
8. TRANSPORTATION → GO TO EM5
9. CHILD CARE → GO TO EM5
10. OTHER (____________________________) → GO TO EM5
11. NOTHING IS HOLDING ME BACK → GO TO EM5
   -1. DON’T KNOW → GO TO EM5
   -2. REFUSED → GO TO EM5
EM4. Sometimes people would like to work for pay, but feel that something is holding them back. In the last 3 months, was this true for you? If so, what has been holding you back from wanting to work? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

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

EM5. In the last 3 months, did you ask for help in getting a job for pay?

1. **YES** → GO TO EM7
2. **NO**
   -1. **DON’T KNOW**
   -2. **REFUSED**
   -3. **UNCLEAR RESPONSE**

EM6. In the last 3 months, did you know you could get help to find a job for pay?

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

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

1. **YES** → GO TO EM8
2. **NO** → GO TO THE ABOUT YOU SECTION
   -1. **DON’T KNOW** → GO TO THE ABOUT YOU SECTION
   -2. **REFUSED** → GO TO THE ABOUT YOU SECTION
   -3. **UNCLEAR RESPONSE** → GO TO THE ABOUT YOU SECTION
EM8. In the last 3 months, did you get all the help you need to find a job?

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

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

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

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

1. YES
2. NO
-1. DON’T KNOW
-2. REFUSED
-3. 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. In the last 3 months, was someone paid to help you with the job you have now?

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

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

____________________________________________________________________
[USE THIS TERM WHEREEVER IT SAYS \{job coach\} BELOW.]

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

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

EM14. In the last 3 months, has your \{job coach\} been with you all the time that you were working?

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

EM15. In the last 3 months, how often did your \{job coach\} give you all the help you needed? Would you say . . .

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

ALTERNATE VERSION: In the last 3 months, did your \{job coach\} give you all the help you needed? Would you say . . .

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

EM16. In the last 3 months, how often did your \{job coach\} treat you with courtesy and respect? Would you say . . .

1 □ Never,
2 □ Sometimes,
3 □ Usually, or
4 □ Always?
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE
ALTERNATE VERSION: In the last 3 months, did your {job coach} treat you with courtesy and respect? Would you say . . .
1☐ Mostly yes or
2☐ Mostly no?
3☐ DON’T KNOW
4☐ REFUSED
5☐ UNCLEAR RESPONSE

EM17. In the last 3 months, how often did your {job coach} explain things in a way that was easy to understand? Would you say . . .
1☐ Never, 
2☐ Sometimes, 
3☐ Usually, or 
4☐ Always? 
5☐ DON’T KNOW
6☐ REFUSED 
7☐ UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did your {job coach} explain things in a way that was easy to understand? Would you say . . .
1☐ Mostly yes or 
2☐ Mostly no? 
3☐ DON’T KNOW 
4☐ REFUSED 
5☐ UNCLEAR RESPONSE

EM18. In the last 3 months, how often did your {job coach} listen carefully to you? Would you say . . .
1☐ Never, 
2☐ Sometimes, 
3☐ Usually, or 
4☐ Always? 
5☐ DON’T KNOW
6☐ REFUSED 
7☐ UNCLEAR RESPONSE

ALTERNATE VERSION: In the last 3 months, did your {job coach} listen carefully to you? Would you say . . .
1☐ Mostly yes or 
2☐ Mostly no? 
3☐ DON’T KNOW 
4☐ REFUSED 
5☐ UNCLEAR RESPONSE

EM19. In the last 3 months, did your {job coach} encourage you to do things for yourself if you could?
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 your {job coach}?

☐ 0 TO 10
☐ DON’T KNOW
☐ REFUSED
☐ UNCLEAR RESPONSE

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.

82. In general, how would you rate your overall health? Would you say . . .

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

83. In general, how would you rate your overall mental or emotional health? Would you say . . .  

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

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

ALTERNATE VERSION: In what year were you born?  
_________________________ (YEAR)  
-1 □ DON’T KNOW  
-2 □ REFUSED  
-3 □ UNCLEAR RESPONSE  

85. [IF NECESSARY, ASK, AND VERIFY IF OVER THE PHONE] Are you male or female?  
1 □ MALE  
2 □ FEMALE  
-1 □ DON’T KNOW  
-2 □ REFUSED
86. What is the highest grade or level of school that you have completed?

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

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

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

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

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

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

1 White → GO TO Q92
2 Black or African-American → GO TO Q92
3 Asian → GO TO Q90
4 Native Hawaiian or other Pacific Islander → GO TO Q91
5 American Indian or Alaska Native → GO TO Q92
6 OTHER → GO TO Q92
-1 DON’T KNOW → GO TO Q92
-2 REFUSED → GO TO Q92
-3 UNCLEAR RESPONSE → GO TO Q92
90. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

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

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

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

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

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

93. What is the language you speak at home?

1. Spanish,
2. Some other language → Which one? __________________________
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

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

1. 1 [JUST THE RESPONDENT] → END SURVEY
2. 2 TO 3
3. 4 OR MORE
95. [IF NECESSARY, ASK] Do you live with any family members?

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

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

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

97. Is there anything else you would like to add?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

END OF QUESTIONS

Thank you for completing this interview with me. If you wish to contact your care manager, the number for his/her agency is:

AASCC: 203-752-3040

CCC Eastern region: 860-885-2960

CCC North Central region: 860-257-1503

CCC Northwest region: 203-596-4800

SWCAA: 203-333-9288

WCAAA: 203-465-1000

Autism waiver: 860-424-5865

Katie Beckett waiver: 860-424-5582
Interviewer: Collect name and phone numbers for participant, proxy, or person who assisted. Information will be entered below.

