

2020 Annual Report:

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

\*Access Agencies de-identified

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## **I. Introduction**

Connecticut has seen a growth in use of Medicaid funded home and community-based services (HCBS) along with increasing use of Access Agencies contracted for case management. Historically each agency has used its own survey to provide the quality assurance data required by Centers for Medicare and Medicaid Services (CMS) and Connecticut Department of Social Services. This lack of a standardized, universal instrument has made it challenging to compare and report results across Medicaid programs and case management providers.

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

Unlike surveys that assess satisfaction with services, the HCBS CAHPS survey elicits program participant feedback on his/her daily experience with HCBS. For example, one item asks if a caregiver comes in on time. Reporting actual experiences across multiple domains is more conducive for measuring quality than satisfaction alone. As a standardized cross-disability instrument, 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, the survey allows for completion of the survey with assistance or by proxy. Another advantage of the HCBS CAHPS is its integration of alternately worded questions and responses. If the participant has difficulty using the typical four-part response options (never, sometimes, usually, or always), a standardized alternate question with a “mostly yes or mostly no” response is provided, 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.

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. All participants are asked how they refer to their paid staff; these responses are then used throughout that individual’s survey.

## **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, homemaker services, case manager, choosing your services, transportation, personal safety, community inclusion and empowerment, demographics, and an employment module. A module specific to Mental Health waiver was added in July, 2020 for consumers on that waiver. 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 2019-2020 full HCBS CAHPS survey, including the employment and Mental Health waiver modules, is attached in Appendix B.

Table 1. Program Services

	CHCP	PCA	ABI	Autism	Katie Beckett	Mental Health waiver
Personal care assistance	X	X	X	X		
Behavioral health			X*	X**		
Recovery assistance (RA)						X
Homemaker/companion	X	X	X	X		
Case manager	X	X	X	X	X	X
Job coach			X	X		X
Community Service Provider (CSP)						X

\*Independent Living Skills Training (ILST)

\*\*Life skills coach or community mentor

### B. Survey Administration

In this third year of administration, the Connecticut Department of Social Services (DSS) implemented the HCBS CAHPS in the Mental Health waiver (MHW). In all, DSS used the HCBS CAHPS to inform quality measurement in eight of its Medicaid programs in year three: CHCP Categories 3 and 5, and the PCA, ABI 1, ABI 2, Autism, Katie Beckett, and MH waivers. All Access Agencies were required to complete surveys for their contracted programs; DSS staff were responsible for completing surveys for the Katie Beckett and Autism waivers. The MHW used administrative staff from one of its contracted case management agencies, Advanced Behavioral Health (ABH), as well as mental health waiver 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 6/30/2019, DSS determined the target number of surveys for each Access Agency, DSS, and MHW to complete between July 1, 2019 to June 30, 2020 in order to reach their representative sample.

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

Waiver participants were encouraged to complete the survey on their own or complete the survey with assistance if needed. Interviewers inquired about an unpaid person who could assist with the interview if the participant failed the cognitive screen or needed assistance because of communication or other challenges. If the participant could not take part in the survey process at all, then the survey was completed by a proxy on behalf of the participant. Proxies could be a family member, legal representative, or friend who knew the participant well, but not a paid staff person. In all cases, interviewers encouraged the participation of the waiver participant if at all possible.

As the training and technical assistance provider, UConn Health Center on Aging (UConn) provided ongoing training for the quality assurance staff from all four Access Agencies, DSS, and MHW. Using role playing, hands-on practice, and didactic teaching, the training covered 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 provided 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 was 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 comprised three to twelve individual questions (see Appendix A). Most of these questions had four response options: never, sometimes, usually, always. Each response was given 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 were 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 were 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 were 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 were any unmet need for personal care or household tasks, a stem question asked if the participant needed assistance for that activity, and if so, did this activity always happen when it was needed. Unmet need was 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 were 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 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. Although not required by DSS, a handful of surveys for CHCP Categories 1, 2, and 4 were also completed. For purposes of analysis, the CHCP data includes all completed CHCP surveys, regardless of Category. Similarly, 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. Similar to last year, the Access Agencies met or exceeded the representative sample for the combined CHCP waivers, the PCA waiver, and the combined ABI 1 and 2 waivers. DSS improved their Autism survey numbers this year (62% 2020; 49% 2019) and completed approximately the same percentage of Katie Beckett surveys as last year. In their first year of HCBS CAHPS collaboration, MHW survey staff completed 85 surveys, or 37% of their representative sample. This report presents the results for these three programs to show trends for these programs.

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	12326	373	390	>100
CHCP Category 5	442	206	230	>100
CHCP Category 1	--	--	1	--
CHCP Category 2	--	--	5	--
CHCP Category 4	--	--	1	--
Total CHCP Surveys			<b>627</b>	>100
<b>PCA</b>	955	272	<b>282</b>	>100
<b>ABI waivers</b>				
ABI 1	368	189	195	>100
ABI 2	202	133	129	97.0
Total ABI Surveys	570	322	<b>324</b>	>100
<b>Autism</b>	110	86	<b>53</b>	61.6
<b>Katie Beckett</b>	324	177	<b>127</b>	71.8
<b>MHW</b>	568	230	<b>85</b>	37.0
<b>Total surveys completed, any program</b>			<b>1498</b>	

-- Not applicable because no surveys were required by DSS from 7/1/2019-6/30/2020.

With the exception of Katie Beckett waiver, most surveys were completed by the consumer or the consumer with assistance (Table 4). Almost half (49%) of all ABI surveys were also completed by someone other than the consumer (by proxy). Compared to last reporting period, this year proportionally more surveys were completed by someone other than the consumer (27% by proxy in 2019; 31% by proxy in 2020). For assisted interviews, the person assisting most often helped by answering some of the questions for the consumer or prompting the consumer. Most proxy respondents were related to the consumer (89.9%). Almost all surveys were completed by telephone (99.0%); 12.1 % were completed in Spanish.

Table 4. Survey Respondents

	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)	Katie Beckett n (%)	MHW n (%)	Total n (%)
By self	497 (79.3)	231 (81.9)	156 (48.2)	23 (43.4)	1 (<1.0)	83 (97.7)	991 (66.2)
With assistance	14 (2.2)	7 (2.5)	11 (3.4)	5 (9.4)	3 (2.4)	1 (1.2)	41 (2.7)
By proxy	116 (18.5)	44 (15.6)	157 (48.5)	25 (47.2)	123 (96.9)	1 (1.2)	466 (31.1)

## B. Consumer Demographics

Consumer demographics by program are presented in Table 5.

Table 5. Consumer Demographics\*

		CHCP %	PCA %	ABI %	Autism %	Katie Beckett %**	MHW %
Age		N=627	N=281	N=323	N=53	N=105	N=85
	<18	0.0	0.0	0.0	13.2	80.0	0.0
	18-24	0.0	1.1	1.5	13.2	20.0	0.0
	25-34	0.0	7.8	12.4	47.2	0.0	2.4
	35-44	0.0	15.7	21.3	17	0.0	5.9
	45-54	0.0	29.9	27.2	5.7	0.0	30.6
	55-64	0.2	43.1	30.9	3.8	0.0	41.2
	65-74	35.1	2.5	6.5	0.0	0.0	16.5
	75+	64.8	0.0	0.0	0.0	0.0	3.5
Language		N=627	N=280	N=323	N=53	N=102	N=85
	English	58.2	72.1	78.3	98.1	86.3	84.7
	Spanish	22.8	1.8	0.0	0.0	0.0	1.2
	Multilingual / Other	19	26.1	21.7	1.9	13.7	14.1
Race		N=613	N=278	N=322	N=53	N=99	N=82
	White	67.9	65.1	82.6	86.8	88.9	80.5
	Black	19.9	29.9	13.0	5.7	4.0	15.9
	Other	12.2	5.0	4.3	7.5	7.1	3.7
Ethnicity		N=623	N=280	N=321	N=53	N=103	N=84
	Non- Hispanic	69	82.9	89.4	92.5	86.4	88.1
	Hispanic	31	17.1	10.6	7.6	13.6	11.9
Education Level		N=610	N=280	N=314	N=53		N=82
	< 8th Grade	29.5	4.3	1.9	1.9		7.3
	Some high school	17.5	20.4	14.3	15.1		15.9
	High school degree	25.7	35.0	45.9	47.2		41.5
	Some college	16.9	31.4	29.3	24.5		25.6
	4-year college	7.2	6.8	7.0	11.3		8.5
	More than 4 year college	3.1	2.1	1.6	0.0		1.2
Gender		N=627	N=281	N=322	N=52		N=85
	Male	22.7	46.6	69.6	78.8		38.8
	Female	77.4	53.4	30.4	21.2		61.2



\*Note that the 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).

Table 6. Program Service Use

	CHCP %	PCA %	ABI %	Autism %	Katie Beckett %	MHW %
	N=627	N=282	N=324	N=53	N=127	N=85
Personal care assistance	43.6	92.2	50.5	25.5		
Behavioral health services			85.0*	81.1**		
Recovery assistance						89.2
Homemaker/companion	85.1	88.1	46.9	5.8		
Case manager	92.1	96.1	98.4	88.7	51.2	53.9
Job coach			17.0	15.1		1.2
Community service provider						80.0

\*Independent Living Skills Training (ILST) services

\*\*Life skills coach or community mentor services

### D. Key Results by Program

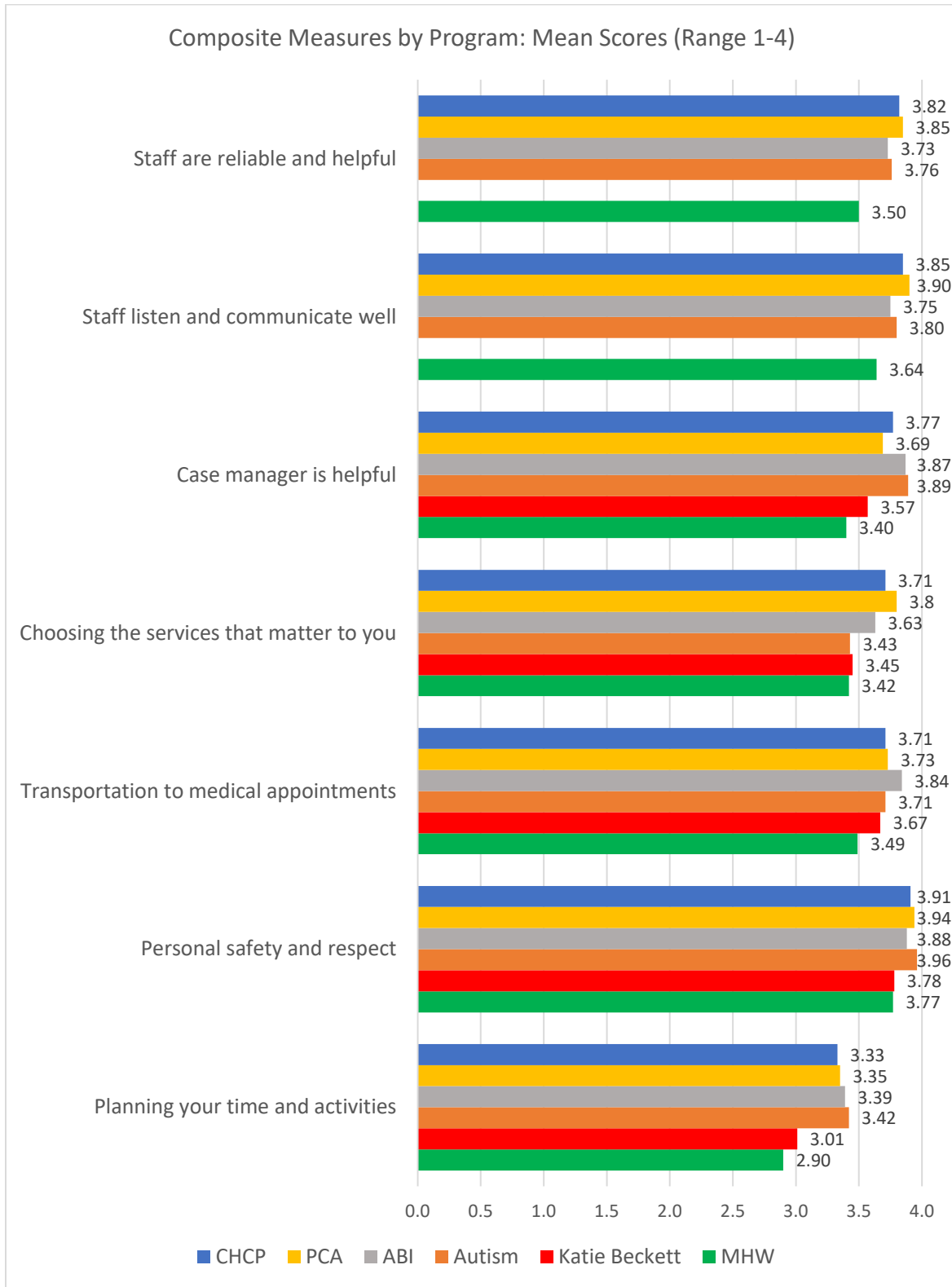
Composite measures, global ratings, and recommendations by program are displayed two ways: the mean score and the percentage reporting the highest score.

#### i. Composite measures by program

Overall, when examined by program, mean scores for most composite measures were high (Figure 1). Across all programs, participants reported higher scores for personal safety and respect, and lower scores for planning your time and activities. More CHCP and PCA participants said they could choose the services which matter to them compared to participants in the other four programs. Compared to the other programs, MHW participants reported noticeably lower scores in all of the composite means.

