2023 Annual Report:
Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS) Survey Results: Connecticut HCBS programs

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I. Introduction

The Consumer Assessment of Healthcare Providers and 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 Healthcare Providers and 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 sixth year of HCBS CAHPS survey administration, using the survey to inform quality measurement in seven of its Medicaid programs: Connecticut Home Care Program Categories 3 and 5 (CHCP), Personal Care Assistance (PCA), Acquired Brain Injury I and II (ABI), Autism, and Katie Beckett (KBW) waivers, and fourth 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 HCBS 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 (see Appendix B). Although the Department of Mental Health and Addiction services (DMHAS) used the standard HCBS CAHPS survey over the three previous years, in FY 2023 DMHAS revised the HCBS CAHPS survey in order to tailor it more for the population they serve. The revised MHW HCBS survey follows a similar structure as the standard HCBS CAHPS, but uses a select subset of the HCBS CAHPS questions. In particular, the MHW HCBS survey does not ask about clinical case management services, limits the questions about MHW staff, and does not include the employment section. As in previous years, the MHW survey includes additional specific questions for overall MHW services. The full HCBS CAHPS survey is attached in Appendix B; the MHW HCBS survey is in Appendix C.

The HCBS CAHPS survey tailors the survey for each participant and waiver program by integrating waiver specific services and terms into the survey. For example, only ABI participants are asked about Independent Living Skills Training Specialists (ILSTs). 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).
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>
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</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>
<td></td>
<td>X*</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Recovery assistance</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></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>X</td>
<td>X</td>
</tr>
<tr>
<td>Job coach</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Service Provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></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 to complete their surveys (hereafter collectively referred to as quality assurance staff).

Using client enrollment numbers as of 7/1/2022, DSS determined the target number of surveys for each Access Agency, DSS, and DMHAS to complete between July 1, 2022 to June 30, 2023 (State Fiscal Year [SFY] 2023) in order to reach their representative sample sizes.

Using random sampling, Access Agency and DSS 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. Although not required, some of the Access Agencies sent notification letters to their waiver participants and/or legal representative. Following HCBS CAHPS protocol, all the Access Agency and DSS surveys were completed with an interviewer, with the great majority completed by telephone.

All waiver participants are encouraged to complete the survey on their own with the interviewer (by self) or with the interviewer and another person (with assistance). 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.

To increase the participation of MHW clients, the MHW HCBS CAHPS included a survey option which was completed without an interviewer. The survey option was available in 2 formats: online using a unique login or a paper survey. Revisions to the wording of the questions were made in the self-administered version. All MHW participants were called a month before their annual reassessment and given the option to do the survey by telephone with an interviewer. If they were unable to be reached, then their care manager or Community Service Provider delivered a paper survey and self-addressed, postage paid envelope to the participant at their next visit. A letter accompanying the paper survey also described the survey and gave instructions to complete it online.

As the training and technical assistance provider, UConn Center on Aging (UConn) provides ongoing training for the quality assurance staff and supervisors 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 telephone and in-person survey platforms. UConn provides and manages secure online HCBS CAHPS platforms 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. The MHW HCBS CAHPS uses a REDCap platform which utilizes branching logic to direct the interviewer to the next appropriate question.

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, Access Agency performance benchmarks, additional findings by program, comparisons by agency, and additional MHW findings.

A. Respondent Sample

HCBS CAHPS surveys were completed for each of the mandated waiver programs: CHCP program Categories 3 and 5, PCA, ABI 1 and 2, Autism, Katie Beckett, and Mental Health 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 CHCP Category 3, the PCA waiver, and the ABI waivers.

CHCP Category 5, Autism, Katie Beckett, and the MHW did not reach their representative sample sizes. However, the MHW representative sample size completion rate jumped from 13% in 2022 to 85% in 2023. The larger number of MHW clients completing surveys this year may provide better insight into how services are being utilized and better ways to address unmet needs among this population. The KBW completion rate stayed the same as last year, while the Autism program completion rate dropped
sharply, from 75% in 2022 to 35% this year. This report presents the results for the KB, Autism, and MH waivers to show program trends.

Table 3. Representative Sample and Completed Surveys by Program

<table>
<thead>
<tr>
<th>Program</th>
<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><strong>CHCP programs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHCP Category 3</td>
<td>12535</td>
<td>373</td>
<td>391</td>
<td>&gt;100</td>
</tr>
<tr>
<td>CHCP Category 5</td>
<td>268</td>
<td>206</td>
<td>186</td>
<td>90.3</td>
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<tr>
<td>CHCP Category 2*</td>
<td></td>
<td></td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>12803</td>
<td>579</td>
<td>584</td>
<td>&gt;100</td>
</tr>
<tr>
<td><strong>PCA</strong></td>
<td>1011</td>
<td>274</td>
<td>283</td>
<td>&gt;100</td>
</tr>
<tr>
<td><strong>ABI waivers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABI 1</td>
<td>311</td>
<td>189</td>
<td>191</td>
<td>&gt;100</td>
</tr>
<tr>
<td>ABI 2</td>
<td>247</td>
<td>133</td>
<td>135</td>
<td>&gt;100</td>
</tr>
<tr>
<td>Totals</td>
<td>558</td>
<td>322</td>
<td>326</td>
<td>&gt;100</td>
</tr>
<tr>
<td><strong>Autism</strong></td>
<td>166</td>
<td>117</td>
<td>41</td>
<td>35.0</td>
</tr>
<tr>
<td><strong>Katie Beckett</strong></td>
<td>332</td>
<td>179</td>
<td>64</td>
<td>36.3</td>
</tr>
<tr>
<td><strong>MHW</strong></td>
<td>499</td>
<td>218</td>
<td>180^</td>
<td>82.6</td>
</tr>
<tr>
<td><strong>Total surveys completed, any program</strong></td>
<td></td>
<td></td>
<td></td>
<td>1478</td>
</tr>
</tbody>
</table>

*Analysis includes these 7 non-required CHCP Category 2 surveys.
^DMHAS revised its Annual HCBS CAHPS survey in June 2022. The 8 surveys completed in June 2022 are included in this year’s data.

All but 5 of the CHCP, PCA, ABI, Autism and KBW surveys were completed by telephone. Eight percent of these participants used the Spanish survey. Sixty-five (35%) of the MHW surveys were completed as online surveys. However, paper surveys were entered by DMHAS staff as telephone surveys. This made it difficult to accurately know how many of the remaining 65% (n=115) MHW surveys were completed with an interviewer and how many were completed as paper surveys without the assistance of an interviewer.

All surveys, including all MHW survey formats, asked if the survey was completed by the consumer alone, the consumer with assistance, or by someone other than the consumer (by proxy). With the exception of KBW and Autism, most surveys were completed by the consumer or the consumer with assistance (Table 4). Notably, 41% of all ABI surveys were completed by proxy. For assisted interviews, the person assisting most often restated some of the questions or prompted the consumer.

