

2021 Annual Report:

Consumer Assessment of Health Provider  
Systems Home and Community-Based Services  
(HCBS CAHPS) Survey Results:

Connecticut HCBS programs\*

\*Access Agencies De-identified

**July 1, 2020 – June 30, 2021**

**December, 2021**

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## Table of Contents –

<b>I.</b>	<b>Introduction</b> .....	<b>1</b>
<b>II.</b>	<b>Methods</b> .....	<b>1</b>
	A. HCBS CAHPS® Survey .....	1
	B. Survey Administration .....	2
	C. Measures .....	2
<b>III.</b>	<b>Results</b> .....	<b>4</b>
	A. Respondent Sample .....	4
	B. Consumer Demographics.....	5
	C. Service Use by Program .....	6
	D. HCBS CAHPS® Key Results by Program .....	6
	E. CHCP, PCA, and ABI Performance Benchmarks by Agency.....	12
	F. Additional Findings by Program.....	22
	G. Employment.....	30
	H. Mental Health Waiver Participant Questions.....	33
	I. CHCP, PCA, and ABI Additional Data by Agency .....	34
<b>IV.</b>	<b>Conclusions</b> .....	<b>41</b>
	A. Survey Completion Rates.....	41
	B. Key Results by Program .....	41
	C. CHCP, PCA, and ABI Performance Benchmarks .....	45
	D. Impact of COVID-19 .....	46
	E. Mental and Emotional Health.....	46
	F. Employment.....	47
	G. Mental Health Waiver Experience .....	47
	H. CHCP, PCA, and ABI Additional Data by Agency .....	47
	I. Respondent Suggestions.....	48
	J. Final Thoughts.....	49
<b>V.</b>	<b>Appendices</b> .....	<b>50</b>
	A. Composite Measures Items .....	51
	B. HCBS CAHPS® Survey – Connecticut version 2019 (CHCP-PCA-ABI-Autism-KBW).....	53
	C. HCBS CAHPS® Survey – Connecticut version 2019 (Mental Health Waiver).....	98

## **I. Introduction**

The Consumer Assessment of Health Provider Systems Home and Community-Based Services (HCBS CAHPS<sup>®</sup>) survey is a standardized, cross-disability tool to assess and improve HCBS program quality. The survey underwent rigorous reliability and validity testing and gained approval from the national Consumer Assessment of Health Provider Systems (CAHPS<sup>®</sup>) 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 means that Connecticut's data includes all participants' perspectives, regardless of disability.

Connecticut is in its fourth year of HCBS CAHPS survey administration, using the survey to inform quality measurement in eight of its Medicaid programs: Connecticut Home Care Program (CHCP) Categories 3 and 5, Personal Care Assistance (PCA), Acquired Brain Injury I and II (ABI), Autism, Katie Beckett (KBW), and Mental Health (MHW) waivers. 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. The Department of Mental Health and Addiction services (DMHAS) added a separate set of questions for MHW participants. To tailor the survey to the participant and waiver program, waiver specific services and terms are integrated directly into the survey. For example, only ABI participants are asked about Independent Living Training Specialists (ILSTs). All participants are asked how they refer to their paid staff; these responses are then used throughout that individual's survey. A participant's waiver program determines which services to ask about and what terms to use to refer to these services (see Table 1). The full HCBS CAHPS surveys are attached in Appendix B (CHCP, PCA, ABI, Autism, KBW) and Appendix C (MHW).

Table 1. Program Services

	CHCP	PCA	ABI	Autism	KBW	MHW
Personal care assistance	X	X	X	X		
Behavioral health services			X*	X**		
Recovery assistance						X
Homemaker/companion or Homemaking services	X	X	X	X		
Case manager or Clinical Case Manager	X	X	X	X	X	X
Job coach			X	X		X
Community Service Provider						X

\*Independent Living Skills Training (ILST)

\*\*Life skills coach or community mentor

## B. Survey Administration

Contracted case management agencies, or Access Agencies, are required to complete surveys for the CHCP, PCA, and ABI waivers. Connecticut Department of Social Services (DSS) staff are responsible for completing surveys for the Katie Beckett and Autism waivers. DMHAS uses quality assurance staff from one of its case management provider agencies, as well as research staff from the University of Connecticut at Storrs to complete their surveys (hereafter collectively referred to as MHW quality assurance staff). Using client enrollment numbers as of 7/1/2020, DSS determined the target number of surveys for each Access Agency, DSS, and DMHAS to complete between July 1, 2020 to June 30, 2021 (Fiscal Year [FY] 2021) in order to reach their representative sample sizes.

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

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

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

## C. Measures

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

Each composite scale comprises three to twelve individual questions (see Appendix A). Most of these questions have four response options: never, sometimes, usually, always. Each response is coded with a number from one to four, with one indicating the most negative and four the most positive response.

A composite's final score is generated by combining the answers from each question, producing one number ranging from one to four. All scores were rounded to the second decimal point.

For global ratings, participants are asked to rate the help they get from each type of staff based on a scale from 0 to 10, or alternatively, using a worded scale from poor to excellent. These responses are grouped to form a five point rating scale with scores ranging from one to five, with the higher the number, the more positive the rating. Recommendations are based on a four point scale derived from asking if the participant would recommend the person using one of the following responses: definitely no, probably no, probably yes, or definitely yes (range 1 to 4; higher numbers indicate more positive recommendation).

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

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

Table 2. Key Measures

Composites	Staff are reliable and helpful Staff listen and communicate well Case manager is helpful Choosing services that matter to you Transportation to medical appointments Personal safety and respect Planning your time and activities
Global ratings	Personal care/Recovery assistance/Behavioral health staff Homemaker/Companion Case manager Job coach Community Service Provider
Recommendations	Personal care/Recovery assistance/Behavioral health staff Homemaker/Companion Case manager Job coach Community Service Provider
Unmet need	Personal care Meals Medications Toileting Household tasks
Physical safety	Did any staff hit or hurt you

### III. Results

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

#### A. Respondent Sample

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

Table 3. Representative Sample and Completed Surveys by Program

	Total number of waiver participants (N)	Representative sample (N)	Completed surveys (N)	Percentage of representative sample completed (%)
<b>CHCP programs</b>				
CHCP Category 3	12966	375	391	>100
CHCP Category 5	373	190	192	>100
CHCP Category 2	--	--	1	--
Total CHCP Surveys	13339	565	<b>584</b>	>100
<b>PCA</b>	982	277	<b>281</b>	>100
<b>ABI waivers</b>				
ABI 1	361	187	195	>100
ABI 2	210	136	136	100.0
Total ABI Surveys	571	324	<b>331</b>	>100
<b>Autism</b>	116	90	<b>66</b>	77.6
<b>Katie Beckett</b>	323	176	<b>70</b>	39.8
<b>MHW</b>	568	230	<b>42</b>	18.3
<b>Total surveys completed, any program</b>			<b>1374</b>	

-- Not applicable because no surveys were required by DSS from 7/1/2020-6/30/2021.

*Similar to last year, all the Access Agencies met or exceeded their respective representative samples for the combined CHCP programs, the PCA waiver, and the combined ABI 1 and 2 waivers.* This is impressive given that COVID-19 made completion of surveys more difficult – fewer people had services and overall people seemed less willing to participate. DSS improved their Autism survey numbers again this year, completing 78% of their representative sample in FY 2021, compared to 62% in FY 2020. Significantly fewer KBW surveys were completed this year (2020 n=127 surveys; 2021 n=70), reaching 39% of the representative sample size in FY 2021, compared to 72% in FY 2020. MWH numbers fell as well; 42 surveys were completed in FY 2021, equaling 18% of the MHW representative sample, compared to 37% (n=85 surveys) in FY 2020. This report still presents the results for these three programs to show program trends.

With the exception of KBW and Autism, most surveys were completed by the consumer or the consumer with assistance (Table 4). Similar to last year, almost half (47%) of all ABI surveys were also completed by someone other than the consumer (by proxy). For assisted interviews, the person assisting most often helped by answering or restating some of the questions, prompting the consumer, or translating for the consumer. The majority of proxy respondents were related to the consumer (75.4%). All but two of the surveys were completed by telephone, and 14.8% were completed in Spanish.

Table 4. Survey Respondents

	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)	KBW n (%)	MHW n (%)	Total n (%)
By self	446 (76.4)	230 (81.9)	161 (48.6)	20 (30.3)	1 (1.4)	40 (95.2)	898 (65.4)
With assistance	56 (9.6)	9 (3.2)	16 (4.8)	2 (3.0)	1 (1.4)	2 (4.8)	86 (6.3)
By proxy	82 (14.0)	42 (15.0)	154 (46.5)	44 (66.7)	68 (97.1)	0 (0)	390 (28.4)

## B. Consumer Demographics

Consumer demographics by program are presented in Table 5.

Table 5. Consumer Demographics\*

	CHCP %	PCA %	ABI %	Autism %	KBW %**	MHW %
Age	N=584	N=281	N=331	N=66	N=70	N=42
<18	0.0	0.0	0.0	13.6	78.6	0.0
18-24	0.0	1.4	1.8	12.1	21.4	0.0
25-34	0.0	6.4	13.3	42.4	0.0	7.1
35-44	0.0	16.4	17.2	21.2	0.0	9.5
45-54	0.0	23.8	28.7	6.1	0.0	19.0
55-64	0.2	49.5	29.0	4.5	0.0	40.5
65-74	33.7	2.5	9.4	0.0	0.0	21.4
75+	66.1	0.0	0.6	0.0	0.0	2.4
Language	N=581	N=280	N=330	N=66	N=68	N=37
English	46.3	66.8	79.4	98.5	85.3	86.5
Spanish	24.8	5.0	0.0	0.0	0.0	2.7
Other	28.9	28.2	20.6	1.5	14.7	10.8
Race	N=571	N=275	N=322	N=65	N=68	N=37
White	67.1	68.4	78.0	84.6	83.8	83.8
Black	16.3	24.0	18.3	9.2	7.4	2.7
Other	16.6	7.6	3.7	6.2	8.8	13.5
Ethnicity	N=583	N=276	N=328	N=66	N=69	N=38
Non-Hispanic	65.5	76.1	92.4	93.9	85.5	86.8
Hispanic	34.5	23.9	7.6	6.1	14.5	13.2
Education	N=568	N=281	N=323	N=66		N=38
< 8th Grade	31.3	6.4	0.9	0.0		7.9
Some high school	16.0	17.4	14.2	19.7		13.2
High school degree	26.2	35.6	48.6	48.5		52.6

Table 5. Consumer Demographics, con't\*

	CHCP %	PCA %	ABI %	Autism %	KBW %**	MHW %
Education	N=568	N=281	N=323	N=66		N=38
Some college	13.2	31.7	28.5	21.2		21.1
4-year college	9.3	7.5	5.6	9.1		2.6
More than 4 year college	3.9	1.4	2.2	1.5		2.6
Gender	N=584	N=281	N=331	N=66		N=42
Male	20.6	44.5	68.9	77.3		40.5
Female	79.5	55.5	31.1	22.7		59.5

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

\*\*Missing data not reported

### C. Service Use by Program

Participants reported using a variety of program services in the three months prior to completing the survey (see Table 6). Compared to FY 2020, consumers overall used fewer services. For example, percentage use of CHCP, PCA, and Autism PCA services and ABI homemaking service decreased by 10% or more compared to last year. Fewer ABI or Autism consumers used ILST, community mentor, or life skills services, and their use of job coach services fell noticeably (17% to 11% ABI, 15% to 8% Autism consumers). MHW CSP use showed an even larger decrease, dropping from 80% in FY 2020 to 60% in FY 2021. As this data collection went from July 1, 2020 to June 30, 2021, it is likely these changes show an effect of the COVID-19 pandemic. People in general did not want non-household members coming into their homes and were less willing to go out into the community. On the other hand, CHCP and MHW participants increased their use of clinical case management services compared to last year.

Table 6. Program Service Use

	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)	KBW n (%)	MHW n (%)
Personal care assistance	188 (32.2)	231 (82.5)	166 (50.8)	8 (12.3)		
Behavioral health services			242 (79.3)*	49 (77.8)**		
Recovery assistance (RA)						37 (94.9)
Homemaker/companion or Homemaking services	475 (81.6)	233 (83.2)	108 (33.5)	3 (4.7)		
Case manager or Clinical case manager	561 (97.6)	268 (98.5)	319 (97.9)	57 (90.5)	29 (44.6)	27 (69.2)
Job coach			37 (11.2)	5 (7.6)		0
Community service provider (CSP)						22 (59.5)

\*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.

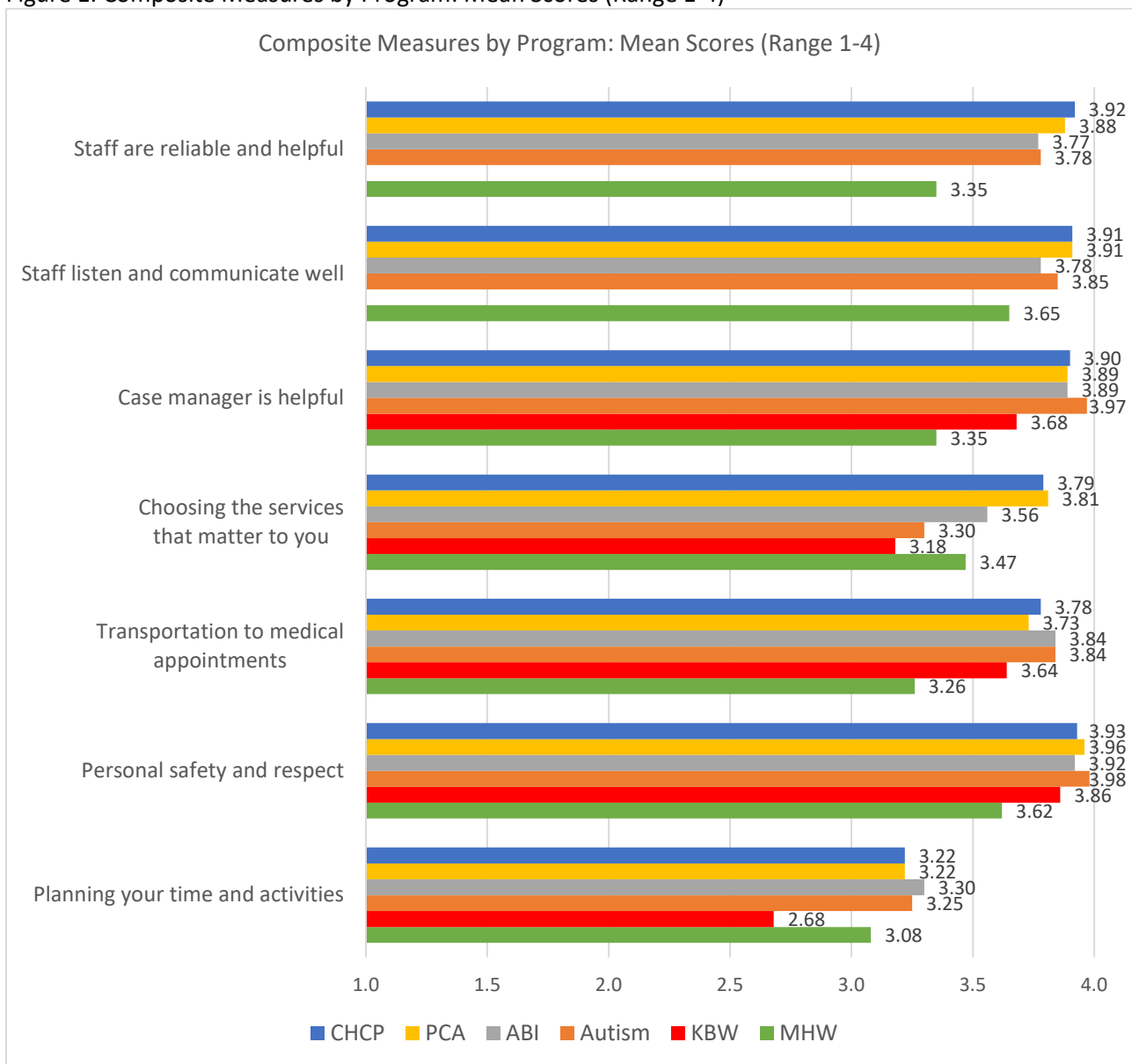


**i. Composite measures by program**

Overall, with the exception of the MHW, mean scores for five of the seven composite measures were high (Figure 1). Notably, program participants reported lower scores for items regarding choice of services and ability to plan one’s time and activities. Both of these composites speak to consumer choice and control, and represent areas which could use more support across all programs. Similar to FY 2020, KBW and MHW participants reported the lowest scores in all but one of the composite measures.

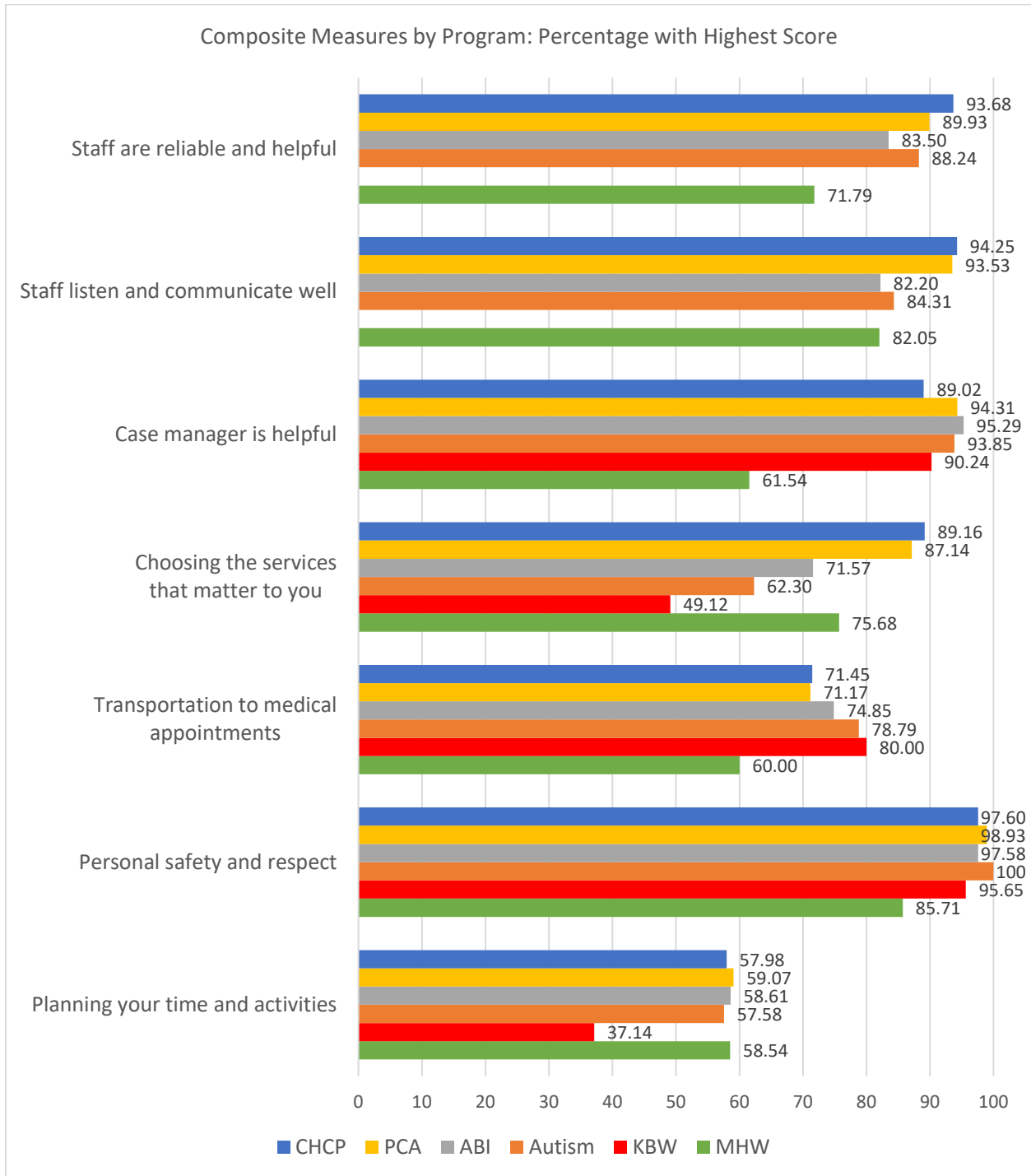
Figure 2 shows the percentage of participants in each program who gave the most positive answer for each composite item. This method highlights any program differences more clearly. For example, when using mean scores for the composite staff listen and communicate well, the CHCP mean score was 3.9 and the ABI mean score was 3.8. By using the percentage highest scores, the differences are more apparent – 94% of CHCP participants gave these composite items the highest scores, compared to 82% of ABI participants. This also highlights the need to improve transportation to medical appointments, especially for MHW participants.

Figure 1. Composite Measures by Program: Mean Scores (Range 1-4)\*



\*In Figures 1 and 2, “Staff” combines all PCA, ILST, recovery assistant, community service provider, homemaking, companion, life skills coach, and community mentor staff.

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



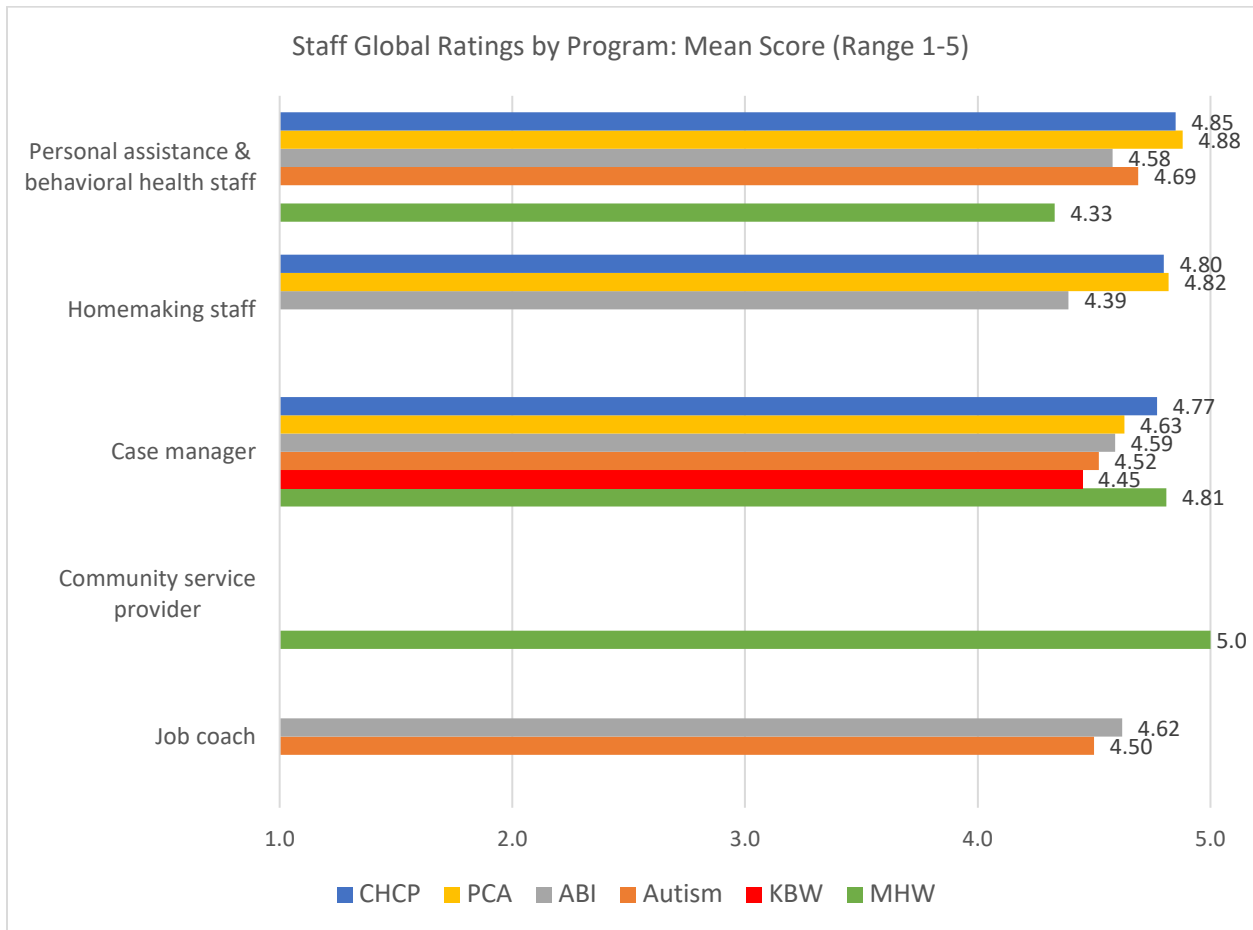
**ii. Staff global ratings by program**

Using a scale from 1 to 5, mean global rating scores varied across programs for all types of staff (Figure 3). While the mean scores for the majority of programs were 4.5 or higher for both program staff and case managers, exceptions to this were MHW recovery assistants, ABI homemaking staff, and KBW case managers.