INTERVIEWER QUESTIONS

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

0) Who completed the interview? (Check only one)
   □ Participant by his/herself
      Participant telephone numbers: ______________________________ → Go to F1
   □ Participant with assistance from another person.
      If Assisted
      Contact information for person who assisted with interview:
      First name: ________________
      Last name: ________________
      Telephone numbers: ___________________ → Go to F1
   □ A proxy - Someone else completed the survey for the participant
      If Proxy:
      Proxy Contact Information:
      Proxy First name: ________________
      Proxy Last name: ________________
      Proxy Telephone numbers: ___________________ → Go to P1

P1. Relationship to participant – the proxy is the...
   □ Spouse/partner
   □ Adult child
   □ Parent
   □ Attorney or legal representative
   □ Other: ________________

P2. Is the proxy also a legal representative?
   □ Yes → GO TO END OF SURVEY
   □ No

P3. Is the proxy paid to provide support to the participant?
   □ Yes → GO TO END OF SURVEY
   □ No → GO TO END OF SURVEY

F1. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?
F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

1 □ YES
2 □ NO → GO TO END OF SURVEY

F3. WHO WAS PRESENT DURING THE INTERVIEW? (MARK ALL THAT APPLY.)

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

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

1 □ YES
2 □ NO → GO TO END OF SURVEY

F5. HOW DID THAT PERSON HELP? [MARK ALL THAT APPLY.]

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

F6. WHO HELPED THE RESPONDENT? (MARK ALL THAT APPLY.)

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

F7. Relationship to participant:

□ Spouse/partner
□ Adult child
□ Parent
□ Attorney or legal representative
□ Paid staff person
□ Other: ____________________

F8. Is the person who assisted also a legal representative?

□ Yes → GO TO END OF SURVEY
□ No → GO TO END OF SURVEY
Interview done by:

☐ Telephone
☐ In-person

Participant Information:

First name: _____________________
Middle name: ___________________
Last name: _____________________

Medicaid ID: ________________
Date of Birth (MM/DD/YYYY): ________________
Town of residence: ________________
ZIP code of residence: ________________

Does the participant have a Conservator of Person or a Legal Guardian?

☐ Yes
☐ No
☐ Do not know

Program:

☐ CHCP
☐ ABI
☐ PCA
☐ Autism
☐ Katie Beckett
☐ CFC Only
☐ DMHAS – Mental Health Waiver

If CHCP: CHCP Category:

☐ Category 1 (State funded)
☐ Category 2 (State funded)
☐ Category 3 (Waiver)
☐ Category 4 (Under 65)
☐ Category 5 (1915i)
☐ Do not know

If ABI waiver:

☐ ABI I
☐ ABI II
☐ Do not know

Community First Choice?
☐ Yes
☐ No
☐ Do not know

Access Agency:
☐ AASCC
☐ CCC
☐ DSS
☐ SWCAA
☐ WCAAA
☐ DMHAS

If CCC client: CCC Region:
☐ Eastern (Region 3)
☐ North Central (Region 4)
☐ Northwest (Region 5)
☐ Do not know

If SWCAA client: SWCAA Region:
☐ Bridgeport Proper
☐ Greater Bridgeport
☐ Norwalk
☐ Stamford
☐ Do not know

Date Interview Complete: ______________

Interviewer: ______________
Appendix C. CAHPS® Home and Community-Based Services Survey – Connecticut version 2019: Mental Health Waiver
CAHPS® Home- and Community-Based Services Survey

Version: 1.0
Population: Adult
Language: English

Connecticut version – 2019

Mental Health Waiver

File name: CAHPSHcbs01192017SurvEng508
Last updated: January 19, 2017
COGNITIVE SCREENING QUESTIONS

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

1. Does someone come into your home to help you?
   1. [ ] YES
   2. [ ] NO \( \rightarrow \) GO TO [Interviewer - Screening Failed]
   -1. [ ] DON’T KNOW \( \rightarrow \) GO TO [Interviewer - Screening Failed]
   -2. [ ] REFUSED \( \rightarrow \) GO TO [Interviewer - Screening Failed]
   -3. [ ] UNCLEAR RESPONSE \( \rightarrow \) GO TO [Interviewer - Screening Failed]

2. How do they help you?

   [EXAMPLES OF CORRECT RESPONSES INCLUDE]
   - HELPS ME GET READY EVERY DAY
   - CLEANS MY HOME
   - WORKS WITH ME AT MY JOB
   - HELPS ME DO THINGS
   - DRIVES ME AROUND
   -1. [ ] DON’T KNOW \( \rightarrow \) GO TO [Interviewer - Screening Failed]
   -2. [ ] REFUSED \( \rightarrow \) GO TO [Interviewer - Screening Failed]
   -3. [ ] UNCLEAR RESPONSE \( \rightarrow \) GO TO [Interviewer - Screening Failed]

3. What do you call them?

   [EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]
   - MY WORKER
   - MY ASSISTANT
   - NAMES OF STAFF (JO, DAWN, ETC.)
   -1. [ ] DON’T KNOW \( \rightarrow \) GO TO [Interviewer - Screening Failed]
   -2. [ ] REFUSED \( \rightarrow \) GO TO [Interviewer - Screening Failed]
   -3. [ ] UNCLEAR RESPONSE \( \rightarrow \) GO TO [Interviewer - Screening Failed]