Table 4. Survey Respondents

<table>
<thead>
<tr>
<th>Program</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>429 (73.5)</td>
<td>230 (81.3)</td>
<td>160 (49.1)</td>
<td>14 (34.2)</td>
<td>0 (0)</td>
<td>162 (90.0)</td>
<td>995 (67.3)</td>
</tr>
<tr>
<td>With assistance</td>
<td>33 (5.7)</td>
<td>5 (1.8)</td>
<td>32 (9.8)</td>
<td>2 (4.9)</td>
<td>0 (0)</td>
<td>17 (9.4)</td>
<td>89 (6.0)</td>
</tr>
<tr>
<td>By proxy</td>
<td>122 (20.9)</td>
<td>48 (17.0)</td>
<td>134 (41.1)</td>
<td>25 (61.0)</td>
<td>64 (100)</td>
<td>1 (&lt;1.0)</td>
<td>394 (26.7)</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>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N=584</td>
<td>N=283</td>
<td>N=326</td>
<td>N=41</td>
<td>N=64</td>
<td>N=175</td>
</tr>
<tr>
<td>&lt;18</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>2.4</td>
<td>67.2</td>
<td>0.0</td>
</tr>
<tr>
<td>18-24</td>
<td>0.0</td>
<td>&lt;1.0</td>
<td>&lt;1.0</td>
<td>9.8</td>
<td>32.8</td>
<td>0.0</td>
</tr>
<tr>
<td>25-34</td>
<td>0.0</td>
<td>6.0</td>
<td>10.7</td>
<td>29.3</td>
<td>0.0</td>
<td>5.7</td>
</tr>
<tr>
<td>35-44</td>
<td>0.0</td>
<td>14.5</td>
<td>20.6</td>
<td>46.3</td>
<td>0.0</td>
<td>12.6</td>
</tr>
<tr>
<td>45-54</td>
<td>0.0</td>
<td>19.1</td>
<td>23.9</td>
<td>4.9</td>
<td>0.0</td>
<td>15.4</td>
</tr>
<tr>
<td>55-64</td>
<td>0.0</td>
<td>56.2</td>
<td>28.8</td>
<td>7.3</td>
<td>0.0</td>
<td>41.7</td>
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<td>65-74</td>
<td>27.6</td>
<td>3.2</td>
<td>14.7</td>
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<tr>
<td>75+</td>
<td>72.4</td>
<td>&lt;1.0</td>
<td>&lt;1.0</td>
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<td>&lt;1.0</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>N=583</td>
<td>N=281</td>
<td>N=326</td>
<td>N=41</td>
<td>N=64</td>
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<tr>
<td>English</td>
<td>54.0</td>
<td>78.3</td>
<td>84.4</td>
<td>95.1</td>
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<td>Spanish only</td>
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<td>0.0</td>
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</tr>
<tr>
<td>Multi-lingual</td>
<td>30.4</td>
<td>19.9</td>
<td>15.6</td>
<td>4.9</td>
<td>21.9</td>
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<tr>
<td><strong>Race</strong></td>
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<tr>
<td></td>
<td>N=567</td>
<td>N=279</td>
<td>N=321</td>
<td>N=39</td>
<td>N=63</td>
<td>N=172</td>
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<td>White</td>
<td>57.5</td>
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<td>77.6</td>
<td>79.5</td>
<td>88.9</td>
<td>83.1</td>
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<td>Black</td>
<td>19.9</td>
<td>29.4</td>
<td>16.5</td>
<td>10.3</td>
<td>6.3</td>
<td>14.0</td>
</tr>
<tr>
<td>Other</td>
<td>22.6</td>
<td>7.2</td>
<td>5.9</td>
<td>10.3</td>
<td>4.8</td>
<td>3.5</td>
</tr>
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<td><strong>Ethnicity</strong></td>
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<td>N=578</td>
<td>N=281</td>
<td>N=323</td>
<td>N=39</td>
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<td>N=171</td>
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<td>Non-Hispanic</td>
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<td>90.1</td>
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<td>6.2</td>
<td>5.1</td>
<td>7.8</td>
<td>9.9</td>
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<td><strong>Education Level</strong></td>
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<tr>
<td></td>
<td>N=561</td>
<td>N=282</td>
<td>N=319</td>
<td>N=41</td>
<td>N=62</td>
<td></td>
</tr>
<tr>
<td>&lt; 8th Grade</td>
<td>26.7</td>
<td>2.8</td>
<td>&lt;1.0</td>
<td>2.4</td>
<td>53.2</td>
<td></td>
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<tr>
<td>Some high school</td>
<td>15.7</td>
<td>10.3</td>
<td>9.4</td>
<td>4.9</td>
<td>33.9</td>
<td></td>
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<td>High school diploma</td>
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<td>55.5</td>
<td>61.0</td>
<td>11.3</td>
<td></td>
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<tr>
<td>Some college</td>
<td>17.1</td>
<td>24.8</td>
<td>26.0</td>
<td>22.0</td>
<td>1.6</td>
<td></td>
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<tr>
<td>4-year college</td>
<td>10.0</td>
<td>5.7</td>
<td>6.3</td>
<td>7.3</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>&gt; 4 year college</td>
<td>5.5</td>
<td>2.8</td>
<td>1.9</td>
<td>2.4</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N=584</td>
<td>N=283</td>
<td>N=326</td>
<td>N=41</td>
<td>N=64</td>
<td>N=174</td>
</tr>
<tr>
<td>Male</td>
<td>25.7</td>
<td>51.6</td>
<td>72.1</td>
<td>73.2</td>
<td>51.6</td>
<td>42.5</td>
</tr>
<tr>
<td>Female</td>
<td>74.3</td>
<td>48.4</td>
<td>27.9</td>
<td>26.8</td>
<td>48.4</td>
<td>57.5</td>
</tr>
</tbody>
</table>

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

**Revised MHW survey did not ask language or education.
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 ABI personal care assistance decreased, while ABI and CHCP homemaking services increased from the previous year. Almost all MHW participants reported receiving RA services (94%), compared to 72% last year, and the percentage reporting CSP services increased as well, from 61% to 77%.

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>315 (54.1)</td>
<td>256 (90.5)</td>
<td>153 (47.1)</td>
<td>1 (2.4)</td>
<td></td>
<td>168 (93.9)</td>
</tr>
<tr>
<td>Behavioral health services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MHW Recovery assistance</td>
<td>485 (83.2)</td>
<td>77 (27.4)</td>
<td>64 (20.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaker/companion or Homemaking services</td>
<td>502 (89.0)</td>
<td>234 (84.8)</td>
<td>294 (93.9)</td>
<td>40 (97.6)</td>
<td>20 (31.8)</td>
<td></td>
</tr>
<tr>
<td>Case manager or Clinical case manager</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Job coach</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MHW Community service provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>135 (77.1)</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. The MHW survey included the full questions for only 2 of the composites, limiting the ability to compare the MHW across other programs. Overall, mean scores were high for most of the composite measures. As reported in previous years, participants across all programs reported lower scores for planning their time and activities, although the ABI waiver stood out as receiving the highest score. In addition, several programs reported lower scores for choosing the services which matter to you. Both composites speak to consumer choice and control and represent areas which could use more support.
Figure 1. Composite Measures by Program: Mean Scores (Range 1-4)*

*In the composite measures Figures 1 and 2, “Staff” combines all PCA, ILST, recovery assistant (RA), community service provider (CSP), 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 listen and communicate well, the range between waiver programs went from 3.79 (ABI) to 3.84 (CHCP), only a .05 difference. By using the percentage highest scores, the differences are more apparent – 92% of CHCP participants gave this composite item the highest scores, compared to 84% of ABI participants. This method also highlights and reaffirms the need to improve choice and control among all programs, but especially among Autism and KBW participants.

Figure 2. Composite Measures by Program: Percentage with Highest Score*

*In the composite measures Figures 1 and 2, “Staff” combines all PCA, ILST, recovery assistant (RA), community service provider (CSP), homemaking, companion, life skills coach, and community mentor staff.
### 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). For the majority of programs, mean scores were either at or above 4.5 for all program staff and case managers. MHW rated their RAs lower than the other programs rated their PCA, ILST, Community Mentor, and Life Skills coach staff. In addition, noticeably lower scores were given to ABI homemaking only services and KBW and Autism 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 56% of Autism participants and 64% of MHW participants gave their personal assistant/behavioral health staff the highest rating, compared to 73-86% of the other waivers. CHCP respondents in particular gave their staff and case managers the highest ratings of all the programs – 86% of personal assistant/behavioral health staff, 81% of homemaking staff, and 85% of case managers received a score of 9 or 10.

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

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

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 higher recommendation scores. Both Autism and KBW participants were much less likely to recommend their case managers, and ABI participants were much less likely to recommend their homemaking staff. This becomes very apparent when one considers the percentage of respondents who would “definitely” recommend their staff, shown in Figure 6. Although MHW participants were asked how they would rate their RAs and CSPs, they were not asked if they would recommend them.
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, and Autism 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). Surprisingly, fewer participants reported needing assistance with some of these everyday activities this year than the previous year. For example, smaller percentages of both CHCP and PCA participants reported needing help with dressing or bathing this year, as did CHCP participants with meals or eating (86% 2022 vs. 74% 2023). As in prior years, the percentage of CHCP consumers receiving assistance with meals may be underrepresented, as many CHCP participants receive this assistance from their homemakers, not PCAs, and meals are asked about in the PCA section.

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. Five ABI, 2 CHCP, and 1 PCA participant reported any unmet need, most frequently with dressing/bathing (data not shown). 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>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing or bathing</td>
<td>249 (79.6)</td>
<td>222 (87.1)</td>
<td>140 (46.1)</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>Meals or eating</td>
<td>233 (74.0)</td>
<td>243 (95.3)</td>
<td>244 (80.3)</td>
<td>15 (46.9)</td>
</tr>
<tr>
<td>Taking medications</td>
<td>222 (70.7)</td>
<td>186 (73.2)</td>
<td>216 (71.3)</td>
<td>4 (12.5)</td>
</tr>
<tr>
<td>Toileting</td>
<td>133 (42.4)</td>
<td>154 (60.9)</td>
<td>72 (23.8)</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

v. Physical safety by program

Physical safety is assessed by the question, “In the last 3 months, did any staff hit you or hurt you?” Two ABI participants and one MHW participant reported that a staff person had hit them or hurt them in the past 3 months. In all three instances, someone was working with the participant to fix the issue.

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 WCAAA. 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 indicate 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 2023, all Access Agencies met or exceeded their required sample sizes for CHCP Category 3. Two agencies did not meet their Category 5 representative sample sizes: AASCC (50.0%) and CCC Northwest (87.5%). AASCC did not start their Category 5 calls until March of 2023, although calls could be started in July, 2022. On the other hand, CCC Northwest started their Category 5 calls in August of 2022. However, by May 2023 the total number of CCC Northwest Category 5 clients had fallen to half the original sample size required, making it impossible to meet the original representative sample size determined in July, 2022.

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 N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHCP Category 3</td>
<td>AASCC</td>
<td>68</td>
<td>84 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - E</td>
<td>33</td>
<td>33 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>141</td>
<td>141 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>37</td>
<td>38urrite&gt;100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>67</td>
<td>67 (100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>27</td>
<td>28 (100)</td>
</tr>
<tr>
<td>CHCP Category 5</td>
<td>AASCC</td>
<td>36</td>
<td>18 (50.0)</td>
</tr>
<tr>
<td></td>
<td>CCC - E</td>
<td>11</td>
<td>11 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>115</td>
<td>115 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>16</td>
<td>14 (87.5)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>16</td>
<td>16 (100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>12</td>
<td>12 (100)</td>
</tr>
</tbody>
</table>

All four Access Agencies met the benchmark 3.5 mean score for all of the CHCP composite measures (Figure 7). All Access Agencies also met 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**
  - AASCC: 3.93, CCC: 4.00, SWCAA: 3.76, WCAA: 3.98

- **Choosing the services that matter to you**
  - AASCC: 3.71, CCC: 3.76, SWCAA: 3.71, WCAA: 3.95

- **Personal safety and respect**
  - AASCC: 3.87, CCC: 3.89, SWCAA: 4.00, WCAA: 3.98
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

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>72</td>
<td>74 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - E</td>
<td>35</td>
<td>38 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>83</td>
<td>87 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>30</td>
<td>30 (100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>40</td>
<td>40 (100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>14</td>
<td>14 (100)</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 benchmark mean scores for two of the three PCA composite measures. AASCC fell slightly below the threshold for the “Care manager is helpful” composite (3.47 vs 3.5). As shown in Figures 11 and 12, AASCC scored under the benchmark for PCA case manager global rating (3.36 vs. 3.5) and did not quite meet the benchmark for case manager recommendation (3.48 vs. 3.5).