Figure 4 presents the percentage of participants in each program who gave their staff or case managers the highest rating possible, a 9 or 10 (range 0-10). Similar to last year, CHCP and PCA participants rated their personal/behavioral care and homemaking staff notably higher than participants in other programs – 88% of CHCP and PCA participants gave their personal/behavioral staff a 9 or 10, compared to 64-71% of other programs. Another notable pattern is that among the CHCP, PCA and ABI waivers, ABI participants consistently gave their staff, including case managers, lower ratings.

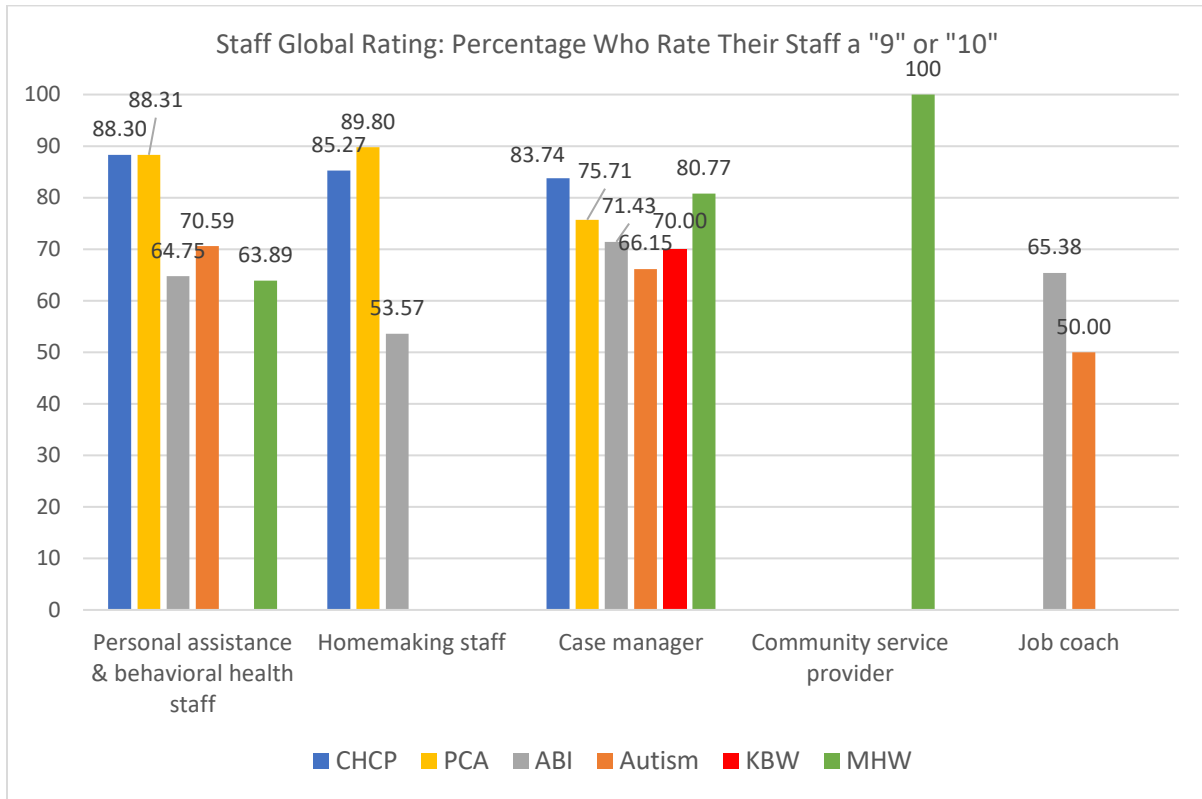
The percentage of MHW and KBW participants who rated their case managers this highly increased noticeably from 2020. However, with such small 2021 sample sizes, especially in the MHW, these numbers do not reliably represent these waivers overall.

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



\*in Figures 3, 4, 5 and 6, "Personal assistance & behavioral health staff" combines all PCA, ILST, recovery assistant, life skills coach, and community mentor staff.

Figure 4. Staff Global Rating by Program: Percentage Who Rate Their Staff a "9" or "10" (Range 0-10)



### 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. While recommendation scores varied among waivers and type of staff, CHCP and PCA participants consistently gave their personal care/behavioral staff, homemaking staff, and case managers higher recommendation scores than participants in other programs.

Figure 5. Staff Recommendations by Program: Mean Score (Range 1-4)

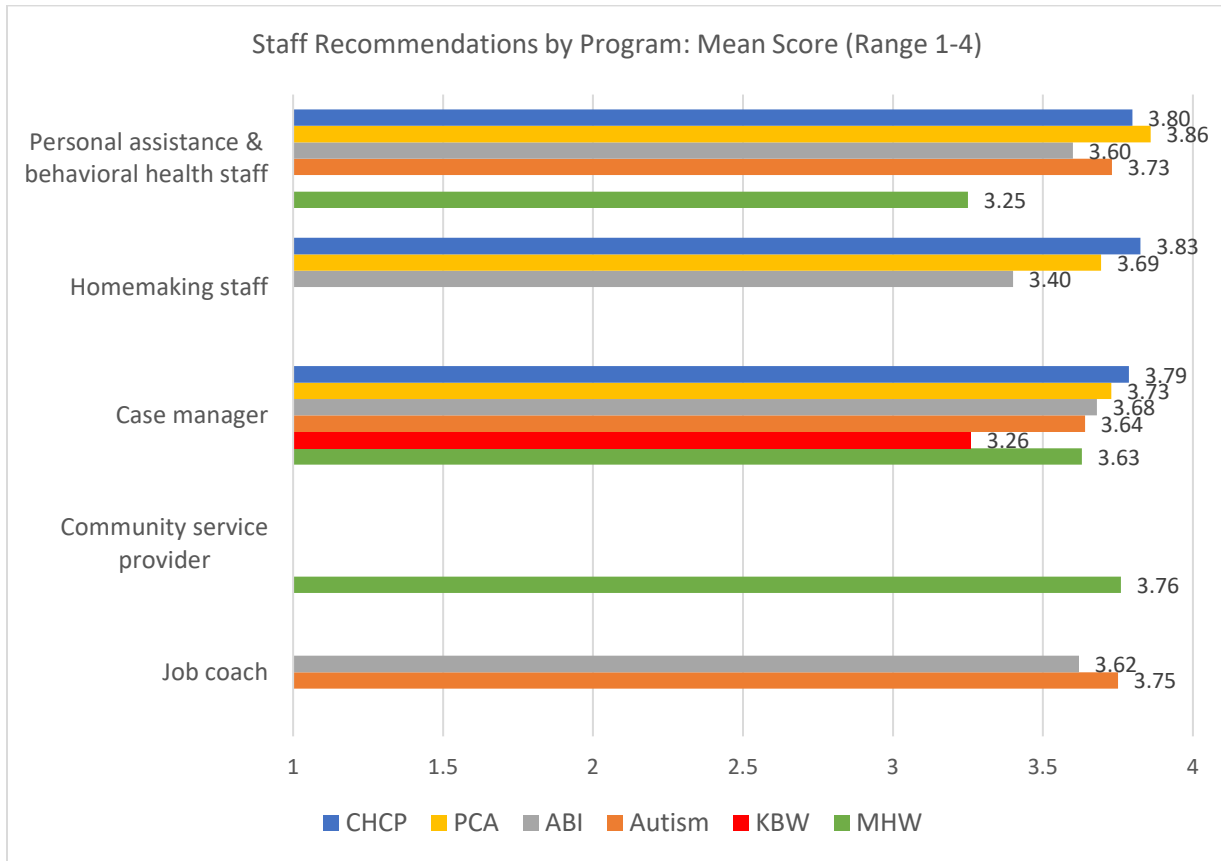
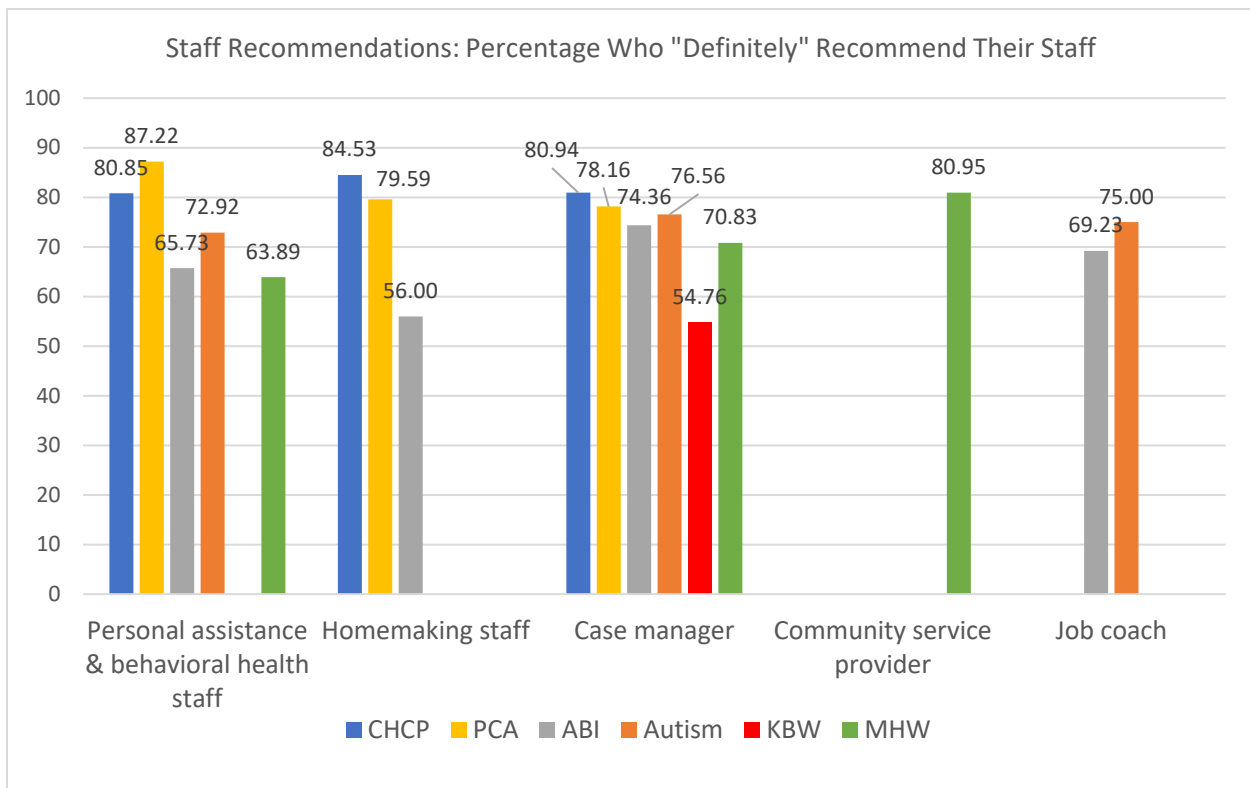


Figure 6. Staff Recommendations by Program: Percentage Who “Definitely” Recommend Staff



#### iv. Unmet needs by program

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

To determine unmet need, participants who received personal care assistance were asked if an activity did not occur because they had no staff to assist them. Two CHCP, three ABI, two Autism, and one MHW participant reported any unmet need, most frequently with toileting and personal care. 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

Needs assistance with:	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)	MHW n (%)
Personal care	172 (91.5)	230 (99.6)	149 (50.7)	8 (15.7)	6 (17.1)
Meals or eating	159 (84.6)	224 (97.0)	238 (80.7)	19 (37.3)	13 (36.1)
Taking medications	116 (62.0)	177 (76.6)	207 (70.4)	6 (11.8)	8 (22.2)
Toileting	90 (48.1)	145 (62.8)	85 (28.8)	1 (2.0)	1 (2.8)

#### v. Physical safety by program

Two CHCP participants reported that a staff person had hit them or hurt them in the past three months; one of them said someone worked with them to resolve the problem. No other participants reported being hit or hurt by a staff person.

### 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: AGENCY L, AGENCY Q, AGENCY G, and AGENCY R. All four agencies provide case management services for the CHCP and PCA waivers; all but one provide ABI waiver case management.

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

**i. CHCP programs**

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

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

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

<b>Program</b>	<b>Agency &amp; Region</b>	<b>Representative sample size</b>	<b>Completed surveys N (%)</b>
CHCP Category 3	AASCC	66	72 (>100)
	CCCI - E	33	33 (100.0)
	CCCI - NC	139	141 (>100)
	CCCI - NW	39	39 (100.0)
	SWCAA	69	77 (>100)
	WCAAA	29	29 (100.0)
CHCP Category 5	AASCC	34	35 (>100)
	CCCI - E	10	10 (100.0)
	CCCI - NC	110	110 (100.0)
	CCCI - NW	15	15 (100.0)
	SWCAA	11	11 (100.0)
	WCAAA	11	11 (100.0)

Figure 7 shows that each Access Agency met and exceeded the performance benchmark score for the three CHCP composite measures. All Access Agencies also met and exceeded the performance benchmark score for CHCP case manager global rating (Figure 8) as well as CHCP case manager recommendation (Figure 9).

Figure 7. CHCP Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)

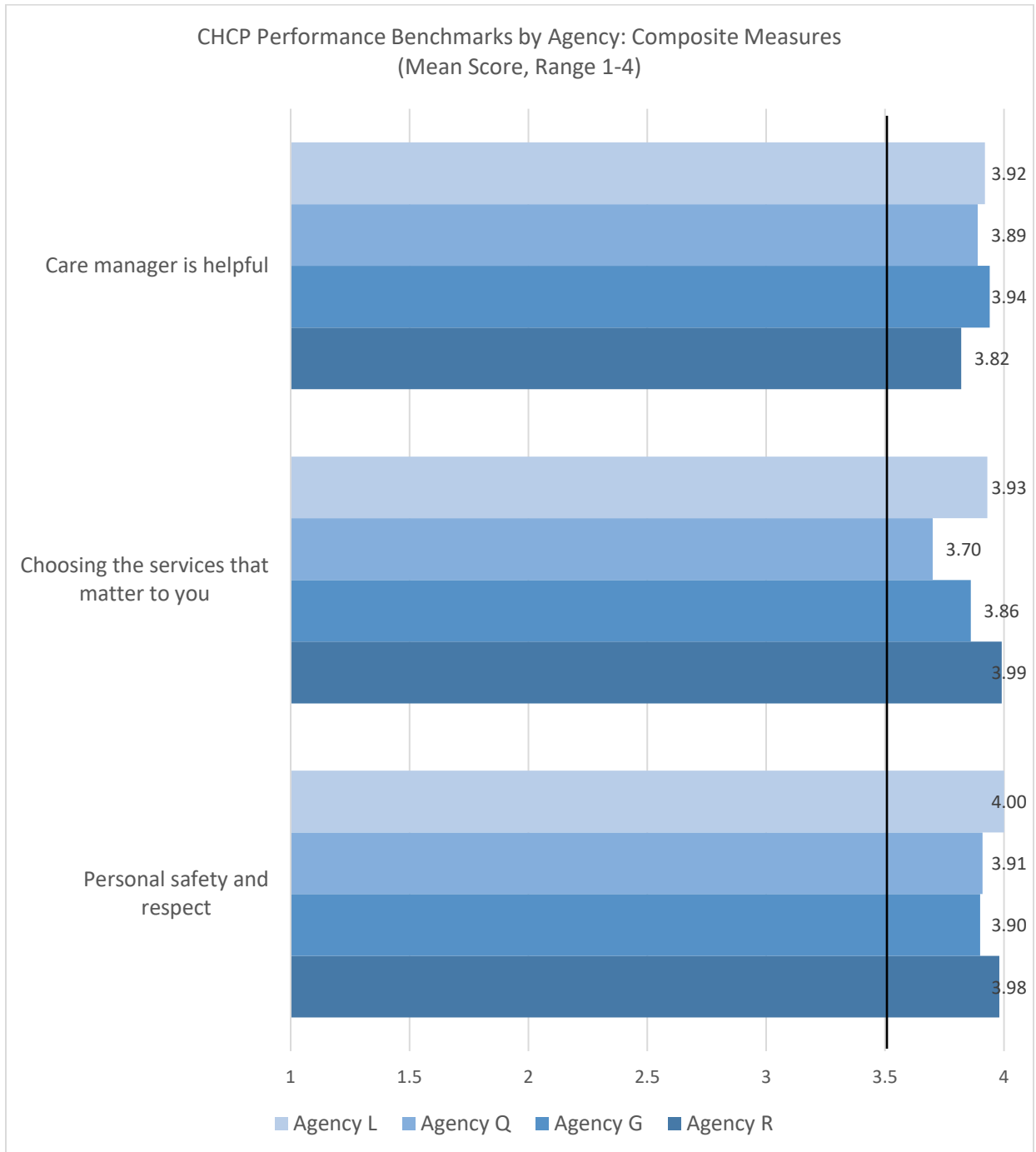




Figure 8. CHCP Performance Benchmarks by Agency: Care Manager Global Rating (Mean Score, Range 1-5)

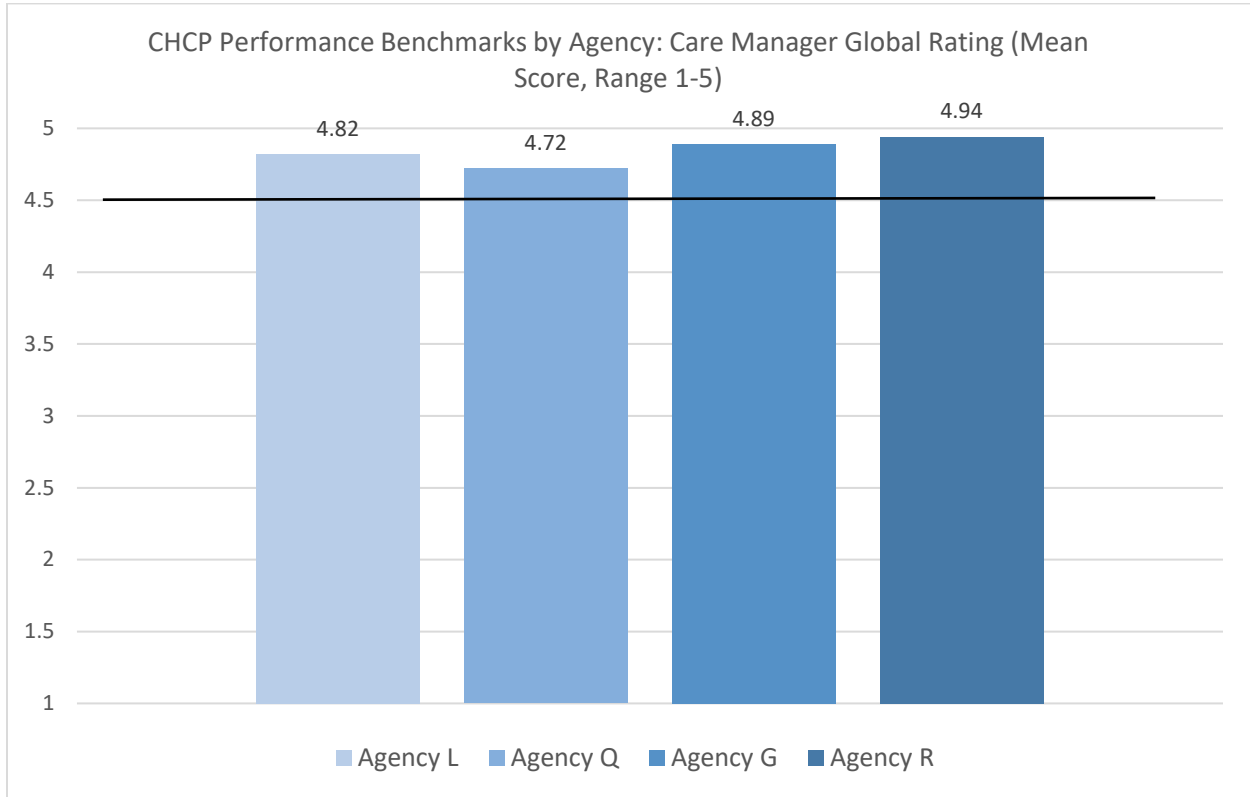
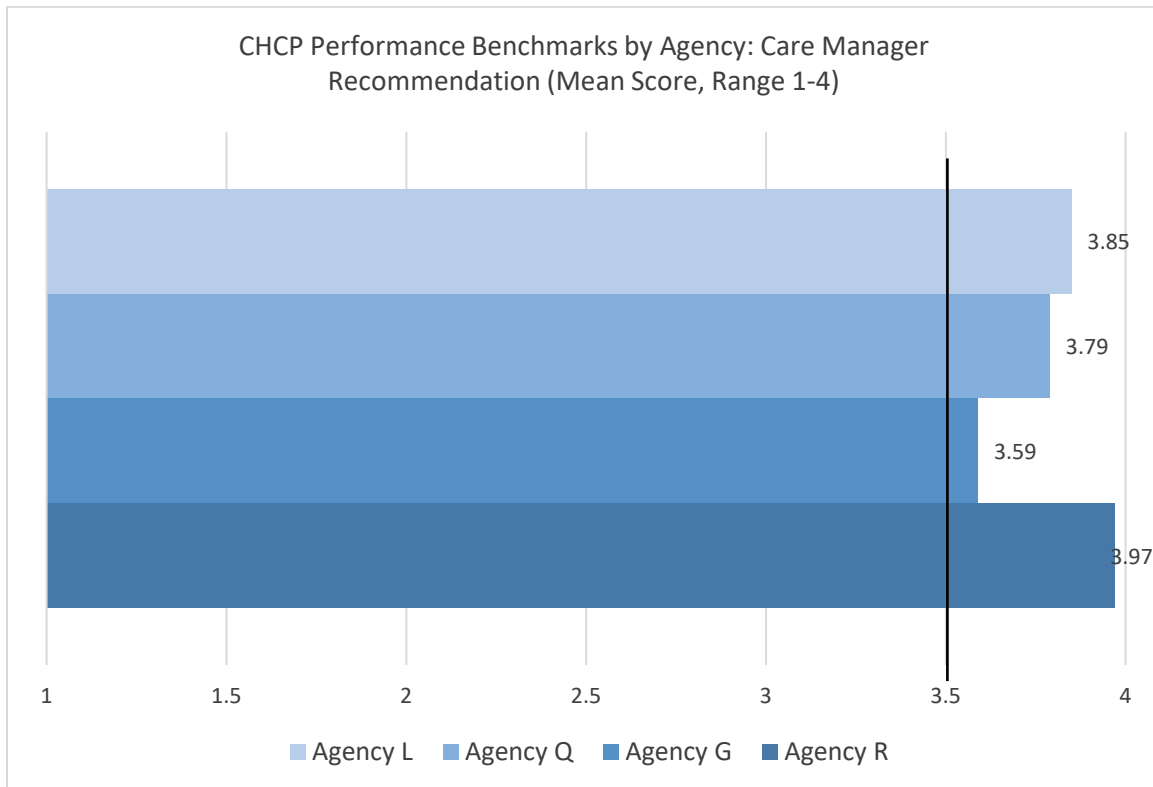


Figure 9. CHCP Performance Benchmarks by Agency: Care Manager Recommendation (Mean Score, Range 1-4)



**ii. PCA waiver**

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

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

Program	Agency & Region	Representative sample size	Completed surveys	
			N	(%)
PCA	AASCC	72	73	(>100)
	CCCI - E	34	34	(100.0)
	CCCI - NC	82	83	(>100)
	CCCI - NW	29	29	(100.0)
	SWCAA	41	41	(100.0)
	WCAAA	20	21	(>100)

Performance benchmark measures for the PCA waiver are shown in Figures 10, 11, and 12. Figure 10 shows that all four Access Agencies met or exceeded a 3.5 mean score for all three composite measures. Three of the four Access Agencies received a mean score of 4.5 or above for case manager global rating; one Access Agency received a score of 4.33 (Figure 11). All four Access Agencies met or exceeded a 3.5 mean score for case manager recommendation (Figure 12).