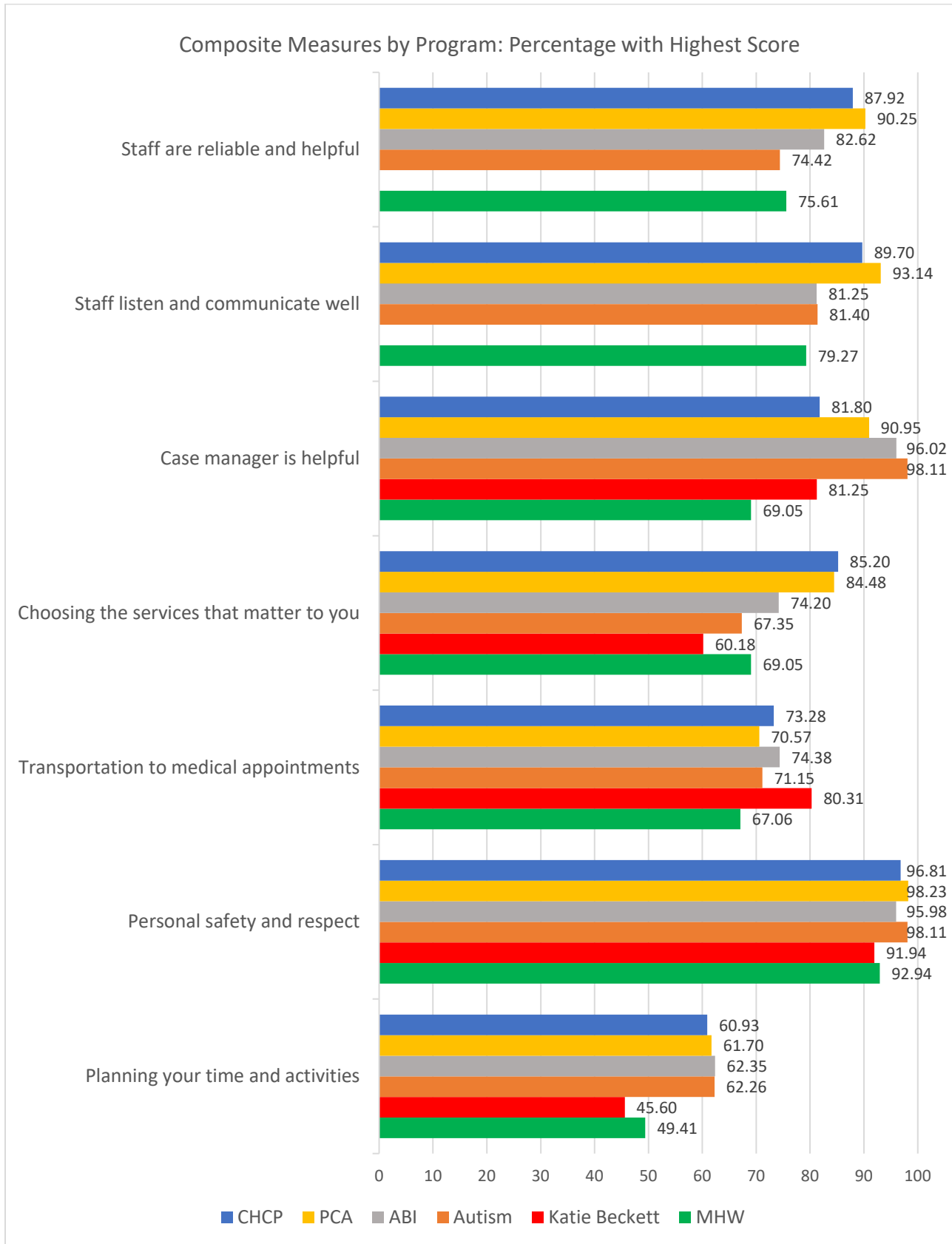
Figure 2 shows the percentage of participants in each program who gave the most positive answer for each composite item. This method highlights the same program differences more clearly. For example, 84 to 85% of CHCP and PCA gave the most positive responses for choice of services, compared to only 69% of MHW, 67% of Autism, and 60% of Katie Beckett participants.

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



\*"Staff" combines all PCA, ILST, recovery assistant, community service provider, homemaker/companion, life skills coach, and community mentor staff.

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



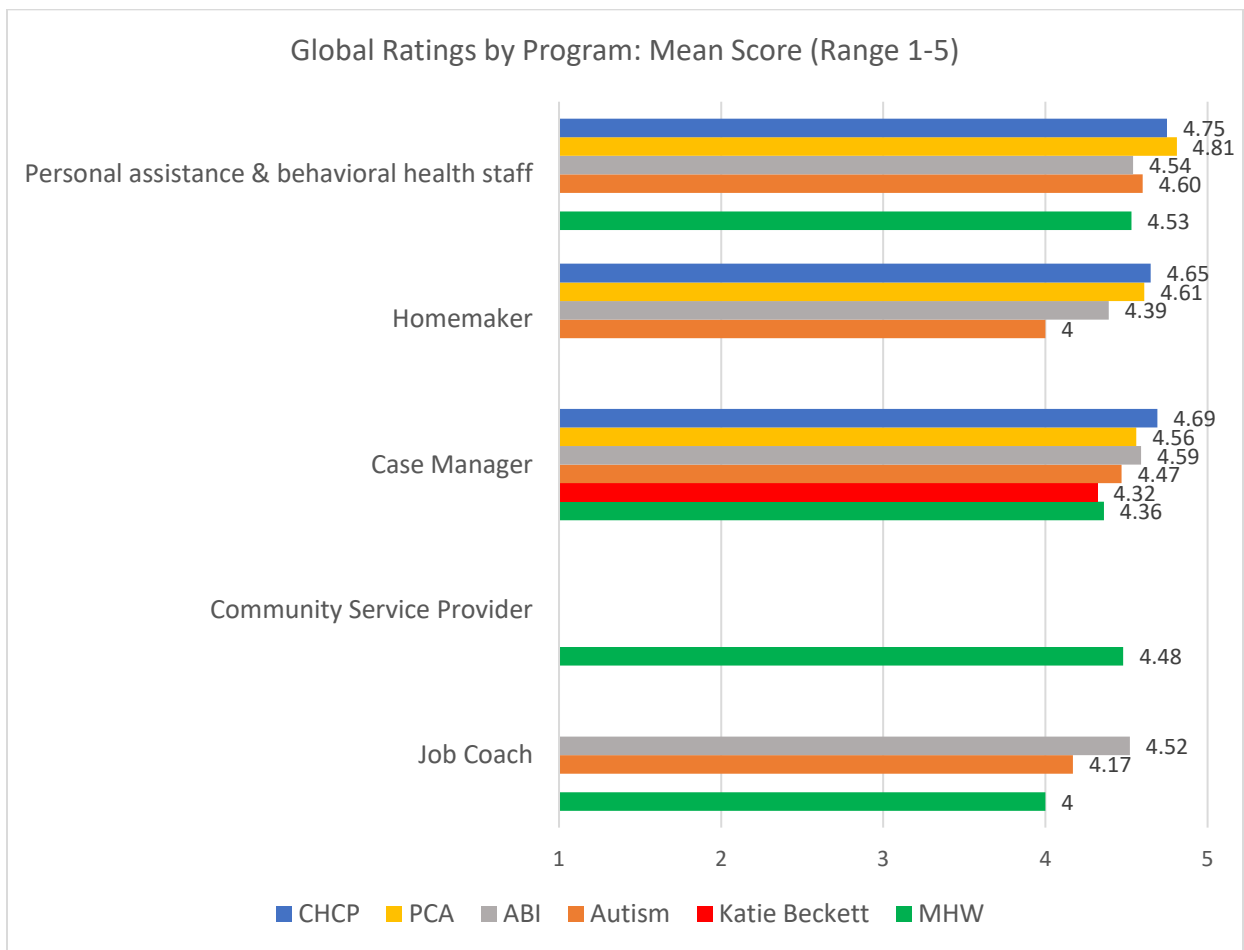
ii. Global ratings by program

When examined using mean scores, the majority of program participants gave their program staff, such as personal care and behavioral health staff,\* homemaker services, case managers, community service providers (CSPs), and job coaches, high scores overall – between 4 to 4.8, on a scale from one to five (Figure 3).

Figure 4 presents the percentage of participants in each program who gave their staff the highest rating possible – a nine or ten, on a scale from zero to ten. CHCP and PCA participants rated their personal/behavioral care staff most highly; 82% of CHCP and PCA participants rated their PCAs a nine or ten. They were followed by MHW – 71% of MHW participants gave their RAs a “9” or “10.” ABI participants, on the other hand, were much less likely to rate their PCA/ILSTs, homemaker services, or job coaches so highly.

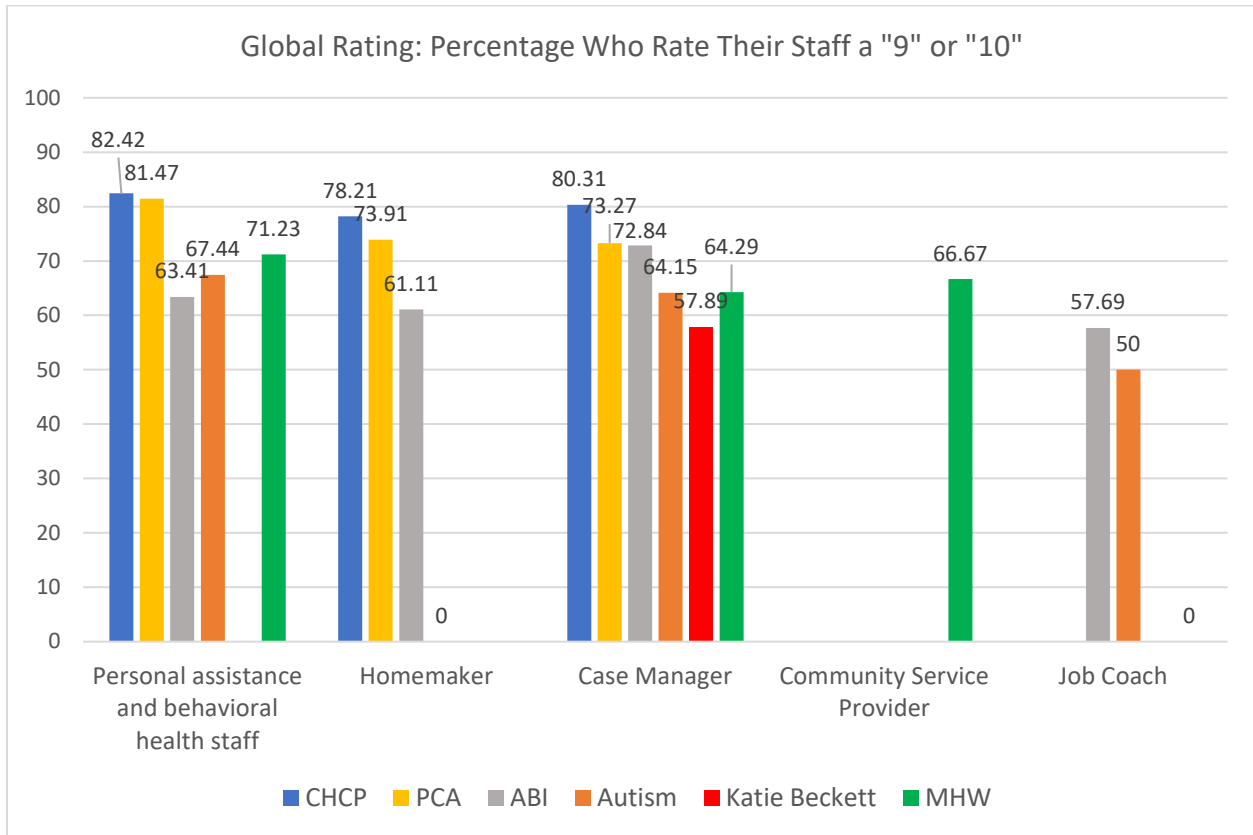
The percentage of participants in each program who gave their case managers a “9” or “10” also varied across the programs, from 80% (CHCP) to 58% (Katie Beckett). Only the MHW provides community program services, and in this first year of HCBS CAHPS participation, two thirds of MHW participants gave their CSPs a “9” or a “10.” Few Autism participants had either homemakers (n=1) or job coaches (n=6), and only one MHW participant had a job coach, making comparisons to those results difficult.

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



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

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



### iii. Recommendations by program

When asked if they would recommend their PCA/ILSTs, homemaker services, or job coaches, ABI participants consistently gave their staff lower mean recommendations, as did MHW participants with respect to their RAs and case managers (Figure 5). Figure 6 shows the percentage of respondents who would "definitely" recommend their staff or services. As with mean scores, fewer ABI participants would "definitely" recommend their PCA/ILST, homemakers or job coaches. However, although MHW had the second lowest personal/behavioral staff mean recommendation score, almost 75% of MHW participants would definitely recommend their RAs. Once again, there were few Autism homemakers (n=1) or job coaches (n=6), and only one MHW job coach, making comparisons to those programs difficult.