Figure 10. PCA Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)
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)](image1)

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)](image2)
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>35</td>
<td>37 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>58</td>
<td>58 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>37</td>
<td>37 (100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>42</td>
<td>42 (100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>17</td>
<td>17 (100)</td>
</tr>
<tr>
<td>ABI 2</td>
<td>CCC - E</td>
<td>19</td>
<td>19 (100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NC</td>
<td>46</td>
<td>48 (&gt;100)</td>
</tr>
<tr>
<td></td>
<td>CCC - NW</td>
<td>19</td>
<td>19 (100)</td>
</tr>
<tr>
<td></td>
<td>SWCAA</td>
<td>43</td>
<td>43 (100)</td>
</tr>
<tr>
<td></td>
<td>WCAAA</td>
<td>6</td>
<td>6 (100)</td>
</tr>
</tbody>
</table>

Three Access Agencies provide case management for the ABI waiver: CCC, SWCAA, and WCAAA. All three Access Agencies met the 3.5 mean score for the three benchmark composites. All three Access Agencies also met the benchmarks for case manager global rating and case manager recommendation (Figures 14 and 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, RA, 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, similar to the previous year, the majority of participants from all waivers reported their staff encouraged them in this way. The only notable difference was for MHW RA staff – 100% of respondents in 2022 said their RA encouraged them to do things for themselves; in 2023 this fell to 92%.

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

Many participants in each program knew who their care manager was (Figure 17). Autism and ABI participants (98%) were the most knowledgeable of their care manager. The percentage of PCA participants who know their care manager decreased substantially this year, from 95% in 2022 to 84% in 2023. Meanwhile, the percentage of KBW participants who know their care manager increased substantially, from 57% in 2022 to 73% in 2023. The MHW survey did not ask about the MHW clinical case managers.
Figure 17. Knows Who Care Manager Is – Percentage Positive Responses

Figure 18 shows how often respondents asked their care manager for help with changing services or with getting or fixing equipment. There were differences among programs, but only one identifiable trend: KBW respondents asked their care managers for help with changing services or equipment much less than the other four programs. Comments included:

*I'm unhappy with the staffing agency. My son needs help to get some technology. I would like more home modification for my son.* ABI

*I would like to take a shower and I need my shower chair.* CHCP

Figure 18. Asked Care Manager for Assistance with Services/Equipment – Percentage Positive Responses
The great majority of participants in all four programs said they knew someone to talk to if they wanted to change their care plan/service plan (Figure 19). When asked to name the person they would talk to, most participants reported they would talk to their case manager (Table 11). Commented one CHCP consumer when asked how she would get additional services, “En el momento de necesitar una persona que me ayude le informare a la trabajadora. Hasta ahora todo bien.” [When I need someone to help me, I will tell my social worker. So far, so good.] Although not shown on Table 11, 48% of KBW respondents who knew someone to talk to would talk to their doctor or other health care provider to change their care plan. Still, not everyone knew what services were available to them, such as this respondent, “We are new to the KBW program and don’t know what services there are to help us. It would be nice if there was a source or a list of potential assistance that my daughter would benefit from, like a condensed list.”

Figure 19. Knows Someone to Talk to if Want to Change Care Plan
Table 11. Who Would You Talk to if You Wanted to Change Your Care Plan?*

<table>
<thead>
<tr>
<th></th>
<th>CHCP N=579</th>
<th>PCA N=283</th>
<th>ABI N=321</th>
<th>Autism N=41</th>
<th>KBW N=62</th>
</tr>
</thead>
<tbody>
<tr>
<td></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>483 (83.4)</td>
<td>240 (84.8)</td>
<td>256 (79.8)</td>
<td>32 (78.1)</td>
<td>34 (54.8)</td>
</tr>
<tr>
<td>Other staff or home care agency/provider</td>
<td>56 (9.7)</td>
<td>12 (4.2)</td>
<td>53 (16.5)</td>
<td>12 (29.3)</td>
<td>3 (4.8)</td>
</tr>
<tr>
<td>Family/friends</td>
<td>143 (24.7)</td>
<td>38 (13.4)</td>
<td>48 (15.0)</td>
<td>2 (4.9)</td>
<td>6 (9.7)</td>
</tr>
<tr>
<td>Someone else</td>
<td>19 (3.3)</td>
<td>8 (2.8)</td>
<td>14 (4.4)</td>
<td>2 (4.9)</td>
<td>36 (58.1)</td>
</tr>
<tr>
<td>Do not know who to talk to</td>
<td>12 (2.1)</td>
<td>8 (2.8)</td>
<td>12 (3.7)</td>
<td>1 (2.4)</td>
<td>5 (8.1)</td>
</tr>
</tbody>
</table>

*Multiple choice

ii. Living situation and social support

Similar to previous years, the majority of MHW participants (87%) lived alone or without other adults, as did 66% of CHCP, 62% of PCA, and 60% of ABI participants (Table 12). In addition to being more likely to live alone, participants in the MHW also had considerably fewer family who lived nearby compared to all other waivers. Compared to the other programs, ABI participants were the least likely to live with family members, but were the most likely to live with a non-family member.

Table 12. Living Situation and Social Support*

<table>
<thead>
<tr>
<th></th>
<th>CHCP N=582</th>
<th>PCA N=283</th>
<th>ABI N=324</th>
<th>Autism N=41</th>
<th>KBW N=62</th>
<th>MHW N=169</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Number of adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>living in household</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>65.8</td>
<td>61.8</td>
<td>60.0</td>
<td>36.6</td>
<td>6.3</td>
<td>87.0</td>
</tr>
<tr>
<td>2-3</td>
<td>32.8</td>
<td>34.3</td>
<td>33.5</td>
<td>46.3</td>
<td>76.6</td>
<td>11.2</td>
</tr>
<tr>
<td>4+</td>
<td>1.4</td>
<td>3.9</td>
<td>6.5</td>
<td>17.1</td>
<td>17.2</td>
<td>1.8</td>
</tr>
<tr>
<td>Lives with family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>76.1</td>
<td>81.5</td>
<td>61.1</td>
<td>96.2</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>23.9</td>
<td>18.5</td>
<td>38.9</td>
<td>3.9</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>Lives with non-family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>19.9</td>
<td>21.3</td>
<td>41.2</td>
<td>7.7</td>
<td>5.0</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>80.1</td>
<td>78.7</td>
<td>58.8</td>
<td>92.3</td>
<td>95.0</td>
<td></td>
</tr>
<tr>
<td>Family live nearby</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>77.2</td>
<td>76.7</td>
<td>76.2</td>
<td>73.2</td>
<td>81.3</td>
<td>51.2</td>
</tr>
<tr>
<td>No</td>
<td>22.9</td>
<td>23.3</td>
<td>23.8</td>
<td>26.8</td>
<td>18.8</td>
<td>48.8</td>
</tr>
<tr>
<td>Friend/s live nearby</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>60.6</td>
<td>62.2</td>
<td>53.1</td>
<td>43.9</td>
<td>64.5</td>
<td>48.5</td>
</tr>
<tr>
<td>No</td>
<td>39.4</td>
<td>37.8</td>
<td>46.9</td>
<td>56.1</td>
<td>35.4</td>
<td>51.5</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 then their mental or emotional health, with response choices from Excellent to Poor. About half of both PCA (51%) and CHCP (50%) participants rated their health as fair or poor, as did 37% of MHW participants (Figure 20).

Figure 20. Self-Reported Physical Health*

*KBW not shown due to missing data

About one-third of MHW (34%), PCA (31%), and CHCP (30%) participants rated their mental or emotional health as fair or poor (Figure 21). On the other hand, both MHW (37%) and Autism (37%) participants had the largest percentage of participants reporting very good or excellent mental health.
iv. Transportation service, home-delivered meals, and day program use

Compared to last year, PCA and Autism waiver participants increased their use of a van or transportation service, while ABI participants’ use decreased (Table 13). For example, 51% of PCA participants used a transportation service in 2023, compared to 43% last year.

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>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25.7</td>
<td>50.7</td>
<td>12.0</td>
<td>12.2</td>
<td>7.8</td>
</tr>
<tr>
<td>No</td>
<td>74.3</td>
<td>49.3</td>
<td>88.0</td>
<td>87.8</td>
<td>92.2</td>
</tr>
</tbody>
</table>

A total of 294 participants reported using a home delivered meal service, including 34% of MHW participants (Figure 22). Use of home delivered meals by CHCP participants decreased from 37% in 2022 to 28% this year. While most participants rated their meal service as “good” or better, substantial
percentages in three programs rated their home delivered meal service as only fair or poor (21% ABI, 27% CHCP, and 32% PCA).