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

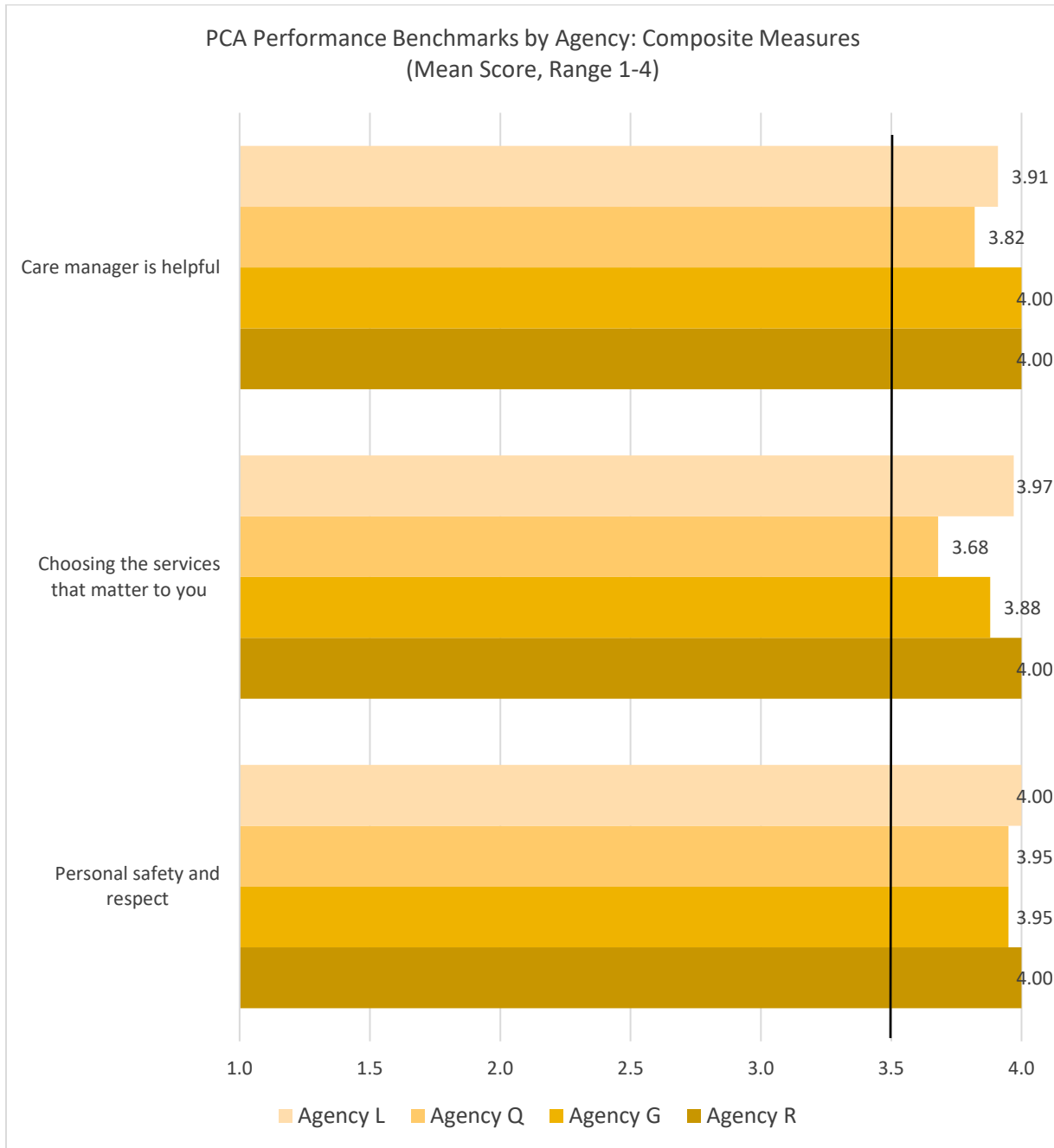


Figure 11. PCA Performance Benchmarks by Agency: Care Manager Global Rating (Mean Score, Range 1-5)

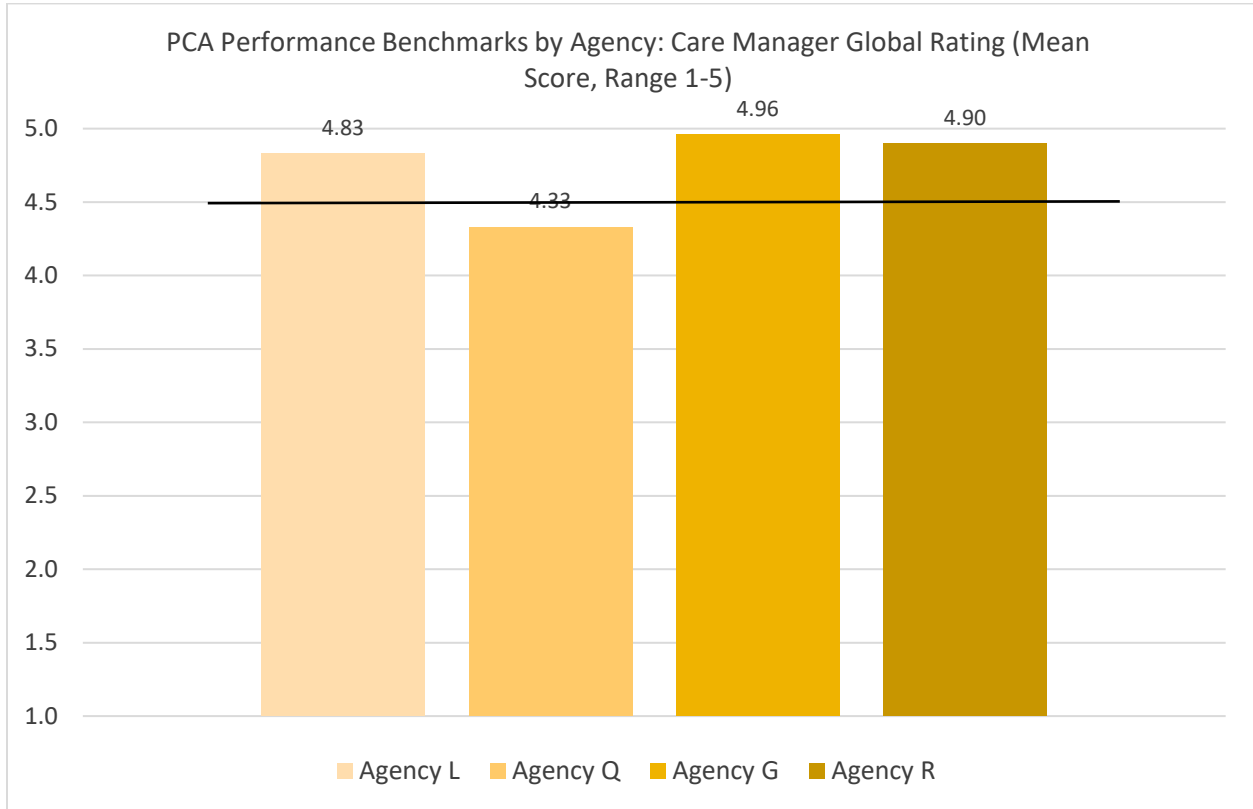
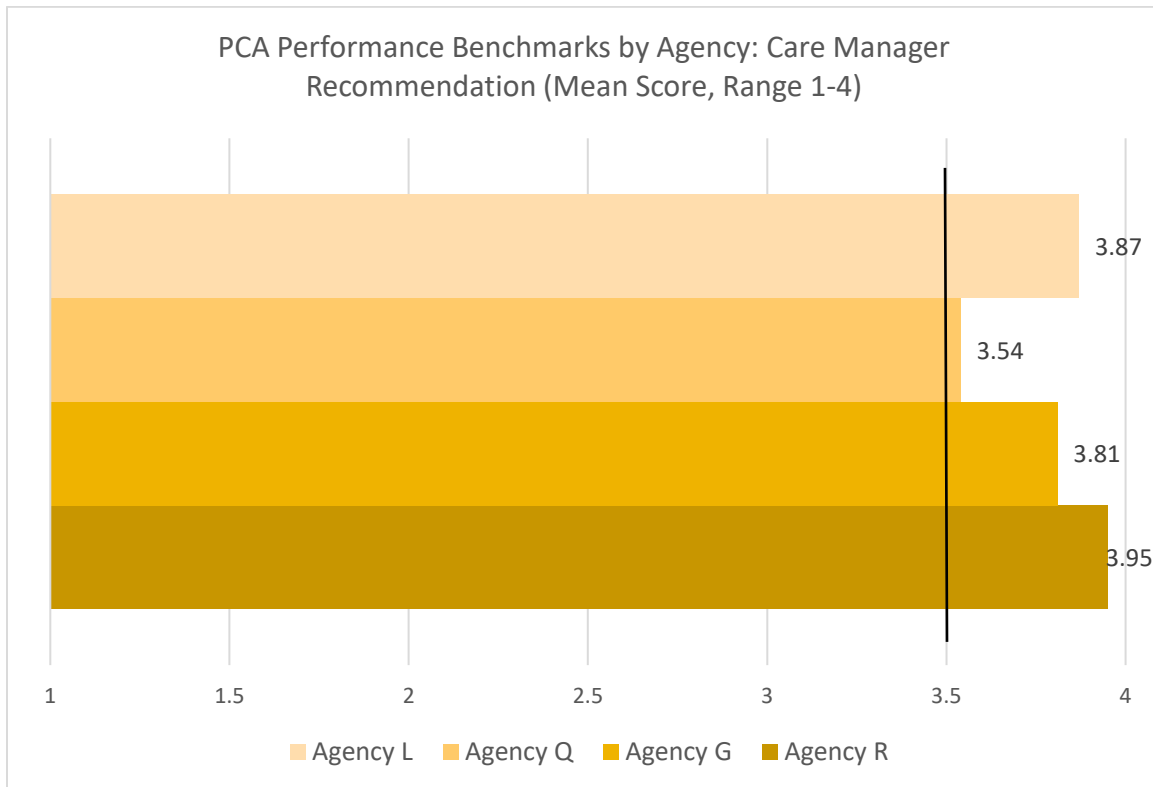


Figure 12. PCA Performance Benchmarks by Agency: Care Manager Recommendation (Mean Score, Range 1-4)



### 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 sample in both ABI waivers.

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

Program	Agency & Region	Representative sample size	Completed surveys	
			N	(%)
ABI 1	CCCI - E	37	37	(100.0)
	CCCI - NC	56	56	(100.0)
	CCCI - NW	36	40	(>100)
	SWCAA	41	41	(100.0)
	WCAAA	17	21	(>100)
ABI 2	CCCI - E	18	18	(100.0)
	CCCI - NC	48	48	(100.0)
	CCCI - NW	20	20	(100.0)
	SWCAA	42	42	(100.0)
	WCAAA	8	8	(100.0)

Figures 13, 14, and 15 show the ABI performance benchmark measures. Three Access Agencies provide case management for the ABI waiver: AGENCY N, AGENCY I, and Agency O. All three Access Agencies met or exceeded a 3.5 mean score for two of the three composites: “Case manager is helpful” and “Personal safety and respect.” Two of the three agencies met the benchmark score of 3.5 for the composite “Choosing the services that matter to you;” one agency scored a 3.49. All three Access Agencies met or exceeded the 4.5 benchmark score for case manager global rating, and all three Access Agencies also met or exceeded the 3.5 benchmark score for case manager recommendation (Figure 15).

Figure 13. ABI Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)

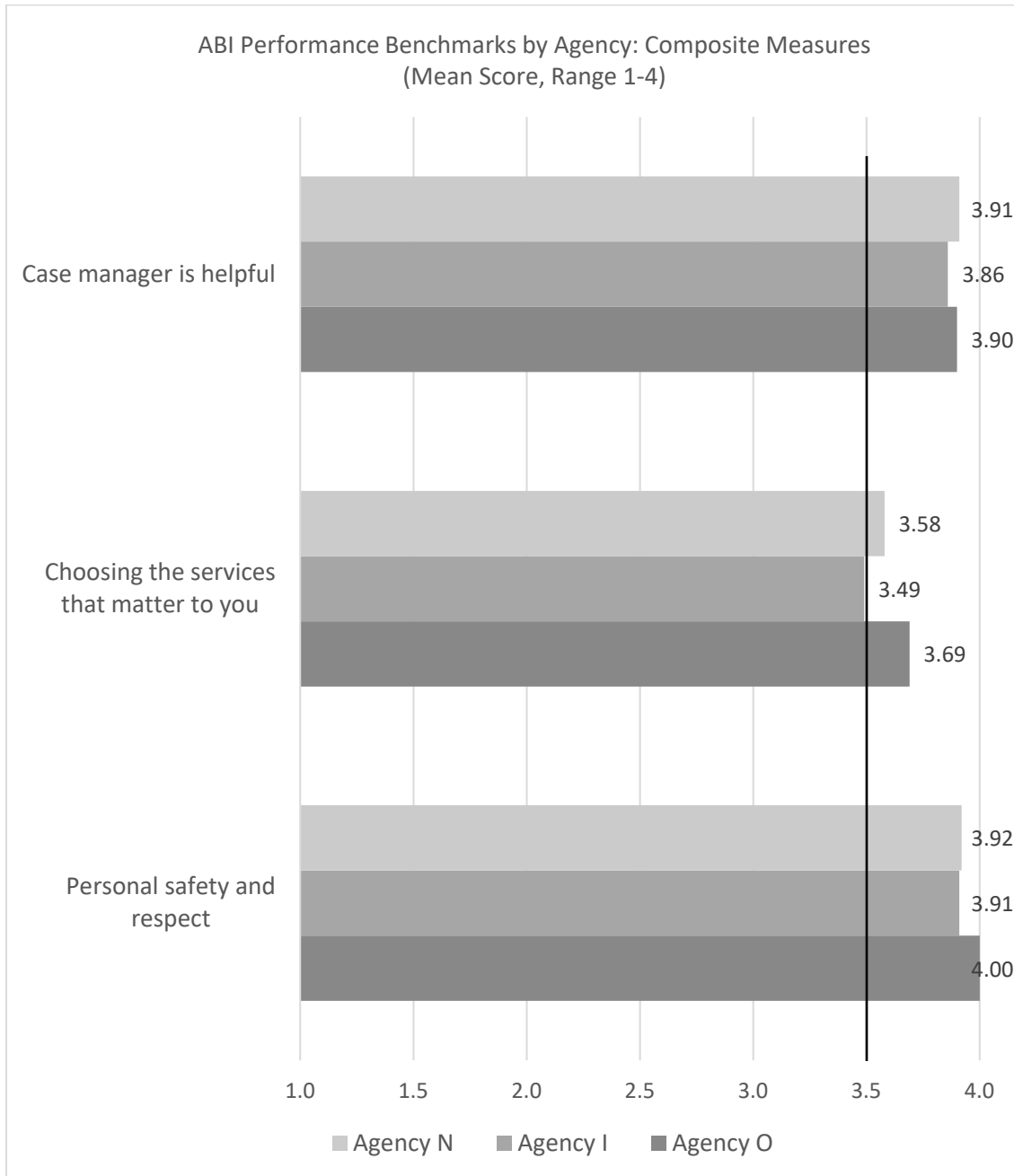


Figure 14. ABI Performance Benchmarks by Agency: Care Manager Global Rating (Mean Score, Range 1-5)

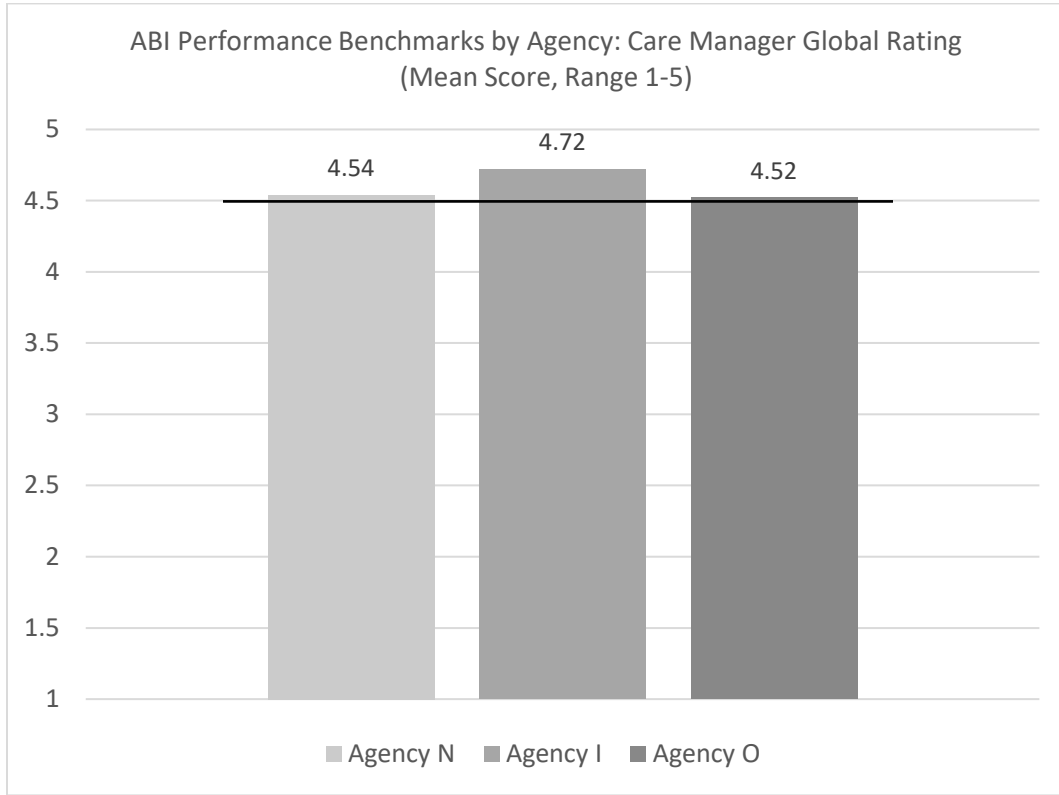
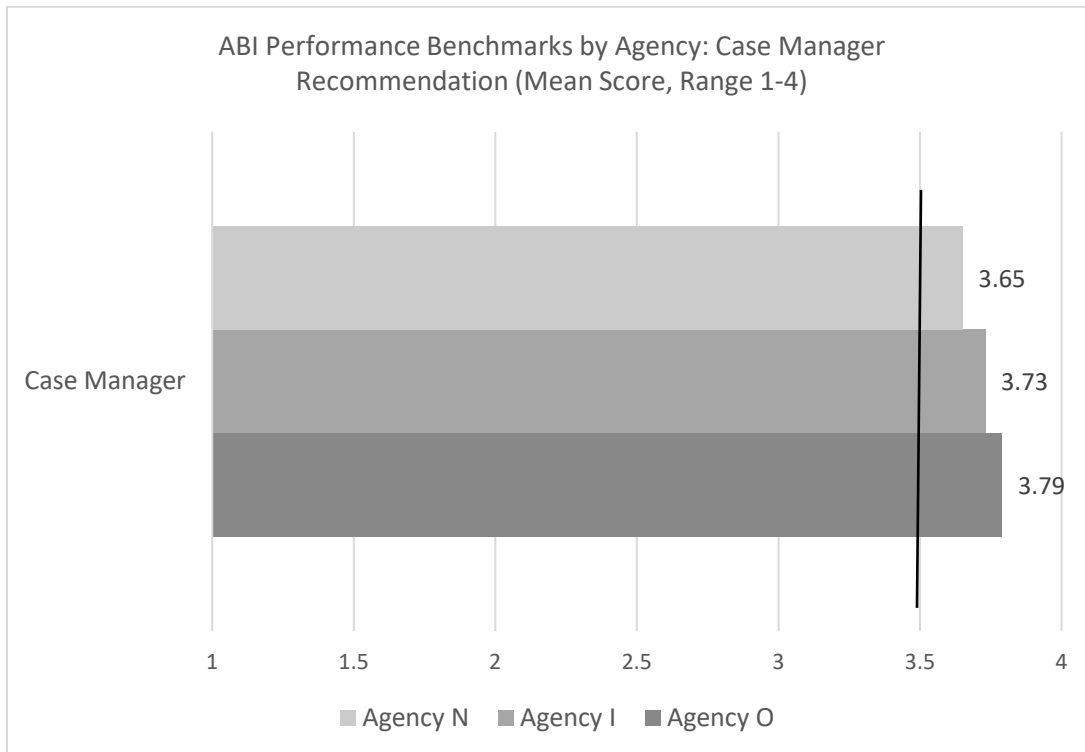


Figure 15. ABI Performance Benchmarks by Agency: Care Manager Recommendation (Mean Score, Range 1-4)



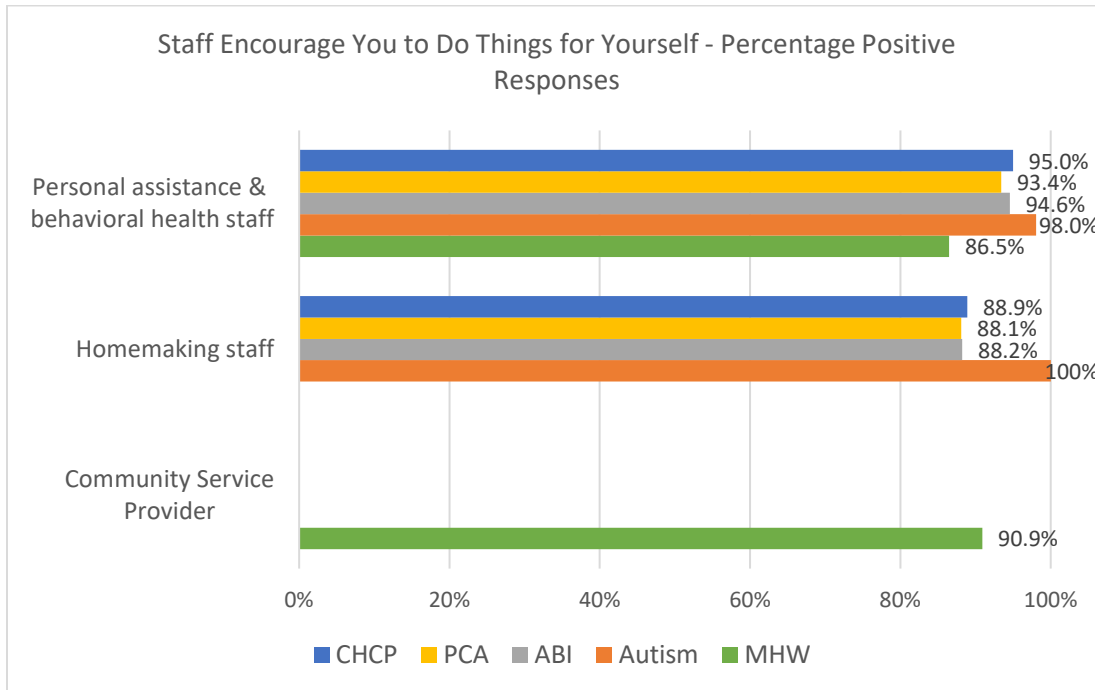
## F. Additional Findings by Program

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

Participants with personal care, behavioral health, homemaking, or CSP services were asked, “Did [staff] encourage you to do things for yourself if you could?” As shown in Figure 16, the great majority of participants from all waivers reported their staff encouraged them in this way. This was especially true for Autism participants – 98% of Autism participants felt that PCA, community mentor, or life skills coach encouraged them to do things for themselves, and 100% felt their homemaking staff did so as well.

Over 90% of MHW consumers felt their community service providers encouraged this way. One MHW participant remarked that her CSP makes her feel more confident in the community than ever before and got her connected with a volunteer job.

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



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

Although the majority of participants in each program knew who their care manager was, there were definite differences among the programs (Figure 17). Autism, CHCP, and ABI participants (87-99%) were the most knowledgeable of their care manager. The percentage of ABI participants who know their care manager increased substantially this year, from 73% in 2020 to 87% in 2021. Meanwhile, 77% of PCA and only 65-66% of MHW and KBW knew who their case manager was.