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

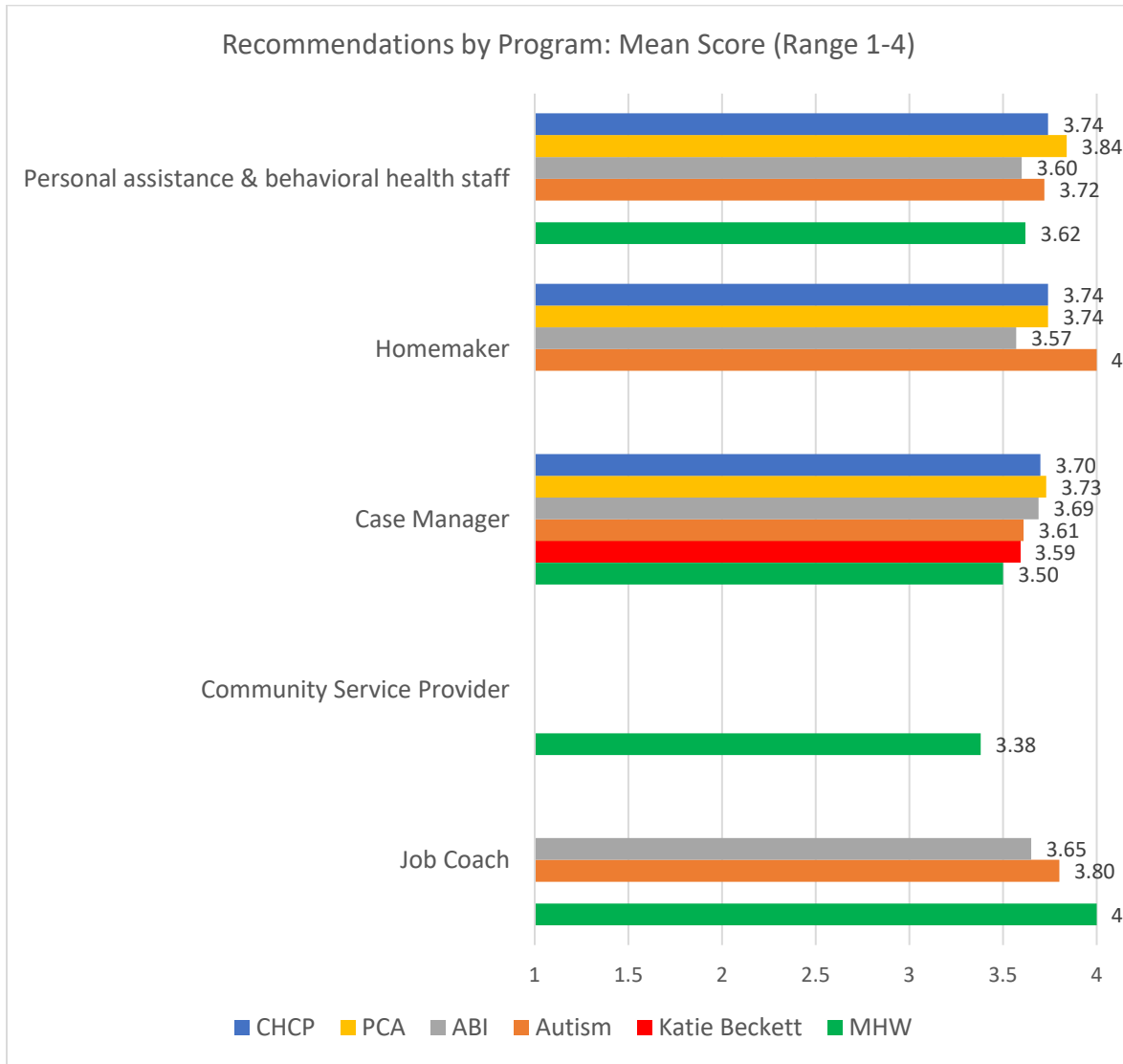
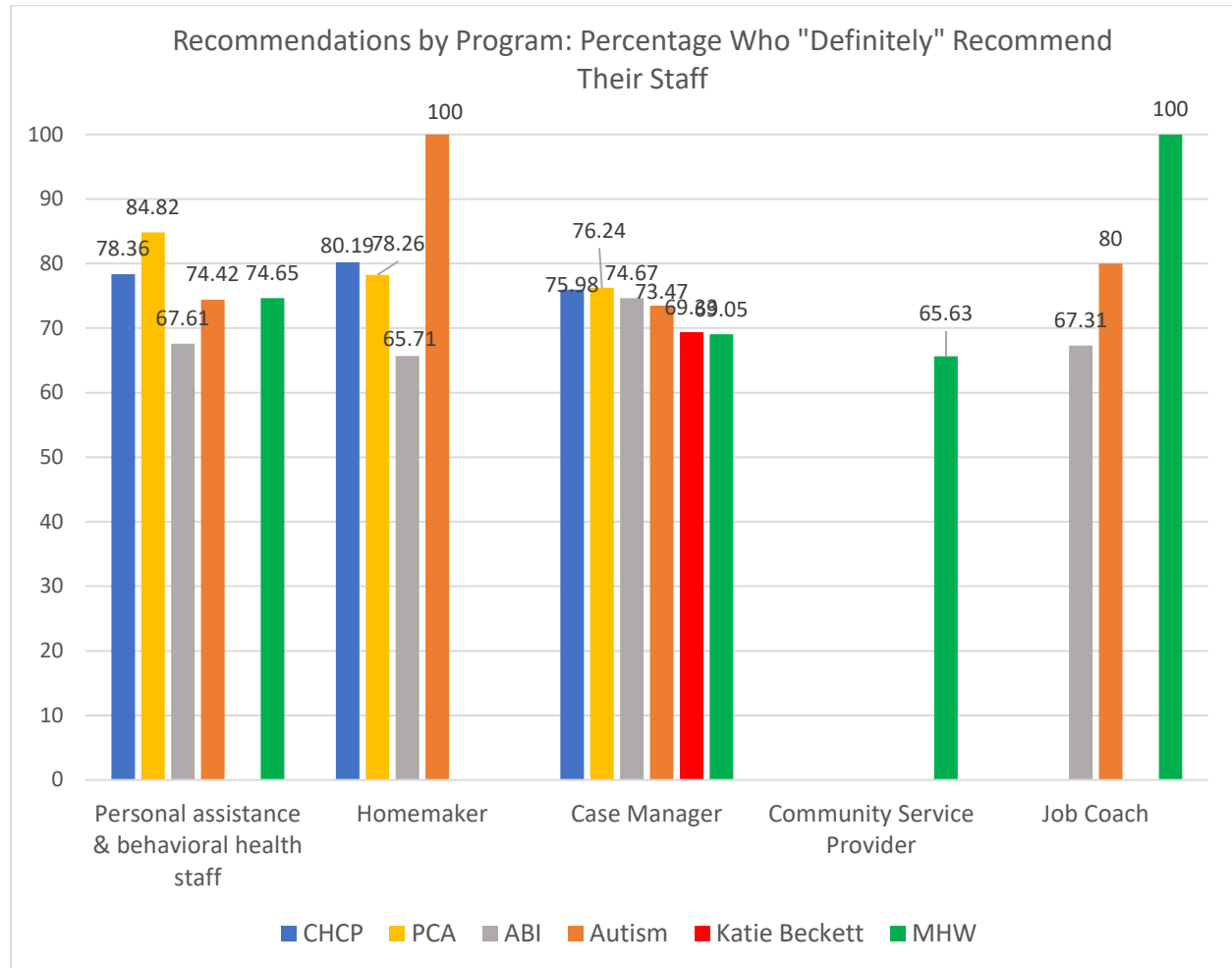


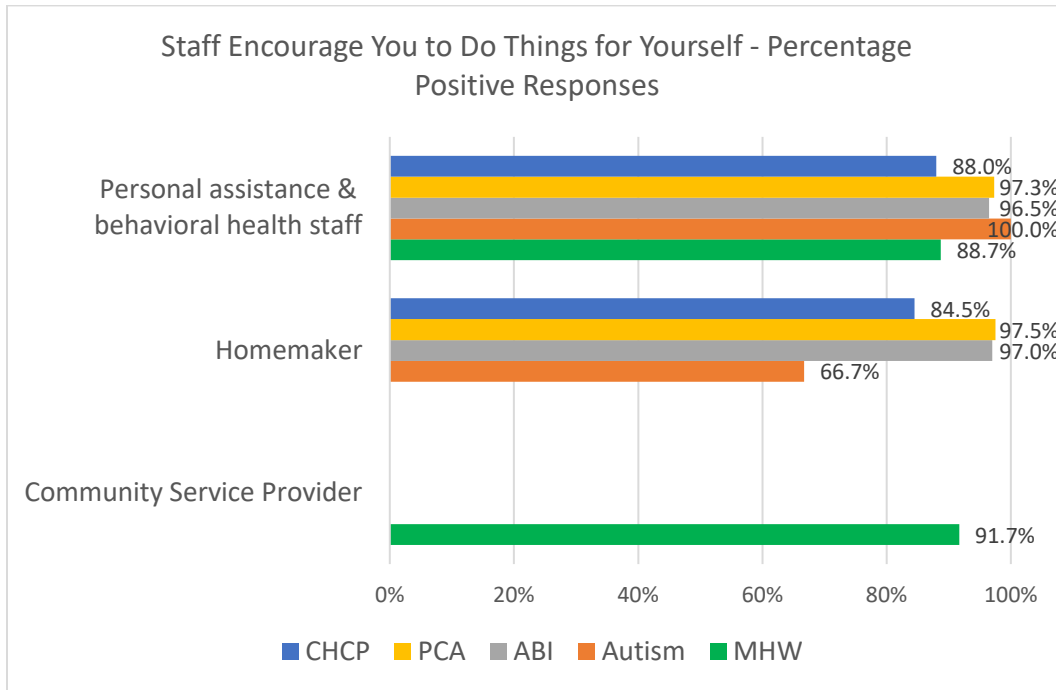
Figure 6. Recommendations by Program: Percentage Who “Definitely” Recommend Staff



iv. Additional staff and case manager measures by program

Participants with personal care, behavioral health, homemaker, or CSP services were asked, “Did [staff] encourage you to do things for yourself if you could?” As shown in Figure 7, 96% or more of PCA, ABI, and Autism participants reported that their staff did encourage them this way. Slightly fewer CHCP and MHW participants felt this way – 88 to 89% said their PCA/RA staff encouraged them to do things for themselves. When asked if their homemakers/companions encourage them to do things for themselves, once again fewer CHCP participants felt this way compared to PCA and ABI participants (only three Autism participants reported homemaker services). Ninety-two percent of MHW participants reported being encouraged by their CSPs to do things for themselves.

Figure 7. Staff Encourage You to Do Things for Yourself - Percentage Positive Responses



The majority of participants in each program knew who their care manager was, with the exception of MHW – about half of MHW participants (51%) knew who their care manager was. Compared to the remaining programs, fewer Katie Beckett participant (65%) knew their care managers as well. All Autism participants said they knew their care manager, followed by 83% of CHCP and 73% of either ABI or PCA participants (Figure 8). The percentage of participants in any one program who had asked their care manager for help with changing their services ranged from 24% (PCA) to 42% (Autism). Twenty-seven percent of ABI participants reported asking their care manager for help with getting or fixing equipment, followed by Katie Beckett (24%) and MHW (22%) (Figure 9).

Figure 8. Knows who care manager is – Percentage Positive Responses

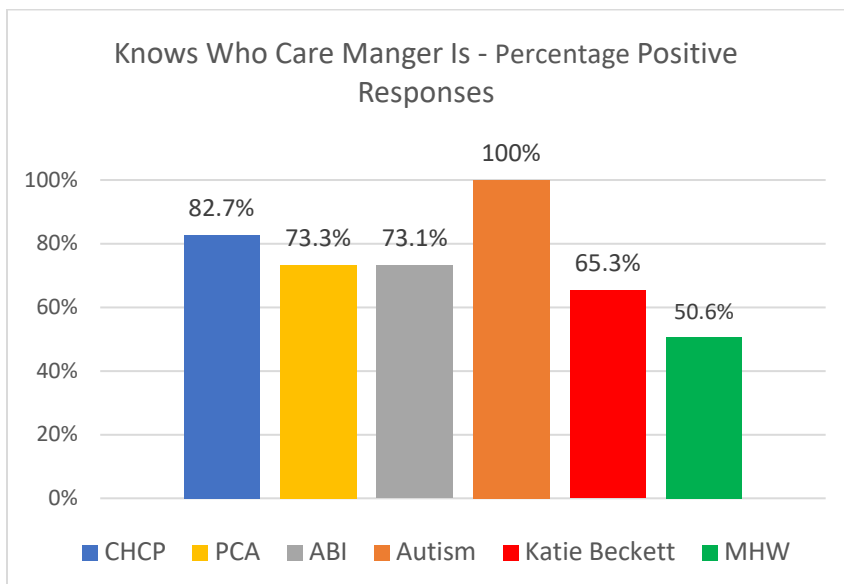
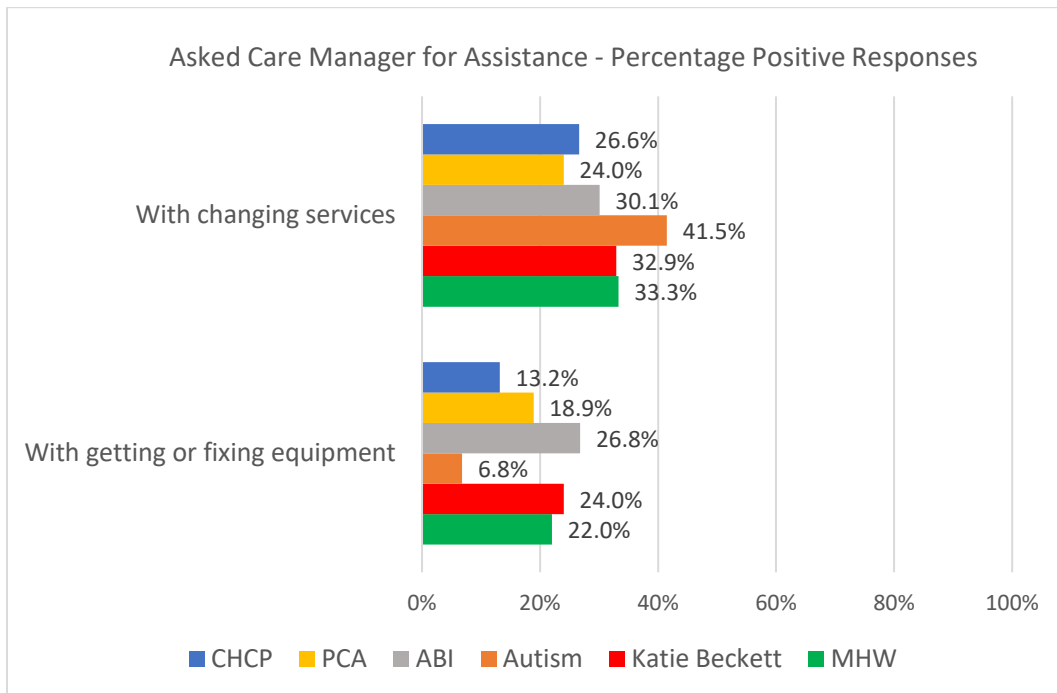




Figure 9. Asked for Care Manager Assistance with Changing Services or Equipment – Percentage Positive Responses



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 the majority of participants reported they did have someone to talk to, nearly one out of every ten ABI participants (9%) said they did not know who they would talk to about changing their care plan (Figure 10). When asked to name the person they would talk to, most participants reported they would talk to their case manager (Table 7). Although not shown on the table, 14% of Katie Beckett participants would talk to their doctor or other health care provider.