Figure 22. Experience with Home Delivered Meal Services

Just 113 participants (9%) reported receiving day program services. Similar to last year, ABI consumers were much less satisfied with their day programs compared to either CHCP or PCA consumers (Figure 23).
v. **Personal safety and respect follow-up**

Twenty-two participants (less than 2% of all participants) said that one of their staff had taken their money or things without permission: 7 MHW, 7 CHCP, 5 ABI, and 3 PCA. Thirteen of these participants said someone was working with them to fix the problem. Twenty participants said that one of their staff had yelled or cursed at them: 7 ABI, 6 MHW, 4 CHCP and 3 PCA. Eleven of them said someone was working with them to fix the problem.

vi. **Emergency contact**

Another open-ended question asked consumers 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. Similar to previous years, 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, as the majority would call 911. In addition, about half (52%) of KBW respondents would call a member of their medical team in an emergency.
Table 14. Who would you contact in case of an emergency?*

<table>
<thead>
<tr>
<th></th>
<th>CHCP N=584</th>
<th>PCA N=283</th>
<th>ABI N=326</th>
<th>Autism N=41</th>
<th>KBW N=64</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Family/friend</td>
<td>58.6</td>
<td>62.2</td>
<td>66.3</td>
<td>85.4</td>
<td>62.5</td>
</tr>
<tr>
<td>Case manager</td>
<td>7.5</td>
<td>2.8</td>
<td>4.9</td>
<td>2.4</td>
<td>6.3</td>
</tr>
<tr>
<td>Home care agency or staff</td>
<td>3.8</td>
<td>3.9</td>
<td>17.5</td>
<td>12.2</td>
<td>1.6</td>
</tr>
<tr>
<td>PERS/Lifeline</td>
<td>34.9</td>
<td>11.3</td>
<td>5.5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>911</td>
<td>52.4</td>
<td>40.6</td>
<td>25.2</td>
<td>19.5</td>
<td>73.4</td>
</tr>
<tr>
<td>Someone else</td>
<td>3.9</td>
<td>3.2</td>
<td>5.8</td>
<td>2.4</td>
<td>53.1</td>
</tr>
</tbody>
</table>

*Multiple choice question. The percentages listed for each item are based on the total number of valid responses to that question (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, 70% of PCA participants hired their own staff, compared to 7% of CHCP (Table 15). However, the percentage of PCA waiver participants using agency-based services increased notably over the past year, from 13% in 2022 to 30% in 2023. Self-directing consumers were then asked if they employed family members as staff. Although only a small percentage of CHCP participants self-directed their services, 60% of self-directing CHCP participants hired family members, as did 69% of self-directing KBW participants. Consumers most frequently employed adult children, siblings, or parents as staff.

Table 15. Self-Direction

<table>
<thead>
<tr>
<th></th>
<th>CHCP %</th>
<th>PCA %</th>
<th>ABI %</th>
<th>Autism %</th>
<th>KBW %</th>
</tr>
</thead>
<tbody>
<tr>
<td>How hire staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agency</td>
<td>92.8</td>
<td>30.2</td>
<td>70.9</td>
<td>81.1</td>
<td>40.7</td>
</tr>
<tr>
<td>Self-hire</td>
<td>7.2</td>
<td>69.8</td>
<td>29.1</td>
<td>18.9</td>
<td>59.3</td>
</tr>
<tr>
<td>Employs family members</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>60.0</td>
<td>45.9</td>
<td>33.7</td>
<td>14.3</td>
<td>68.8</td>
</tr>
<tr>
<td>No</td>
<td>40.0</td>
<td>54.1</td>
<td>66.3</td>
<td>85.7</td>
<td>31.3</td>
</tr>
</tbody>
</table>

G. Employment

PCA, ABI, and Autism participants were asked 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. In particular almost half (49%) of Autism participants reported being employed, compared to 24% of ABI and just 3% of PCA participants. It is notable that 48% of unemployed Autism participants would like to work, as would 30% of ABI participants. COVID was only mentioned by 3 respondents, including this parent speaking on behalf of her son on the ABI waiver, “[Consumer] is beginning next week working at a grocery store and will have Supportive Employment assist. [Consumer] is looking forward to getting back to work because he had to stop due to COVID.” Notably this ABI participant plans to use the employment support provided by the ABI waiver. The percentage of unemployed PCA participants who would like to work decreased from 27% in 2022 to 14% in 2023.
Table 16 shows that unemployed PCA and ABI respondents who wanted to work most often cited physical disability or mental health related concerns as a reason for not working. Meanwhile 62% of unemployed ABI respondents and 46% of unemployed PCA respondents said they just did not want to work. Half (52%) of unemployed PCA participants who did not want to work mentioned disability related concerns.

Table 16. Most Common Reasons for Not Working*

<table>
<thead>
<tr>
<th>Reason</th>
<th>PCA N=37 n (%)</th>
<th>ABI N=65 n (%)</th>
<th>Autism N=9 n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of benefits</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical or mental health/disability</td>
<td>28 (75.7)</td>
<td>9 (13.8)</td>
<td>1 (11.1)</td>
</tr>
<tr>
<td>Don’t know about job resources</td>
<td>0 (0.0)</td>
<td>9 (7.7)</td>
<td>1 (11.1)</td>
</tr>
<tr>
<td>Training/education needed</td>
<td>1 (2.7)</td>
<td>3 (4.6)</td>
<td>2 (22.2)</td>
</tr>
<tr>
<td>Looking for but cannot find work</td>
<td>3 (8.1)</td>
<td>10 (15.4)</td>
<td>4 (44.4)</td>
</tr>
<tr>
<td>Transportation</td>
<td>0 (0.0)</td>
<td>4 (6.2)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (8.1)</td>
<td>10 (15.4)</td>
<td>3 (33.3)</td>
</tr>
<tr>
<td>Nothing is holding me back</td>
<td>1 (2.7)</td>
<td>5 (7.7)</td>
<td>1 (11.1)</td>
</tr>
</tbody>
</table>

*Multiple choice
One quarter (25%) of unemployed ABI participants who wanted to work asked for assistance with finding a job, as did 11% of PCA and 4 of the 10 unemployed Autism participants (Figure 26). The majority of unemployed participants who did not ask for help knew that employment assistance was available (Figure 27).

**Figure 26. Sought Out Employment Assistance**

**Figure 27. Aware of Employment Assistance**

### ii. ABI and Autism Employment Experiences

The ABI and Autism waivers provide employment services for working participants. When employed ABI and Autism participants were asked who helped them find their current job, both ABI and Autism participants most often found their jobs using waiver/vocational staff.

**ABI Job Coach**

Sixty-six percent (n=48) of employed ABI participants said someone was paid to help them with their job; 37 answered job coach questions. Almost all of these participants (95%) said that their job coaches encouraged them to do things for themselves, and 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 4.68, out of 5) and recommendations (mean score 3.77, out of 4).
**Autism Job Coach**

Forty-nine percent (n=20) of Autism participants were employed, and eight of these (42%) reported someone was paid to help them with their job. Six out of the eight participants stated that their job coach usually or always gave them all the help they needed. Most participants reported that their job coach usually or always treated them with courtesy and respect, explained things in a way that was easy to understand, and listened carefully to them. All the participants reported receiving encouragement from their job coach to do things for themselves if they could.

**H. 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. Except for care manager related items, the ratings and recommendations of other staff and most composite scores do not reflect the quality of the agency providing the case management.* Other factors to consider include the area or town where the participant lives, the number and quality of homecare agencies and staff, access to transportation, and the number and quality 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 29). CHCP participants gave high scores for the composite case manager is helpful, ranging from 92% (AASCC) to 100% (WCAAA). Scores for choosing services which matter to you varied from 83% (AASCC) to 98% (WCAAA). All agencies had low scores for planning your time and activities, indicating areas for program improvement.

Global ratings for CHCP homemaker/companions and case managers also showed differences among agencies (Figure 30). Between 77% (AASCC) to 94% (SWCAA) rated their case manager a 9 or 10.

The percentage of CHCP participants from each agency who definitely recommended their PCAs, homemaker/companions, or case managers also varied among agencies (Figure 31). The percentage of CHCP participants who would definitely recommend their care managers ranged from 61% (AASCC) to 97% (SWCAA).

Figure 29. CHCP Composite Measures by Agency: Percentage with Highest Score

![CHCP Composite Measures by Agency: Percentage with Highest Score](image)
Figure 30. CHCP Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”

Figure 31 CHCP Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff
ii. PCA waiver

Figure 32 shows there was interagency variation across most of the PCA composite measures. Highest scores for case manager is helpful varied widely this year, from 84% (AASCC) to 100% (WCAAA). Once again participants gave the lowest scores for the composite planning your time and activities, although this also varied from 50% (WCAAA) to 61% (CCC). Most global ratings and recommendations for PCA waiver staff and case managers also showed agency variation (Figures 33 and 34). The percentage of PCA participants who rated their case managers a 9 or 10 ranged from 50% (AASCC) to 93% (WCAAA), and from 58% (AASCC) to 93% (WCAAA) of participants would definitely recommend their case manager.

Figure 32. PCA Composite Measures by Agency: Percentage with Highest Score
Figure 33. PCA Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”*

*Only 21 consumers across all agencies had distinct homemaking staff who did not also provide personal care.

Figure 34. PCA Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff*

*Only 21 consumers across all agencies had distinct homemaking staff who did not also provide personal care.
iii. **ABI waivers**

Most ABI composite scores, staff global ratings, and staff recommendations showed wide variation across the 3 ABI care management agencies (Figures 35, 36, and 37). Scores for the composite case manager is helpful were all high, ranging from 91% (WCAAA) to 96% (CCC). The percentage of ABI participants who rated their case managers a 9 or 10 varied greatly, from 69% (CCC) to 96% (WCAAA), while between 71% (SWCAA) and 100% (WCAAA) of ABI participants would definitely recommend their case manager.