*I would like to learn more about supports. I don't know who to reach out to to ask for help. I wish I knew who was my contact – KBW*



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

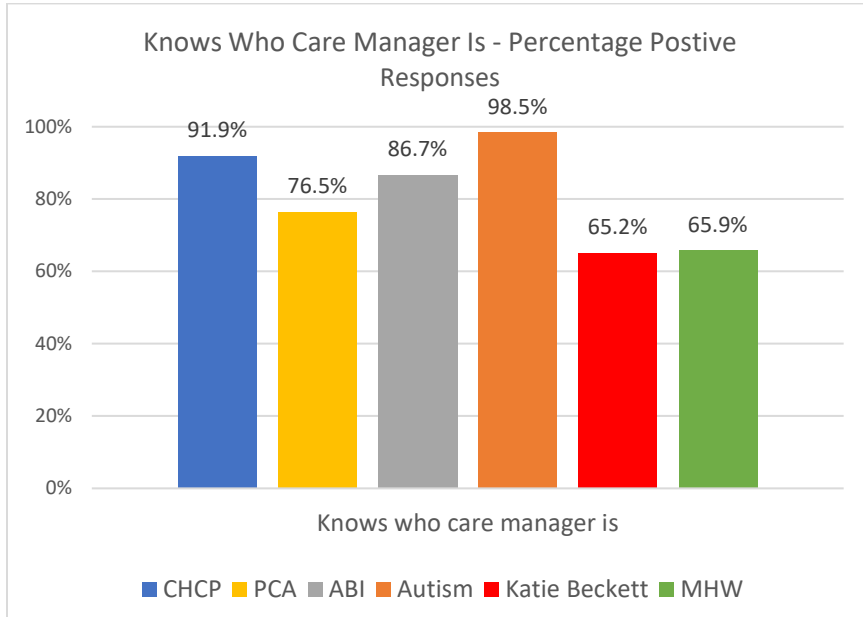
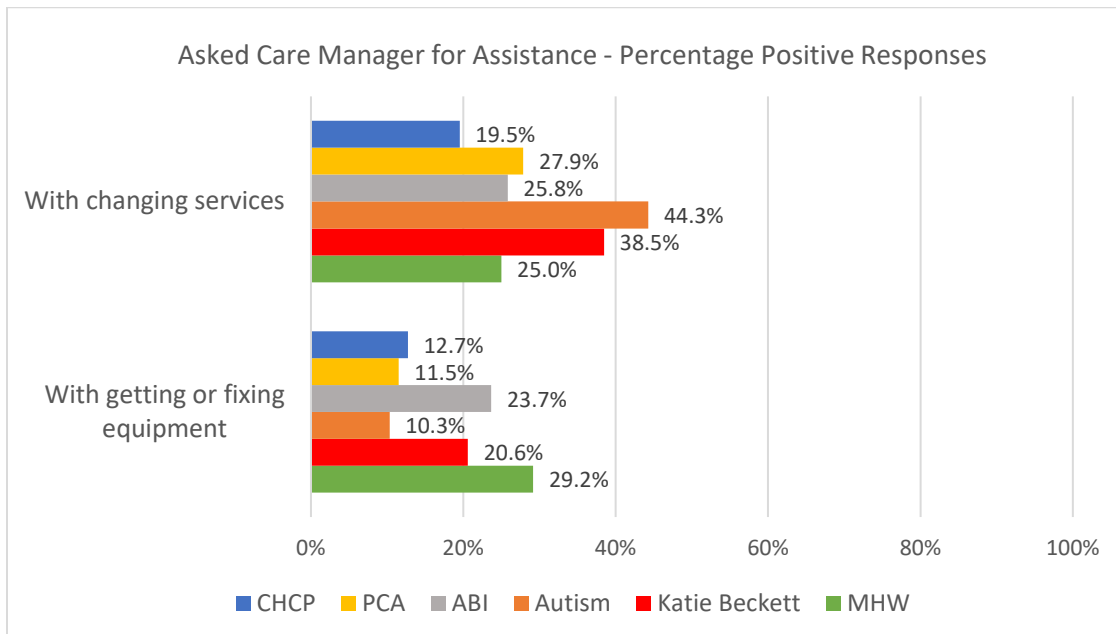


Figure 18 shows how often respondents asked their care manager for help with changing services or with equipment. Similar to 2020, Autism waiver participants were the most likely to ask for assistance with changing services. Unexpectedly, this year MHW respondents were the most likely to ask for help with getting or fixing equipment, while in FY 2020 it was ABI respondents. Although not specifically asked about, several respondents expressed a need for a hospital bed.

Figure 18. Asked Care Manager Assistance with Services or Equipment – Percentage Positive Responses



Participants were asked the open-ended question, “In the last 3 months, who would you have talked to if you wanted to change your care plan/service plan?” While 96% or more of CHCP, PCA, ABI and Autism participants reported they did have someone to talk to, 19% of MHW and 23% of KBW participants said they did not know who they would talk to about changing their care 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). Although not shown on the table, 28% of Katie Beckett participants would talk to their doctor or other health care provider.

*The part about care management is confusing to me because I think we have a care manager through DDS, but not DSS. I'm honestly not sure, that's how confusing this stuff is. And care plan? I think I remember sitting down with someone and going over [consumer's] needs, but nothing came out of it – KBW*

*You asked me about a care plan. What care plan? I don't remember one ever being made or discussed – Autism*

Figure 19. Knows Someone to Talk to if Want to Change Care Plan

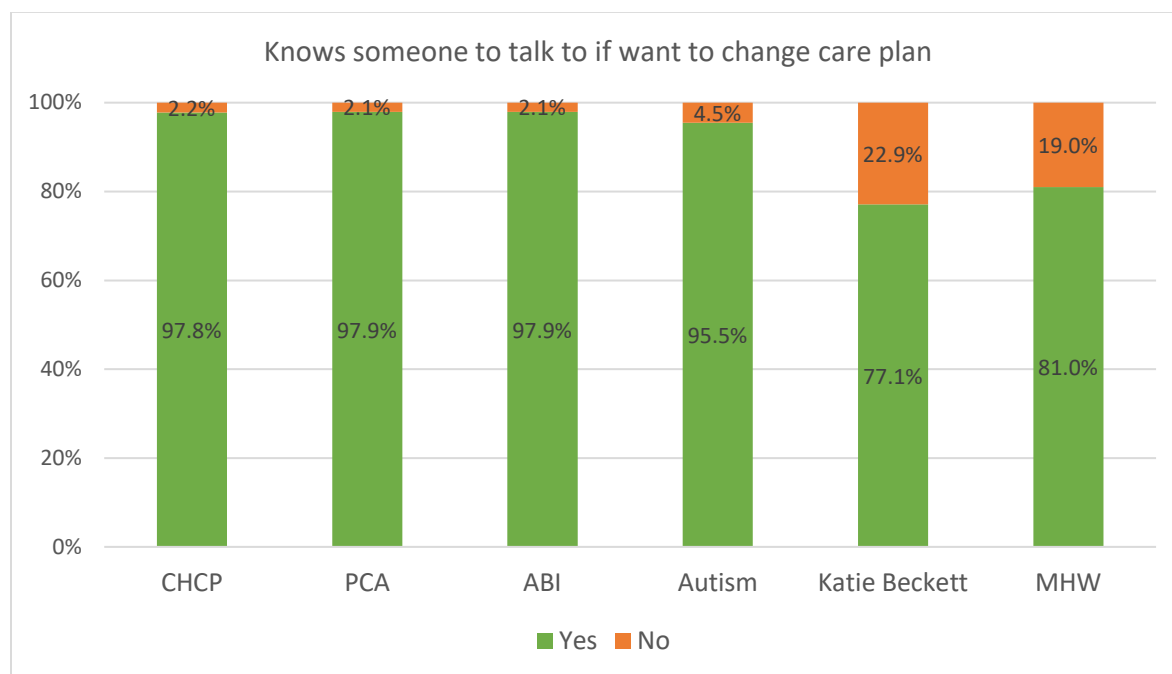


Table 11. Who Would You Talk to if You Wanted to Change Your Care Plan?\*

	CHCP N=571 n (%)	PCA N=275 n (%)	ABI N=324 n (%)	Autism N=63 n (%)	KBW N=54 n (%)	MHW N=34 n (%)
Case manager or social worker	522 (91.4)	255 (92.7)	303 (93.5)	53 (84.1)	35 (64.8)	27 (79.4)
Other staff or home care agency/provider	35 (6.1)	7 (2.5)	19 (5.9)	18 (28.6)	5 (9.3)	6 (17.6)
Family/friends	110 (19.3)	34 (12.4)	31 (9.6)	7 (11.1)	8 (14.8)	4 (11.8)
Someone else	16 (2.8)	9 (3.3)	14 (4.3)	9 (14.3)	18 (33.3)	3 (8.8)
Do not know who to talk to	12 (2.1)	6 (2.2)	5 (1.5)	3 (4.8)	10 (18.5)	5 (14.7)

\*Multiple choice

ii. Living situation and social support

Similar to previous years, the great majority of MHW participants (85%) lived alone or without other adults, as did 67% of CHCP and 60% of ABI participants (Table 12). Participants in the MHW also had considerably fewer family or friends who live nearby compared to all other waivers. Overall, MHW participants had considerably less nearby social support: 40% of MHW participants both lived alone and had no nearby family or friends, compared to 8% or less in the other waivers. However, comments at the end of the survey indicated that CHCP participants who lived alone were especially in need of more social support.

*Sometimes I wish I had a roommate – CHCP*

*I feel really lonely. I need a companion – someone to read to [me] – CHCP*

MHW participants were also the least likely to see their family who live nearby – between 44% (MHW) to 67% (CHCP) of participants said they “usually” or “always” can see their nearby family when they want to. When compared to last year, participants in every program said they were less likely to see either their nearby family or friends in 2021. Most likely this was an effect of the social distancing caused by COVID-19 and concerns over getting sick. One comment in particular mentioned the effect of COVID-19 on seeing even their family:

*Normally I get to do what I want [to do] in the community and see my family, but due to COVID I am mostly home – CHCP*

Table 12. Living Situation and Social Support\*

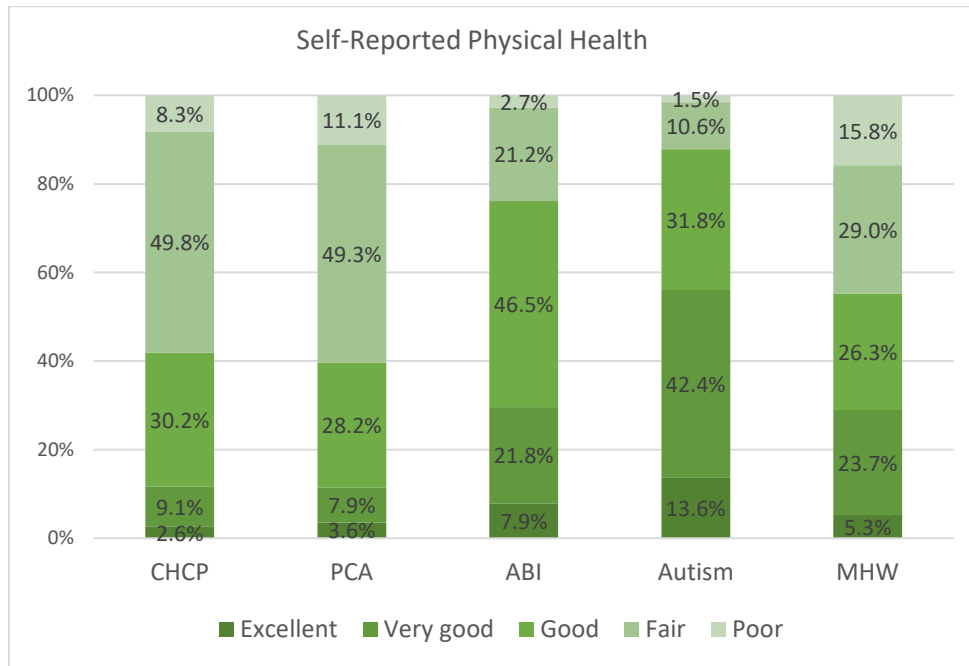
	CHCP	PCA	ABI	Autism	KBW	MHW
	%	%	%	%	%	%
Number of adults living in household	N=582	N=280	N=327	N=66	N=70	N=40
1	66.8	50.7	59.6	27.3	10.0	85.0
2-3	31.4	45.0	36.4	51.5	78.6	12.5
4+	1.7	4.3	4.0	21.2	11.4	2.5
Lives with family member/s	N=194	N=138	N=134	N=48	N=63	N=6
Yes	82.0	90.6	66.4	89.6	81.0	83.3
No	18.0	9.4	33.6	10.4	19.1	16.7
Lives with non-family	N=193	N=138	N=134	N=48	N=62	N=6
Yes	14.5	13.8	33.6	10.4	3.2	16.7
No	85.5	86.2	67.2	89.6	96.8	83.3
Family member/s live nearby	N=583	N=280	N=330	N=66	N=70	N=41
Yes	81.5	75.0	73.9	72.7	74.3	61.0
No	18.5	25.0	26.1	27.3	25.7	39.0
Friend/s live nearby	N=581	N=281	N=329	N=66	N=68	N=40
Yes	64.4	70.5	58.4	43.9	67.6	30.0
No	35.6	29.5	41.6	56.1	32.4	70.0

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

iii. Physical and mental health

In two separate questions, respondents were asked to rate their physical health and mental or emotional health with response choices from Excellent to Poor. Physical health showed the same trends as in previous years, with CHCP and PCA reporting the worst physical health, followed by MHW participants (Figure 20). Compared to the previous year, the percentage of CHCP and PCA respondents reporting fair to poor physical health increased by 4% (CHCP) and 5% (PCA).

Figure 20. Self-Reported Physical Health



KBW not shown due to missing data

Not surprisingly, MHW participants reported the worst mental health, with 41% reporting fair to poor mental health (Figure 21). Similar to last year, Autism respondents reported the best mental health. At the same time, the percentage of Autism respondents reporting fair to poor mental health significantly increased this year – 15% of Autism participants in FY 2020 reported fair to poor health, while 26% did so in FY 2021. Autism consumers in particular mentioned that the COVID-19 pandemic prevented them from doing their regular community or job activities, which may be part of this large increase.

*The pandemic has affected the things [consumer] is able to do normally prior to the pandemic, such as going out with family and friends, possibly looking for employment, going to the library and other public places – Autism*

Figure 21. Self-Reported Mental Health



KBW not shown due to missing data

iv. Transportation service, home-delivered meals, and day program use

Once again MHW and PCA consumers used a van or transportation service more often than the other programs (Table 13). Both CHCP and Autism consumers used a van less often than the previous year. Most respondents (81%) said the van picked them up on time “usually” or “always.” Comments indicated 1) that sometimes family filled in when a transportation service was not available, 2) there is an unmet need for wheelchair accessible transportation, and 3) lack of nonmedical transportation hinders opportunities for social engagement.

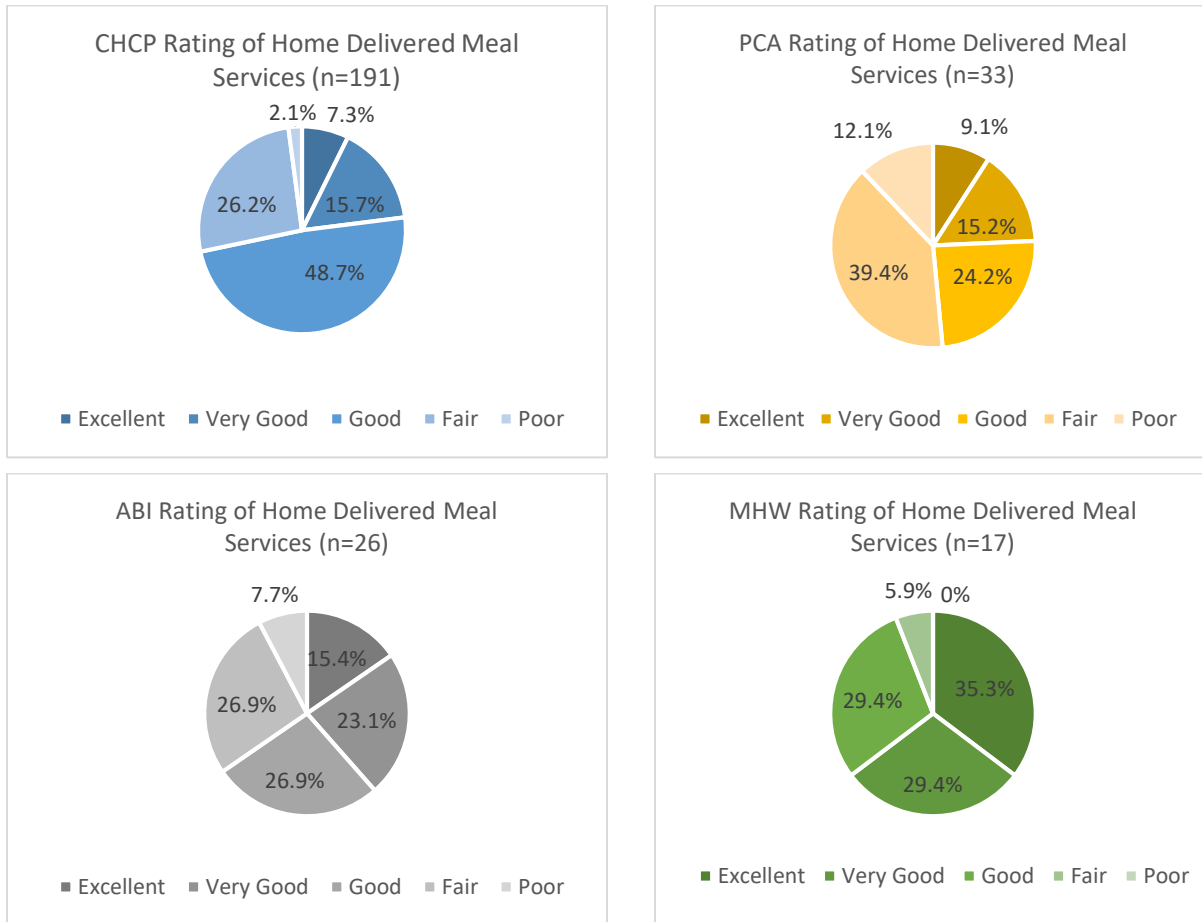
*Independent transportation is a great need for children with wheelchairs. There is a gaping hole for persons who cannot be without their wheelchair for support or sit independently – KBW*

Table 13. Use of Van or Transportation Service

	CHCP % N=579	PCA % N=281	ABI % N=330	Autism % N=66	KBW % N=70	MHW % N=40
Yes	12.4	37.7	15.2	6.1	15.7	40.0
No	87.6	62.3	84.9	93.9	84.3	60.0

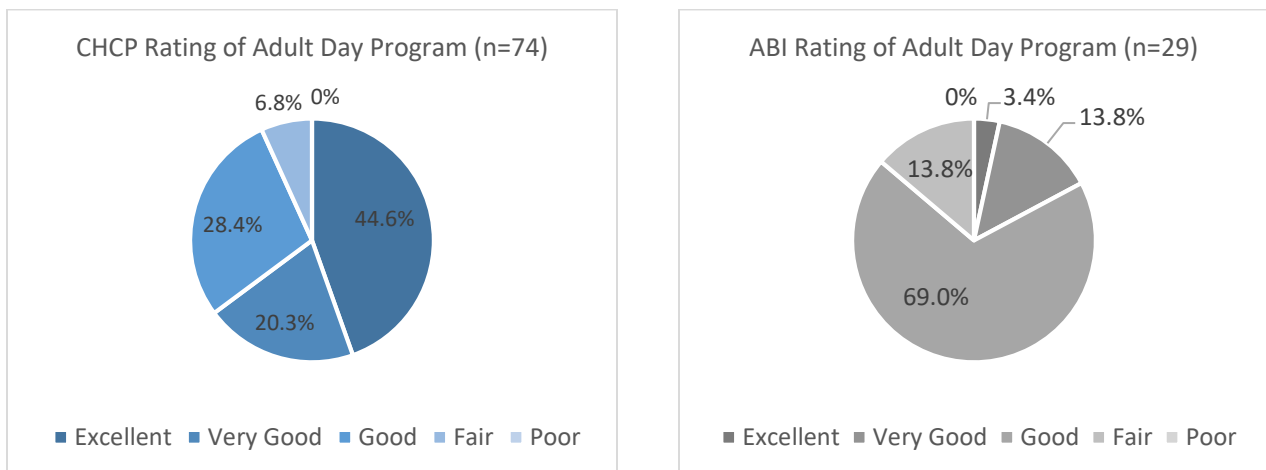
A total of 267 participants rated their home delivered meal service, including 33% of CHCP and 40% of MHW participants (Figure 22). Similar to last year, MHW participants reported the highest ratings for home delivered meals. Even though they were overall satisfied, one consumer expressed, “The food is fine, but you get the same one repeatedly.”

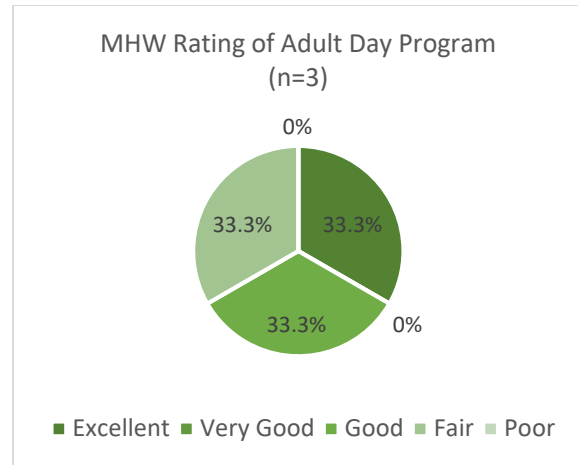
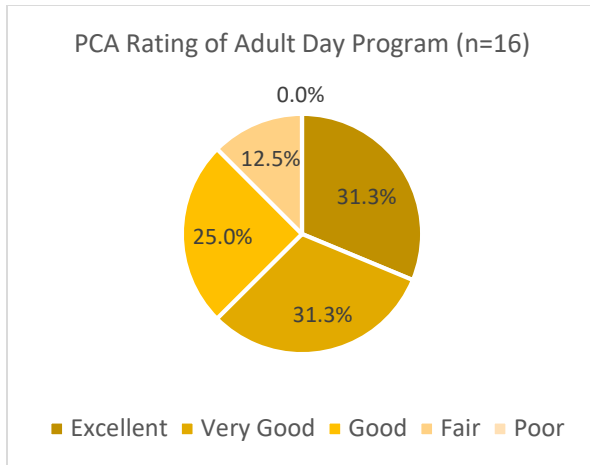
Figure 22. Experience with Home Delivered Meal Services



Another 122 participants rated their day program services, including 13% of CHCP and 9% of ABI participants. Similar to last year, ABI consumers were less satisfied with their day programs when compared to either CHCP or PCA consumers (Figure 23). One ABI respondent who did not have a day program commented, “I would love for someone to get a day program for someone with brain injury.”

Figure 23. Experiences with Day Program Services





v. Personal safety and respect follow-up

Twenty-two participants (1.6% of all participants) said that one of their staff had taken their money or things without permission: 11 CHCP, 5 MHW, 4 ABI, and 2 PCA. Over half of these participants (55%) said someone was working with them to fix the problem, most often either the case manager or the HCBS provider agency. Fifteen participants (1.1% of all participants) said that one of their staff had yelled or cursed at them: 9 ABI, 3 PCA, and 1 each in CHCP, MHW, and Autism. Two-thirds said someone was working with them to fix the problem, most often either their case manager or the HCBS provider.

Although the numbers in each program are small, proportionately more MHW participants (11.9%) reported being stolen from, and proportionately more ABI participants (2.7%) reported being yelled at. It is also notable that only two-thirds or less of these participants said someone was working with them to resolve these concerns.

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. With the exception of KBW, the majority of participants would contact their family or friends; the next highest percentage would contact 911. For KBW this was reversed – the majority would call 911. One out of five KBW respondents would call a member of their medical team, while a common “someone else” response for ABI respondents was conservator or lawyer.

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

	CHCP N=584 %	PCA N=281 %	ABI N=331 %	Autism N=66 %	KBW N=70 %	MHW N=42 %
Family/friend	<b>62.5</b>	<b>84.3</b>	<b>67.7</b>	<b>95.5</b>	41.4	<b>73.8</b>
Case manager	6.5	5.3	7.3	4.6	10.0	26.2
Home care agency or staff	6.7	5.7	12.4	9.1	11.4	4.8
PERS/Lifeline	42.1	8.5	8.5	0	0	9.5
911	53.1	34.9	29.9	31.8	<b>72.9</b>	28.6
Someone else	<1.0	1.4	6.0	4.6	20.0	11.9

\*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, eight out of ten PCA participants hired their own staff, while only 4% of CHCP did (Table 15). These self-directing consumers were then asked if they employed family members as staff. Hiring a family member was most prevalent in the CHCP, KBW, and PCA waivers, and consumers most frequently employed adult children, siblings, or parents as staff. Self-directing consumers mentioned benefits such as being able to choose who works for them, although one downside mentioned was working with Allied.

*I really like the self-hire program because it gives me the ability to customize who works with [consumer] and I can make sure that they work well with [him]... The only downside is dealing with Allied... It's so hard to get a hold of them, they never provide enough information, they are always late with payments, and honestly I just have nothing good to say about them – Autism*

Table 15. Self-Direction

	CHCP %	PCA %	ABI %	Autism %	KBW %	MHW %
How hire staff	N=551	N=276	N=299	N=62	N=31	N=39
Agency	96.2	17.0	66.2	72.6	45.2	89.7
Self-hire	3.8	83.0	33.8	27.4	54.8	10.3
Employs family members	N=21	N=228	N=101	N=17	N=17	N=4
Yes	52.4	41.2	24.8	17.7	47.1	0
No	47.6	58.8	75.3	82.4	52.9	100

**G. Employment**

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

i. Employment status

Figures 24 and 25 show employment status and goals. There is a striking difference with respect to rate of employment – none of MHW and less than 5% of PCA participants were working, compared to 16% of ABI and 33% of Autism participants. It is notable that 44% of unemployed Autism participants would like to work, compared to 23-30% of ABI, PCA, and MHW participants. Finances may be one motivating factor for some participants, as expressed by a MHW consumer, “I really want a part-time job – I would love to start making money.”