Figure 10. Knows Someone to Talk to if Want to Change Care Plan

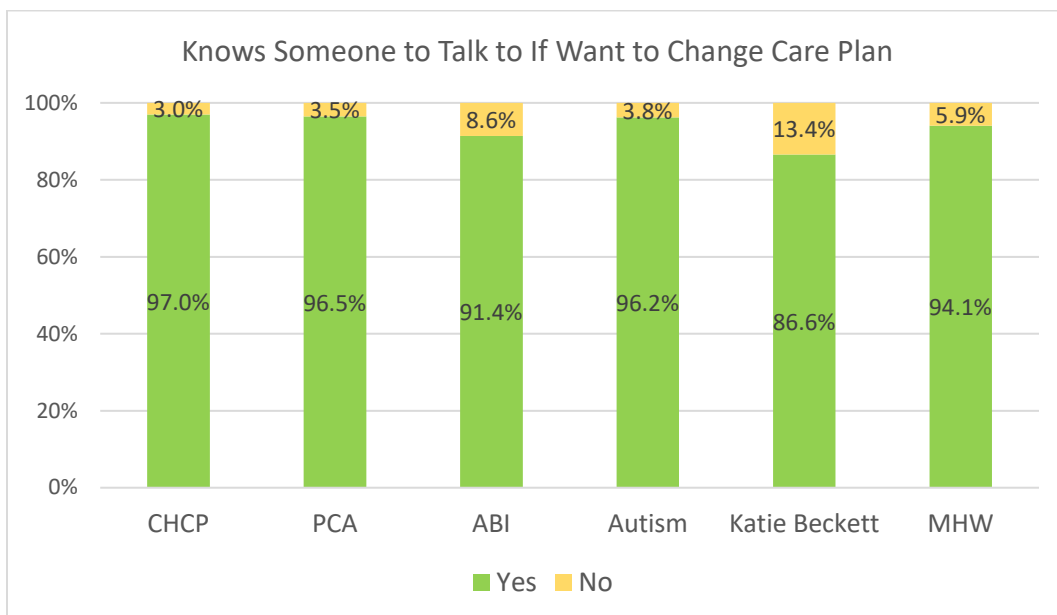


Table 7. Who Would You Talk to if You Wanted to Change Your Care Plan?\*

	CHCP N=608 n (%)	PCA N=272 n (%)	ABI N=296 n (%)	Autism N=51 n (%)	Katie Beckett N=110 n (%)	MHW N=80 n (%)
Case manager or social worker	545 (89.6)	253 (93.0)	273 (92.2)	43 (84.3)	90 (81.8)	72 (90.0)
Other staff or home care agency/provider	34 (5.6)	11 (4.0)	22 (7.4)	18 (35.3)	5 (13.6)	8 (10.0)
Family/friends	74 (12.2)	27 (9.9)	15 (5.1)	9 (17.6)	11 (10.0)	11 (13.8)
Someone else	10 (1.6)	21 (7.7)	8 (2.7)	3 (5.9)	25 (22.7)	10 (12.5)

\*Multiple choice

v. Unmet needs by program

CHCP, PCA, ABI, Autism, and MHW participants who reported receiving some type of personal care, behavioral health, homemaker paid assistance were further asked if they needed help with five everyday activities: personal care (dressing/bathing), meals, medications, toileting, and housekeeping (Table 8). The greatest need for assistance for CHCP participants was for personal care (89%), followed by housekeeping (85%) and meals (79%). Almost all of PCA participants needed assistance with either personal care or meals, and over three-quarters (77%) needed assistance with taking medications. About three-quarters of ABI participants also needed assistance with taking medications (74%), and 78% needed assistance with meals. Over half (54%) of MHW participants and 45% of Autism participants needed assistance with meals.

Table 8. Self-reported Assistance with Everyday Activities

Needs assistance with:	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)	MHW n (%)
Personal care	242 (88.6)	253 (98.1)	165 (57.7)	6 (14.0)	8 (10.8)
Meals or eating	214 (79.0)	254 (97.7)	224 (78.3)	19 (45.2)	40 (54.1)
Taking medications	152 (55.9)	200 (76.9)	212 (74.1)	8 (18.6)	23 (31.1)
Toileting	124 (45.8)	177 (68.3)	85 (29.7)	0 (0.0)	6 (8.2)
Housekeeping or laundry	527 (85.1)	244 (88.1)	150 (46.9)	3 (5.8)	--

-- Item not asked.

To determine unmet need in these areas, participants who needed assistance with each task were asked if they did not do the activity in the past three months specifically because of lack of staff to assist them. Less than 1% of participants in any program reported any unmet needs with personal care, meals, medications, toileting, or homemaking tasks with a few exceptions in the CHCP and MHW programs. Most notably, 5.4 percent of MHW participants (n=4) reported an unmet need with taking medications. One MHW participant (1.4%) reported an unmet need with meals, and one MHW participant (1.4%) reported an unmet need with toileting. Four CHCP participants (1.5%) reported an unmet need with dressing or bathing, and three CHCP participants (1.1%) reported an unmet need with meals or eating.

vi. Physical safety by program

Two PCA and two ABI participants reported that a staff person had hit them or hurt them in the past three months. No other participants reported being hit or hurt by a staff person. Three of the four participants (1 PCA, 2 ABI) said someone worked with them to resolve the issue.

E. Performance Benchmarks by Agency

i. CHCP programs

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 A, AGENCY B, AGENCY B, and AGENCY D. 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 CHCP performance benchmarks in each of the five measures based on 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). Figures 11, 12, and 13 show the CHCP performance benchmark results by Access Agency, with each benchmark indicated by the bold black line.

Figure 11 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 12) as well as CHCP case manager recommendation (Figure 13).

Figure 11. CHCP Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)

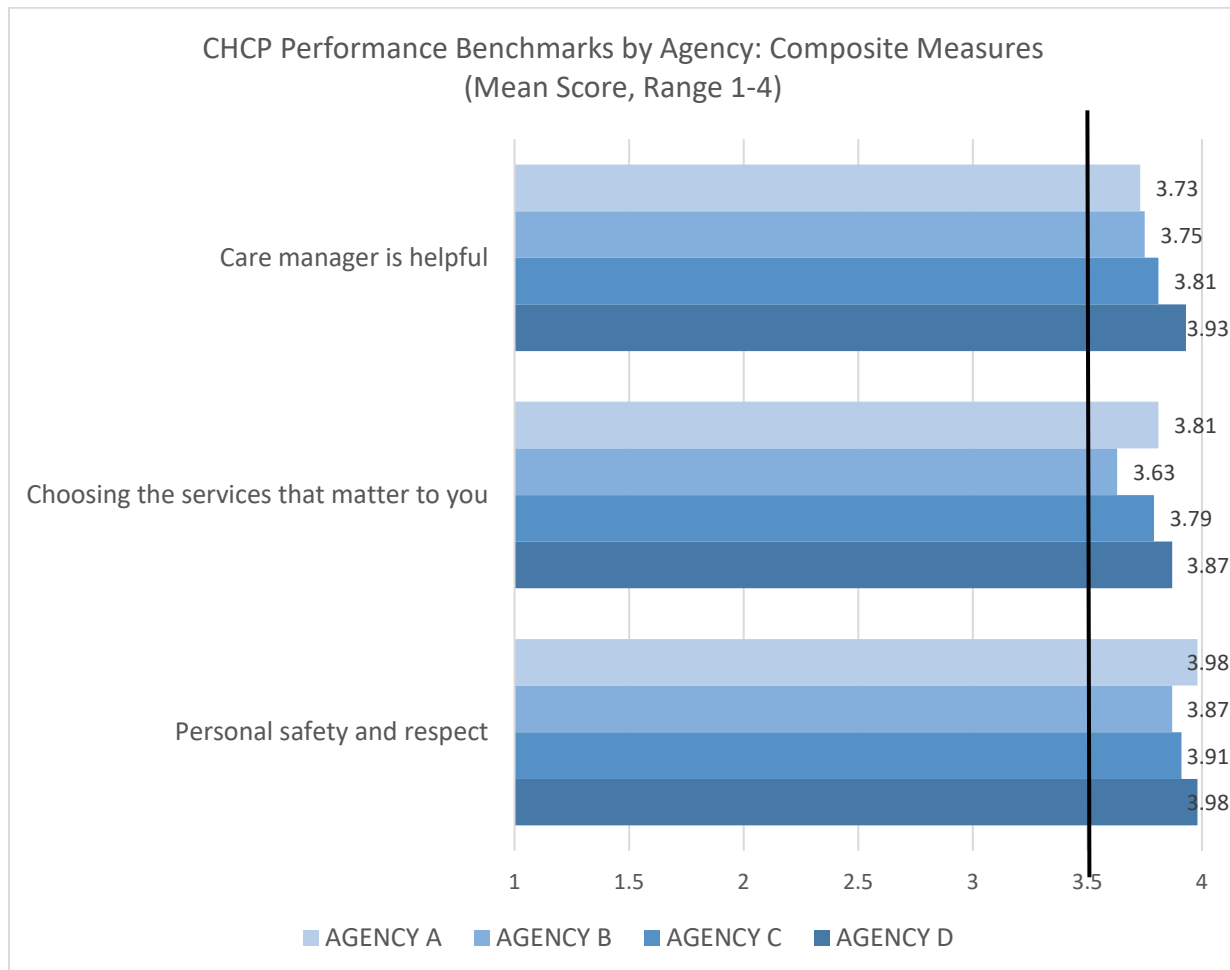


Figure 12. CHCP Performance Benchmarks by Agency: Case Manager Global Rating (Mean Score, Range 1-5)

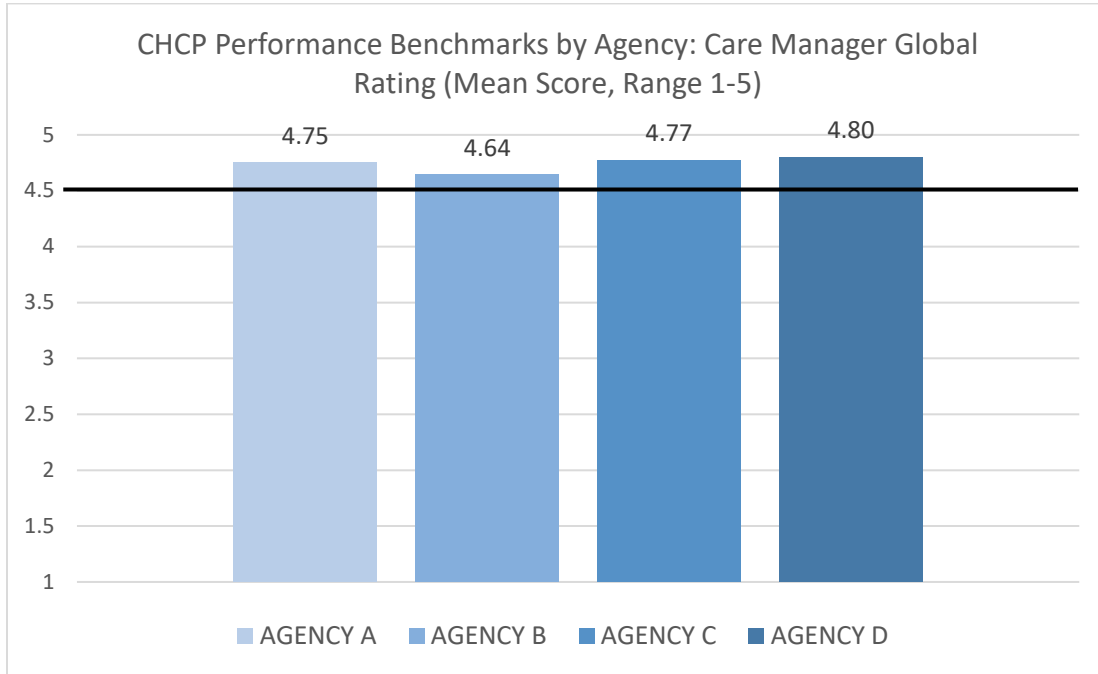
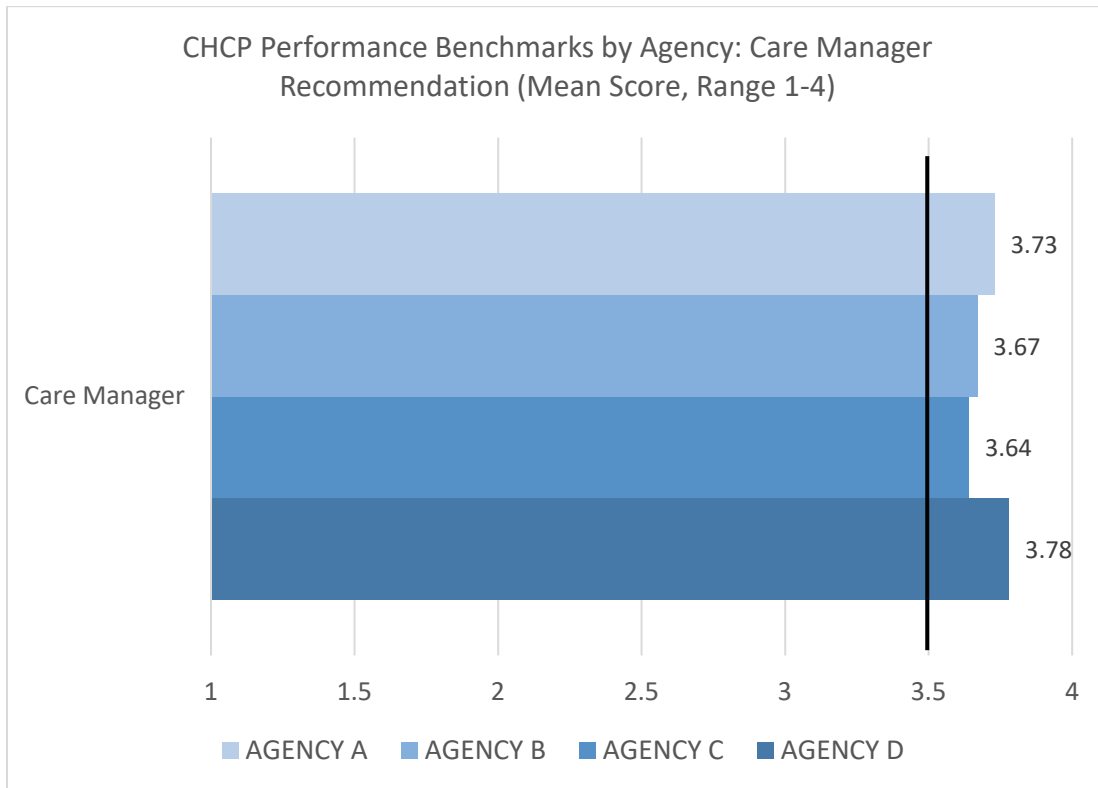