**Figure 35. ABI Composite Measures by Agency: Percentage with Highest Score**
Figure 36. ABI Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”*

<table>
<thead>
<tr>
<th>Agency</th>
<th>Personal assistance &amp; ILST staff</th>
<th>Homemaking staff</th>
<th>Case Manager</th>
<th>Job Coach</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCC</td>
<td>69.95</td>
<td>40.00</td>
<td>95.65</td>
<td>100</td>
</tr>
<tr>
<td>SWCAA</td>
<td>77.22</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WCAAA</td>
<td>90.48</td>
<td>0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*WCAAA homemaking only staff n=0

Figure 37. ABI Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff*

<table>
<thead>
<tr>
<th>Agency</th>
<th>Personal assistance &amp; ILST staff</th>
<th>Homemaker</th>
<th>Case Manager</th>
<th>Job Coach</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCC</td>
<td>75.90</td>
<td>20.00</td>
<td>83.67</td>
<td>50.00</td>
</tr>
<tr>
<td>SWCAA</td>
<td>80.95</td>
<td></td>
<td>70.89</td>
<td>66.67</td>
</tr>
<tr>
<td>WCAAA</td>
<td>75.00</td>
<td>0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*WCAAA homemaking only staff n=0
I. Mental Health Waiver Consumer Experience

This section shows the collective experience of the 180 MHW clients who completed a revised MHW HCBS survey between June 23, 2022 and June 30, 2023. In addition to using a subset of the HCBS CAHPS questions, the MHW also offered an online and a paper survey option to be completed without an interviewer. In all, significantly more MHW surveys were completed this year. However, the revised approach may have affected the validity of survey responses. The validity of the HCBS CAHPS was established by asking all the applicable items in a specific order and having an interviewer administer the survey. In addition, with self-administered surveys there is no way to determine the presence of a paid provider. The use of a subset of questions also limited the ability to compare the experience of MHW participants to participants in other waivers, most notably CHCP, PCA and ABI programs.

Recovery Assistants

All but one MHW participant received RA assistance in the last 3 months. Ninety-three percent of these participants felt that their RA knew what kind of help they needed with their everyday activities, like getting ready in the morning, getting groceries, or going places in the community. At least 90% of mental health waiver clients responded “always” or “usually” in response to the other RA experience questions (Figure 38). Ninety-five percent felt that their RA treated them with courtesy and respect most of the time.

Figure 38. Recovery Assistant Experience

Community Support Providers

Three-quarters (n=135) of MHW participant received CSP services in the last 3 months. The majority of respondents (94%) agreed that their CSP encouraged them to do things for themselves if they could, while an even higher number (97%) felt their CSP knew what kind of help they needed. At least 91% of mental health waiver clients responded “always” or “usually” in response to the other CSP experience questions (Figure 39). Ninety-five percent felt that the CSP listened carefully to them most or all of the time.
The MHW survey asked one question regarding transportation. Eighty-two percent said they usually or always had a way to get to their medical appointments (Table 18).

Table 18. Access to Medical Transportation

<table>
<thead>
<tr>
<th>Always</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>103 (62.4)</td>
<td>33 (20.0)</td>
<td>26 (15.8)</td>
<td>3 (1.8)</td>
</tr>
</tbody>
</table>

**Mental Health Waiver Participant Experience**

MHW participants were asked to what extent their MHW services affected their lives in three key areas (Figure 40). Participants gave positive responses – 85% or more either agreed or strongly agreed with each statement. In particular, 91% of MHW respondents agreed or strongly agreed that the MHW services helped them stay in the community, and 89% felt their MHW services helped them deal more effectively with problems.
IV. Conclusions

This is the sixth 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). 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. Although the MHW used the full HCBS CAHPS in the past 3 years, this year the MHW used a subset of the HCBS CAHPS survey questions. This report presents results from surveys conducted in FY 2023, from July 1, 2022 to June 30, 2023.

A. Survey Completion Rates

In FY 2023 each Access Agency met or exceeded their respective representative samples for CHCP Category 3, PCA, ABI 1 and ABI 2 programs. Two agencies did not meet their sample size for CHCP Category 5. AASCC, which did not start their Category 5 calls until March 2023, reached 50% of their sample. CCC NW Region began calling their NW Region Category 5 waiver participants in August 2022. However, the number of NW region Category 5 participants dropped from 21 in July, 2022 to 11 by June, 2023, which is less than the sample size required. These 11 participants had already been called and/or surveyed. Still, CCC reach 88% of its NW Category 5 representative sample, most likely due to the early start of their Category 5 calls.

This brings up an issue not discussed in previous years. For the smaller programs in particular, a decrease in number of clients over the course of the fiscal year can affect the sample size needed and the agency’s ability to reach the representative sample size determined by the client numbers at the beginning of the fiscal year. One recommendation is to redetermine the sample size needed halfway through the fiscal year.
through the fiscal year to see if the number of clients in that program decreased. Another suggestion for Category 5 to consider is to combine Categories 3 and 5 to one CHCP program. Something else to consider is to revise the calculation of the sample size especially for the very small programs where as high as an 80% response rate is needed to reach the representative sample size.

As in previous years, the other 3 waiver programs did not reach their representative sample sizes – Autism completed 35% (n=41), KBW 36% (n=64), and MHW 83% (n=180) of their respective sample sizes. The most notable differences between FY 2022 and FY 2023 include the decreased completion rates for Autism waiver (75% to 35%), while MHW completion rates increased from 13% to 83%. This report still presents the results for the KBW, Autism, and MHW 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, Autism, and the MHW programs will need to improve or change their survey strategies to increase their survey numbers. Unfortunately, the Autism program lost its staff person who did the majority of surveys, but the program did not replace that role. As discussed earlier, the revisions to the MHW survey and survey administration, as well as the added support from the MHW survey leadership, increased the number of completed surveys. Enhanced strategies, especially to reach the consumer by telephone, would likely further improve the MHW 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.

B. Key Results by Program

Composite measures

The composite item scores varied among the composites and the programs. The MHW survey only included enough items for 2 of the 7 composites. Choosing the services that matter to you once again showed the great variation this year, with CHCP, PCA, and ABI reporting higher scores than the other three programs. The care manager is helpful composite also exhibited marked variation among programs, with PCA, ABI, and CHCP reporting much higher scores than Autism or KBW. Although all programs reported lower scores for planning your time and activities, the ABI waiver stood out as achieving a higher score than other programs for this composite. 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 lower scores compared to the other composites. ABI participants reported the highest score for this composite, as evidenced by one ABI parent who stated, “[Consumer name] enjoys going to the day program with [name of agency], and he enjoys doing art there.” Another ABI respondent remarked, “[My son] gets out of the house often with his staff and is very happy with ABI program, his care manager, and services.”

Unfortunately, a lack of nearby community activities and transportation can be a problem, especially in the more rural areas of the state or where there are fewer community or program resources. Meaningful community involvement, social engagement, and enhanced choice and control are all important elements of successful community living, and these areas represent an opportunity for improvement across all programs. Commented another ABI respondent:

The program and service are fine, but we are limited to what is offered. Getting him out to socialize with others has been a challenge. ABI
• **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. This year CHCP, PCA, and ABI 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 all staff would improve services for waiver participants. However, for agency-based consumers in particular, finding staff which match those interests can be difficult.

> It's good that the [Autism] division is looking for more case managers. I am still looking for providers, and the [Autism] division needs more agencies that work with higher functioning individuals. There are few providers in New Haven county. Autism

• **Transportation to medical appointments**

Although overall scores for the composite transportation to medical appointments improved this year, multiple comments about the primary provider indicated dissatisfaction and difficulty using this service.

> Better transportation to get to medical appointments would be great. PCA

> The transportation system with Veyo is terrible. They are not reliable and don’t send the right kind of vehicles to pick me up. PCA

**Case Manager Items**

As in previous years, CHCP participants gave their case managers the highest ratings and recommendations among all the programs. Eighty-five percent of CHCP participants gave their case manager the highest rating, compared to 46% (KBW) to 75% (ABI) of other programs. While 87% of CHCP and 82% of ABI participants would definitely recommend their care manager, only 60% of Autism participants would do so. Remarks indicated that consumers highly valued care managers who responded to their calls in a timely manner and tried to address issues, as well as care managers who listened empathetically and made an effort to understand and not dismiss their concerns.

> [Care manager name] is amazing. Every time I call, she gets back to me. I appreciate everything [Access Agency] does for me. PCA

> I feel that my care manager is very easy to talk to, and she goes above and beyond for me. PCA

> [Care manager agency] has been very generous and so helpful over the years. We are very grateful. CHCP

> The care manager is very professional and friendly. She remembers details about [consumer name] – it's not just checking off a box. She seems to really care. KBW

> I need to find new PCAs. I don't have anyone right now. I called my care manager to help me with this, and she is trying to help me. PCA

Comments also indicated that there is still room for improvement, such as the family member of an Autism participant who said she “hoped to get a permanent case manager who can get to know [consumer] and the family.” In addition to providing a timely and empathetic response, Access Agencies and waiver program staff could improve communication including returning calls more quickly and effectively communicating any change in care managers.

> I wish that it wouldn't be so difficult to get through to case managers. CHCP

> [My case manager] has a very heavy caseload that pulls her in too many directions. ABI
I want the care manager to work on returning calls and would have liked to [have] been informed of the care manager’s role when referred to program. PCA

Why do we keep getting different social workers? Otherwise, I’m satisfied with services Mom is receiving. CHCP

Other comments suggested that consumers had needs which care managers might be able to assist with, such as transportation, meals on wheels, food stamps, or durable medical equipment.

I would like to find out if I qualify for SNAP or food stamps. CHCP

Hace 4 años estoy esperando la aprobación de una silla de ruedas y nadie hace nada. Todos lo demas estoy satisfecha. [I have been waiting for approval for a wheelchair for four years and no one does anything. Everything else I’m satisfied.] CHCP

[I do] not know how to access help in the home. [I’ve been] told there is a nursing shortage, and the only option is to get her a CNA [certified nursing assistant]. [I need help to access diapers. [The] care manager is not calling [me] back. KBW

Almost all (98%) of ABI and Autism participants knew who their case manager was, compared to 84% of CHCP and PCA, and 73% of KBW. Between 78-85% of PCA, CHCP, ABI, and Autism participants said they would contact their care manager if they wanted to change their service or care plan, compared to 73% of KBW. 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. Consumers and their family members would benefit from DSS effectively communicating the specific case management and other services provided by the waiver and DSS. Stated one KBW parent, “I’m constantly filling out forms for renewal for Medicaid, Katie Beckett, CFC, etc. It’s very confusing. The rules and DSS services are very cryptic. I keep pushing to try to know more. There are so many people who don’t even know what I know.”