[Interviewer - Screening Failed]
   1. [ ] Continue anyhow
   2. [ ] End Survey \( \rightarrow \) GO TO [END SURVEY SECTION]
IDENTIFICATION QUESTIONS

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

4. In the last 3 months, did you get recovery assistant services at home?
   - 1 □ YES
   - 2 □ NO → GO TO Q8
   - 1 □ DON’T KNOW → GO TO Q8
   - 2 □ REFUSED → GO TO Q8
   - 3 □ UNCLEAR RESPONSE → GO TO Q8

5. What do you call the person or people who gave recovery assistant services? For example, do you call them recovery assistants, RAs, staff, personal care attendants, PCAs, workers, or something else?
   __________________________________________________________________________
   [USE THIS TERM WHEREVER IT SAYS {recovery assistant staff} BELOW.]

8. In the last 3 months, did you get CSP or case management services at home?
   - 1 □ YES
   - 2 □ NO → GO TO Q11
   - 1 □ DON’T KNOW → GO TO Q11
   - 2 □ REFUSED → GO TO Q11
   - 3 □ UNCLEAR RESPONSE → GO TO Q11

9. What do you call the person or people who give you CSP or case management services? For example, do you call them CSPs, case managers, or something else?
   __________________________________________________________________________
   [USE THIS TERM WHEREVER IT SAYS {CSPs} BELOW.]

11. In the last 3 months, did you get help from Mental Health Waiver clinician services at the Department of Mental Health and Addiction Services, DMHAS, or ABH to help make sure that you have all the services you need?
    - 1 □ YES
    - 2 □ NO
    - 1 □ DON’T KNOW
    - 2 □ REFUSED
    - 3 □ UNCLEAR RESPONSE

12. What do you call the person who gives you Mental Health Waiver clinician services? For example, do you call the person a Mental Health Waiver clinician, case manager, care manager, service coordinator, supports coordinator, social worker, or something else?
GETTING NEEDED SERVICES FROM RECOVERY ASSISTANTS -
QUESTIONS 13-36 ARE ASKED IF QUESTION 4=YES. OTHERWISE SKIP THESE QUESTIONS.

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

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

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

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

14. In the last 3 months, how often did {recovery assistant staff} work as long as they were supposed to? Would you say . . .

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

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

1. Mostly yes or
2. Mostly no?
-1. DON’T KNOW
15. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that \textit{(recovery assistant staff)} could not come that day?

- 1 \[ \text{YES} \]
- 2 \[ \text{NO} \]
- 3 \[ \text{DON'T KNOW} \]
- 4 \[ \text{REFUSED} \]
- 5 \[ \text{UNCLEAR RESPONSE} \]

16. In the last 3 months, did you need help from \textit{(recovery assistant staff)} to get dressed, take a shower, or bathe?

- 1 \[ \text{YES} \]
- 2 \[ \text{NO} \] → GO TO Q20
- 3 \[ \text{DON'T KNOW} \] → GO TO Q20
- 4 \[ \text{REFUSED} \] → GO TO Q20
- 5 \[ \text{UNCLEAR RESPONSE} \] → GO TO Q20

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

- 1 \[ \text{YES} \] → GO TO Q19
- 2 \[ \text{NO} \]
- 3 \[ \text{DON'T KNOW} \] → GO TO Q19
- 4 \[ \text{REFUSED} \] → GO TO Q19
- 5 \[ \text{UNCLEAR RESPONSE} \] → GO TO Q19

18. In the last 3 months, was this because there were no \textit{(recovery assistant staff)} to help you?

- 1 \[ \text{YES} \]
- 2 \[ \text{NO} \]
- 3 \[ \text{DON'T KNOW} \]
- 4 \[ \text{REFUSED} \]
- 5 \[ \text{UNCLEAR RESPONSE} \]

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

- 1 \[ \text{Never,} \]
- 2 \[ \text{Sometimes,} \]
- 3 \[ \text{Usually, or} \]
- 4 \[ \text{Always?} \]
- 5 \[ \text{DON'T KNOW} \]
- 6 \[ \text{REFUSED} \]
- 7 \[ \text{UNCLEAR RESPONSE} \]
ALTERNATE VERSION: In the last 3 months, did {recovery assistant staff} make sure you had enough personal privacy when you dressed, took a shower, or bathed? Would you say . . .

1 [ ] Mostly yes or
2 [ ] Mostly no?
3 [ ] DON’T KNOW
4 [ ] REFUSED
5 [ ] UNCLEAR RESPONSE

20. In the last 3 months, did you need help from {recovery assistant staff} with your meals, such as help making or cooking meals or help eating?

1 [ ] YES
2 [ ] NO → GO TO Q23
3 [ ] DON’T KNOW → GO TO Q23
4 [ ] REFUSED → GO TO Q23
5 [ ] UNCLEAR RESPONSE → GO TO Q23

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

1 [ ] YES → GO TO Q23
2 [ ] NO
3 [ ] DON’T KNOW → GO TO Q23
4 [ ] REFUSED → GO TO Q23
5 [ ] UNCLEAR RESPONSE → GO TO Q23

22. In the last 3 months, was this because there were no {recovery assistant staff} to help you?

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

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

1 [ ] YES
2 [ ] NO → GO TO Q26
3 [ ] DON’T KNOW → GO TO Q26
4 [ ] REFUSED → GO TO Q26
5 [ ] UNCLEAR RESPONSE → GO TO Q26

24. In the last 3 months, did you always take your medicine when you were supposed to?

1 [ ] YES → GO TO Q26
25. In the last 3 months, was this because there were no *recovery assistant staff* to help you?