Figure 13. CHCP Performance Benchmarks by Agency: Case Manager Recommendation (Mean Score, Range 1-4)



ii. PCA waiver

Similar performance benchmark measures are presented for the PCA waiver in Figures 14, 15, and 16. Figure 14 shows that the 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 4.31 (Figure 15). All four Access Agencies met or exceeded a 3.5 mean score for case manager recommendation (Figure 16).

Figure 14. PCA Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)

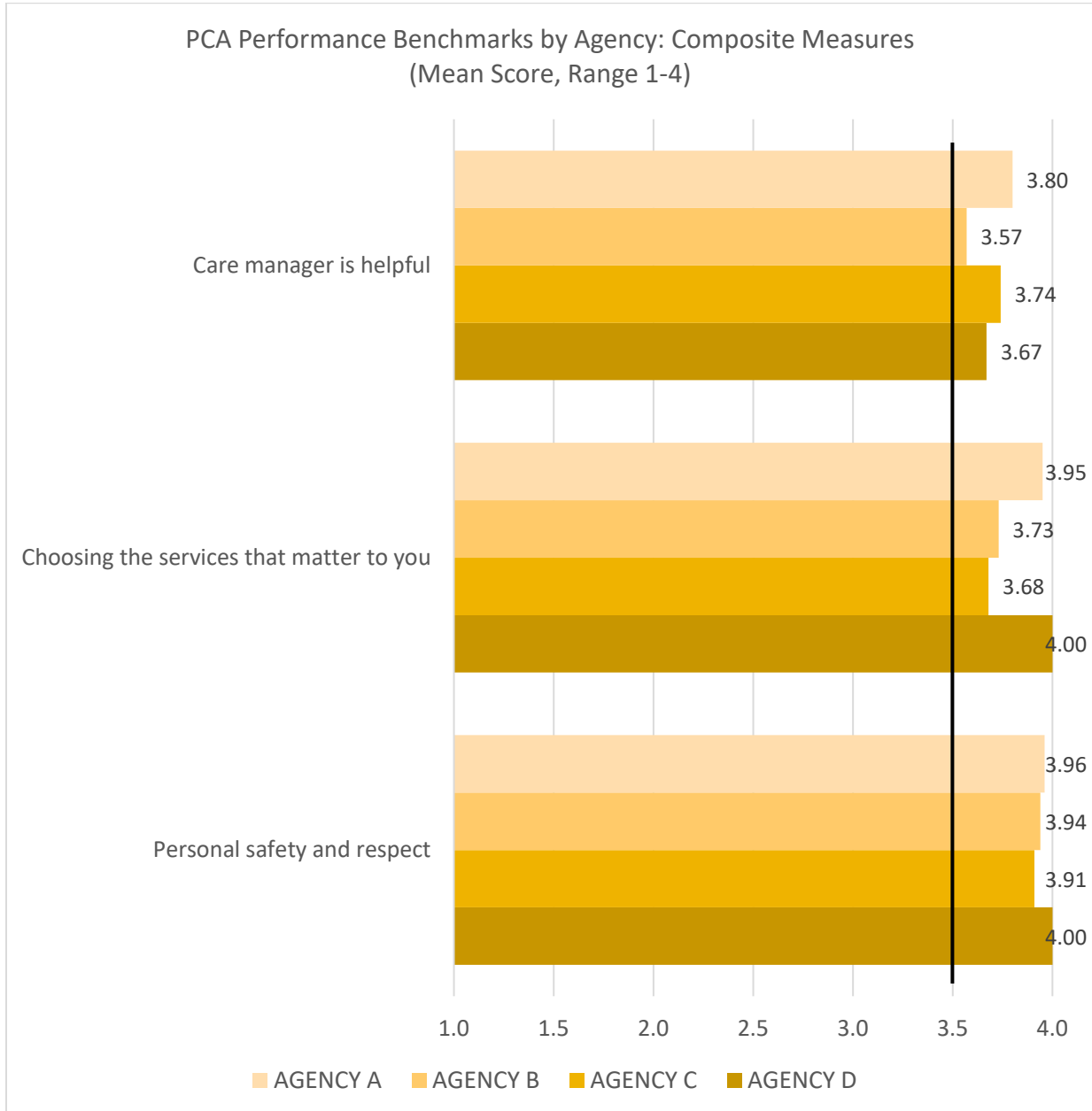


Figure 15. PCA Performance Benchmarks by Agency: Case Manager Global Rating (Mean Score, Range 1-5)

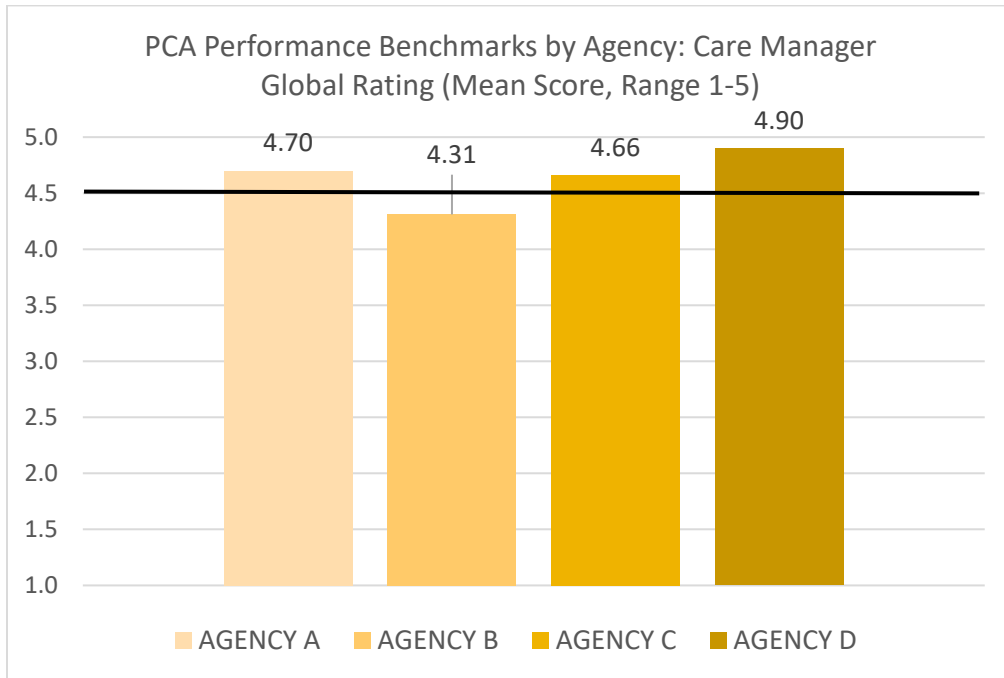
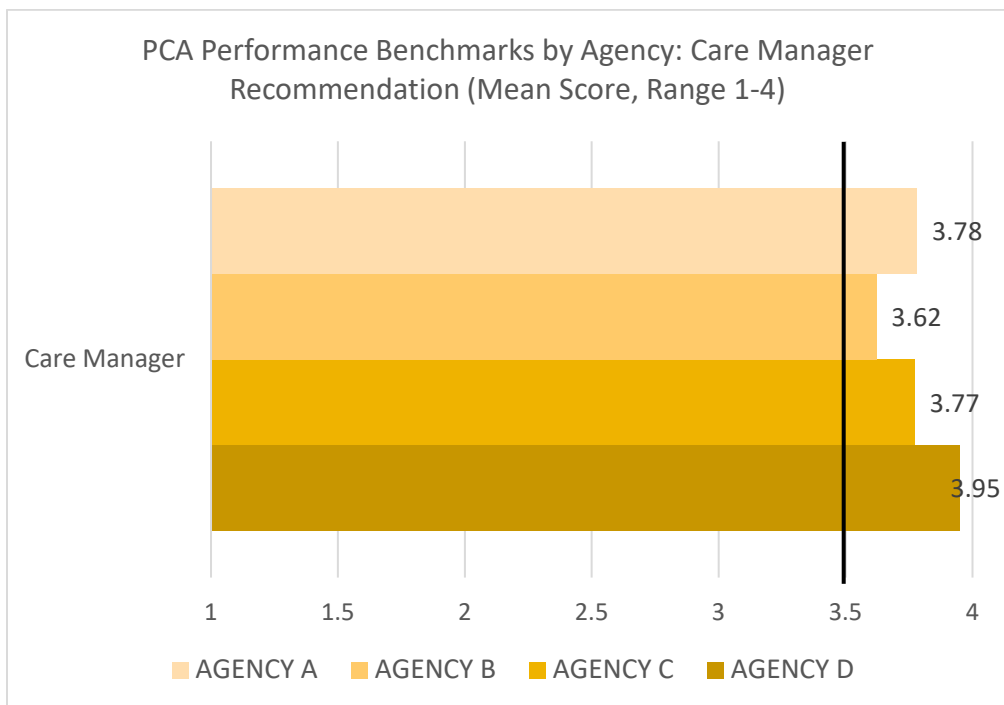


Figure 16. PCA Performance Benchmarks by Agency: Case Manager Recommendation (Mean Score, Range 1-4)



iii. ABI Waiver

The ABI performance benchmark measures are presented in Figures 17, 18, and 19. Three Access Agencies provide case management for the ABI waiver. Figure 17 shows that all three Access Agencies met or exceeded a 3.5 mean score for all three composite measures. Two of the three Access Agencies received a mean score of 4.5 or above for case manager global rating; one Access Agency received a score of 4.45 (Figure 18). All Access Agencies also met and exceeded the performance benchmark score of 3.5 for ABI case manager recommendation (Figure 19).

Figure 17. ABI Performance Benchmarks by Agency: Composite Measures (Mean Score, Range 1-4)

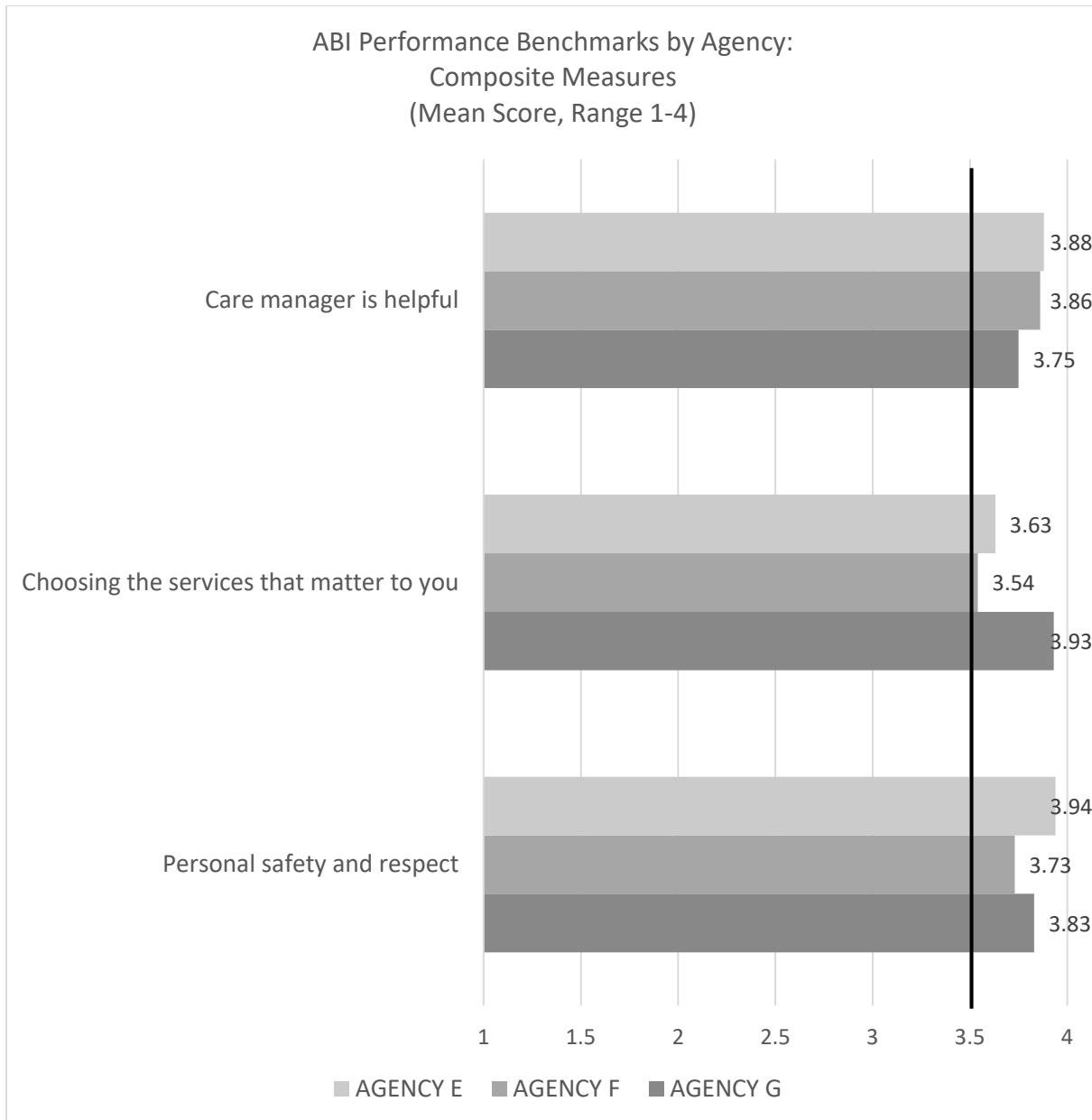


Figure 18. ABI Performance Benchmarks by Agency: Case Manager Global Rating (Mean Score, Range 1-5)