Program Services

When asked for any additional comments, many consumers echoed this CHCP participant, “Estoy satisfecho con los servicios que actualmente recibo.” [I am satisfied with the services I currently receive.] At the same time, other participants expressed the need for additional services or hours not provided in their care plan. One CHCP consumer described how she needed, but was not getting, the dressing and showering assistance she needed due to her ongoing health issues. Stated another CHCP consumer, “I’d like more services, if my care plan could afford, on Sunday evening to put me to bed.”

One comment indicated a need for services not yet available in the state, such as community Ombudsman services, or that it should be easier to get more information about the state HCBS available.

I’m disabled, but not mentally disabled, and I get treated that way. There should be a go to person that we can go to. CHCP

There should be more information about how to get onto PCA program. It is a difficult process to go through. PCA

I’m constantly filling out forms for renewal for Medicaid, Katie Beckett, CFC, etc. It’s very confusing. The rules and DSS services are very cryptic. I keep pushing to try to know more. There are so many people who don’t even know what I know. KBW
Comments also indicated a need for family and caregiver supports. A CHCP consumer remarked that he relies on the help from his wife as his PCA “doesn’t do anything” for him. The nephew of a CHCP consumer with a live-in PCA expressed feeling “overwhelmed” with his aunt’s cognitive decline and described the toll it has taken on him and their family. Like many other dedicated family caregivers, even with these challenges, he wants to continue keeping his aunt at home for as long as possible. On the other hand, consumers and family members are making more use of the Adult Family Living program and finding that it works well for them.

*Can you help me find someone to help me with [consumer]? It’s very difficult. It’s just me, my husband, and my son helps too. Lately she’s been having a lot of mucous, and it’s hard for her to eat. She is nonverbal but when you speak to her, she turns her head. KBW*

*I have really needed more bathing assistance so that my father won’t miss work. It takes two people to help me. ABI*

**Staff Ratings and Recommendations**

CHCP and PCA participants were much more likely than other program participants to highly rate and definitely recommend their personal/behavioral staff. For example, 90% of CHCP participants would definitely recommend their personal assistance staff, while just 72% of ABI participants would definitely recommend their PCAs and/or ILSTs. Eighty-six percent of CHCP would rate their PCAs a 9 or 10, compared to just 56% of Autism participants. Only 64% of MHW participants gave their RAs a 9 or 10. Some consumers remarked that their PCAs “were like family,” especially for those who had the same PCAs for a long time. Remarked one CHCP consumer about her caregivers, “If we can get 100 Vicky and Marys, the elderly would be in much better care.” Other positive comments about HCBS staff included:

*My PCA is also my friend. He’s good to me. PCA*

*Estoy contenta con la empleada pero la tengo por muy poco tiempo. Estoy satisfecha con los servicios. [I am happy with my employee, but I have her for a short time. I am satisfied with the services.] CHCP*

*We’ve had to change the caregiver twice previously. Since getting a new caregiver, we are very happy with her help – [consumer] seems to be doing much better with [new caregiver]. CHCP*

*My helpers are nice girls – polite and nice and do everything I need. CHCP*

- **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, and difficulties finding staff on weekends. Issues with agency communication and agency-based staff supervision were also mentioned, such as the consumer being told that staff would help with something, but the staff person saying they could not or would not provide that assistance. Consumers from various programs expressed that sometimes they had to change agencies or ask for different staff in order to find the agency or staff they were happy with. Having reliable, consistent staff is very important for individuals who have difficulty 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. More than one consumer suggested that PCAs or ILSTs get paid more. Remarks reflecting staffing challenges as well as suggestions for improvements include:

*There is a need for more companies who offer PCA services. PCAs are hard to find. PCA*

*The [homecare] agency does not tell the PCAs to shower me. CHCP*
You have to go through a lot of caregivers to find the right one. PCA

Lo único que me gustaría que las chicas que me vienen ayudar usen menos su teléfono personal. [The only thing I would like is for the girls who come to help me to use their personal phone less.] CHCP

PCAs need more training. They don’t know how to perform basic tasks. CHCP

We hope they find someone soon to help him as he is falling behind on some of his goals. Autism

I wish they could send an African American. CHCP

My daytime aide is excellent, but my nighttime aides are atrocious. That is why I refused to answer several questions because I didn’t want them to reflect on my daytime aide. CHCP

There needs to be more background checks on workers. ABI

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 and technique to provide personal care. 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 and gain specialized skills. 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**

Even though 70% of PCA participants still reported hiring their own staff this year, the percentage of PCA waiver participants using agency-based services increased notably from 13% in 2022 to 30% in 2023. Consistent with the previous year, only a small percentage of CHCP participants self-directed their services. Sixty percent of self-directing CHCP participants hired family members, as did 69% of self-directing KBW participants. Consumers most frequently employed adult children, siblings, or parents as 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, and self-directing consumers still also had difficulties finding staff.

We hire PCAs thru CFC. We’re qualified for 55 hours a week but we can’t find quality people, so we are getting about 15 to 20 hours a week. KBW

Two self-directing PCA consumer offered some advice for other self-directing consumers:

*People should make a list of the help they need from their PCA. Communication is important.* PCA

*If you want to keep your PCAs, be decent to them.* PCA

Once again self-directed consumers remarked on their difficulties working with Allied, the State’s current Fiscal Intermediary, such as struggles getting their staff paid on time or getting reimbursed for covered items. Hopefully a new fiscal intermediary will provide higher quality support for self-directed consumers. Regularly updating and expanding the PCA directory, including descriptions for specialized skills, would also be helpful for self-directing consumers.

*The main issue is when [I go] to [the Allied] directory to find help, it isn’t updated. There should be other resources aside of the directory to find PCAs. Also, PCAs should get paid more and [get] benefits.* PCA
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 the CHCP performance benchmark for all three composites. All Access Agencies also met the performance benchmarks for CHCP case manager global rating and care manager recommendation. The CHCP performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.64 to 4.00
- Choosing the service which matter to you composite: 3.71 to 3.95
- Personal safety and respect composite: 3.87 to 4.00
- Case manager global rating: 4.69 to 4.94
- Case manager recommendation: 3.54 to 3.97

**PCA waiver**

All four Access Agencies met the benchmark for two of three PCA composites (choosing the 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. AASCC’s score was slightly under this performance benchmark (3.47 vs. 3.5). Three of the four Access Agencies met the performance benchmarks for PCA care manager global rating and care manager recommendation. AASCC’s score for care manager global rating was 4.36 (Benchmark 4.5). AASCC’s score for care manager recommendation was slightly below the benchmark (3.48 vs. 3.5). The PCA performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.47 to 4.00
- Choosing the service which matter to you composite: 3.60 to 4.00
- Personal safety and respect composite: 3.88 to 4.00
- Case manager global rating: 4.36 to 4.93
- Case manager recommendation: 3.48 to 3.99

**ABI waiver**

Three Access Agencies provide care manager for the ABI waivers. All three agencies met the ABI performance benchmarks for all three composite measures, care manager global rating, and care manager recommendation. The ABI performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.84 to 3.93
- Choosing the service which matter to you composite: 3.58 to 3.76
- Personal safety and respect composite: 3.91 to 3.93
- Case manager global rating: 4.52 to 4.96
- Case manager recommendation: 3.61 to 4.00
D. Mental and Emotional Health

Similar to previous years, mental health is an area of concern for all 5 waiver programs – between 20% (Autism) to 34% (MHW) of respondents in each waiver program reported fair or poor mental or emotional health. On the encouraging side, larger percentages of Autism and ABI respondents reported very good to excellent mental health compared to last year. Comments included:

- *Esta en una depression y necesita ayuda professional.* [He is in a depression and needs professional help.] CHCP
- *Most of the time I’m not feeling well emotionally.* CHCP
- *[Creo que] La soledad es mala, pero mejor estar solo que mal acompañada.* [I think loneliness is bad, but better to be alone than in bad company.] CHCP

A large majority (87%) of MHW participants lived alone or without other adults, as did between 60%-66% of ABI, PCA, and CHCP participants. 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 as facilitators. Another 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.

E. Employment

This year almost half (49%) of Autism participants reported being employed, up from 39% in 2022. In comparison, 24% of ABI participants were employed. Unemployed Autism respondents were much more likely to want to work compared to unemployed respondents in the other waivers. Stated one respondent speaking on behalf of her son on the Autism waiver who wants to work, “He knows it may take a while to find employment. He is interested in publishing.” 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. 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.

F. CHCP, PCA, ABI Additional Data by Agency

CHCP, PCA, and ABI composites, staff ratings, and staff recommendations are 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 most likely reflect other factors such as the town where the participant lives, the quality of the home care agencies and PCAs providing services to that area, and access to transportation, not the quality of the Access Agency providing the case management.

Scores for the CHCP case manager is helpful composite and CHCP care manager recommendations showed much interagency variation. For example, between 78% to 95% of CHCP participants would definitely recommend their care managers. Meanwhile CHCP care manager global rating scores showed almost no variation.

Scores for most of the PCA composite measures showed variation across agencies. For example, highest scores for the composite case manager is helpful ranged from m84% to 100%. PCA case manager global ratings and recommendations also showed interagency variation. The percentage of PCA participants who would give their care managers a 9 or 10 ranged from 80% to 100%, and between 77% to 84% of PCA participants would definitely recommend their care managers.
All ABI composite scores, staff global ratings, and staff recommendations showed wide variation across the 3 care management agencies. For example, between 70% to 91% of ABI respondents from different agencies would rate their ABI care managers a 9 or 10, and the percentage of respondents who would definitely recommend their case manager ranged from 60-81%.