- □ YES
- □ NO
- □ DON’T KNOW → GO TO Q26
- □ REFUSED → GO TO Q26
- □ UNCLEAR RESPONSE

26. Help with toileting includes helping someone get on and off the toilet or help changing disposable briefs or pads. In the last 3 months, did you need help from *recovery assistant staff* with toileting?

- □ YES
- □ NO → GO TO Q28
- □ DON’T KNOW → GO TO Q28
- □ REFUSED → GO TO Q28
- □ UNCLEAR RESPONSE

27. In the last 3 months, did you get all the help you needed with toileting from *recovery assistant staff* when you needed it?

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

**HOW WELL RECOVERY ASSISTANT STAFF COMMUNICATE AND TREAT YOU**

The next several questions ask about how *recovery assistant staff* treat you.

28. In the last 3 months, how often did *recovery assistant staff* treat you with courtesy and respect? Would you say . . .

- □ Never,
- □ Sometimes,
- □ Usually, or
- □ Always?
- □ DON’T KNOW
- □ REFUSED
- □ UNCLEAR RESPONSE
ALTERNATE VERSION: In the last 3 months, did {recovery assistant staff} treat you with courtesy and respect? Would you say . . .

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

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

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

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

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

30. In the last 3 months, how often did {recovery assistant staff} treat you the way you wanted them to? Would you say . . .

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

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

1 □ Mostly yes or
2 □ Mostly no?
-1 □ DON’T KNOW
-2 □ REFUSED
31. In the last 3 months, how often did {recovery assistant staff} explain things in a way that was easy to understand? Would you say . . .

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

ALTERNATE VERSION: In the last 3 months, did {recovery assistant staff} explain things in a way that was easy to understand? Would you say . . .

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

32. In the last 3 months, how often did {recovery assistant staff} listen carefully to you? Would you say . . .

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

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

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

33. In the last 3 months, did you feel {recovery assistant staff} knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?

1 □ YES
2 □ NO
34. In the last 3 months, did {recovery assistant staff} encourage you to do things for yourself if you could?

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

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

- __0 TO 10
- -1 [DON'T KNOW]
- -2 [REFUSED]
- -3 [UNCLEAR RESPONSE]

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

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

36. Would you recommend the {recovery assistant staff} who help you to your family and friends if they needed help with everyday activities? Would you say you would recommend the {recovery assistant staff} . . .

- 1 [Definitely no,]
- 2 [Probably no,]
- 3 [Probably yes, or]
- 4 [Definitely yes?]
- -1 [DON'T KNOW]
- -2 [REFUSED]
- -3 [UNCLEAR RESPONSE]
GETTING NEEDED SERVICES FROM CSPs
QUESTIONS 37-47 ARE ASKED IF QUESTION 8=YES. OTHERWISE SKIP THESE QUESTIONS.

The next several questions are about the {CSPs}, the staff who are paid to help you manage things and stay organized — such as complete paperwork, make a budget, and find resources in the community.

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

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

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

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

38. In the last 3 months, how often did {CSPs} work as long as they were supposed to? Would you say . . .

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

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

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

38a. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months,
when staff could not come to work on a day that they were scheduled, did someone let you know that {CSPs} could not come that day?

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

38b. In the last 3 months, how often did {CSPs} explain things in a way that was easy to understand? Would you say . . .

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

ALTERNATE VERSION: In the last 3 months, did {CSPs} explain things in a way that was easy to understand? Would you say . . .

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

38c. In the last 3 months, did {CSPs} encourage you to do things for yourself if you could?

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

HOW WELL CSPs COMMUNICATE AND TREAT YOU

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

41. In the last 3 months, how often did {CSPs} treat you with courtesy and respect? Would you say . . .

1 □ Never,
2 □ Sometimes,
3 □ Usually, or
4 □ Always?
42. In the last 3 months, how often were the explanations {CSPs} gave you hard to understand because of an accent or the way the {CSPs} spoke English? Would you say . . .

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

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

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

43. In the last 3 months, how often did {CSPs} treat you the way you wanted them to? Would you say . . .

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

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

1. Mostly yes or
44. In the last 3 months, how often did {CSPs} listen carefully to you? Would you say . . .

- 1 □ Never,
- 2 □ Sometimes,
- 3 □ Usually, or
- 4 □ Always?

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

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

- 1 □ Mostly yes or
- 2 □ Mostly no?

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

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

- 1 □ YES
- 2 □ NO

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

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

- __0 TO 10

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

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

- 1 □ Excellent,
- 2 □ Very good,
- 3 □ Good,
- 4 □ Fair, or
47. Would you recommend the {CSPs} who help you to your family and friends if they needed CSP or case management services? Would you say you would recommend the {CSPs} . . .

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

YOUR CASE MANAGER

Now I would like to talk to you about your Mental Health Waiver clinician at the Department of Mental Health and Addiction Services, DMHAS, or ABH, the person who helps make sure you have the services you need.

48. Do you know who your {Mental Health Waiver clinician} at the Department of Mental Health and Addiction Services, DMHAS, or ABH is?