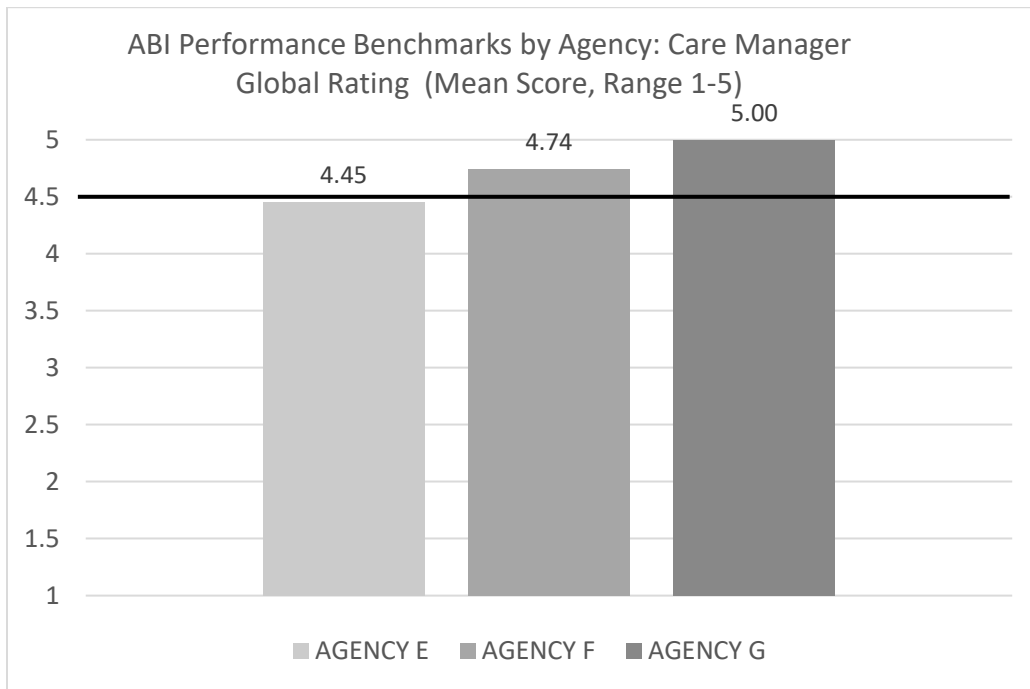
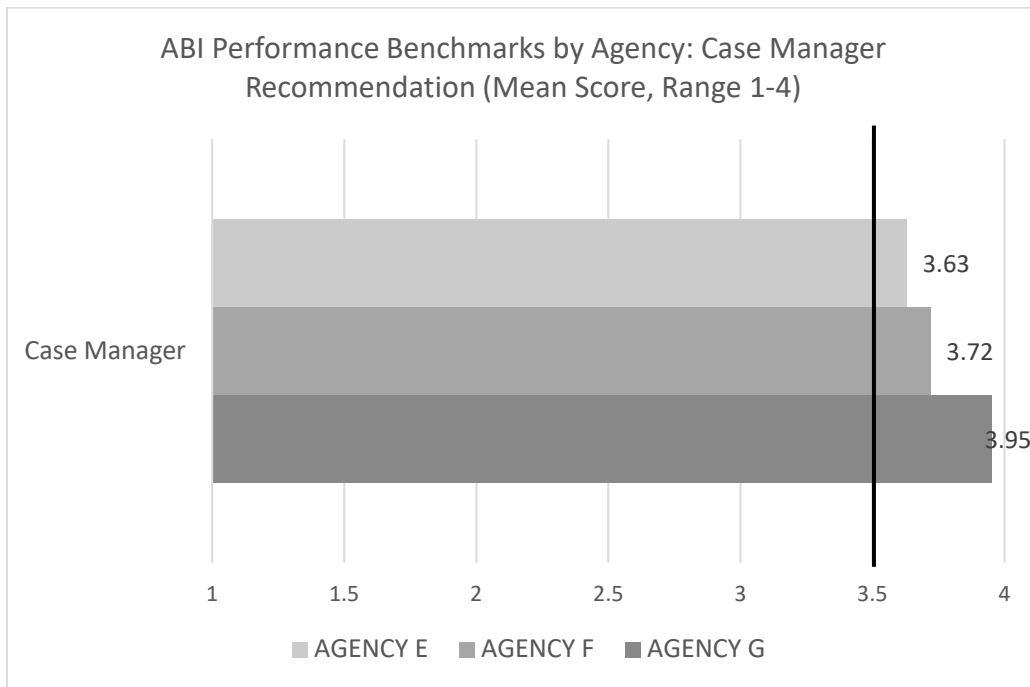


Figure 19. ABI Performance Benchmarks by Agency: Case Manager Recommendation (Mean Score, Range 1-4)





F. Additional Findings by Program

i. Living situation and social support

The great majority of MHW participants (86%) lived alone or without other adults, as did two-thirds of CHCP and about half of PCA and ABI participants (Table 9). Greater percentages of participants in the other waivers also reported having family or friends who live nearby. MHW participants had considerably less nearby social support: one quarter of MHW participants both lived alone/without other adults and had no nearby family or friends. This compares to 5% of PCA and 7% of either CHCP or ABI participants.

Table 9. Living Situation and Social Support\*

		CHCP %	PCA %	ABI %	Autism %	Katie Beckett %	MHW %
Number of adults living in household		N=626	N=281	N=323	N=53	N=110	N=85
	1	68.5	50.9	55.7	35.9	7.3	85.9
	2-3	28.4	45.2	39.3	50.9	79.1	14.1
	4+	3.0	3.9	5.0	13.2	13.6	0
Lives with family member/s		N=198	N=138	N=143	N=53	N=103	N=12
	Yes	78.3	87.0	63.6	91.2	79.6	66.7
	No	21.7	13.0	36.4	8.8	20.4	33.3
Lives with non-family		N=198	N=138	N=143	N=53	N=101	N=12
	Yes	23.2	15.2	37.8	14.7	1.0	25.0
	No	76.8	84.8	62.2	85.3	99.0	75.0
Family member/s live nearby		N=626	N=282	N=324	N=53	N=125	N=85
	Yes	79.4	77.0	80.3	79.3	76.0	55.3
	No	20.6	23.1	19.8	20.8	24.0	44.7
Friend/s live nearby		N=625	N=281	N=322	N=53	N=123	N=83
	Yes	65.3	71.5	49.4	60.4	76.7	39.8
	No	34.7	28.5	50.6	39.6	23.3	60.2

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

MHW participants reported not only fewer nearby family or friends, but were also the least likely group to see these family or friends. When asked how often can you get together with your nearby family when you want to, between 58% (MHW) to 73% (CHCP) of participants said they “usually” or “always” can see their nearby family members when they want to. Overall, waiver participants could not get together as often with their nearby friends, ranging from 44% (MHW) to 65% (ABI).

The Governor’s “Stay Safe, Stay Home” Executive Order enacted March 24, 2020 noticeably affected participants’ ability to see their family or friends. It especially affected MHW participants’ ability to see their nearby family as often as they wanted (24% could do so after March 24, 2020, compared to 58%

across the full year), and ABI participants' ability to see their friends as often as they liked (25% could do so after March 24, 2020, compared to 65% across the full year).

ii. Physical and mental health

Not surprisingly, PCA and CHCP participants were most likely to report fair or poor physical health (Figure 20). Just under half of MHW respondents (47%) also reported fair or poor health. Autism participants reported the best physical and mental health (Figure 21). Notably, approximately one third of CHCP, MHW, PCA, and ABI respondents rated their overall mental health as fair or poor. Katie Beckett is not included due to missing data.

Figure 20. Self-Reported Physical Health

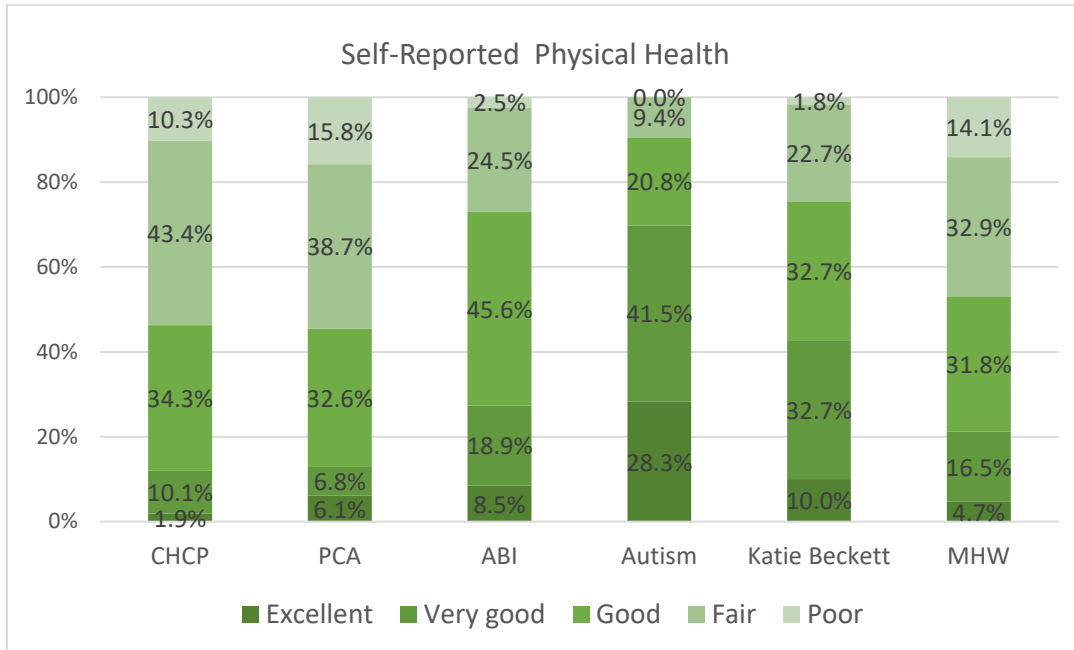
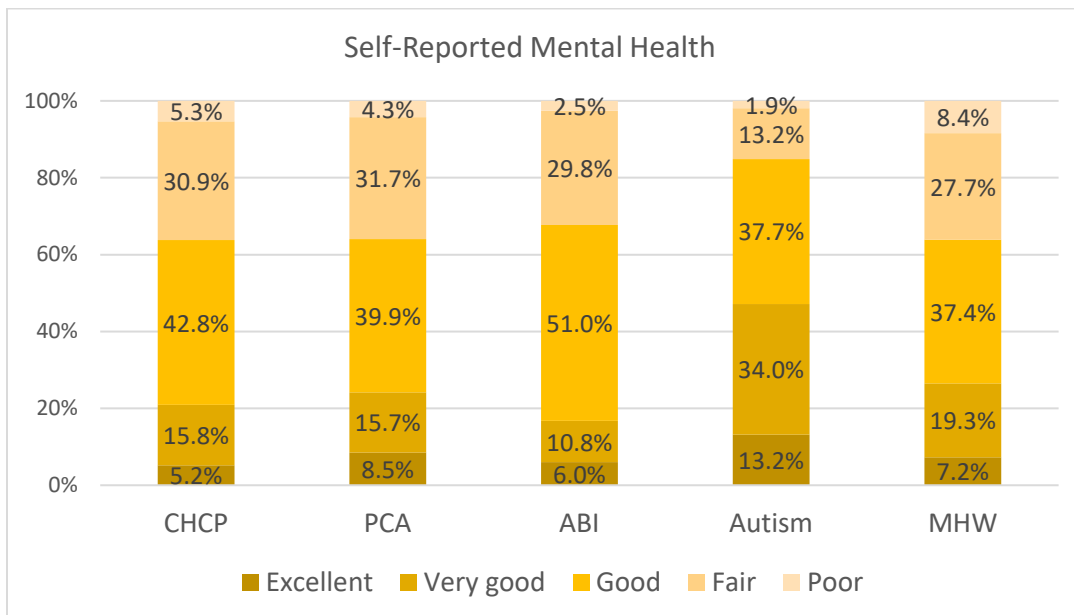