Figure 24. Employment Status

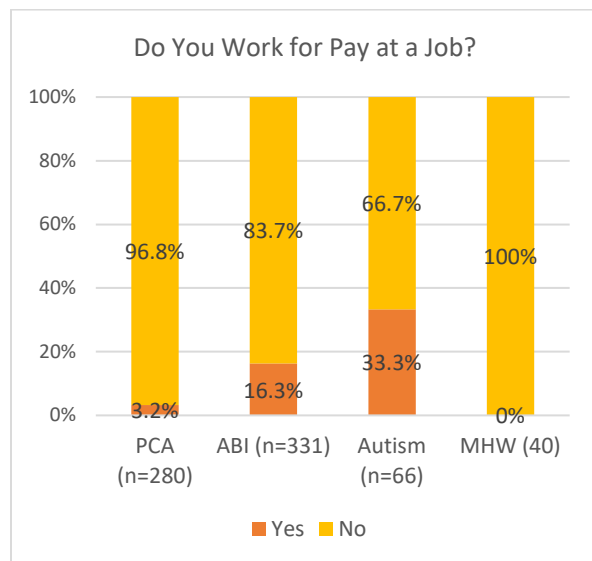
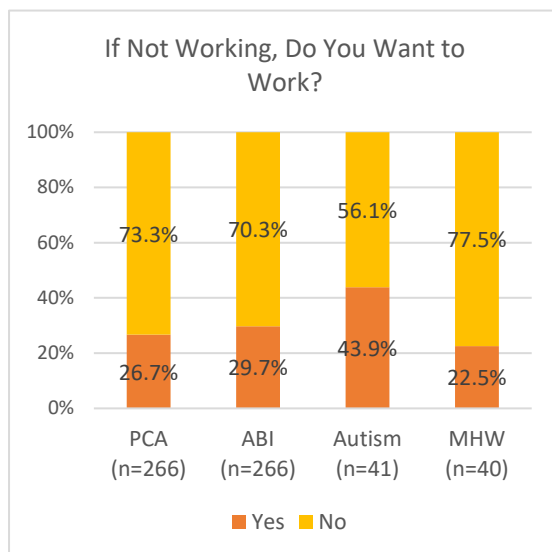


Figure 25. Employment Goal





Physical or mental health and disability related concerns were the most frequently reported reason for not working, most notably for PCA and MHW participants (Table 16). COVID was also a barrier to employment, especially for Autism and ABI consumers, as businesses closed and people were afraid they would get sick. Compared to the other waivers, MHW participants were the most concerned with losing their benefits if they got a paying job. One respondent commented on how staffing can impact working at a job for pay:

*As far as the work piece, it's not that he couldn't work for pay, [but] as far as his staffing, he has different staff and sometimes the staff are out ... It is hard for [consumer] to commit to a job when he has changes in staff. He does volunteer 5 days a week but does not work for pay. The rest of his time is social activities, such as going to the library – Autism*

Between 23% (PCA and MHW) to 66% (ABI) of participants who did not want a job reported that nothing was holding them back from working.

Table 16. Most Common Reasons for Not Working\*

*Respondents who would like to work*

	PCA N=69 n (%)	ABI N=73 n (%)	Autism N=18 n (%)	MHW N=9 n (%)
Physical or mental health/disability	52 (75.4)	29 (39.7)	5 (27.8)	6 (66.7)
COVID-19 pandemic	5 (7.2)	22 (30.1)	8 (44.4)	2 (22.2)
Looking for but cannot find work	2 (2.9)	5 (6.8)	3 (16.7)	2 (22.2)
Transportation	4 (5.8)	6 (8.2)	1 (5.6)	0 (0)
Other	4 (5.8)	4 (5.5)	4 (22.2)	1 (11.1)
Nothing is holding me back	2 (2.9)	6 (8.2)	1 (5.6)	0 (0)

*Participants who do not want to work*

	PCA N=194 n (%)	ABI N=183 n (%)	Autism N=23 n (%)	MHW N=30 n (%)
Physical or mental health/disability	147 (75.8)	45 (24.6)	5 (21.7)	22 (73.3)
COVID-19 pandemic	0 (0)	10 (5.5)	5 (21.7)	1 (3.3)
Loss of benefits	1 (<1.0)	5 (2.7)	0 (0)	6 (20.0)
Other	3 (1.5)	9 (4.9)	7 (30.4)	1 (3.3)
Do not want to work	45 (23.2)	121 (66.1)	10 (43.5)	7 (23.3)

\*Multiple choice

A small number of unemployed participants had asked for assistance with finding a job (Figure 26). The vast majority of unemployed participants knew that help finding a job was available, although most of them did not seek it out (Figure 27). Some consumers commented on the effect of the COVID-19 pandemic on receiving job services, or that they had pursued job assistance in the past, but found it was not as helpful as they thought it would be.

*They can help if [consumer] was receiving need based services – one example is job finding assistance. BRS has not been helpful when used and [we were] told BRS is the only agency able to help him – Autism*

Figure 26. Sought Out Employment Assistance

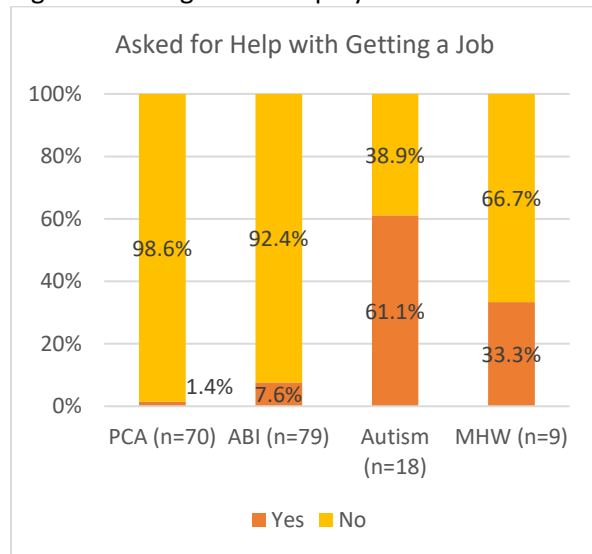
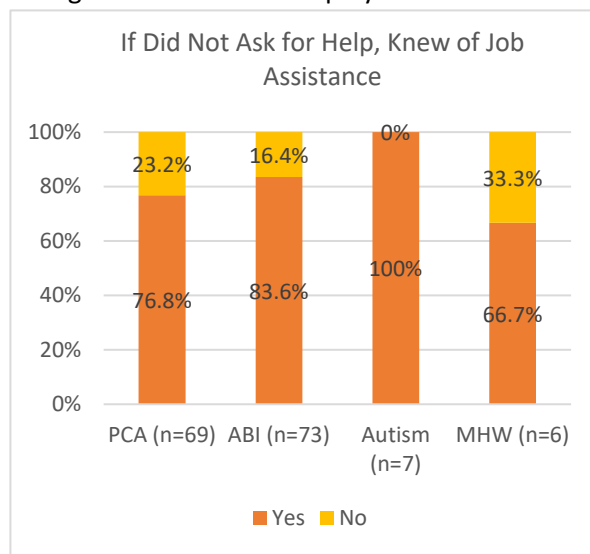


Figure 27. Aware of Employment Assistance



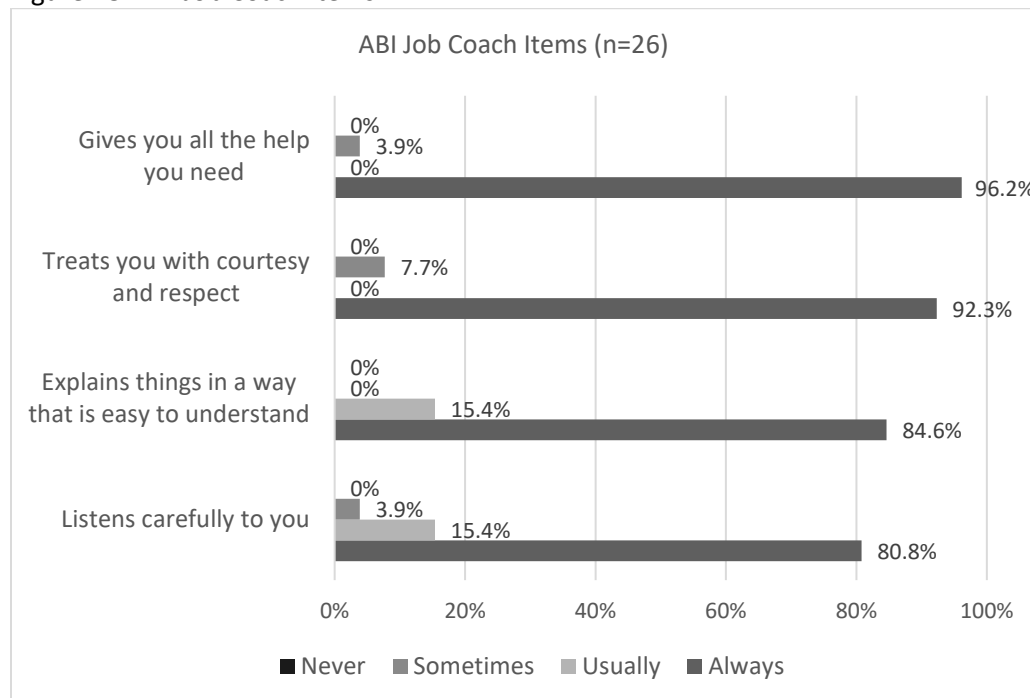
ii. ABI and Autism Employment Experiences

The ABI, Autism, and MHW waivers provide various employment specific services for employed participants. When asked who helped them find their job, ABI participants most often found their jobs using waiver/vocational staff or family/friends, while Autism consumers found their jobs through a variety of ways, including waiver/vocational staff or they found it themselves.

*ABI Job Coach*

Sixty-nine percent (n=37) of the 54 employed ABI participants said someone was paid to help them with their job; 26 answered job coach questions. All of these participants said that their job coaches encouraged them to do things for themselves; the 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 4.62, out of 1-5) and recommendations (mean score 3.62, out of 1-4).

Figure 28. ABI Job Coach Items



*Autism Job Coach*

One third (n=22) of Autism respondents were employed. Six of them (27%) reported someone was paid to help them with their job; 4 answered job coach questions. All four participants said their job coach “usually” or “always” gives them all the help they need, treats them with courtesy and respect, explains things in a way that is easy to understand, and listens carefully. All four participants also said their job coach encouraged them to do things for themselves if they could. As reported in Figures 3 and 5, these Autism participants gave their job coaches high ratings (mean 4.5, range 1-5) and recommendations (mean 3.75, range 1-4).

**H. Mental Health Waiver Participant Questions**

Five questions provided by the MHW program manager asked MHW participants to what extent the services they receive through the MHW have affected their lives in five key areas (Figure 29). As in the previous year, participants gave positive responses – 80% or more either agreed or strongly agreed with each statement. In particular, 91% of MHW participants agreed or strongly agreed that the MHW services help them stay in the community. One participant said that without the waiver services, they would be in a nursing home. Another commented that although it was “bumpy” for several years, they now have a new agency which connected them with a volunteer job.

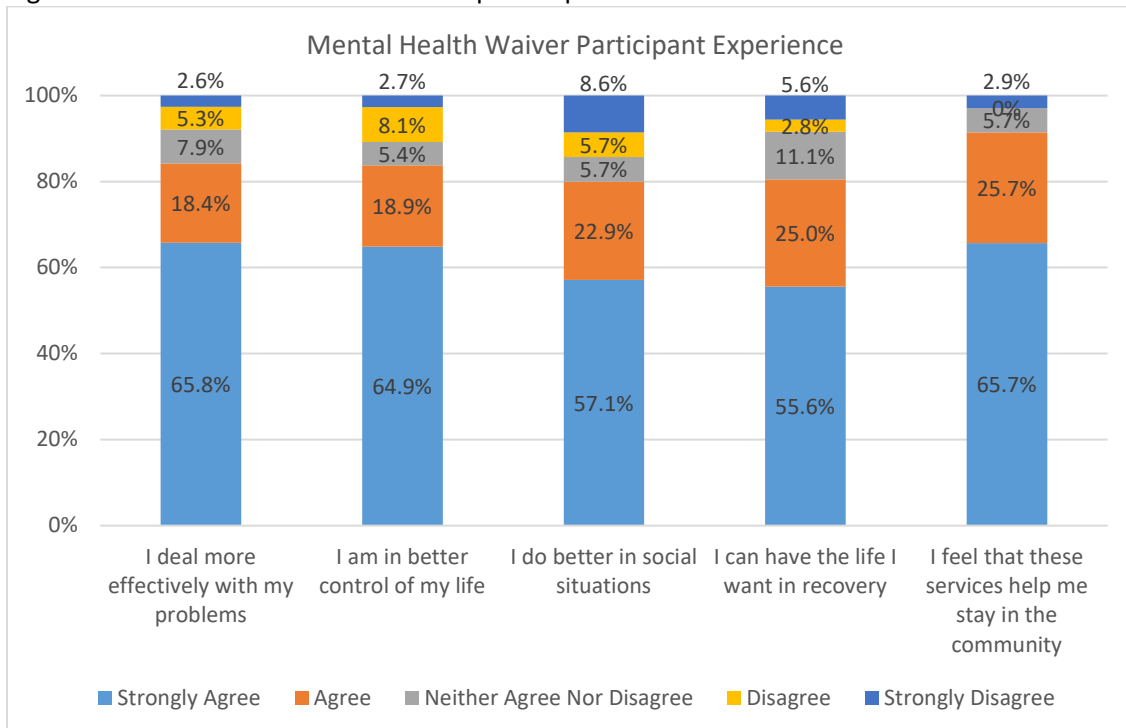
*Life is good right now and it's because of the [new] agency. ... Even on the days they're not with me I'm doing well. If it's a day they don't usually come in and I need support, they'll brainstorm with me and someone can always come if I need them.*

*The programs help me a lot and I've been so much better since having my companion [RA]. I am able to live independently and have a good life because of [RA] – MHW*

Similar to other programs, MHW participants experienced difficulties with getting and retaining staff and switching agencies. Participants expressed that when left without staff, they had difficulty getting everyday activities like household tasks and laundry done.

One MHW participant suggested that the waiver provide “resources for people to advocate for themselves – like a sheet with all the resources to become self-advocates in these systems.”

Figure 29. Mental Health Waiver Participant Experience



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

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

### i. CHCP programs

Similar to last year, CHCP composite scores were universally high across agencies for all but three of the key composite measures: planning your time and activities, medical transportation, and case manager is helpful (Figure 30). Percentage of participants who gave the highest scores for case manager is helpful and choosing the services that matter to you showed the greatest agency variation. The percentage of CHCP participants who gave the highest score for the composite case manager is helpful ranged from 81% (Agency Q) to 98% (Agency L). All agencies had low scores for planning your time and activities and medical transportation, which indicates an area for program improvement.

Global ratings for CHCP personal assistants, homemakers, and case managers also varied across agencies (Figure 31). For example, the percentage of care managers who received a 9 or 10 varied from 81% (Agency Q) to 94% (Agency R).

The percentage of CHCP participants from each agency who “definitely” recommended their staff and care managers also showed striking differences (Figure 32). CHCP care manager recommendations showed the greatest variation: 97% of Agency R participants would definitely recommend their care managers, compared to 62% of Agency G participants.

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

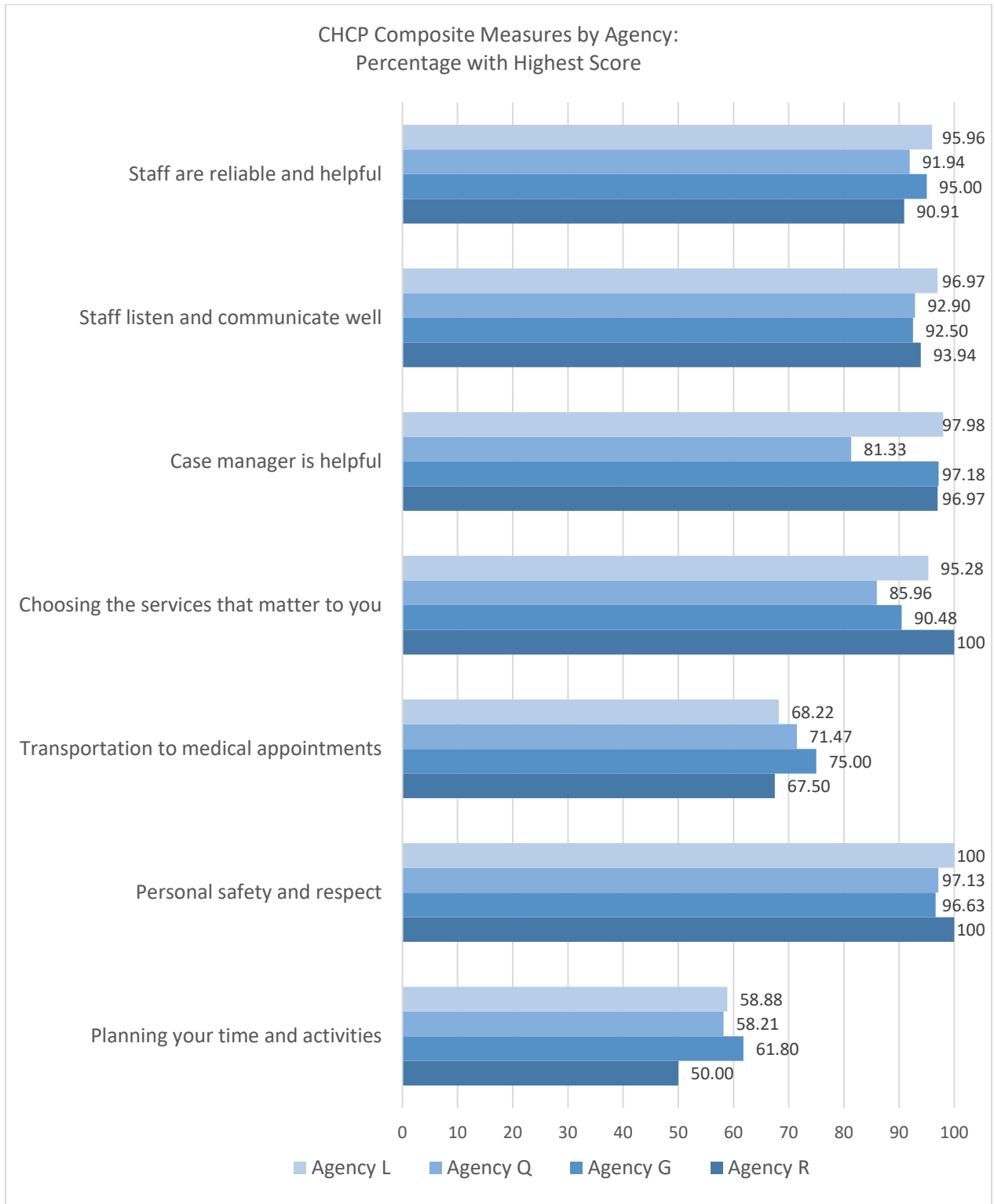


Figure 31. CHCP Global Ratings by Agency: Percentage Who Rate Their Staff a "9" or "10"

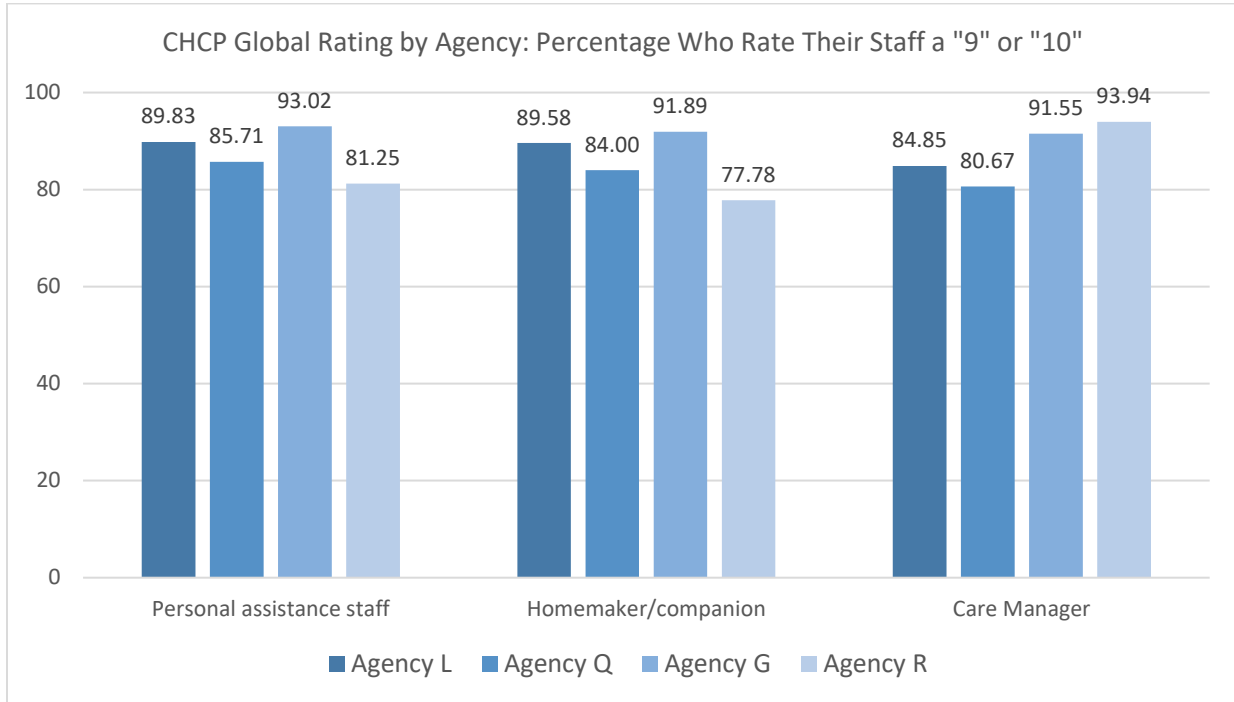
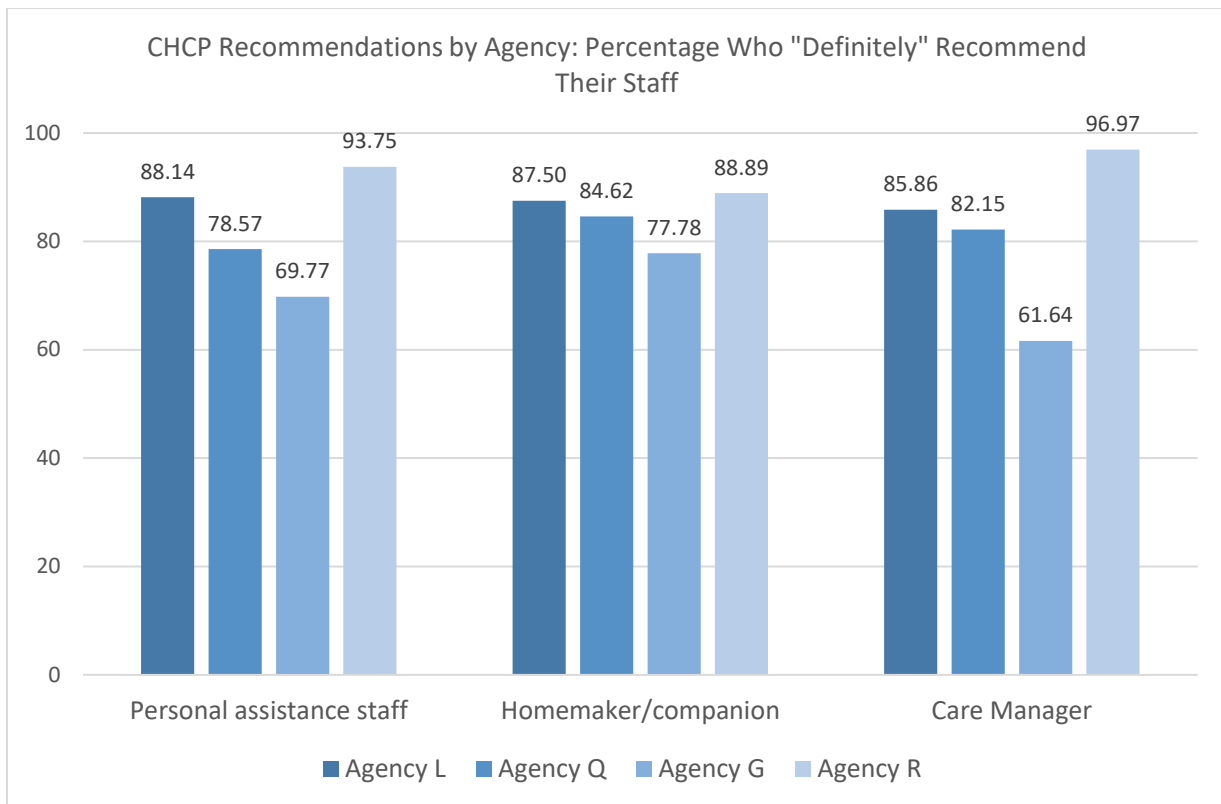


Figure 32. CHCP Recommendations by Agency: Percentage Who "Definitely" Recommend Their Staff



ii. PCA waiver

PCA composite scores were high across all agencies for all but three of the composite measures: planning your time and activities, transportation to medical appointments, and choice of services (Figure 33). The percentage with highest score for the composite case manager is helpful were all very high, ranging from 91% (Agency Q) to 100% (Agency G and Agency R). Global ratings and recommendations for PCA waiver staff and case managers showed marked agency variation (Figures 34 and 35). Compared to participants from the other agencies, a much lower percentage of Agency Q PCA participants rated their case managers a 9 or 10 or would definitely recommend their case managers.