1 [ ] YES
2 [ ] NO → GO TO Q55a
-1 [ ] DON'T KNOW → GO TO Q55a
-2 [ ] REFUSED → GO TO Q55a
-3 [ ] UNCLEAR RESPONSE → GO TO Q55a
-4 [ ] NOT APPLICABLE → GO TO Q55a

49. In the last 3 months, could you contact this {Mental Health Waiver clinician} when you needed to?

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

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

1 [ ] YES
51. In the last 3 months, did this {Mental Health Waiver clinician} work with you when you asked for help with getting or fixing equipment?

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

52. In the last 3 months, did you ask this {Mental Health Waiver clinician} for help in getting any changes to your services, such as more help from {recovery assistants, RAs, and/or CSPs, case managers if applicable}, or for help with getting places or finding a job?

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

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

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

54. Using any number from 0 to 10, where 0 is the worst help from {Mental Health Waiver clinician} possible and 10 is the best help from {Mental Health Waiver clinician} possible, what number would you use to rate the help you get from {Mental Health Waiver clinician}?

_0 TO 10

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

ALTERNATE VERSION: How would you rate the help you get from the {Mental Health Waiver clinician}? Would you say . . .

1. Excellent,
55. Would you recommend the \{Mental Health Waiver clinician\} who helps you to your family and friends if they needed Mental Health Waiver clinician services? Would you say you would recommend the \{Mental Health Waiver clinician\} . . .

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

HOME-DELIVERED MEALS, ADULT DAY PROGRAM

The next questions ask about home-delivered meals and adult day programs.

55a. In the last 3 months, how would you rate your overall experience with Meals on Wheels or a home-delivered meal service? Would you say . . .

- 1 [ ] Excellent,
- 2 [ ] Very good,
- 3 [ ] Good,
- 4 [ ] Fair, or
- 5 [ ] Poor?
- 1 [ ] DON’T KNOW
- 2 [ ] REFUSED
- 3 [ ] UNCLEAR RESPONSE or DID NOT USE HOME-DELIVERED MEAL SERVICE

55b. In the last 3 months, how would you rate your adult day program? Would you say . . .

- 1 [ ] Excellent,
- 2 [ ] Very good,
- 3 [ ] Good,
- 4 [ ] Fair, or
- 5 [ ] Poor?
- 1 [ ] DON’T KNOW
- 2 [ ] REFUSED
- 3 [ ] UNCLEAR RESPONSE or DID NOT USE AN ADULT DAY PROGRAM
CHOOSING YOUR SERVICES

56. In the last 3 months, did your recovery plan include . . .

1. None of the things that are important to you,
2. Some of the things that are important to you,
3. Most of the things that are important to you, or
4. All of the things that are important to you?

-1 DON’T KNOW → GO TO 57a
-2 REFUSED → GO TO Q57a
-3 UNCLEAR RESPONSE → GO TO Q57a

57. In the last 3 months, did you feel {recovery assistant staff} knew what’s on your recovery plan, including the things that are important to you?

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

QUESTIONS 57A-57B ARE ASKED IF QUESTION 4=YES. OTHERWISE SKIP THESE QUESTIONS.

57a. I would like to ask you about how you find and hire your paid caregivers or aides. Does a homecare agency provide them? Or, do you or a family member find and hire your aides, and do you sign and send in their timesheets?

Probes (Use only if respondent does not know):
How do you hire and pay your aides or caregivers?
Do you work with Allied, Sunset Shores, or Advanced Behavioral Health/ABH to pay your aides?

1 AGENCY → GO TO Q 58
2 SELF-HIRE → GO TO Q 57b
3 BOTH AGENCY AND SELF-HIRE → GO TO Q 57b
-1 DON’T KNOW → GO TO Q 58
-2 REFUSED → GO TO Q 58
-3 UNCLEAR RESPONSE → GO TO Q 58
-4 NOT APPLICABLE → GO TO Q 58

57b. Are any of your family members paid to help you?

1 YES, Please specify relationship/s _____________________
2 NO
-1 DON’T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE
58. In the last 3 months, who would you have talked to if you wanted to change your recovery plan? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

- [ ] CASE MANAGER
- [ ] OTHER STAFF
- [ ] FAMILY/FRIENDS
- [ ] SOMEONE ELSE, PLEASE SPECIFY ____________________
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

TRANSPORTATION

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

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

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

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

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

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

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

61. In the last 3 months, were you able to get in and out of this ride easily?
62. In the last 3 months, how often did this ride arrive on time to pick you up? Would you say . . .

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

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

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

PERSONAL SAFETY

The next few questions ask about your personal safety.

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

1 □ FAMILY MEMBER OR FRIEND
2 □ CASE MANAGER
3 □ AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES
4 □ PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)
5 □ 9–1–1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)
6 □ SOMEONE ELSE, PLEASE SPECIFY __________________________
7 □ DON’T KNOW
8 □ REFUSED
9 □ UNCLEAR RESPONSE

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

1 □ YES
2 □ NO
3 □ DON’T KNOW
The next few questions ask if anyone paid to help you treated you badly in the last 3 months. This includes {recovery assistants, CSPs, and/or Mental Health Waiver Clinician}. We are asking everyone the next questions—not just you. I want to remind you that, although your answers are confidential, I have a responsibility to tell my supervisor if I hear something that makes me think you are being hurt or are in danger.

65. In the last 3 months, did any {recovery assistants, CSPs, and/or Mental Health Waiver Clinician} take your money or your things without asking you first?