Figure 21. Self-Reported Mental Health



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

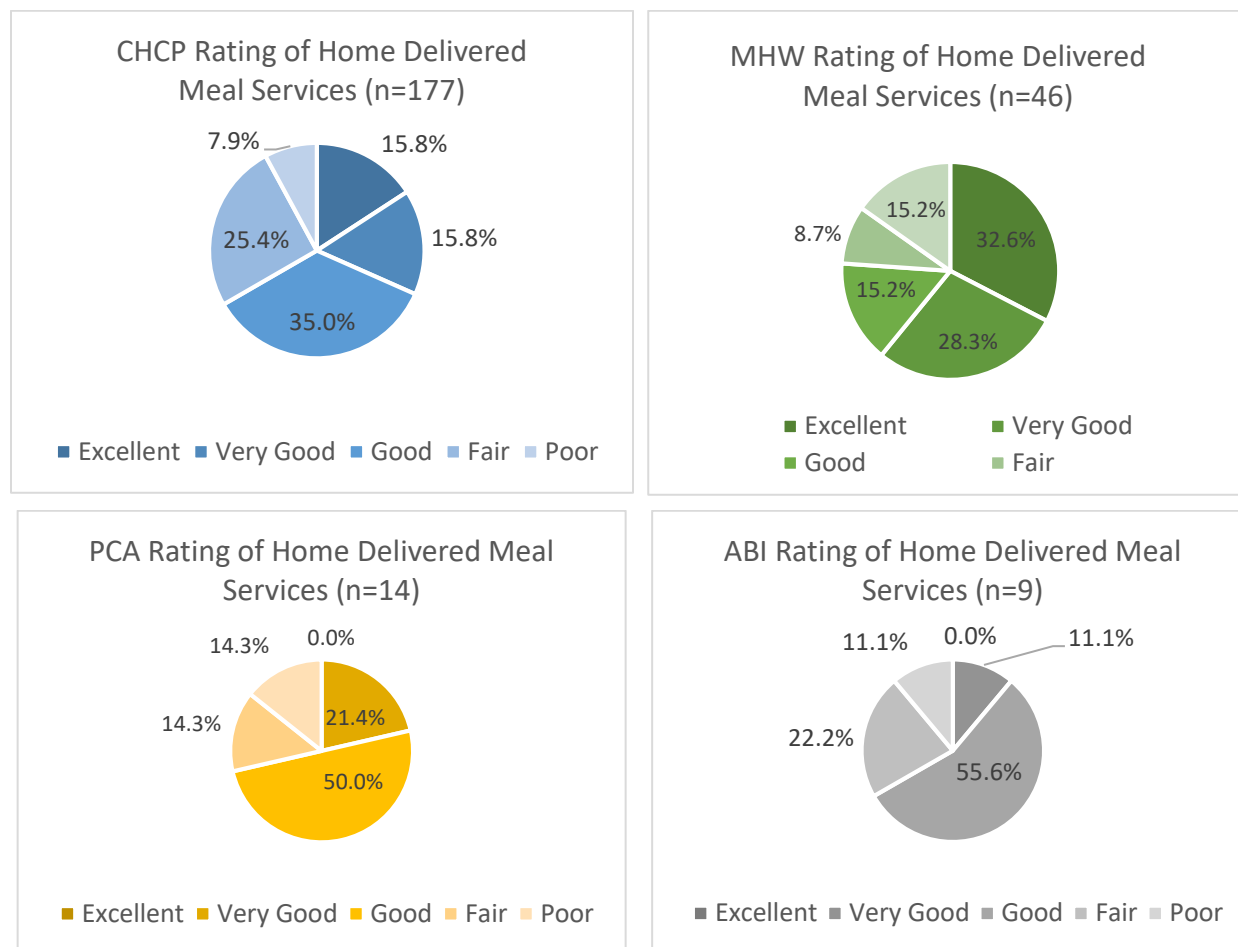
Unexpectedly, more MHW (45%) than PCA (40%) participants reported using a van or transportation service. One quarter of both CHCP and Autism participants also used a van or transportations service.

Table. 10. Use of a Van or Transportation Service

	CHCP % N=623	PCA % N=281	ABI % N=321	Autism % N=53	Katie Beckett % N=127	MHW % N=83
Yes	25.4	39.9	14.6	22.6	15.0	44.6
No	74.6	60.1	85.4	77.4	85.0	55.4

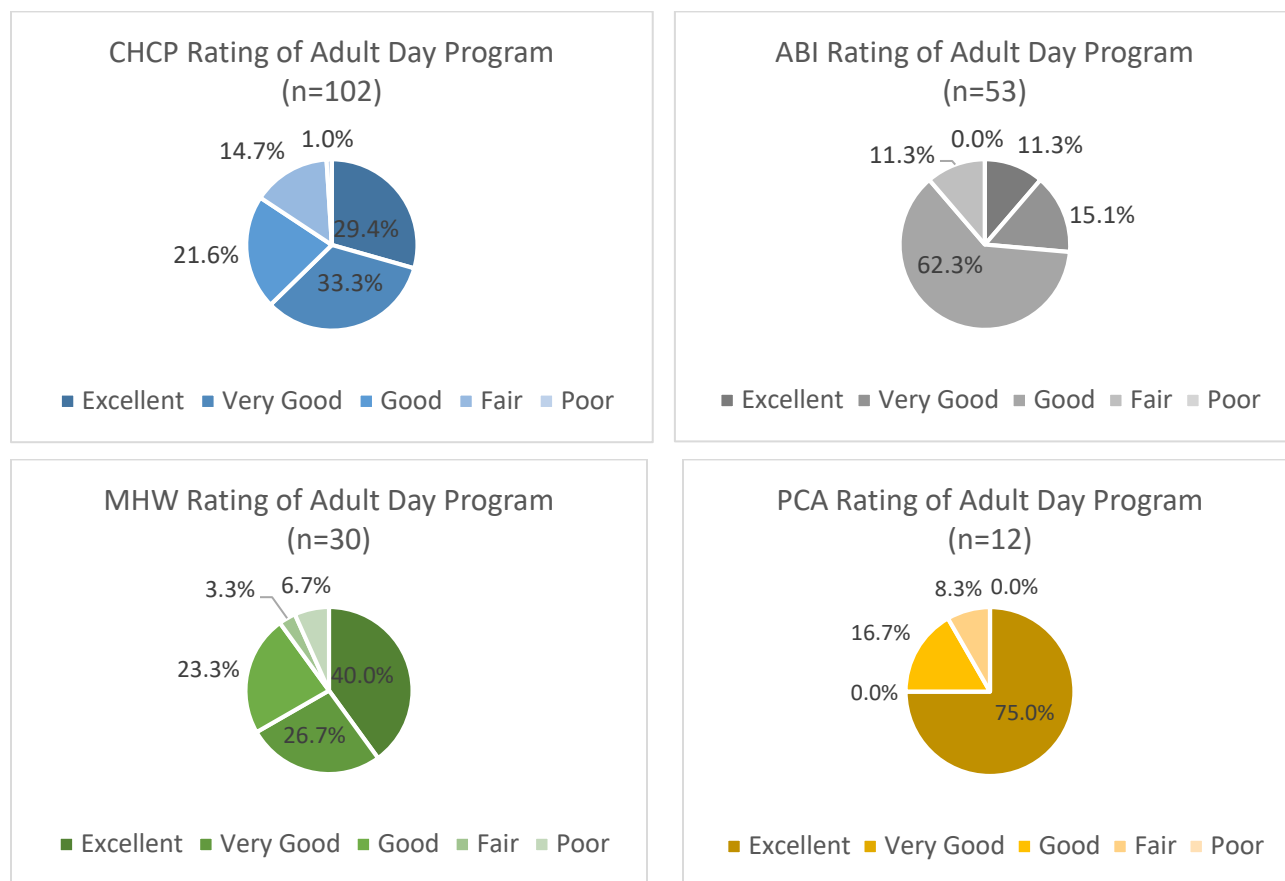
A total of 253 participants rated their home delivered meal service: 177 CHCP, 46 MHW, 14 PCA, 9 ABI, 6 Kate Beckett, and 1 Autism participant. As shown in Figure 22, MHW participants were more satisfied with their meal services than CHCP participants. Sixty-one percent of MHW participants rated their meal service as very good or excellent, compared to only 32% of CHCP participants.

Figure 22. Experience with Home Delivered Meal Services



Another 203 participants rated their day program services: 102 CHCP, 30 MHW, 12 PCA, 53 ABI, 3 Katie Beckett, and 3 Autism participants. MHW and CHCP participants were much happier with their day program experiences than were ABI participants: 67% of MHW and 63% of CHCP participants rated their day program as very good or excellent, compared to 26% of ABI participants (Figure 23).

Figure 23. Experiences with Day Program Services



iv. Personal safety and respect follow-up

Twenty-five participants (1.7% of all participants) said that one of their staff had taken their money or things without permission: 9 CHCP, 2 PCA, 12 ABI, 1 Autism, and 1 MHW. About half of these participants (48%) said someone was working with them to fix the problem; Family or friends and the HCBS provider agency were most frequently turned to for assistance. Thirty-one participants (2.1% of all participants) said that one of their staff had yelled or cursed at them: 6 CHCP, 4 PCA, 15 ABI, and 6 MHW. Just over half (55%) said someone had been working with them to fix the problem, most often either their case manager or HCBS provider. Although the number in each program are small, in both of these instances, proportionately more ABI participants reported these incidents: 3.7% of ABI participants reported being stolen from, and 4.6% of ABI participants reported being yelled or sworn at. It is also notable that only half of participants from any program who were stolen from or yelled at said someone else was working with them to resolve these concerns.

v. Emergency contact

Another open-ended question asked, “The next few questions ask about your personal safety. Who would you contact in case of an emergency?” Neither the survey nor the interviewers defined what “emergency” meant, and participants could identify more than one person. Who participants would contact showed some differences across programs. For example, the majority of Autism, PCA, ABI, MHW, and CHCP participants would contact a family member or friend, while the majority of Katie Beckett participants would call 911 (Table 11). In addition, one out of five Katie Beckett participants would call a health care provider in case of an emergency, compared to less than 2% in any other program.

Table 11. Who would you contact in case of an emergency?\*

	CHCP N=620 %	PCA N=279 %	ABI N=315 %	Autism N=53 %	Katie Beckett N=125 %	MHW N=82 %
Family/friend	70.3	81.74	72.7	90.6	62.4	72.0
Case manager	4.4	6.5	5.4	5.7	18.4	39.0
Home care agency or staff	4.5	9.7	10.8	9.4	13.6	18.3
PERS/Lifeline	32.2	12.2	6.0	0	4.8	9.8
911	46.0	34.1	26.0	22.6	81.6	61.0
Someone else	2.3	2.5	5.1	7.5	21.6	2.4

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

vi. Self-directed employment of paid assistants

To measure use of consumer employer self-direction, consumers were asked how their caregivers were hired: “Do your caregivers come from an agency, or do you or a family member find and hire your aides?” Not surprisingly, nearly all CHCP and MHW participants reported an agency provided their caregivers, while nine out of ten of PCA participants reported they hired their own staff, as did over half of Katie Beckett participants (Table 12). Consumers who reported hiring their own staff were asked if any of their family members were paid to assist them. Less than half of all program participants reported hiring a family member, most often CHCP (42%) and PCA (44%) participants. Consumers with paid family caregivers most frequently employed adult children, siblings, and parents as staff.

Table 12. Self-Direction\*

	CHCP %	PCA %	ABI %	Katie Beckett %	Autism %	MHW %
How hire staff	N=581	N=280	N=301	N=67	N=49	N=75
Agency	95.5	10.7	67.4	44.8	71.4	96.0
Self-hire	4.5	89.3	32.6	55.2	28.6	4.0
Agency and Self-hire	0.0	0.0	0.0	0.0	0.0	0.0
Employs family member/s	N=26	N=250	N=98	N=37	N=14	N=2
Yes	42.3	43.6	20.4	32.4	14.3	0.0
No	57.7	56.4	79.6	67.6	85.7	100.0

vii. Employment

The employment module covered work status, assistance finding a job, and on-the-job employment support. The ABI, Autism, and MHW programs offer job supports – these participants were asked the entire module. PCA participants answered the questions regarding work status and assistance finding employment.

Figures 24 and 25 show employment statistics for all four programs. There is a striking difference with respect rate of employment – less than 5% of either PCA or MHW participants were working, compared to 30% of ABI and 40% of Autism participants. It is notable that approximately one-quarter of both unemployed PCA and MHW participants would like to work, along with about one-third of both unemployed Autism and ABI participants.

Figure 24. Employment Status

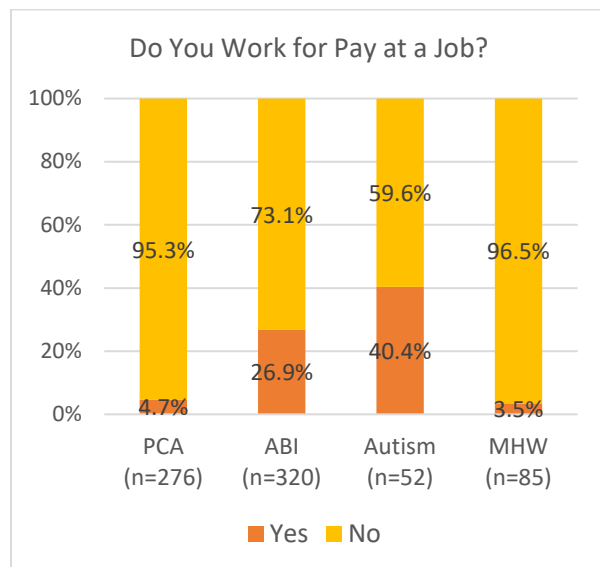
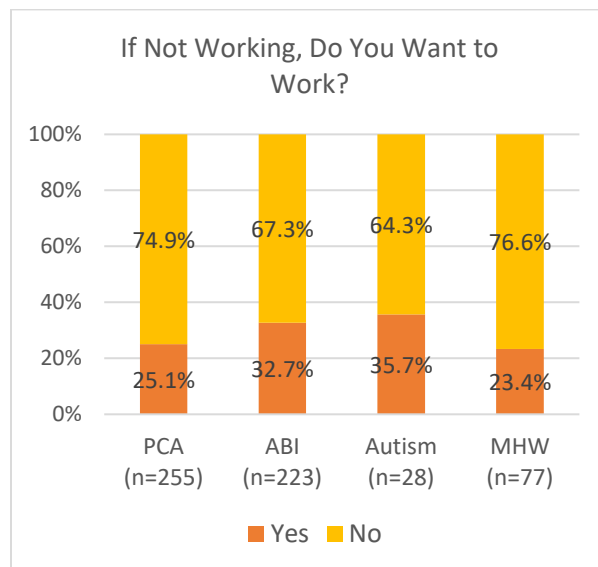


Figure 25. Employment Goal



Health and disability related concerns were the most frequently reported reason for not working for PCA, ABI, and MHW participants (Table 13). Few (less than 10) ABI or PCA participants reported that training/education, transportation, potential loss of benefits, or employment resources were challenges to employment. MHW participants who did not want to work were noticeably more concerned about losing their benefits (43%), reported they did not know about job resources (30%), and cited transportation challenges (13%).