Figure 33. PCA Composite Measures by Agency: Percentage with Highest Score

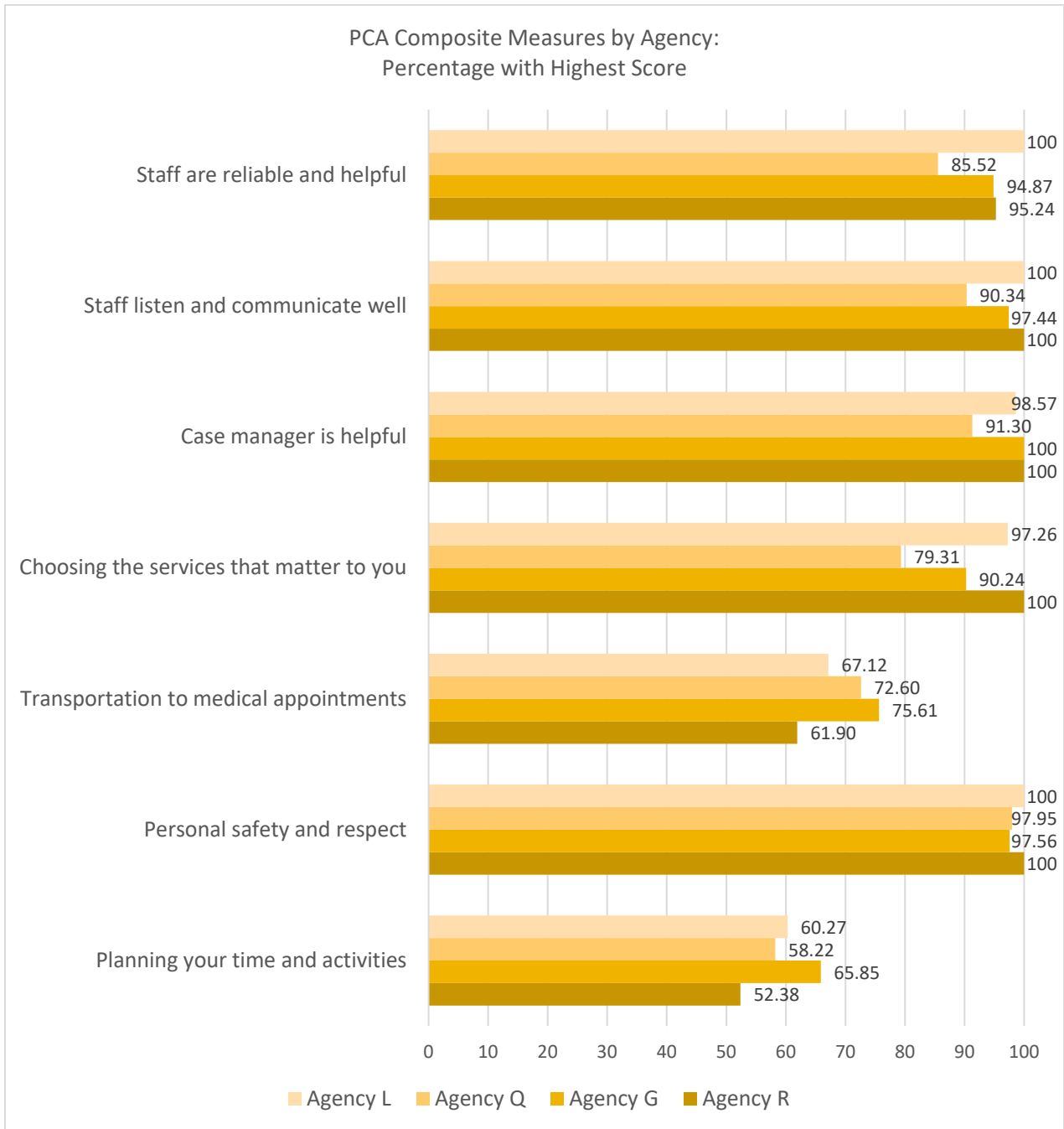


Figure 34. PCA Global Ratings by Agency: Percentage Who Rate Their Staff a "9" or "10"

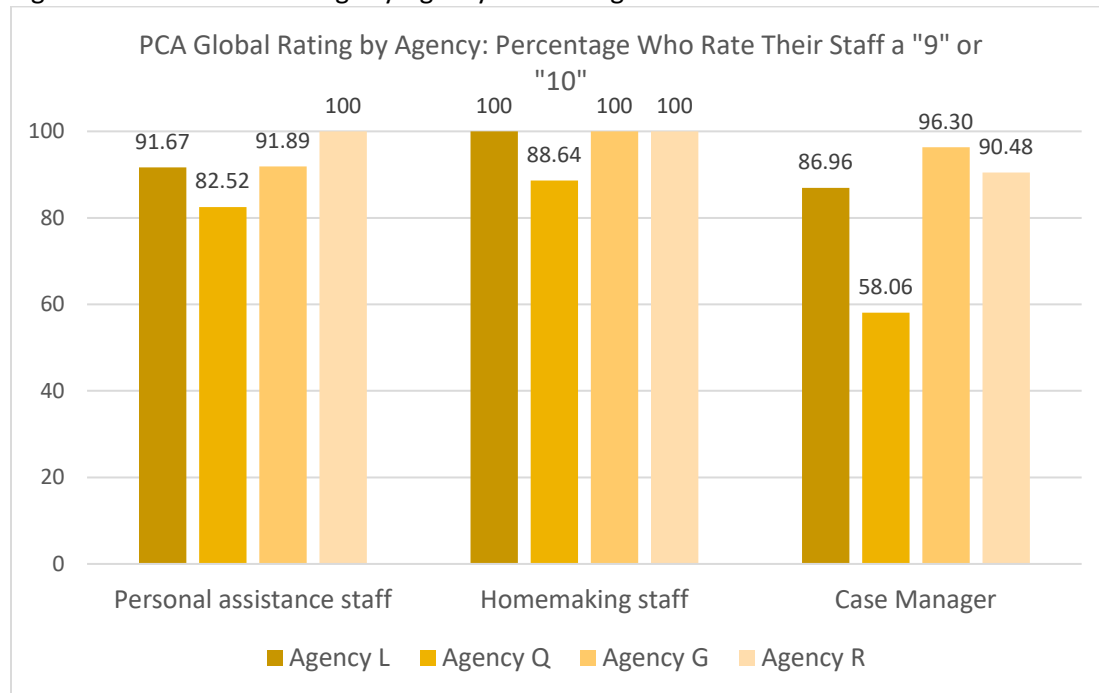
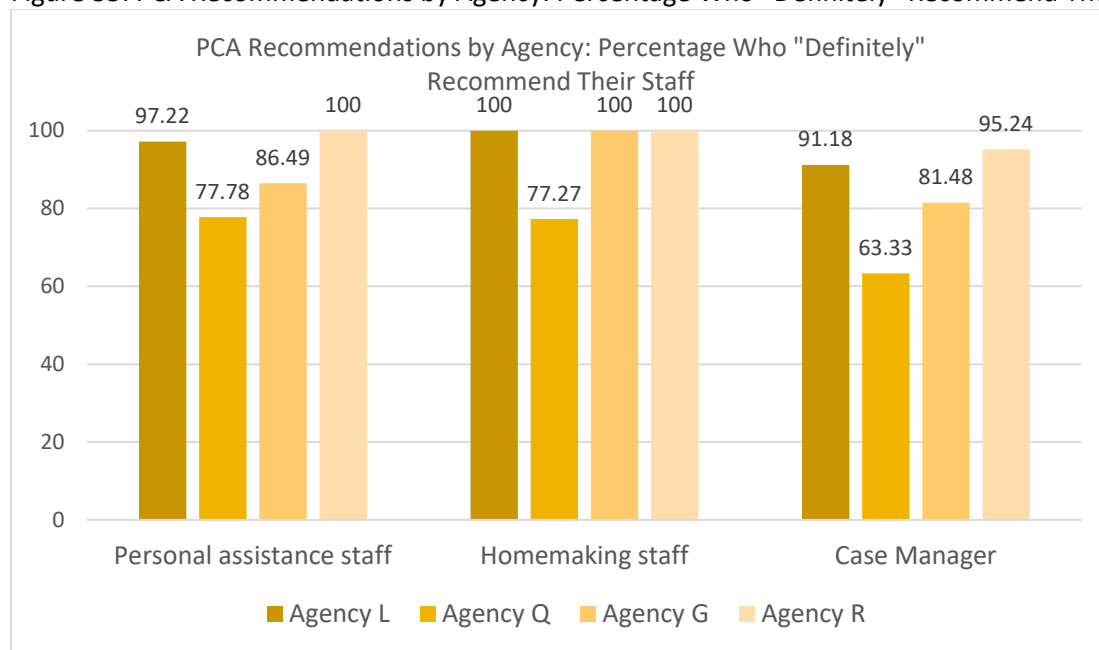


Figure 35. PCA Recommendations by Agency: Percentage Who "Definitely" Recommend Their Staff



iii. ABI waivers

As with the CHCP and PCA waivers, the composite planning your time and activities received the lowest scores across all agencies (Figure 36). ABI medical transportation also received lower scores, ranging from 66% (Agency O) to 76% (Agency N and Agency I). Compared to the other waivers, choice of services was not rated as highly by ABI participants; scores ranged from 70% (Agency N) to 83% (Agency O). On the other hand, scores for the composite care manager is helpful were high across all agencies, ranging from 95% (Agency N) to 100% (Agency O).



Care manager rating and recommendations varied across agencies (Figures 37 and 38). The percentage of ABI participants who rated their case managers a 9 or 10 ranged from 62% (Agency O) to 77% (Agency I), while between 71% (Agency N) and 82% (Agency O) of ABI participants would definitely recommend their case manager.

Figure 36. ABI Composite Measures by Agency: Percentage with Highest Score

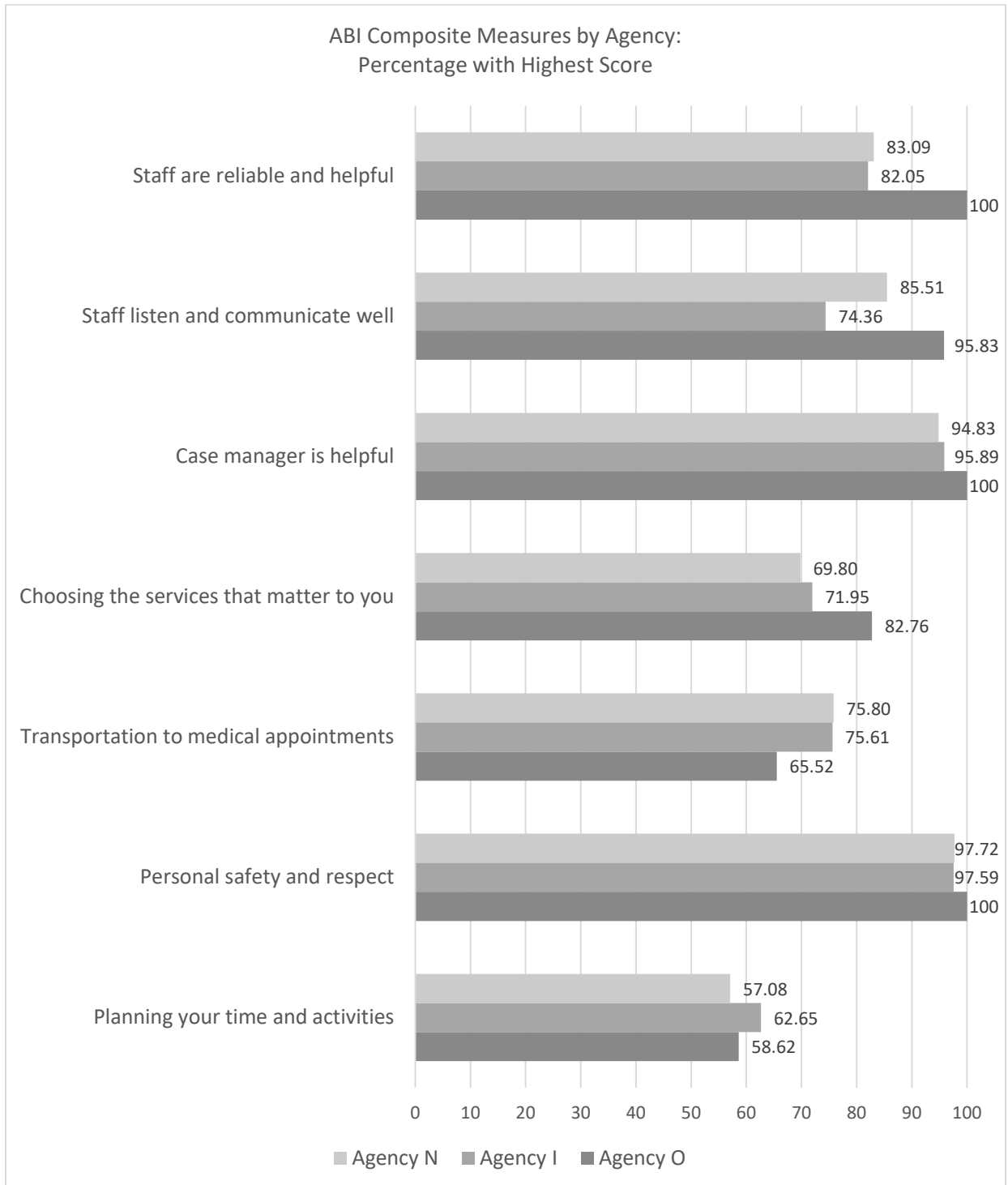
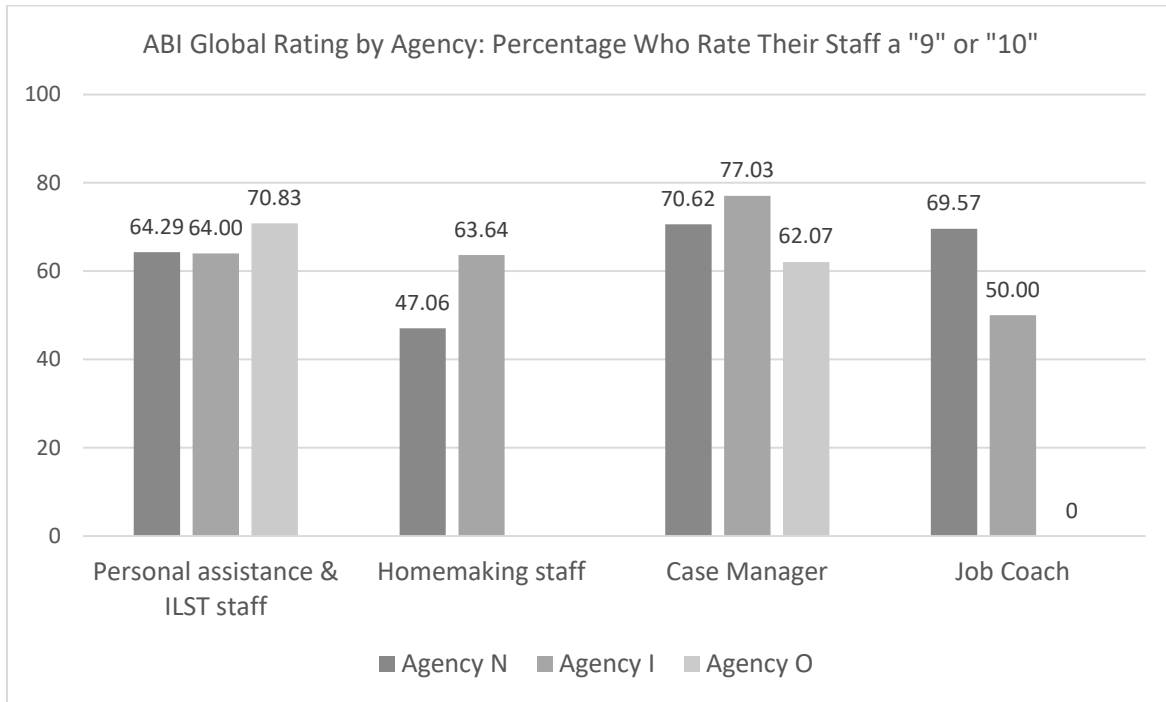
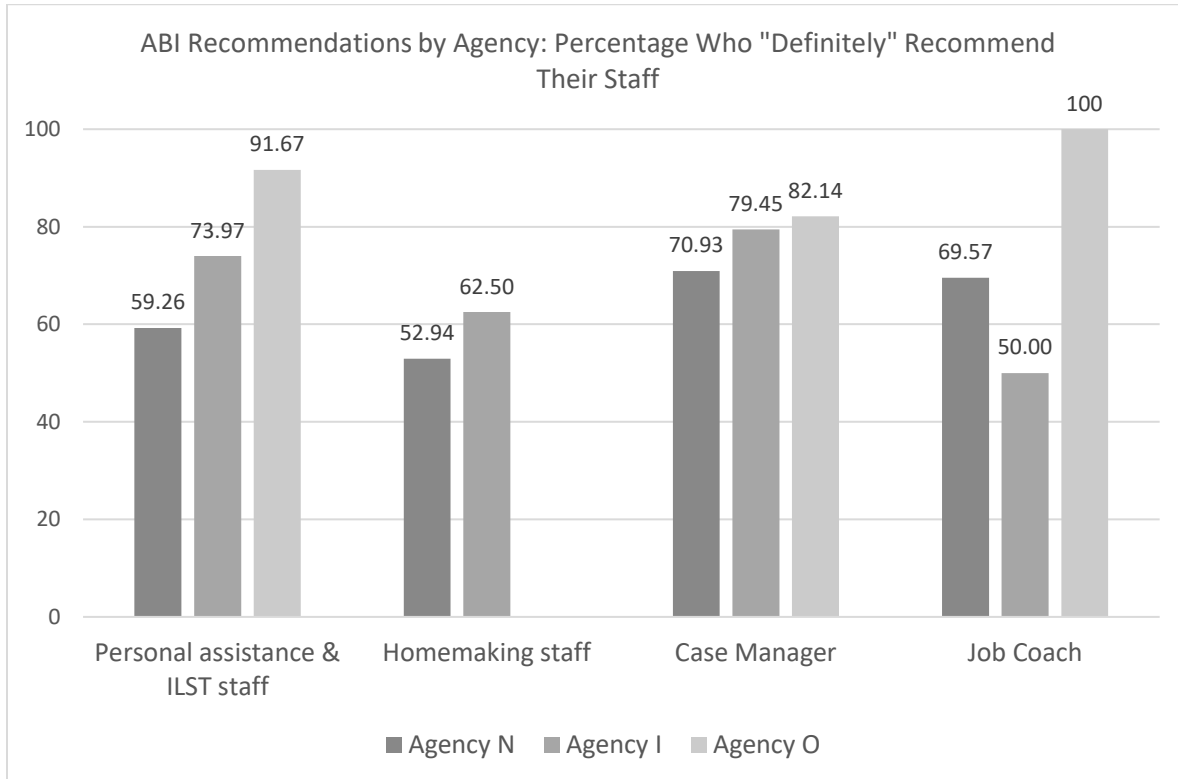


Figure 37. ABI Global Ratings by Agency: Percentage Who Rate Their Staff a "9" or "10"\*



\*No Agency O job coaches received a 9 or 10 rating

Figure 38. ABI Recommendations by Agency: Percentage Who "Definitely" Recommend Their Staff



## IV. Conclusions

This is the fourth year Connecticut has used the HCBS CAHPS survey to inform quality measurement in seven of its Medicaid programs (CHCP Categories 3 and 5, PCA, ABI I and II, Autism, and KBW), and the second year in the MHW program. As a standardized, cross-disability survey, the HCBS CAHPS provides Connecticut with the ability to compare participant experiences in the same domains across different waivers. The HCBS CAHPS survey is also part of quality and performance assessment for the Access Agencies contracted to provide CHCP, PCA, and ABI case management services. This report presents results from surveys conducted in FY 2021, from July 1, 2020 to June 30, 2021.

### A. Survey Completion Rates

In FY 2021, each Access Agency met or exceeded their respective representative samples for each of the programs they case manage. While Autism improved its completion rate this year, reaching 77% of its representative sample, the KBW completion rate fell considerably from last year, from 72% to 40%. This was the second year of HCBS CAHPS implementation in the MHW. Half as many MHW HCBS CAHPS surveys were completed this year (n=42), representing just 18% of its representative sample.

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 the KBW will need a different survey strategy this year to improve their survey numbers. The 18% MHW completion rate in particular is very concerning. It is recommended that DSS work with the MHW program managers to meaningfully implement the HCBS CAHPS survey into that waiver. As the training and technical assistance provider, the UConn Health Center on Aging is available to support these programs and agencies, for example, by developing a personalized recruitment strategy for each of those programs.

### B. Key Results by Program

#### Composite measures

The composite items showed more variation this year, both among the composites and the programs. Choosing the services that matter to you showed the greatest variation this year, with CHCP and PCA reporting much higher scores than the other four programs. All programs reported low scores for planning your time and activities, and most had high scores for personal safety and respect. Overall, similar to FY 2020, KBW 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). Consumers in all waiver programs have given this composite the lowest score compared to the other composites in the past, and all but MHW did so again in FY 2021. While COVID-19 most likely disrupted many participants' social and community activities, this does not explain this composite's historically low scores. Commented some participants:

*It would be nice if they had more services for entertainment – ABI*

*The biggest gap of supports is social supports, largely due to location and transportation issues – Autism*

Positive social engagement, community involvement, and choice and control are all important elements of successful community living, and these areas represent an opportunity for improvement across all programs.

- **Choosing the services that matter to you**

Choosing the services that matter to you asks if the consumer's care/service plan includes the things that are important to the consumer and if their staff know what is on their care plan. These items speak to person-centered care, as well as choice and control. CHCP and PCA had higher scores in this composite compared to other programs. Still, developing methods to elicit and then include in the care plan activities and tasks that are important to the consumer, as well as ways to effectively communicate these to the staff, would improve services for all waiver participants.

- **Transportation to medical appointments**

When compared by percentage given the highest score, transportation to medical appointments was also given lower scores by all programs. As with other assistance and services, family members and other unpaid personal supports often stepped in to fill the gap. Commented one consumer's sister:

*Right now I take [consumer] to her doctor appointments, but eventually she will need transportation. I will do what I can until I can't anymore – CHCP*

### Case Manager Items

CHCP participants gave their case managers the highest ratings and recommendations among all the programs. Eighty-four percent of CHCP participants gave their case manager the highest rating, followed by MHW (81%) and PCA participants (77%). With the exception of KBW, 71-81% of participants in the other programs would definitely recommend their care manager; only 55% of KBW would do so. Some CHCP consumers in particular commented that they were happy that they got regular check-in calls from their case manager or care manager agency. A few comments indicated that there is still room for improvement, especially with respect to communication and responsiveness. For example, one CHCP respondent commented that the care manager communication "should be more thorough," while another said they "desperately needed" a ramp, but indicated the case manager had not worked with them about this.

Autism, CHCP, and ABI participants (87-99%) were the most knowledgeable of their care manager, while less than two-thirds of MHW and KBW respondents knew who their care manager was. Most participants in each program said they would contact their care manager if they wanted to change their service or care plan. However, 19-23% of MHW and KBW respondents did not know whom they would talk to. Comments indicated that KBW parents in particular could use increased case manager support. The MHW has multiple supports available to participants, and knowing who to go to might help some participants take advantage of all the waiver services available to them. These results indicate a continued need for DSS and DMHAS to improve and support quality case management for all waivers.