All agencies had low scores for planning your time and activities and most had relatively low scores for medical transportation. Choosing the services which matter to you also had some lower scores. These indicate areas for program improvement.

**G. Mental Health Waiver Consumer Experience**

MHW participants rated their RAs very highly. For example, at least 90% of mental health waiver clients responded “always” or “usually” to the RA experience questions, such as how often do your RAs listen carefully to you. In addition, 95% felt that their RA treated them with courtesy and respect most of the time. MHW participants also rated their CSPs very highly. For example, 94% of participants agreed that their CSP encouraged them to do things for themselves if they could, while an even higher number (97%) felt their CSP knew what kind of help they needed. At least 91% of mental health waiver clients responded “always” or “usually” in response to the other CSP experience questions. For example, 95% felt that their CSP listened carefully to them most or all of the time.

MHW participants were asked 3 questions to determine to what extent their MHW services helped them deal more effectively with problems, have the life I want in recovery, or stay in the community. At least 85% of participants either agreed or strongly agreed with each statement. In particular, 91% of MHW respondents agreed or strongly agreed that the MHW services helped them stay in the community.

**H. Final thoughts**

Quality assurance staff from the Access Agencies and DSS are currently completing HCBS CAHPS telephone and in-person surveys for the CHCP, PCA, ABI, Autism, and Katie Beckett waivers. Meanwhile, DMHAS staff continue to complete the modified MHW HCBS CAHPS survey using both telephone and consumer self-administration. UConn Health Center on Aging continues to provide training and technical assistance, including survey modifications, survey site administration, online platforms for survey entry, training, and other support. Respondents expressed appreciation for their waiver services and commented on the impact of the waiver programs on their lives, such as the CHCP participant who stated that the home care services are “vital” to seniors. Other comments included:

*We’re very happy with the services and ABI waiver. ABI*

*I really appreciate the people whom I have, everyone is doing a good job. [They are] almost family to me. CHCP*

*I’m very appreciative for the help that I get. I could not exist without the help I receive. CHCP*

*Muy bueno agradesco lo que han hecho por mi. Estoy satisfecha con todo. [Very good. I appreciate what they have done for me. I am satisfied with everything.] CHCP*

*Everything is going good for me. This program is great! PCA*

*This program is a God-send. My wife needs all the help she can get. They call all the time to ask how she is doing. PCA*

*I am so incredibly grateful to the waiver program. Thankful for all services I have [which] allow [me] to have a wonderful quality of life through self-direction. Autism*
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 2022
### Appendix A. Composite Measures Items

<table>
<thead>
<tr>
<th>Staff are reliable and helpful</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>
</tr>
<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>
</tr>
<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>
</tr>
<tr>
<td>In the last 3 months, how often did {homemakers} come to work on time?</td>
</tr>
<tr>
<td>In the last 3 months, how often did {homemakers} work as long as they were supposed to?</td>
</tr>
<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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</table>

<table>
<thead>
<tr>
<th>Staff listen and communicate well</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} treat you with courtesy and respect?</td>
</tr>
<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>
</tr>
<tr>
<td>In the last 3 months, how often did {personal assistance/behavioral health staff} treat you the way you wanted them to?</td>
</tr>
<tr>
<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>
</tr>
<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>
</tr>
<tr>
<td>In the last 3 months, how often did {homemakers} treat you with courtesy and respect?</td>
</tr>
<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>
</tr>
<tr>
<td>In the last 3 months, how often did {homemakers} treat you the way you wanted them to?</td>
</tr>
<tr>
<td>In the last 3 months, did you feel {homemakers} knew what kind of help you needed?</td>
</tr>
<tr>
<td>In the last 3 months, how often did {homemakers} explain things in a way that was easy to understand?*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case manager is helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last 3 months, could you contact this {case manager} when you needed to?</td>
</tr>
<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>
</tr>
<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>
</tr>
</tbody>
</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

File name: CAHPSHcbs01192017SurvEng508
Last updated: January 19, 2017
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
   3. DON'T KNOW → GO TO Q6
   4. REFUSED → GO TO Q6
   5. 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 WHEREEVER 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
   3. DON'T KNOW → GO TO Q8
   4. REFUSED → GO TO Q8
   5. 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 WHEREEVER 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. \[[IF (Q4 \text{ OR } Q6) \text{ AND } Q8 = \text{YES}, \text{ASK}] \] In the last 3 months, did the same people who help you with everyday activities also help you clean your home?

\begin{itemize}
  \item[1] YES
  \item[2] NO
  \item[-1] DON’T KNOW
  \item[-2] REFUSED
  \item[-3] UNCLEAR RESPONSE
\end{itemize}

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?

\begin{itemize}
  \item[1] YES
  \item[2] NO
  \item[-1] DON’T KNOW
  \item[-2] REFUSED
  \item[-3] UNCLEAR RESPONSE
\end{itemize}
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
3. DON’T KNOW
4. REFUSED
5. 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
3. DON’T KNOW → GO TO Q20
4. REFUSED → GO TO Q20
5. 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
3. DON’T KNOW → GO TO Q19
4. REFUSED → GO TO Q19
5. 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
3. DON’T KNOW
4. REFUSED
5. 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
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
2. NO
3. DON’T KNOW → GO TO Q26
4. REFUSED → GO TO Q26
5. 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
3. DON’T KNOW
4. REFUSED
5. 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
3. DON’T KNOW → GO TO Q28
4. REFUSED → GO TO Q28
5. 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
3. DON’T KNOW
4. REFUSED
5. 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 . . .
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} 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 {personal assistance/behavioral health staff} knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?
1. YES
2. NO
-1. DON’T KNOW
-2. REFUSED
-3. UNCLEAR RESPONSE

34. 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
-1. DON’T KNOW
-2. REFUSED
-3. 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
-1. DON’T KNOW
-2. REFUSED
UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from {personal assistance/behavioral health 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 {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 \{homemakers\} 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 \{homemakers\} 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 \{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?
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ UNCLEAR RESPONSE OR NOT APPLICABLE

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 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
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ 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
-1 □ DON’T KNOW → GO TO Q41
-2 □ REFUSED → GO TO Q41
-3 □ 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
-1 □ DON’T KNOW
-2 □ REFUSED
-3 □ 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 . . .
19

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
- -1 DON’T KNOW
- -2 REFUSED
- -3 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?
- -1 DON’T KNOW
- -2 REFUSED
- -3 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?
- -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 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 . . .
ALTERNATE VERSION: Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. In the last 3 months, did you have a way to get to your medical appointments? Would you say . . .

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

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?

1 □ YES
2 □ NO → GO TO Q68
-1 □ DON’T KNOW → GO TO Q68
-2 □ REFUSED → GO TO Q68
-3 □ UNCLEAR RESPONSE → GO TO Q68

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

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

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

1 □ YES
2 □ NO → GO TO Q71
-1 □ DON’T KNOW → GO TO Q71
-2 □ REFUSED → GO TO Q71
-3 □ UNCLEAR RESPONSE → GO TO Q71

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

1 □ YES
2 □ NO → GO TO Q71
-1 □ DON’T KNOW → GO TO Q71
-2 □ REFUSED → GO TO Q71
-3 □ UNCLEAR RESPONSE → GO TO Q71

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
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 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. ADVERTISMENT
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?

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

1. YES → GO TO THE ABOUT YOU SECTION
2. NO
3. DON’T KNOW
4. REFUSED
5. 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
3. DON’T KNOW
4. REFUSED
5. 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?
5. DON’T KNOW
6. REFUSED
7. 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?
3. DON’T KNOW
4. REFUSED
5. 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?
5. DON’T KNOW
6. REFUSED
7. 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?
1 □ DON’T KNOW
2 □ REFUSED
3 □ 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?
1 □ DON’T KNOW
2 □ REFUSED
3 □ 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\}? 

\[ 0 \text{ TO } 10 \]

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

ALTERNATE VERSION: How would you rate the help you get from your \{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 \{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\} . . .

1 Definitely no,  
2 Probably no,  
3 Probably yes, or  
4 Definitely yes?  
-1 DON'T KNOW  
-2 REFUSED  
-3 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 . . .

1 Excellent,  
2 Very good,
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

39
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
     □ 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 □ RESTATES 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
END OF SURVEY – INTERVIEWER COMPLETE FOR EVERYONE:

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. Mental Health Waiver HCBC Survey - 2022
Telephone Mental Health Waiver Participant Survey

I’m calling because we are doing a survey to learn about the services you receive at home or in the community. I’d like to ask you some questions about the people who are paid to help you, access to care, transportation, and things you do. Results of the study will help Connecticut evaluate how well its programs are meeting the needs of people who receive services like you. Can I ask you some questions about the services you receive? It will take about 20 minutes.

Before we begin, let me assure you that all information collected will be kept strictly confidential and will not be reported in any way that identifies you personally. Your answers will be combined with the answers of others and reported in such a way that no single individual could ever be identified. None of the people who help you will know what you say, unless you want them in the room while you answer the questions. Also, the services and supports you get will not change. We are collecting this information for program evaluation only. Although the information you give me is confidential, you should know that if I see hear anything that makes me think you are being hurt or are in danger, I have a responsibility to tell my supervisor. Your participation is completely voluntary and if we come to any question you prefer not to answer, just tell me and we’ll move on to the next one. If you have any questions, please stop me and ask me. Also, please let me know if you do not understand a question or if you would like me to repeat it.