1. YES
2. NO → GO TO Q68
3. DON’T KNOW → GO TO Q68
4. REFUSED → GO TO Q68
5. UNCLEAR RESPONSE → GO TO Q68

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

1. YES
2. NO → GO TO Q68
3. DON’T KNOW → GO TO Q68
4. REFUSED → GO TO Q68
5. UNCLEAR RESPONSE → GO TO Q68

67. In the last 3 months, who has been working with you to fix this problem? Anyone else?

[Interviewer marks all that apply]

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

68. In the last 3 months, did any {recovery assistants, CSPs, and/or Mental Health Waiver Clinician} yell, swear, or curse at you?

1. YES
2. NO → GO TO Q71
3. DON’T KNOW → GO TO Q71
4. REFUSED → GO TO Q71
5. UNCLEAR RESPONSE → GO TO Q71

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

1. FAMILY MEMBER OR FRIEND  
2. CASE MANAGER  
3. AGENCY  
4. SOMEONE ELSE, PLEASE SPECIFY _________________

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

71. In the last 3 months, did any {recovery assistants, CSPs, and/or Mental Health Waiver Clinician} hit you or hurt you?

1. YES  
2. NO → GO TO Q74

-1. DON’T KNOW → GO TO Q74  
-2. REFUSED → GO TO Q74  
-3. UNCLEAR RESPONSE → GO TO Q74

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

1. YES  
2. NO → GO TO Q74

-1. DON’T KNOW → GO TO Q74  
-2. REFUSED → GO TO Q74  
-3. UNCLEAR RESPONSE → GO TO Q74

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

1. FAMILY MEMBER OR FRIEND  
2. CASE MANAGER  
3. AGENCY  
4. SOMEONE ELSE, PLEASE SPECIFY _________________

-1. DON’T KNOW  
-2. REFUSED  
-3. UNCLEAR RESPONSE
COMMUNITY INCLUSION AND EMPOWERMENT

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

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

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

75. In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby? Would you say . . .

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

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these family members who live nearby? Would you say . . .

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

76. Do you have any friends who live nearby?

1. YES
2. NO → GO TO Q78
1. DON’T KNOW → GO TO Q78
2. REFUSED → GO TO Q78
3. UNCLEAR RESPONSE → GO TO Q78

77. In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby? Would you say . . .

1. Never,
2. Sometimes,
3. Usually, or
4. Always?
1. DON’T KNOW
78. In the last 3 months, when you wanted to, how often could you do things in the community that you like? Would you say . . .

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

79. In the last 3 months, did you need more help than you get from {recovery assistant staff} to do things in your community?

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

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

1 □ YES
2 □ NO
1 □ DON’T KNOW
2 □ REFUSED
3 □ UNCLEAR RESPONSE
81. In the last 3 months, did you take part in deciding **when** you do things each day—for example, deciding when you get up, eat, or go to bed?

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

**Employment Module**

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

1. YES → GO TO EM9
2. NO
-1. DON’T KNOW → GO TO THE DMHAS QUESTIONS SECTION
-2. REFUSED → GO TO THE DMHAS QUESTIONS SECTION
-3. UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

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

1. YES
2. NO → GO TO EM4
-1. DON’T KNOW → GO TO THE DMHAS QUESTIONS SECTION
-2. REFUSED → GO TO THE DMHAS QUESTIONS SECTION
-3. UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

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

1. BENEFITS → GO TO EM5
2. HEALTH CONCERNS → GO TO EM5
3. DON’T KNOW ABOUT JOB RESOURCES → GO TO EM5
4. ADVICE FROM OTHERS → GO TO EM5
5. TRAINING/EDUCATION NEED → GO TO EM5
6. LOOKING FOR AND CAN’T FIND WORK → GO TO EM5
7. ISSUES WITH PREVIOUS EMPLOYMENT → GO TO EM5
8. TRANSPORTATION → GO TO EM5
9. CHILD CARE → GO TO EM5
10. OTHER (______________________________) → GO TO EM5
11. NOTHING IS HOLDING ME BACK → GO TO EM5
-1. DON’T KNOW → GO TO EM5
-2. REFUSED → GO TO EM5
-3. UNCLEAR RESPONSE → GO TO EM5
EM4. Sometimes people would like to work for pay, but feel that something is holding them back. In the last 3 months, was this true for you? If so, what has been holding you back from wanting to work? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

1. [ ] BENEFITS → GO TO THE DMHAS QUESTIONS SECTION
2. [ ] HEALTH CONCERNS → GO TO THE DMHAS QUESTIONS SECTION
3. [ ] DON’T KNOW ABOUT JOB RESOURCES → GO TO THE DMHAS QUESTIONS SECTION
4. [ ] ADVICE FROM OTHERS → GO TO THE DMHAS QUESTIONS SECTION
5. [ ] TRAINING/EDUCATION NEED → GO TO THE DMHAS QUESTIONS SECTION
6. [ ] LOOKING FOR AND CAN’T FIND WORK → GO TO THE DMHAS QUESTIONS SECTION
7. [ ] ISSUES WITH PREVIOUS EMPLOYMENT → GO TO THE DMHAS QUESTIONS SECTION
8. [ ] TRANSPORTATION → GO TO THE DMHAS QUESTIONS SECTION
9. [ ] CHILD CARE → GO TO THE DMHAS QUESTIONS SECTION
10. [ ] OTHER (__________________________________) → GO TO THE DMHAS QUESTIONS SECTION
11. [ ] NOTHING/DON’T WANT TO WORK → GO TO THE DMHAS QUESTIONS SECTION
-1. [ ] DON’T KNOW → GO TO THE DMHAS QUESTIONS SECTION
-2. [ ] REFUSED → GO TO THE DMHAS QUESTIONS SECTION
-3. [ ] UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

EM5. In the last 3 months, did you ask for help in getting a job for pay?