Care manager comments included:

*I never have felt like a number. [Care manager] has always been nice and helpful, and always tries to find solutions and dig deep to make sure my brother has all services he needs – ABI*

*The [care management agency] does a good job. If I would change anything, a volunteer program could help. Maybe the care manager has too many clients – PCA*

*The care manager has been really helpful with getting [consumer] the services he needs. They are working on getting [consumer] connected with the Level Up program through BRS which [care manager] is assisting with – Autism*

*[Care manager] is a professional person, and I hope she continues to be my social worker for a long time – CHCP*

*I am very pleased with how the care manager has explained the services my son can get at home – PCA*

*[Care manager] is very easy to get a hold of and communication is great – ABI*

*The care manager is doing an excellent job – CHCP*

### **Staff Ratings and Recommendations**

CHCP and PCA participants were once again more likely than participants from other programs to highly rate and recommend their personal/behavioral staff or homemaker services. For example, 88% of CHCP and PCA would rate their personal/behavioral staff a nine or ten, compared to 64-71% of other program participants. CHCP respondents in particular also expressed that they appreciated the program and the services it provides. MHW participants gave high scores to their community service providers, although the low scores given to their RAs indicate room for improvement with the RA services. Comments about various types of HCBS staff included:

*I could not ask for any better aides – PCA*

*My homemaker-companion is excellent – the best I've ever had – CHCP*

*I am very pleased with the 3 girls [sic] I have. It's a wonderful thing when you have such great help – thank you so much – CHCP*

*Life is good right now and it's because of the [Community Services Provider] agency. Even on the days they're not with me, I'm doing well. If it's a day they don't usually come in and I need support, they'll brainstorm with me and someone can always come if I need them – MHW*

- ***Staffing issues***

Comments indicated some issues with staffing or finding the right staff. Participants mentioned difficulties with consistency and quality of staff, not enough available HCBS staff, and a need for disability-specific training. A couple of respondents reported a need for Spanish speaking staff. Comments indicated communication from the homecare agencies themselves could be improved, such as when no call is made that the caregiver cannot come on time or when caregivers are changed without notice. A few illustrated how unpaid family members filled in when staff were absent. More than one consumer suggested that PCAs or ILSTs get paid more. Remarks reflecting staffing or agency-related challenges include:

*In general it is hard to find people to work with [consumer].... [They] really do not understand autism and how it affects people who are unable to get [their] needs met and the family as a whole – Autism*

*I am desperate to hire people – PCA*

*I'm having difficulty finding nurses in my area. As soon as I get one, they leave the agency – KBW*

*[PCA] has not been working with me for 3 weeks and [homecare agency] has not communicated with me... I am alone and without help. For now my daughter is with me until she gets a job – CHCP*

*We're struggling for ILST staff and it's completely unexcusable [sic]. No one can provide the quality of care that was promised and that we really want – ABI*

*Homemaking [agencies] should be careful on how they hire their staff – CHCP*

Both self-directing consumers and those using agency-based services expressed the need for a better trained and qualified workforce. For example, one parent said they had to train the community mentor on how to assist their child, while an ABI respondent stated, "They [homecare agencies] can't just hire

people off the street. You need someone with some kind of knowledge of ABI. A lot don't even know what this is." Increased workforce training opportunities for agency-based and self-employed HCBS staff would also help those working in this field to expand their skill set or gain specialized skills.

In addition, some participants from all waivers expressed a need for additional services or hours not provided in their care plan, such as an "extra day a week" or more help with household tasks. Comments indicated the real physical or psychological effects of not having enough or the right paid supports, such as the respondent who stated, "[CHCP participant] can't get out of bed at all. She does not have enough help," or the CHCP participant who remarked, "I am not comfortable with the caregiver I have right now – I feel alone." One Spanish speaking CHCP consumer explained that because the homecare nurse did not speak Spanish, the consumer had difficulty understanding the nurse's reporting of her vital signs. Remarks like these indicate a need for the state to focus on workforce development – building a quality, multi-lingual workforce – as well as focusing on improving person-centered care at the state and HCBS agency level.

- **Self-Direction**

Not surprisingly, 83% of PCA participants hired their own caregivers, while nearly all CHCP and MHW participants, as well as the majority of ABI and Autism participants, used an agency to provide staff. Unlike in previous years, self-directing CHCP participants were the most likely to employ family members, followed by KBW and PCA. Unfortunately, as indicated in the previous section, finding the right person to hire is not always easy. 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.

Comments pointed to a need to better connect people interested in hiring their own staff with information and education about the self-direction process. The state may want to re-evaluate and expand the current self-direction training and outreach to current and potential consumer/family member employers.

*We hire [a family member] through some other state program [CFC] to come help [consumer] get dressed and other things, but he is getting too big for her. We need to hire someone else, but they said we would have to find them ourselves. We do not know how to do that and do not have time. I wish there was a list of people or something – KBW*

One downside to self-direction repeated more than once was difficulties working with Allied. This echoes comments from previous survey years and points to the need for the state to address concerns about Allied or find a new DSS fiscal intermediary for the CFC program. With any fiscal intermediary, it is suggested that measurable quality measures be included in the contract such as responsiveness, consumer experience, and the fiscal intermediary's internal quality assurance practices. Comments also indicated a need to improve the Allied staff directory. Perhaps Allied could include a short biographical statement listing the person's specialized skills and create a method to sort or filter the list by specialization so that different types of staff could be found more easily.

*They [Allied] need to do more research on the people they put on the list to hire – PCA*

*It would be great to have a directory of ILSTs that have a specialization – ABI*

*The new payroll system for Allied is horrible. It is not user friendly – Autism*

### **C. CHCP, PCA, and ABI Performance Benchmarks**

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

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

#### **CHCP programs**

All four Access Agencies met or exceeded the CHCP performance benchmark scores for each of the five performance measures. The CHCP performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.82 to 3.94
- Choosing the service which matter to you composite: 3.70 to 3.99
- Personal safety and respect composite: 3.90 to 4.0
- Case manager global rating: 4.72 to 4.94
- Case manager recommendation: 3.59 to 3.97

#### **PCA waiver**

Similar to last year, one Access Agency did not meet one of the five PCA performance benchmarks. For PCA care manager global rating, Agency Q received a score of 4.33, while the benchmark is 4.5. All four agencies met the PCA performance benchmarks for all composite measures and for case manager recommendation. The PCA performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.82 to 4.0
- Choosing the service which matter to you composite: 3.68 to 4.0
- Personal safety and respect composite: 3.95 to 4.0
- Case manager global rating: 4.33 to 4.96
- Case manager recommendation: 3.54 to 3.95

#### **ABI waiver**

All three agencies met the ABI performance benchmarks for two composite measures – care manager rating and care manager recommendation. Agency N Agency received a score of 3.49 for the composite choosing the services which matter to you; the benchmark is 3.5. All three agencies met the ABI performance benchmarks for care manager rating, and care manager recommendation. The ABI performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.86 to 3.91
- Choosing the service which matter to you composite: 3.49 to 3.69
- Personal safety and respect composite: 3.91 to 4.0
- Case manager global rating: 4.52 to 4.72
- Case manager recommendation: 3.65 to 3.79

## D. Impact of COVID-19

Some comments specially mentioned COVID-19 and its effect on services, community activities, and seeing friends and family over the past year. Participants reported that COVID-19 made it harder to have services as not as many caregivers, either agency-based or self-hiring, were available. Other consumers cancelled their services in order to limit their exposure, or kept their services while at the same time expressing concerns such as caregiver vaccination status. COVID-19 was also a factor in consumers' employment status and goals. Consumers lost their jobs, did not have access to job assistance because agencies were shut down, or decided not to pursue employment because of COVID concerns.

*I am concerned that [my] caregivers don't have their COVID vaccines – CHCP*

*Although there has been some telehealth services, due to COVID [consumer] has not been able to get his normal aides to get into the home – Autism*

*COVID has prevented [consumer] from doing everything he wanted and receiving some of the services he would normally receive. He was able to go out and was active prior to the pandemic. - Autism*

Autism consumers in particular mentioned that COVID prevented them from activities out in the community including working. Still, some consumers and family members found ways to continue services such as care management or behavioral health services virtually, and there were comments that the care managers kept in touch through the pandemic:

*Everything has been virtual this past year - all services pertaining to in-person or going out into the community ceased due to COVID. Instead, he has virtual visits with his community mentor online. Sometimes [the community mentor] tells him about videos or things to read, and they discuss it the next time – Autism*

*My care manager has been wonderful through COVID – CHCP*

The COVID-19 pandemic affected everyone's lives and was especially difficult for those who live alone or rely on others for assistance, such as those receiving HCBS. As one PCA consumer put it, "Basically I am just trying to get through COVID."

## E. Mental and Emotional Health

Similar to previous years, mental health is an area of concern for the three largest waiver programs. At least one-third of CHCP, PCA, and ABI participants rated their mental or emotional health as fair or poor. Not surprisingly, MHW participants reported the worst mental health overall, with 41% reporting fair or poor mental health. Although Autism participants continue to report the best mental health, this year there was a large increase in the percentage of Autism participants reporting fair or poor mental health. The previously mentioned effect of COVID-19 on community engagement for Autism consumers in particular may account in part for this large increase. When compared to last year, participants in every program said they were less likely to see either their nearby family or friends in FY 2021. Most likely this was an effect of the social distancing caused by COVID-19 and concerns over getting sick. Helping participants find ways to connect with other people, even during a public health emergency, is an area which could improve participants' lives.

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 throughout the waivers. Groups could meet virtually, and the state could draw upon experienced self-advocates and other stakeholders to help facilitate. Perhaps DSS could reach out directly to waiver participants and ask what would be helpful for them to increase community engagement and socialization.



## F. Employment

MHW and PCA participants were the least likely to either be employed or want to work compared to either ABI or Autism participants. They were also much more likely to report that physical or mental health issues affected their employment status or goals and were older than Autism and ABI consumers. These PCA and MHW participants may face, or anticipate facing, disability or age-related job discrimination or stigma (Hastuti & Timming, 2021) (Heymann et al., 2021). Fear of loss of disability benefits was greatest among unemployed MHW participants. These consumers may have concerns that a potential mental illness exacerbation could affect their ability to keep a job, and that a change in employment status would then affect their disability benefits. Meanwhile, COVID related concerns were most often cited by Autism and ABI consumers as an employment barrier.

*COVID has made things difficult lately. Hopefully when things get better he [consumer] will be able to go out. He hasn't been able to do everything he wants to. He hopefully will be able to do a job search when COVID is over – Autism*

## G. Mental Health Waiver Experience

Five questions ask MHW participants how the MHW has affected their lives. As in the previous year, participants gave positive responses – 80% or more either agreed or strongly agreed with each statement. In particular, 91% of MHW participants agreed or strongly agreed that the MHW services help them stay in the community. One area not rated not quite as high was the MHW effect on the item, “I do better in social situations” – 80% agreed or strongly agreed with this statement. Working with MHW participants on their social skills and social connections represents a potential opportunity for improvement.

## H. CHCP, PCA, ABI Additional Data by Agency

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

In the CHCP waiver, the case manager is helpful composite scores ranged from 81% to 98%. CHCP care manager ratings and recommendations also showed interagency variation. In particular, the percentage of CHCP participants who would definitely recommend their case manager ranged from 62% to 97%. Still, of the three waivers, CHCP care managers received the highest case manager rating and recommendation scores overall.

The PCA case manager composite had high scores of 91% or above for all agencies. The percentage of PCA participants who gave the highest scores for choice of services varied across the agencies, from 79% to 100%. Agency Q participants gave their PCA case managers noticeably lower rating and recommendation scores.

Unlike CHCP and PCA participants, ABI participants across all agencies gave relatively lower scores for choosing the services which matter to you. The composite care manager is helpful got very high scores

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Hastuti, R. & Timming, A. R. (2021). An inter-disciplinary review of the literature on mental illness disclosure in the workplace: Implications for human resource management. *The International Journal of Human Resource Management*, 32:15, 3302-3338, DOI: 10.1080/09585192.2021.1875494

Heymann, J., Wong, E., & Waisath, W. (2021). A Comparative Overview of Disability-Related Employment Laws and Policies in 193 Countries. *Journal of Disability Policy Studies*, 10442073211006396.

of 95% or above for all agencies. Still, of the three waivers, ABI care managers received the lowest rating and recommendation scores overall.

Scores for the composites planning your time and activities and medical transportation were universally low across all waivers and agencies. As stated above, these are areas to focus on for program improvement.

## I. Respondent Suggestions

At the end of the survey, some respondents offered suggestions as to how to improve the waiver programs or expressed a desire for specific services which would help other consumers and family members navigate the often confusing world of Connecticut's Medicaid HCBS programs. These are all included below for DSS consideration, with some supporting quotes.

- More easily accessible information on available services and supports, in print, videos, and recorded webinars and in multiple languages. Some comments indicated that even current waiver participants may not be aware of all the services provided in that waiver, such as the Autism respondent who wanted their son to have a job coach, or the ABI respondent who said they would "love for someone to get a day program for someone with brain injury."

*I feel lost in this whole process. I don't know what services are available or how to get them. My friends said that I could get help, but I don't know where to go or who to contact. We have paid for his hospital bed, remodeled the bathroom, and bought a special wheelchair van. Maybe DSS can do a webinar for parents so we do not feel so lost – KBW*

- Create regional and waiver specific "point persons" to provide individualized program support.

*What we really need is a "point person." Someone that not only knows the ins and outs of this program, but someone who can get to know [consumer] and my family, so they can see and know what our specific needs are. Someone who can explain to me how everything works and to do more of the heavy lifting – KBW*

- Support people to become self-advocates, such as providing a comprehensive resource list or directory of services.

*Provide resources for people to advocate for themselves – like a sheet with all the resources to become self-advocates in these systems – MHW*

*A guide to services would be helpful – KBW*

*I would like to participate in any collaborations to improve communication about the Waiver – KBW*

- Suggestions from self-directing respondents: Provide more training for self-directed consumers. Assist self-directed participants with finding and hiring caregivers. Improve the Allied directory by doing a more thorough vetting of potential PCAs/ILSTs before adding the person to the list. Include special skills in the Allied directory. Train all types of staff so they know how to do the jobs they are hired to do on day one. Allow spouses to be paid as PCAs. Provide PCA/ILST applications and verbal assistance in multiple languages.

*They need to do more research on the people they put on the list to hire – PCA*

*Why can't spouses be paid to help? – PCA*

*Staff need to have more outlets for people who speak a different language to fill out the ILST application – ABI*

## J. Final thoughts

Quality assurance staff from the Access Agencies and DSS are currently in the fifth year of completing HCBS CAHPS surveys for the CHCP, PCA, ABI, Autism, and Katie Beckett waivers, and DMHAS is currently in its third year for MHW HCBS CAHPS surveys. UConn Health Center on Aging continues to provide technical assistance, including survey site administration, training, and other support. In final comments, respondents also expressed appreciation for the waiver services. Remarkd one CHCP respondent, "I am grateful we have had the opportunity to have people taking care of her."

*Without the ABI waiver I would be lost – ABI*

*[Consumer] is really happy with the services being received through the Autism waiver. It is just amazing and self-direction empowers the person to have a better life – Autism*

*The WISE program changed my whole life – it kept me out of a group program. It saved me – MHW*

*I have an awesome caregiver, and this program saved my life – PCA*

*This is a great program and it does so much for elders – CHCP*

*We are very thankful for this program. Everyone we've been in contact with has been so nice...*

*[Consumer] will be graduating high school this year and headed to college. We are so thankful – KBW*

## **V. Appendices**

**Appendix A. Composite Measures Items**

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

**Appendix C. CAHPS® Home and Community-Based Services Survey (Mental Health Waiver) – Connecticut version 2019**

## Appendix A. Composite Measures Items

<b>Staff are reliable and helpful</b>
In the last 3 months, how often did {personal assistance/behavioral health staff} come to work on time?
In the last 3 months, how often did {personal assistance/behavioral health staff} work as long as they were supposed to?
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?
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?
In the last 3 months, how often did {homemakers} come to work on time?
In the last 3 months, how often did {homemakers} work as long as they were supposed to?
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?*
<b>Staff listen and communicate well</b>
In the last 3 months, how often did {personal assistance/behavioral health staff} treat you with courtesy and respect?
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?
In the last 3 months, how often did {personal assistance/behavioral health staff} treat you the way you wanted them to?
In the last 3 months, how often did {personal assistance/behavioral health staff} explain things in a way that was easy to understand?
In the last 3 months, how often did {personal assistance/behavioral health staff} listen carefully to you?
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?
In the last 3 months, how often did {homemakers} treat you with courtesy and respect?
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?
In the last 3 months, how often did {homemakers} treat you the way you wanted them to?
In the last 3 months, how often did {homemakers} listen carefully to you?
In the last 3 months, did you feel {homemakers} knew what kind of help you needed?
In the last 3 months, how often did {homemakers} explain things in a way that was easy to understand?*
<b>Case manager is helpful</b>
In the last 3 months, could you contact this {case manager} when you needed to?
In the last 3 months, did this {case manager} work with you when you asked for help with getting or fixing equipment?

In the last 3 months, did this {case manager} work with you when you asked for help with getting other changes to your services?
<b>Choosing services that matter to you</b>
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?
<b>Transportation to medical appointments</b>
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?
<b>Personal safety and respect</b>
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?
<b>Planning your time and activities</b>
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

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# CAHPS® Home- and Community-Based Services Survey

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**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?

- <sup>1</sup>  YES  
<sup>2</sup>  NO → END SURVEY  
<sup>-1</sup>  DON'T KNOW → END SURVEY  
<sup>-2</sup>  REFUSED → END SURVEY  
<sup>-3</sup>  UNCLEAR RESPONSE → END SURVEY

2. How do they help you?

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[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
- <sup>-1</sup>  DON'T KNOW → END SURVEY  
<sup>-2</sup>  REFUSED → END SURVEY  
<sup>-3</sup>  UNCLEAR RESPONSE → END SURVEY

3. What do you call them?

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[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

- MY WORKER
  - MY ASSISTANT
  - NAMES OF STAFF (JO, DAWN, ETC.)
- <sup>-1</sup>  DON'T KNOW → END SURVEY  
<sup>-2</sup>  REFUSED → END SURVEY  
<sup>-3</sup>  UNCLEAR RESPONSE → END SURVEY

[Interviewer - Screening Failed]

- Continue Anyway → 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?
- <sup>1</sup>  YES
  - <sup>2</sup>  NO → GO TO Q6
  - <sup>-1</sup>  DON'T KNOW → GO TO Q6
  - <sup>-2</sup>  REFUSED → GO TO Q6
  - <sup>-3</sup>  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?

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

6. In the last 3 months, did you get *{program specific term for behavioral health specialist services}* at home?
- <sup>1</sup>  YES
  - <sup>2</sup>  NO → GO TO Q8
  - <sup>-1</sup>  DON'T KNOW → GO TO Q8
  - <sup>-2</sup>  REFUSED → GO TO Q8
  - <sup>-3</sup>  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?

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

8. In the last 3 months, did you get *{program specific term for homemaker services}* at

home?

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q11
- <sup>-1</sup>  DON'T KNOW → GO TO Q11
- <sup>-2</sup>  REFUSED → GO TO Q11
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q11

9. What do you call the person or people who gave you *{program specific term for homemaker services}*? For example, do you call them *{program-specific term for homemaker}*, aides, homemakers, chore workers, or something else?
- 

[ADD RESPONSE WHEREVER IT SAYS “homemaker”]

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  UNCLEAR RESPONSE

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  UNCLEAR RESPONSE

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

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[ADD RESPONSE WHEREVER IT SAYS “*case manager*”]

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

ITEM AND RESPONSE—FOLLOW ALL ROWS THAT APPLY	ACTION
IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES),  AND  Q8 = NO, DON'T KNOW, REFUSE, UNCLEAR (HOMEMAKER SERVICES)	ASK Q13–Q36, AND Q48 ONWARD
IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES),  AND  Q8 = YES (HOMEMAKER SERVICES)	ASK Q13 ONWARD
IF Q4 AND Q6 = NO (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES)	SKIP Q13–36, Q57 AND Q79
IF Q8 = YES (HOMEMAKER SERVICES)	ASK Q37 ONWARD
IF Q10 = YES (HOMEMAKER AND PERSONAL ASSISTANCE STAFF SAME)	ASK Q13–Q36, Q39, Q40, AND Q48 ONWARD
IF Q11 = ANY RESPONSE (CASE MANAGER)	ASK Q48 ONWARD

**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 . . .

- <sup>1</sup>  Never,
- <sup>2</sup>  Sometimes,
- <sup>3</sup>  Usually, or
- <sup>4</sup>  Always?
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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 . . .

- <sup>1</sup>  Mostly yes or
- <sup>2</sup>  Mostly no?
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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 . . .

- <sup>1</sup>  Never,
- <sup>2</sup>  Sometimes,
- <sup>3</sup>  Usually, or
- <sup>4</sup>  Always?
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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 . . .

- <sup>1</sup>  Mostly yes or
- <sup>2</sup>  Mostly no?
- <sup>-1</sup>  DON'T KNOW

- 2  REFUSED
- 3  UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q26
- <sup>-1</sup>  DON'T KNOW → GO TO Q26
- <sup>-2</sup>  REFUSED → GO TO Q26
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q26

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

- <sup>1</sup>  YES → GO TO Q26
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW → GO TO Q26
- <sup>-2</sup>  REFUSED → GO TO Q26
- <sup>-3</sup>  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?

- <sup>1</sup>  YES
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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?

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q28
- <sup>-1</sup>  DON'T KNOW → GO TO Q28
- <sup>-2</sup>  REFUSED → GO TO Q28
- <sup>-3</sup>  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?

- <sup>1</sup>  YES
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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 . . .

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Mostly yes or  
<sup>2</sup> Mostly no?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> 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 ...

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> 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. . .

- <sup>1</sup> Mostly yes or  
<sup>2</sup> Mostly no?  
<sup>-1</sup> DON'T KNOW

- 2  REFUSED
- 3  UNCLEAR RESPONSE

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

<sup>-3</sup>  UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from {*personal assistance/behavioral health staff*}? Would you say . . .

- <sup>1</sup>  Excellent,
- <sup>2</sup>  Very good,
- <sup>3</sup>  Good,
- <sup>4</sup>  Fair, or
- <sup>5</sup>  Poor?
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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*} . . .

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

- <sup>1</sup>  Never,
- <sup>2</sup>  Sometimes,
- <sup>3</sup>  Usually, or
- <sup>4</sup>  Always?
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  UNCLEAR RESPONSE

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

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

38. In the last 3 months, how often did {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 . . .

- 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

<sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q55a

49. In the last 3 months, could you contact this {*case manager*} when you needed to?

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-1</sup>  DON'T KNOW

<sup>-2</sup>  REFUSED

<sup>-3</sup>  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?

<sup>1</sup>  YES

<sup>2</sup>  NO → GO TO Q52

<sup>3</sup>  DON'T NEED → GO TO Q52

<sup>-1</sup>  DON'T KNOW → GO TO Q52

<sup>-2</sup>  REFUSED → GO TO Q52

<sup>-3</sup>  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?

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-1</sup>  DON'T KNOW

<sup>-2</sup>  REFUSED

<sup>-3</sup>  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?

<sup>1</sup>  YES

<sup>2</sup>  NO → GO TO 54

<sup>3</sup>  DON'T NEED → GO TO Q54

<sup>-1</sup>  DON'T KNOW → GO TO Q54

<sup>-2</sup>  REFUSED → GO TO Q54

<sup>-3</sup>  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?

<sup>1</sup>  YES

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

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 . . .

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

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

- 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?

- 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

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

- 2  CASE MANAGER
- 3  AGENCY
- 4  SOMEONE ELSE, PLEASE SPECIFY \_\_\_\_\_
- 1  DON'T KNOW
- 2  REFUSED
- 3  UNCLEAR RESPONSE

71. In the last 3 months, did any {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

- 2  REFUSED → GO TO Q76
- 3  UNCLEAR RESPONSE → GO TO Q76

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

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

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

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

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

- 1  YES
- 2  NO → GO TO Q78
- 1  DON'T KNOW → GO TO Q78
- 2  REFUSED → GO TO Q78
- 3  UNCLEAR RESPONSE → GO TO Q78

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

- 1  Never,
- 2  Sometimes,
- 3  Usually, or
- 4  Always?
- 1  DON'T KNOW
- 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?

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

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

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

**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

<sup>-3</sup>  UNCLEAR RESPONSE → GO TO EM5

EM4. Sometimes people would like to work for pay, but feel that something is holding them back. In the last 3 months, was this true for you? If so, what has been holding you back from wanting to work? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

<sup>1</sup>  BENEFITS → GO TO THE ABOUT YOU SECTION

<sup>2</sup>  HEALTH CONCERNS → GO TO THE ABOUT YOU SECTION

<sup>3</sup>  DON'T KNOW ABOUT JOB RESOURCES → GO TO THE ABOUT YOU SECTION

<sup>4</sup>  ADVICE FROM OTHERS → GO TO THE ABOUT YOU SECTION

<sup>5</sup>  TRAINING/EDUCATION NEED → GO TO THE ABOUT YOU SECTION

<sup>6</sup>  LOOKING FOR AND CAN'T FIND WORK → GO TO THE ABOUT YOU SECTION

<sup>7</sup>  ISSUES WITH PREVIOUS EMPLOYMENT → GO TO THE GO TO THE ABOUT YOU SECTION

<sup>8</sup>  TRANSPORTATION → GO TO THE GO TO THE ABOUT YOU SECTION

<sup>9</sup>  CHILD CARE → GO TO THE ABOUT YOU SECTION

<sup>10</sup>  OTHER ( \_\_\_\_\_ ) → GO TO THE ABOUT YOU SECTION

<sup>11</sup>  NOTHING/DON'T WANT TO WORK → GO TO THE ABOUT YOU SECTION

<sup>-1</sup>  DON'T KNOW → GO TO THE ABOUT YOU SECTION

<sup>-2</sup>  REFUSED → GO TO THE ABOUT YOU SECTION

<sup>-3</sup>  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?

<sup>1</sup>  YES → GO TO EM7

<sup>2</sup>  NO

<sup>-1</sup>  DON'T KNOW

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  YES → GO TO THE ABOUT YOU SECTION

<sup>2</sup>  NO → GO TO THE ABOUT YOU SECTION

<sup>-1</sup>  DON'T KNOW → GO TO THE ABOUT YOU SECTION

<sup>-2</sup>  REFUSED → GO TO THE ABOUT YOU SECTION

<sup>-3</sup>  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?