**GETTING NEEDED SERVICES FROM RECOVERY ASSISTANTS**

1. In the last 3 months, did you get recovery assistant or RA services? An RA or aide helps teach you skills to clean your apartment, shop, prepare meals, and maintain a healthy lifestyle.
   - Yes → GO TO #2
   - No  → GO TO #10
   - Do not know  → GO TO #10
   - Refused  → GO TO #10

2. In the last 3 months, how often did your recovery assistant come to work on time?
   - Always
   - Usually
   - Sometimes
   - Never
   - Do not know
   - Refused

3. In the last 3 months, how often did your recovery assistant work as long as they were supposed to?
   - Always
   - Usually
   - Sometimes
   - Never
   - Do not know
   - Refused
4. In the last 3 months, how often did your recovery assistant treat you with courtesy and respect?
   - Always
   - Usually
   - Sometimes
   - Never
   - Do not know
   - Refused

5. In the last 3 months, how often did your recovery assistant explain things in a way that was easy to understand?
   - Always
   - Usually
   - Sometimes
   - Never
   - Do not know
   - Refused

6. In the last 3 months, how often did your recovery assistant listen carefully to you?
   - Always
   - Usually
   - Sometimes
   - Never
   - Do not know
   - Refused

7. In the last 3 months, did you feel your recovery assistant 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
   - Do not know
   - Refused

8. In the last 3 months, did your recovery assistant encourage you to do things for yourself if you could?
   - Yes
   - No
   - Do not know
   - Refused
9. How would you rate the help you get from your recovery assistant?
   □ Excellent
   □ Very good
   □ Good
   □ Fair
   □ Poor
   □ Do not know
   □ Refused

GETTING NEEDED SERVICES FROM CSPs OR CSP CASE MANAGERS

10. In the last 3 months, did you get CSP, Community Service Provider, or CSP case management services? A CSP or CSP case manager helps you with things like benefits, paperwork, and budgeting.
   □ Yes → GO TO #11
   □ No → GO TO #19
   □ Do not know → GO TO #19
   □ Refused → GO TO #19

11. In the last 3 months, how often did your CSP come to work on time?
   □ Always
   □ Usually
   □ Sometimes
   □ Never
   □ Do not know
   □ Refused

12. In the last 3 months, how often did your CSP work as long as they were supposed to?
   □ Always
   □ Usually
   □ Sometimes
   □ Never
   □ Do not know
   □ Refused

13. In the last 3 months, how often did your CSP explain things in a way that was easy to understand?
   □ Always
   □ Usually
   □ Sometimes
   □ Never
   □ Do not know
   □ Refused
14. In the last 3 months, did your CSP encourage you to do things for yourself if you could?
   - Yes
   - No
   - Do not know
   - Refused

15. In the last 3 months, how often did your CSP treat you with courtesy and respect?
   - Always
   - Usually
   - Sometimes
   - Never
   - Do not know
   - Refused

16. In the last 3 months, how often did your CSPs listen carefully to you?
   - Always
   - Usually
   - Sometimes
   - Never
   - Do not know
   - Refused

17. In the last 3 months, did you feel your CSP knew what kind of help you needed?
   - Yes
   - No
   - Do not know
   - Refused

18. How would you rate the help you get from your CSP?
   - Excellent
   - Very good
   - Good
   - Fair
   - Poor
   - Do not know
   - Refused
**HOME DELIVERED MEALS**

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

- [ ] Excellent
- [ ] Very good
- [ ] Good
- [ ] Fair
- [ ] Poor
- [ ] Do not know
- [ ] Refused
- [ ] Not Applicable – Did not use home-delivered meal service

**CHOOSING YOUR SERVICES**

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

- [ ] All of the things that are important to you
- [ ] Most of the things that are important to you
- [ ] Some of the things that are important to you
- [ ] None of the things that are important to you
- [ ] Do not know
- [ ] Refused

21. In the last 3 months, did you feel your staff knew what is on your recovery plan, including the things that are important to you?

- [ ] Yes
- [ ] No
- [ ] Do not know
- [ ] Refused

**TRANSPORTATION**

22. 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?

- [ ] Always
- [ ] Usually
- [ ] Sometimes
- [ ] Never
- [ ] Do not know
- [ ] Refused
PERSONAL SAFETY

The next few questions ask if anyone paid to help you treated you badly in the last 3 months. This includes an RA, aide, or CSP 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 hear something that makes me think you are being hurt or are in danger.

23. 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?
   - Yes
   - No
   - Do not know
   - Refused

24. In the last 3 months, did any staff take your money or your things without asking you first?
   - Yes \(\rightarrow\) GO TO #24a
   - No \(\rightarrow\) GO TO #25
   - Do not know \(\rightarrow\) GO TO #25
   - Refused \(\rightarrow\) GO TO #25

   24a. In the last 3 months, did someone work with you to fix this problem?
   - Yes
   - No
   - Do not know
   - Refused

25. In the last 3 months, did any staff yell, swear, or curse at you?
   - Yes \(\rightarrow\) GO TO #25a
   - No \(\rightarrow\) GO TO #26
   - Do not know \(\rightarrow\) GO TO #26
   - Refused \(\rightarrow\) GO TO #26

   25a. In the last 3 months, did someone work with you to fix this problem?
   - Yes
   - No
   - Do not know
   - Refused

26. In the last 3 months, did any staff hit you or hurt you?
   - Yes \(\rightarrow\) GO TO #26a
   - No \(\rightarrow\) GO TO #27
   - Do not know \(\rightarrow\) GO TO #27
   - Refused \(\rightarrow\) GO TO #27

   26a. In the last 3 months, did someone work with you to fix this problem?
   - Yes
   - No
   - Do not know
   - Refused
COMMUNITY INCLUSION AND EMPOWERMENT

27. Do you have any family members who live nearby? Do not include family members you live with.
   [ ] Yes
   [ ] No
   [ ] Do not know
   [ ] Refused

28. Do you have any friends who live nearby?
   [ ] Yes
   [ ] No
   [ ] Do not know
   [ ] Refused

29. In the last 3 months, when you wanted to, how often could you do things in the community that you like?
   [ ] Always
   [ ] Usually
   [ ] Sometimes
   [ ] Never
   [ ] Do not know
   [ ] Refused

30. In the last 3 months, did you need more help than you get from your staff to do things in your community?
   [ ] Yes
   [ ] No
   [ ] Do not know
   [ ] Refused

31. In the last 3 months, did you take part in deciding what you do with your time each day?
   [ ] Yes
   [ ] No
   [ ] Do not know
   [ ] Refused

32. 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?
   [ ] Yes
   [ ] No
   [ ] Do not know
   [ ] Refused
MENTAL HEALTH WAIVER QUESTIONS

How much do you Agree or Disagree with each statement?

33. As a result of the services I have received from the Mental Health Waiver, I deal more effectively with my daily problems.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Neither agree nor disagree
   - [ ] Disagree
   - [ ] Strongly Disagree
   - [ ] Do not know
   - [ ] Refused

34. As a result of the services I have received from the Mental Health Waiver, I can have the life I want in recovery.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Neither agree nor disagree
   - [ ] Disagree
   - [ ] Strongly Disagree
   - [ ] Do not know
   - [ ] Refused

35. 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.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Neither agree nor disagree
   - [ ] Disagree
   - [ ] Strongly Disagree
   - [ ] Do not know
   - [ ] Refused

FINAL QUESTIONS

36. In general, how would you rate your overall health?
   - [ ] Excellent
   - [ ] Very good
   - [ ] Good
   - [ ] Fair
   - [ ] Poor
   - [ ] Do not know
   - [ ] Refused
37. In general, how would you rate your overall mental or emotional health?
   □ Excellent
   □ Very good
   □ Good
   □ Fair
   □ Poor
   □ Do not know
   □ Refused

38. How many adults live at your home, including you?
   □ 1 (Just the waiver participant)
   □ 2 to 3
   □ 4 or more
   □ Do not know
   □ Refused

39. What is your age?
   □ 18 to 24
   □ 25 to 34
   □ 35 to 44
   □ 45 to 54
   □ 55 to 64
   □ 65 to 74
   □ 75 or older
   □ Do not know
   □ Refused

40. Are you male or female?
   □ Male
   □ Female
   □ Non-binary (not exclusively male or female, or transgender)
   □ Other gender (specify) ________________________
   □ Do not know
   □ Refused

41. Are you of Hispanic, Latino/a, or Spanish origin?
   □ Yes, Hispanic, Latino/a, or Spanish
   □ No, Not Hispanic, Latino/a, or Spanish
   □ Other ethnicity (specify) ________________________
   □ Do not know
   □ Refused
42. What is your race? You may choose one or more of the following. Would you say you are...

☐ White
☐ Black or African-American
☐ Asian
☐ Native Hawaiian or other Pacific Islander
☐ American Indian or Alaska Native
☐ Some other race (specify) ___________________________
☐ Do not know
☐ Refused

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

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Thank you for completing this interview with me.
If you wish to contact Advanced Behavioral Health, Inc. (ABH),
the number is: 860-704-6186.

INTERVIEWER: PLEASE COMPLETE THE FOLLOWING QUESTIONS AFTER THE INTERVIEW IS FINISHED:

44. Who completed this survey?
☐ The waiver participant on his/her own
☐ The waiver participant with assistance from another person
☐ A proxy – Someone else completed the survey for the waiver participant

45. Did a Recovery Assistant, Aide, CSP, Case manager, or any other Paid Staff person help the waiver participant complete this survey?
☐ Yes
☐ No

46. Interview done by:
☐ Telephone
☐ Video (for example, Zoom, MS Teams, etc.)
☐ In-person
☐ Other _______________

Waiver Participant First Name: _______________________________
Waiver Participant Last Name: _______________________________
ABH Client ID: _____________________
Interviewer Name: _______________________________
Date Interview Completed: ______________