1. [ ] YES → GO TO EM7
2. [ ] NO
-1. [ ] DON’T KNOW
-2. [ ] REFUSED
-3. [ ] UNCLEAR RESPONSE

EM6. In the last 3 months, did you know you could get help to find a job for pay?

1. [ ] YES → GO TO THE DMHAS QUESTIONS SECTION
2. [ ] NO → GO TO THE DMHAS QUESTIONS SECTION
-1. [ ] DON’T KNOW → GO TO THE DMHAS QUESTIONS SECTION
-2. [ ] REFUSED → GO TO THE DMHAS QUESTIONS SECTION
-3. [ ] UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

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

1. [ ] YES → GO TO EM8
2. [ ] NO → GO TO THE DMHAS QUESTIONS SECTION
-1. [ ] DON’T KNOW → GO TO THE DMHAS QUESTIONS SECTION
-2. [ ] REFUSED → GO TO THE DMHAS QUESTIONS SECTION
-3. [ ] UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

EM8. In the last 3 months, did you get all the help you need to find a job?
EM9. Who helped you find the job that you have now? [MARK ALL THAT APPLY]

1     YES  →  GO TO THE DMHAS QUESTIONS SECTION
2     NO   →  GO TO THE DMHAS QUESTIONS SECTION
-1    DON’T KNOW  →  GO TO THE DMHAS QUESTIONS SECTION
-2    REFUSED  →  GO TO THE DMHAS QUESTIONS SECTION
-3    UNCLEAR RESPONSE  →  GO TO THE DMHAS QUESTIONS SECTION

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

1     YES
2     NO
-1    DON’T KNOW
-2    REFUSED
-3    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. In the last 3 months, was someone paid to help you with the job you have now?

1     YES
2     NO  →  GO TO THE DMHAS QUESTIONS SECTION
-1    DON’T KNOW  →  GO TO THE DMHAS QUESTIONS SECTION
-2    REFUSED  →  GO TO THE DMHAS QUESTIONS SECTION
-3    UNCLEAR RESPONSE  →  GO TO THE DMHAS QUESTIONS SECTION

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 \textit{job coach} yourself?

- [ ] YES \rightarrow GO TO THE DMHAS QUESTIONS SECTION
- [ ] NO
- [ ] DON’T KNOW
- [ ] REFUSED
- [ ] UNCLEAR RESPONSE

EM14. In the last 3 months, has your \textit{job coach} been with you all the time that you were working?

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

EM15. In the last 3 months, how often did your \textit{job coach} give you all the help you needed? Would you say . . .

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

ALTERNATE VERSION: In the last 3 months, did your \textit{job coach} give you all the help you needed? Would you say . . .

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

EM16. In the last 3 months, how often did your \textit{job coach} treat you with courtesy and respect? Would you say . . .

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

ALTERNATE VERSION: In the last 3 months, did your \textit{job coach} treat you with courtesy
and respect? Would you say . . .

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

EM17. In the last 3 months, how often did your \emph{job coach} explain things in a way that was easy to understand? Would you say . . .

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

**ALTERNATE VERSION:** In the last 3 months, did your \emph{job coach} explain things in a way that was easy to understand? Would you say . . .

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

EM18. In the last 3 months, how often did your \emph{job coach} listen carefully to you? Would you say . . .

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

**ALTERNATE VERSION:** In the last 3 months, did your \emph{job coach} listen carefully to you? Would you say . . .

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

EM19. In the last 3 months, did your \emph{job coach} encourage you to do things for yourself if you could?

1. YES
EM20. Using any number from 0 to 10, where 0 is the worst help from \(\text{job coach}\) possible and 10 is the best help from \(\text{job coach}\) possible, what number would you use to rate the help you get from your \(\text{job coach}\)?

\[0\text{ TO } 10\]

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

ALTERNATE VERSION: How would you rate the help you get from your \(\text{job coach}\)?
Would you say . . .
1 Excellent,
2 Very good,
3 Good,
4 Fair, or
5 Poor?
-1 DON'T KNOW
-2 REFUSED
-3 UNCLEAR RESPONSE

EM21. Would you recommend the \(\text{job coach}\) who helps you to your family and friends if they needed supported employment? Would you say you recommend the \(\text{job coach}\) . . .

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

DMHAS MODULE (MENTAL HEALTH WAIVER QUESTIONS)
The next questions ask how the services you’ve received through the Mental Health Waiver have affected your life. Please tell me how much you agree or disagree with each statement.

DMHAS_1. As a result of the services I have received from the Mental Health Waiver, I deal more effectively with my daily problems. Would you say you...

- Strongly agree
- Agree
- Neither agree nor disagree
DMHAS_2. As a result of the services I have received from the Mental Health Waiver, I am better in control of my life. Would you say you...

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don’t know
- Refused
- Unclear response

DMHAS_3. As a result of the services I have received from the Mental Health Waiver, I do better in social situations. Would you say you...

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don’t know
- Refused
- Unclear response

DMHAS_4. As a result of the services I have received from the Mental Health Waiver, I can have the life I want in recovery. Would you say you...

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don’t know
- Refused
- Unclear response

DMHAS_5. As a result of the services I have received from the Mental Health Waiver, I feel that these services help me stay in the community. Would you say you...