<sup>1</sup>  YES → GO TO EM8

<sup>2</sup>  NO → GO TO THE ABOUT YOU SECTION

<sup>-1</sup>  DON'T KNOW → GO TO THE ABOUT YOU SECTION

<sup>-2</sup>  REFUSED → GO TO THE ABOUT YOU SECTION

<sup>-3</sup>  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?

- <sup>1</sup>  YES → GO TO THE ABOUT YOU SECTION
- <sup>2</sup>  NO → GO TO THE ABOUT YOU SECTION
- <sup>-1</sup>  DON'T KNOW → GO TO THE ABOUT YOU SECTION
- <sup>-2</sup>  REFUSED → GO TO THE ABOUT YOU SECTION
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

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

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

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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?

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO THE ABOUT YOU SECTION
- <sup>-1</sup>  DON'T KNOW → GO TO THE ABOUT YOU SECTION
- <sup>-2</sup>  REFUSED → GO TO THE ABOUT YOU SECTION
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

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

---



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

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

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

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

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

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

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

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

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

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

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

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

- <sup>1</sup> Mostly yes or
- <sup>2</sup> Mostly no?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> 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 . . .

- <sup>1</sup> Never,
- <sup>2</sup> Sometimes,
- <sup>3</sup> Usually, or
- <sup>4</sup> Always?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Mostly yes or
- <sup>2</sup> Mostly no?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Never,
- <sup>2</sup> Sometimes,
- <sup>3</sup> Usually, or
- <sup>4</sup> Always?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Mostly yes or
- <sup>2</sup> Mostly no?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

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

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

\_\_ 0 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,

- 3  Good,
- 4  Fair, or
- 5  Poor?
- 1  DON'T KNOW
- 2  REFUSED
- 3  UNCLEAR RESPONSE

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

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

84. What is your age?

- 1  18 TO 24 YEARS
- 2  25 TO 34 YEARS
- 3  35 TO 44 YEARS
- 4  45 TO 54 YEARS
- 5  55 TO 64 YEARS
- 6  65 TO 74 YEARS
- 7  75 YEARS OR OLDER
- 1  DON'T KNOW
- 2  REFUSED
- 3  UNCLEAR RESPONSE

ALTERNATE VERSION: In what year were you born?

\_\_\_\_\_ (YEAR)

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

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

- 1  MALE
- 2  FEMALE
- 1  DON'T KNOW
- 2  REFUSED

-3  UNCLEAR RESPONSE

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

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

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?

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**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?



- <sup>1</sup>  YES
- <sup>2</sup>  NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO END OF SURVEY

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

- <sup>1</sup>  SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- <sup>2</sup>  STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO END OF SURVEY

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

- <sup>1</sup>  ANSWERED **ALL** THE QUESTIONS FOR RESPONDENT
- <sup>2</sup>  ANSWERED **SOME** OF THE QUESTIONS FOR THE RESPONDENT
- <sup>3</sup>  RESTATED THE QUESTIONS IN A DIFFERENT WAY OR REMINDED/PROMPTED THE RESPONDENT
- <sup>4</sup>  TRANSLATED THE QUESTIONS OR ANSWERS INTO THE RESPONDENT'S LANGUAGE
- <sup>5</sup>  HELPED WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS
- <sup>6</sup>  HELPED THE RESPONDENT IN ANOTHER WAY, SPECIFY \_\_\_\_\_

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

- <sup>1</sup>  SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- <sup>2</sup>  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. CAHPS® Home and Community-Based Services Survey – Connecticut version 2019:  
Mental Health Waiver**

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# **CAHPS<sup>®</sup> Home- and Community-Based Services Survey**

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**Version: 1.0**

**Population: Adult**

**Language: English**

**Connecticut version – 2019**

**Mental Health Waiver**



File name: CAHPShcbs01192017SurvEng508

Last updated: January 19, 2017

**COGNITIVE SCREENING QUESTIONS**

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

1. Does someone come into your home to help you?

<sup>1</sup>  YES

<sup>2</sup>  NO → GO TO [Interviewer - Screening Failed]

<sup>-1</sup>  DON'T KNOW → GO TO [Interviewer - Screening Failed]

<sup>-2</sup>  REFUSED → GO TO [Interviewer - Screening Failed]

<sup>-3</sup>  UNCLEAR RESPONSE → GO TO [Interviewer - Screening Failed]

2. How do they help you?

---

[EXAMPLES OF CORRECT RESPONSES INCLUDE]

- HELPS ME GET READY EVERY DAY
- CLEANS MY HOME
- WORKS WITH ME AT MY JOB
- HELPS ME DO THINGS
- DRIVES ME AROUND

<sup>-1</sup>  DON'T KNOW → GO TO [Interviewer - Screening Failed]

<sup>-2</sup>  REFUSED → GO TO [Interviewer - Screening Failed]

<sup>-3</sup>  UNCLEAR RESPONSE → GO TO [Interviewer - Screening Failed]

3. What do you call them?

---

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

- MY WORKER
- MY ASSISTANT
- NAMES OF STAFF (JO, DAWN, ETC.)

<sup>-1</sup>  DON'T KNOW → GO TO [Interviewer - Screening Failed]

<sup>-2</sup>  REFUSED → GO TO [Interviewer - Screening Failed]

<sup>-3</sup>  UNCLEAR RESPONSE → GO TO [Interviewer - Screening Failed]

[Interviewer - Screening Failed]

<sup>1</sup>  Continue anyhow

<sup>2</sup>  End Survey → GO TO [END SURVEY SECTION]

**IDENTIFICATION QUESTIONS**

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

4. In the last 3 months, did you get recovery assistant services at home?

- <sup>1</sup>  YES  
<sup>2</sup>  NO → GO TO Q8  
<sup>-1</sup>  DON'T KNOW → GO TO Q8  
<sup>-2</sup>  REFUSED → GO TO Q8  
<sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q8

5. What do you call the person or people who gave recovery assistant services? For example, do you call them recovery assistants, RAs, staff, personal care attendants, PCAs, workers, or something else?

---

[USE THIS TERM WHEREVER IT SAYS {*recovery assistant staff*} BELOW.]

8. In the last 3 months, did you get CSP or case management services at home?

- <sup>1</sup>  YES  
<sup>2</sup>  NO → GO TO Q11  
<sup>-1</sup>  DON'T KNOW → GO TO Q11  
<sup>-2</sup>  REFUSED → GO TO Q11  
<sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q11

9. What do you call the person or people who give you CSP or case management services? For example, do you call them CSPs, case managers, or something else?

---

[USE THIS TERM WHEREVER IT SAYS {*CSPs*} BELOW.]

11. In the last 3 months, did you get help from Mental Health Waiver clinician services at the Department of Mental Health and Addiction Services, DMHAS, or ABH to help make sure that you have all the services you need?

- <sup>1</sup>  YES  
<sup>2</sup>  NO  
<sup>-1</sup>  DON'T KNOW  
<sup>-2</sup>  REFUSED  
<sup>-3</sup>  UNCLEAR RESPONSE

12. What do you call the person who gives you Mental Health Waiver clinician services? For example, do you call the person a Mental Health Waiver clinician, case manager, care manager, service coordinator, supports coordinator, social worker, or something else?

---

[USE THIS TERM WHEREVER IT SAYS {*Mental Health Waiver clinician*} BELOW.]

### GETTING NEEDED SERVICES FROM RECOVERY ASSISTANTS -

QUESTIONS 13-36 ARE ASKED IF QUESTION 4=YES. OTHERWISE SKIP THESE QUESTIONS.

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

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Mostly yes or  
<sup>2</sup> Mostly no?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Mostly yes or  
<sup>2</sup> Mostly no?  
<sup>-1</sup> DON'T KNOW



- 2  REFUSED  
 -3  UNCLEAR RESPONSE

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 {*recovery assistant staff*} could not come that day?

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

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

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

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

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

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

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

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

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

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

- 1 YES  
 2 NO → GO TO Q23  
 -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 *{recovery assistant 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 *{recovery assistant staff}* to take your medicines?

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

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

- 1 YES → GO TO Q26

- NO  
 DON'T KNOW → GO TO Q26  
 REFUSED → GO TO Q26  
 UNCLEAR RESPONSE → GO TO Q26

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

- YES  
 NO  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

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

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

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

- YES  
 NO  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

## HOW WELL RECOVERY ASSISTANT STAFF COMMUNICATE AND TREAT YOU

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

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

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

ALTERNATE VERSION: In the last 3 months, did *{recovery assistant staff}* treat you with courtesy and respect? Would you say . . .

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

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

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

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

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

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

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

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

- 1 Mostly yes or  
 2 Mostly no?  
 -1 DON'T KNOW  
 -2 REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

31. In the last 3 months, how often did *{recovery assistant staff}* explain things in a way that was easy to understand? Would you say . . .

<sup>1</sup>  Never,  
<sup>2</sup>  Sometimes,  
<sup>3</sup>  Usually, or  
<sup>4</sup>  Always?  
<sup>-1</sup>  DON'T KNOW  
<sup>-2</sup>  REFUSED  
<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  Mostly yes or  
<sup>2</sup>  Mostly no?  
<sup>-1</sup>  DON'T KNOW  
<sup>-2</sup>  REFUSED  
<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  Never,  
<sup>2</sup>  Sometimes,  
<sup>3</sup>  Usually, or  
<sup>4</sup>  Always?  
<sup>-1</sup>  DON'T KNOW  
<sup>-2</sup>  REFUSED  
<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  Mostly yes or  
<sup>2</sup>  Mostly no?  
<sup>-1</sup>  DON'T KNOW  
<sup>-2</sup>  REFUSED  
<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  YES  
<sup>2</sup>  NO

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

34. In the last 3 months, did *{recovery assistant staff}* encourage you to do things for yourself if you could?

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

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

- \_\_ 0 TO 10
- 1  DON'T KNOW
  - 2  REFUSED
  - 3  UNCLEAR RESPONSE

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

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

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

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

**GETTING NEEDED SERVICES FROM CSPs**

QUESTIONS 37-47 ARE ASKED IF QUESTION 8=YES. OTHERWISE SKIP THESE QUESTIONS.

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

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

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

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

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

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

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

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

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

38a. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months,

when staff could not come to work on a day that they were scheduled, did someone let you know that {CSPs} could not come that day?

- <sup>1</sup> YES  
<sup>2</sup> NO  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Mostly yes or  
<sup>2</sup> Mostly no?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> YES  
<sup>2</sup> NO  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

## HOW WELL CSPs COMMUNICATE AND TREAT YOU

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

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

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?



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

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

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

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

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

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

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

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

- 1  Mostly yes or

- <sup>2</sup> Mostly no?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Never,
- <sup>2</sup> Sometimes,
- <sup>3</sup> Usually, or
- <sup>4</sup> Always?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Mostly yes or
- <sup>2</sup> Mostly no?
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> YES
- <sup>2</sup> NO
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

\_\_ 0 TO 10

- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Excellent,
- <sup>2</sup> Very good,
- <sup>3</sup> Good,
- <sup>4</sup> Fair, or

- 5  Poor?  
 -1  DON'T KNOW  
 -2  REFUSED  
 -3  UNCLEAR RESPONSE

47. Would you recommend the {CSPs} who help you to your family and friends if they needed CSP or case management services? Would you say you would recommend the {CSPs} . . .

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

## YOUR CASE MANAGER

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

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

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

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

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

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

- 1  YES

- NO → GO TO Q52  
 DON'T NEED → GO TO Q52  
 DON'T KNOW → GO TO Q52  
 REFUSED → GO TO Q52  
 UNCLEAR RESPONSE → GO TO Q52

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

- YES  
 NO  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

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

- YES  
 NO → GO TO 54  
 DON'T NEED → GO TO Q54  
 DON'T KNOW → GO TO Q54  
 REFUSED → GO TO Q54  
 UNCLEAR RESPONSE → GO TO Q54

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

- YES  
 NO  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

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

\_\_ 0 TO 10

- DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

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

- Excellent,

- <sup>2</sup> Very good,  
<sup>3</sup> Good,  
<sup>4</sup> Fair, or  
<sup>5</sup> Poor?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

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

- <sup>1</sup> Excellent,  
<sup>2</sup> Very good,  
<sup>3</sup> Good,  
<sup>4</sup> Fair, or  
<sup>5</sup> Poor?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE or DID NOT USE HOME-DELIVERED MEAL SERVICE

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

- <sup>1</sup> Excellent,  
<sup>2</sup> Very good,  
<sup>3</sup> Good,  
<sup>4</sup> Fair, or  
<sup>5</sup> Poor?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE or DID NOT USE AN ADULT DAY PROGRAM

**CHOOSING YOUR SERVICES**

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

- 1  **None** of the things that are important to you,  
 2  **Some** of the things that are important to you,  
 3  **Most** of the things that are important to you, or  
 4  **All** of the things that are important to you?  
 -1  DON'T KNOW → GO TO 57a  
 -2  REFUSED → GO TO Q57a  
 -3  UNCLEAR RESPONSE → GO TO Q57a

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

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

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

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

Probes (*Use only if respondent does not know*):

How do you hire and pay your aides or caregivers?

Do you work with Allied, Sunset Shores, or Advanced Behavioral Health/ABH to pay your aides?

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

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

- 1  YES, Please specify relationship/s \_\_\_\_\_  
 2  NO  
 -1  DON'T KNOW  
 -2  REFUSED  
 -3  UNCLEAR RESPONSE

58. In the last 3 months, who would you have talked to if you wanted to change your recovery plan? Anyone else? [INTERVIEWER MARKS ALL THAT APPLY]

- CASE MANAGER  
 OTHER STAFF  
 FAMILY/FRIENDS  
 SOMEONE ELSE, PLEASE SPECIFY \_\_\_\_\_  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

## TRANSPORTATION

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

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

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

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

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

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

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

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

- 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 {*recovery assistants, CSPs, and/or Mental Health Waiver Clinician*}. We are asking everyone the next questions—not just you. I want to remind you that, although your answers are confidential, I have a responsibility to tell my supervisor if I hear something that makes me think you are being hurt or are in danger.

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

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

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

- 1  YES  
 2  NO → GO TO Q68  
 -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 {*recovery assistants, CSPs, and/or Mental Health Waiver Clinician*} 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?

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q71
- <sup>-1</sup>  DON'T KNOW → GO TO Q71
- <sup>-2</sup>  REFUSED → GO TO Q71
- <sup>-3</sup>  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]

- <sup>1</sup>  FAMILY MEMBER OR FRIEND
- <sup>2</sup>  CASE MANAGER
- <sup>3</sup>  AGENCY
- <sup>4</sup>  SOMEONE ELSE, PLEASE SPECIFY \_\_\_\_\_
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  UNCLEAR RESPONSE

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q74
- <sup>-1</sup>  DON'T KNOW → GO TO Q74
- <sup>-2</sup>  REFUSED → GO TO Q74
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q74

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q74
- <sup>-1</sup>  DON'T KNOW → GO TO Q74
- <sup>-2</sup>  REFUSED → GO TO Q74
- <sup>-3</sup>  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]

- <sup>1</sup>  FAMILY MEMBER OR FRIEND
- <sup>2</sup>  CASE MANAGER
- <sup>3</sup>  AGENCY
- <sup>4</sup>  SOMEONE ELSE, PLEASE SPECIFY \_\_\_\_\_
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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.

- <sup>1</sup> YES  
<sup>2</sup> NO → GO TO Q76  
<sup>-1</sup> DON'T KNOW → GO TO Q76  
<sup>-2</sup> REFUSED → GO TO Q76  
<sup>-3</sup> UNCLEAR RESPONSE → GO TO Q76

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

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> 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 . . .

- <sup>1</sup> Mostly yes or  
<sup>2</sup> Mostly no?  
<sup>-1</sup> DON'T KNOW  
<sup>-2</sup> REFUSED  
<sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> YES  
<sup>2</sup> NO → GO TO Q78  
<sup>-1</sup> DON'T KNOW → GO TO Q78  
<sup>-2</sup> REFUSED → GO TO Q78  
<sup>-3</sup> 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 . . .

- <sup>1</sup> Never,  
<sup>2</sup> Sometimes,  
<sup>3</sup> Usually, or  
<sup>4</sup> Always?  
<sup>-1</sup> 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?

-1  DON'T KNOW

-2  REFUSED

-3  UNCLEAR RESPONSE

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 {recovery assistant staff} to do things in your community?

1  YES

2  NO

-1  DON'T KNOW

-2  REFUSED

-3  UNCLEAR RESPONSE

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

1  YES

2  NO

-1  DON'T KNOW

-2  REFUSED

-3  UNCLEAR RESPONSE

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

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

## Employment Module

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

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

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

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

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

- 1  BENEFITS → GO TO EM5  
 2  HEALTH CONCERNS → GO TO EM5  
 3  DON'T KNOW ABOUT JOB RESOURCES → GO TO EM5  
 4  ADVICE FROM OTHERS → GO TO EM5  
 5  TRAINING/EDUCATION NEED → GO TO EM5  
 6  LOOKING FOR AND CAN'T FIND WORK → GO TO EM5  
 7  ISSUES WITH PREVIOUS EMPLOYMENT → GO TO EM5  
 8  TRANSPORTATION → GO TO EM5  
 9  CHILD CARE → GO TO EM5  
 10  OTHER ( \_\_\_\_\_ ) → GO TO EM5  
 11  NOTHING IS HOLDING ME BACK → GO TO EM5  
 -1  DON'T KNOW → GO TO EM5  
 -2  REFUSED → GO TO EM5  
 -3  UNCLEAR RESPONSE → GO TO EM5

EM4. Sometimes people would like to work for pay, but feel that something is holding them back. In the last 3 months, was this true for you? If so, what has been holding you back from wanting to work? (INTERVIEWER LISTENS AND MARKS ALL THAT APPLY)

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

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

- <sup>1</sup>  YES → GO TO EM7
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  UNCLEAR RESPONSE

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

- <sup>1</sup>  YES → GO TO THE DMHAS QUESTIONS SECTION
- <sup>2</sup>  NO → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-1</sup>  DON'T KNOW → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-2</sup>  REFUSED → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

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

- <sup>1</sup>  YES → GO TO EM8
- <sup>2</sup>  NO → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-1</sup>  DON'T KNOW → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-2</sup>  REFUSED → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

EM8. In the last 3 months, did you get all the help you need to find a job?

- <sup>1</sup> YES → GO TO THE DMHAS QUESTIONS SECTION
- <sup>2</sup> NO → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-1</sup> DON'T KNOW → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-2</sup> REFUSED → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-3</sup> UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

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

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

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

- <sup>1</sup> YES
- <sup>2</sup> NO
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> 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?

- <sup>1</sup> YES
- <sup>2</sup> NO → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-1</sup> DON'T KNOW → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-2</sup> REFUSED → GO TO THE DMHAS QUESTIONS SECTION
- <sup>-3</sup> UNCLEAR RESPONSE → GO TO THE DMHAS QUESTIONS SECTION

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

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

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

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

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

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

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

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

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

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

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

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

ALTERNATE VERSION: In the last 3 months, did your *{job coach}* treat you with courtesy



and respect? Would you say . . .

- 1 Mostly yes or  
 2 Mostly no?  
 -1 DON'T KNOW  
 -2 REFUSED  
 -3 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

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

- 1 Mostly yes or  
 2 Mostly no?  
 -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

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

- 1 Mostly yes or  
 2 Mostly no?  
 -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?

- 1 YES

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

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

\_\_ 0 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 supported employment? 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

**DMHAS MODULE (MENTAL HEALTH WAIVER QUESTIONS)**

The next questions ask how the services you've received through the Mental Health Waiver have affected your life. Please tell me how much you agree or disagree with each statement.

DMHAS\_1. As a result of the services I have received from the Mental Health Waiver, I deal more effectively with my daily problems. Would you say you...

- Strongly agree
- Agree
- Neither agree nor disagree

- Disagree
- Strongly disagree
- Don't know
- Refused
- Unclear response

DMHAS\_2. As a result of the services I have received from the Mental Health Waiver, I am better in control of my life. Would you say you...

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

DMHAS\_3. As a result of the services I have received from the Mental Health Waiver, I do better in social situations. Would you say you...

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

DMHAS\_4. As a result of the services I have received from the Mental Health Waiver, I can have the life I want in recovery. Would you say you...

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

DMHAS\_5. As a result of the services I have received from the Mental Health Waiver, I feel that these services help me stay in the community. Would you say you...

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

**ABOUT YOU**

Now I just have a few more questions about you.

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

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

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

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

84. What is your age?

- 1 18 TO 24 YEARS
- 2 25 TO 34 YEARS
- 3 35 TO 44 YEARS
- 4 45 TO 54 YEARS
- 5 55 TO 64 YEARS
- 6 65 TO 74 YEARS
- 7 75 YEARS OR OLDER
- 1 DON'T KNOW
- 2 REFUSED
- 3 UNCLEAR RESPONSE

ALTERNATE VERSION: In what year were you born?

\_\_\_\_\_ (YEAR)

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

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

- 1 MALE

- FEMALE
- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

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

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

- YES, HISPANIC, LATINO, OR SPANISH
- NO, NOT HISPANIC, LATINO, OR SPANISH → GO TO Q89
- DON'T KNOW → GO TO Q89
- REFUSED → GO TO Q89
- UNCLEAR RESPONSE → GO TO Q89

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

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

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

- White → GO TO Q92
- Black or African-American → GO TO Q92
- Asian → GO TO Q90
- Native Hawaiian or other Pacific Islander → GO TO Q91
- American Indian or Alaska Native → GO TO Q92
- OTHER → GO TO Q92
- DON'T KNOW → GO TO Q92
- REFUSED → GO TO Q92
- UNCLEAR RESPONSE → GO TO Q92

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

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

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

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

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

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

93. What is the language you speak at home?

- 1  Spanish,  
 2  Some other language → Which one? \_\_\_\_\_  
 -1  DON'T KNOW  
 -2  REFUSED  
 -3  UNCLEAR RESPONSE

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

- 1  1 [JUST THE RESPONDENT] → GO TO QUESTION 97  
 2  2 TO 3  
 3  4 OR MORE  
 -1  DON'T KNOW  
 -2  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-1</sup>  DON'T KNOW

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-1</sup>  DON'T KNOW

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

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**END OF QUESTIONS**

**Thank you for completing this interview with me.**

**If you wish to contact your care manager, the number for his/her agency is:**

DMHAS: 866-548-0265

**Interviewer:** Collect name and phone numbers for participant, proxy, or person who assisted. Information will be entered below.

**QUESTIONS FOR THE INTERVIEWER**

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

0) Who completed the interview? (Check only one)

Participant by his/herself

Participant telephone numbers: \_\_\_\_\_ → Go to F1

- Participant with assistance from another person.

If Assisted

OPTIONAL: Contact information for person **who assisted** with interview:

First name: \_\_\_\_\_

Last name: \_\_\_\_\_

Telephone numbers: \_\_\_\_\_ → Go to F1

- A proxy – Someone else completed the survey for the participant.

If Proxy:

**Proxy Contact Information:**

Proxy First name: \_\_\_\_\_

Proxy Last name: \_\_\_\_\_

Proxy Telephone numbers: \_\_\_\_\_ → Go to P1

P1. Relationship to participant – the proxy is the...

- Spouse/partner
- Adult child
- Parent
- Attorney or legal representative
- Other: \_\_\_\_\_

P2. Is the proxy also a legal representative?

- Yes
- No

P3. Is the proxy paid to provide support to the participant?

- Yes → GO TO END SURVEY SECTION
- No → GO TO END SURVEY SECTION

F1. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

- <sup>1</sup> YES
- <sup>2</sup> NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

- <sup>1</sup> YES
- <sup>2</sup> NO → GO TO END SURVEY SECTION

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

- <sup>1</sup> SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- <sup>2</sup> STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?



- <sup>1</sup> YES
- <sup>2</sup> NO → GO TO END SURVEY SECTION

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

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

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

- <sup>1</sup> SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- <sup>2</sup> STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F7. Relationship to participant:

- Spouse/partner
- Adult child
- Parent
- Attorney or legal representative
- Paid staff person
- Other: \_\_\_\_\_

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

- Yes → GO TO END SURVEY SECTION
- No → GO TO END SURVEY SECTION

### END OF SURVEY

Interview done by:

- Telephone
- In-person

Participant Information:

- Medicaid ID: \_\_\_\_\_ (Please verify)
- Date of Birth: \_\_\_\_\_ (MM/DD/YYYY)
- Town of residence: \_\_\_\_\_
- ZIP code of residence: \_\_\_\_\_

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

- Yes

- No
- Do not know

Program:

- DMHAS

Community First Choice?

- Yes
- No
- Do not know

Recovery Assistant Agency: \_\_\_\_\_ [CHOOSE FROM AGENCY LIST DROP DOWN]

Community Support Program Agency: \_\_\_\_\_ [CHOOSE FROM AGENCY LIST DROP DOWN]

Mental Health Waiver Agency: \_\_\_\_\_ [CHOOSE FROM AGENCY LIST DROP DOWN]

Name of interviewer: \_\_\_\_\_

Date Interview Completed: \_\_\_\_\_

**Submit and Return to Dashboard**