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don’t know
- Refused
- Unclear response
ABOUT YOU

Now I just have a few more questions about you.

82. In general, how would you rate your overall health? Would you say . . .

[ ] Excellent,
[ ] Very good,
[ ] Good,
[ ] Fair, or
[ ] Poor?
[ ] DON’T KNOW
[ ] REFUSED
[ ] UNCLEAR RESPONSE

83. In general, how would you rate your overall mental or emotional health? Would you say . . .

[ ] Excellent,
[ ] Very good,
[ ] Good,
[ ] Fair, or
[ ] Poor?
[ ] DON’T KNOW
[ ] REFUSED
[ ] UNCLEAR RESPONSE

84. What is your age?

[ ] 18 TO 24 YEARS
[ ] 25 TO 34 YEARS
[ ] 35 TO 44 YEARS
[ ] 45 TO 54 YEARS
[ ] 55 TO 64 YEARS
[ ] 65 TO 74 YEARS
[ ] 75 YEARS OR OLDER
[ ] DON’T KNOW
[ ] REFUSED
[ ] UNCLEAR RESPONSE

ALTERNATE VERSION: In what year were you born?

[ ] DON’T KNOW
[ ] REFUSED
[ ] UNCLEAR RESPONSE

85. [IF NECESSARY, ASK, AND VERIFY IF OVER THE PHONE] Are you male or female?

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

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

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

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

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

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

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

1. White → GO TO Q92
2. Black or African-American → GO TO Q92
3. Asian → GO TO Q90
4. Native Hawaiian or other Pacific Islander → GO TO Q91
5. American Indian or Alaska Native → GO TO Q92
6. OTHER → GO TO Q92
-1 DON’T KNOW → GO TO Q92
-2 REFUSED → GO TO Q92
-3 UNCLEAR RESPONSE → GO TO Q92
90. Which group best describes you? [READ ALL ANSWER CHOICES. CODE ALL THAT APPLY.]

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

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

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

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

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

93. What is the language you speak at home?

1. Spanish,
2. Some other language → Which one? _____________________
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

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

1. 1 [JUST THE RESPONDENT] → GO TO QUESTION 97
2. 2 TO 3
3. 4 OR MORE
-1. DON’T KNOW
-2. REFUSED
95. [IF NECESSARY, ASK] Do you live with any family members?

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

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

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

97. Is there anything else you would like to add?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

END OF QUESTIONS

Thank you for completing this interview with me.

If you wish to contact your care manager, the number for his/her agency is:
DMHAS: 866-548-0265

Interviewer: Collect name and phone numbers for participant, proxy, or person who assisted. Information will be entered below.

QUESTIONS FOR THE INTERVIEWER

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

0) Who completed the interview? (Check only one)

□ Participant by his/herself

Participant telephone numbers: ______________________________ → Go to F1
☐ Participant with assistance from another person.
   If Assisted
   OPTIONAL: Contact information for person who assisted with interview:
   First name: ________________
   Last name: ________________
   Telephone numbers: ________________ → Go to F1

☐ A proxy – Someone else completed the survey for the participant.
   If Proxy:
   Proxy Contact Information:
   Proxy First name: ________________
   Proxy Last name: ________________
   Proxy Telephone numbers: ________________ → Go to P1

P1. Relationship to participant – the proxy is the...
   ☐ Spouse/partner
   ☐ Adult child
   ☐ Parent
   ☐ Attorney or legal representative
   ☐ Other: ________________

P2. Is the proxy also a legal representative?
   ☐ Yes
   ☐ No

P3. Is the proxy paid to provide support to the participant?
   ☐ Yes → GO TO END SURVEY SECTION
   ☐ No → GO TO END SURVEY SECTION

F1. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?
   1 ☐ YES
   2 ☐ NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?
   1 ☐ YES
   2 ☐ NO → GO TO END SURVEY SECTION

F3. WHO WAS PRESENT DURING THE INTERVIEW? (MARK ALL THAT APPLY.)
   1 ☐ SOMEONE NOT PAID TO PROVIDE SUPPORT TO THE RESPONDENT
   2 ☐ STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?
F5. HOW DID THAT PERSON HELP? [MARK ALL THAT APPLY.]

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

F6. WHO HELPED THE RESPONDENT? (MARK ALL THAT APPLY.)

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

F7. Relationship to participant:

☐ Spouse/partner
☐ Adult child
☐ Parent
☐ Attorney or legal representative
☐ Paid staff person
☐ Other: _______________

F8. Is the person who assisted also a legal representative?

☐ Yes → GO TO END SURVEY SECTION
☐ No → GO TO END SURVEY SECTION

END OF SURVEY

Interview done by:

☐ Telephone
☐ In-person

Participant Information:

Medicaid ID: _______________ (Please verify)
Date of Birth: _______________ (MM/DD/YYYY)
Town of residence: _______________
ZIP code of residence: _______________

Does the participant have a Conservator of Person or a Legal Guardian?

☐ Yes
☐ No
☐ Do not know

Program:
☐ DMHAS

Community First Choice?
☐ Yes
☐ No
☐ Do not know

Recovery Assistant Agency: ____________________  [CHOOSE FROM AGENCY LIST DROP DOWN]

Community Support Program Agency: ____________________  [CHOOSE FROM AGENCY LIST DROP DOWN]

Mental Health Waiver Agency: ____________________  [CHOOSE FROM AGENCY LIST DROP DOWN]

Name of interviewer: ___________________

Date Interview Completed: ________________

Submit and Return to Dashboard