Unemployed MHW participants showed another difference as well. Only 9% of MHW participants who did not want to work reported that nothing was holding them back from working, compared to 21% of PCA, 41% of ABI, and 50% of Autism participants who reported that nothing was holding them back.

It should be noted that of the participants with a health or disability concern who wanted to work, three mentioned COVID 19 specifically, and as did one participant who did not want to work.

Table 13. Most Common Reasons for Not Working\*

<i>Respondents who would like to work</i>			
	PCA N=64 n (%)	ABI N=67 n (%)	MHW N=18 n (%)
Health/disability	47 (73.4)	40 (59.7)	12 (66.7)
Looking for but cannot find work	7 (10.9)	9 (13.4)	0 (0)
Nothing is holding me back	1 (1.6)	7 (10.4)	0 (0)
<i>Participants who do not want to work</i>			
	PCA N=188 n (%)	ABI N=145 n (%)	MHW N=56 n (%)
Health/disability	146 (77.7)	82 (56.6)	37 (66.1)
Nothing is holding me back	40 (21.3)	59 (40.7)	5 (8.9)

\*Multiple choice

A small number of unemployed ABI, PCA, Autism, or MHW participants had asked for assistance with finding a job (Figure 26). Unlike MHW participants, the majority of unemployed ABI, Autism, and PCA participants knew that such help was available, although most of them did not seek it out (Figure 27). Very few unemployed ABI (n=5) or Autism (n=3) participants reported that someone was paid to help them get a job; all eight said they got all the help they needed despite continuing to be unemployed.

Figure 26. Sought Out Employment Assistance

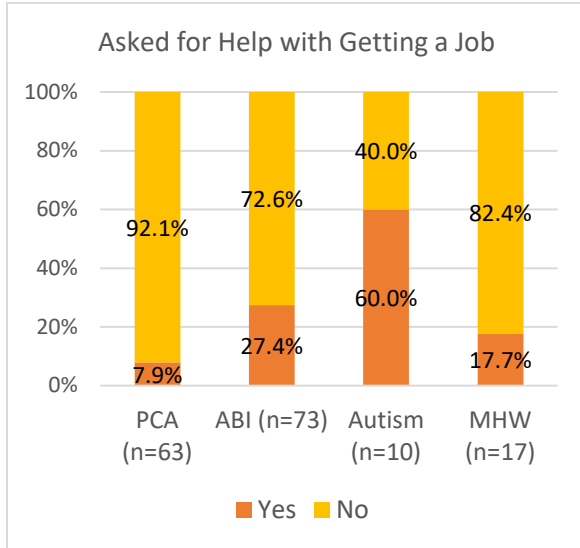
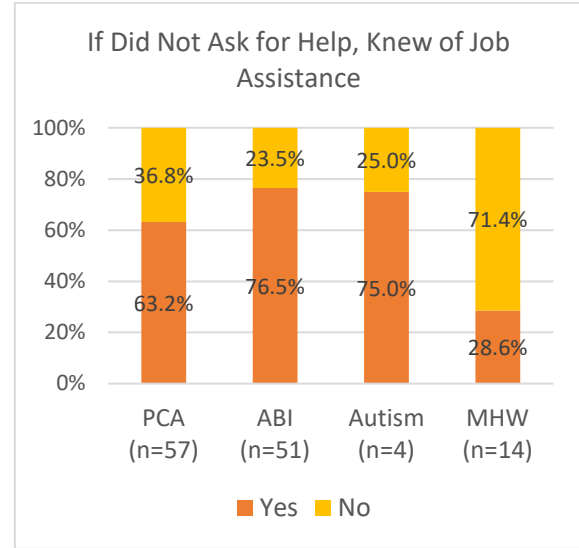


Figure 27. Aware of Employment Assistance



ABI, Autism, and MHW Employment Experiences

The ABI, Autism, and MHW waivers all provide various employment specific services, and employed participants from these waivers were asked further employment questions. When asked who helped them find their job, ABI participants (49%) most often said that vocational staff helped them find their jobs, while Autism participants (29%) most frequently received assistance from their provider agency (Table 14). Fifteen percent of ABI and 19% of Autism participants found their jobs themselves. Two of the three employed MHW participants got help finding their jobs from family or friends. When asked if they helped choose their job, the majority of employed ABI (77%) and Autism (94%) participants said they did, as did the three employed MHW participants.

Table 14. Who helped you find your job?\*

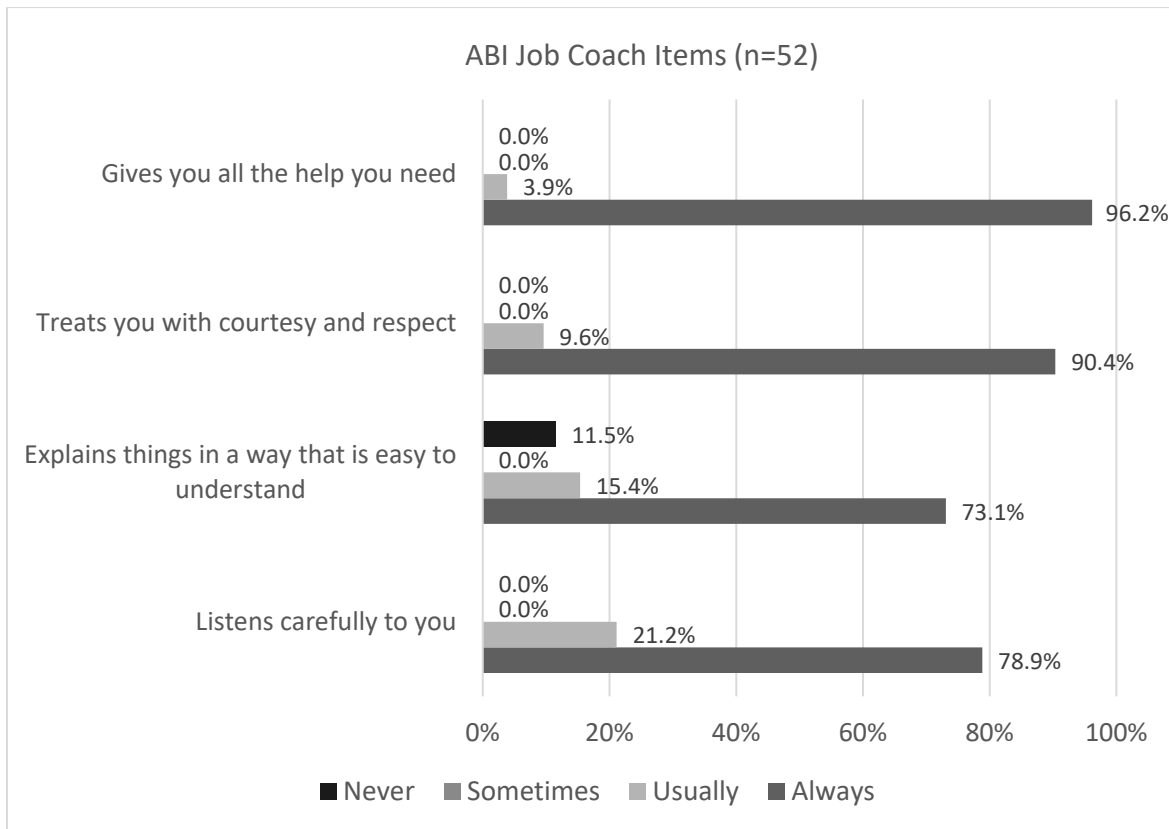
	ABI N=83 n (%)	Autism N=21 n (%)
Vocational staff	38 (45.8)	3 (14.3)
Provider agency	13 (15.7)	6 (28.6)
Other career services	3 (3.6)	4 (19.0)
Family/friends	8 (9.6)	4 (19.0)
No one - I found it myself	12 (14.5)	4 (19.0)

\*Multiple choice

### ABI Job Coach

Sixty-seven percent (n=55) of working ABI participants reported that someone was paid to help them with their job. Nearly all of these participants (n=52) reported that they did not hire their job coaches themselves and were asked further job coach questions. Almost all (98%) said their job coaches were always with them at work, and all reported that their job coaches encouraged them to do things for themselves. Overall, the majority of these participants 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 4.52, out of 1-5) and recommendations (mean score 3.65, out of 1-4).

Figure 28. ABI Job Coach Items

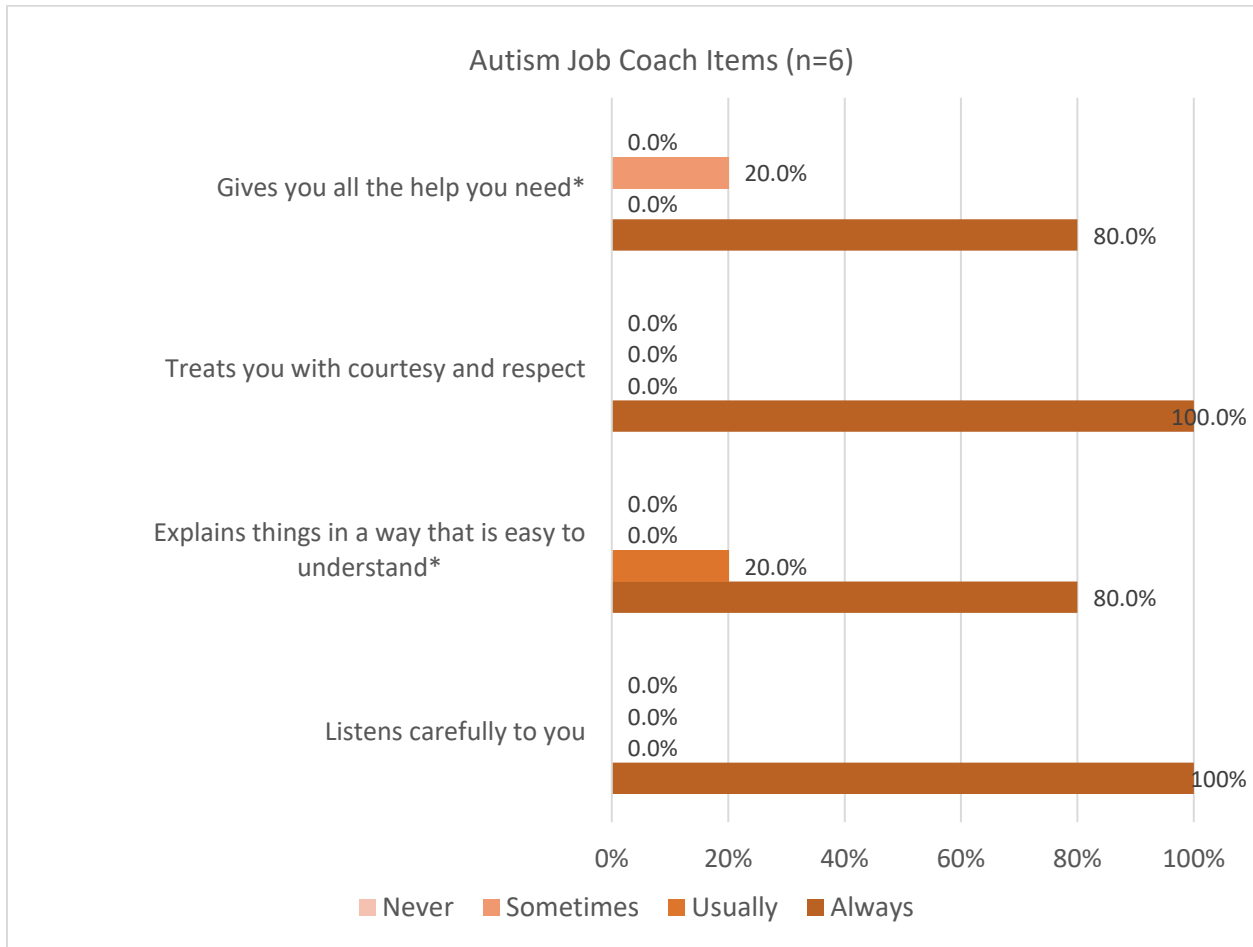


### Autism Job Coach

Less than 40 percent of working Autism participants (n=8) reported someone was paid to help them with their job. Six of these participants reported that they did not hire their job coach themselves and were asked further job coach questions. Three participants said their job coach was always with them at work. Overall, the majority of these participants reported positive experiences with their job support staff (Figure 29). All participants also said their job coach encouraged them to do things for themselves if they could. As reported in Figures 3 and 5, Autism participants gave their job coaches a mean rating of 4.17 (out of 1-5) and highly recommended them (mean score 3.80, out of 1-4).



Figure 29. Autism Job Coach Items



\*n=5

*MHW Job Coach*

One of the three employed MHW participants had a job coach who helped them with their current job. The participant reported that their job coach was always with them at work, usually treated them respectfully, always explained things in a way that was easy to understand, and always listened carefully to them. As shown in Figure 5, they would definitely recommend this job coach to their friends or family (mean score of 4, out of 1-4).

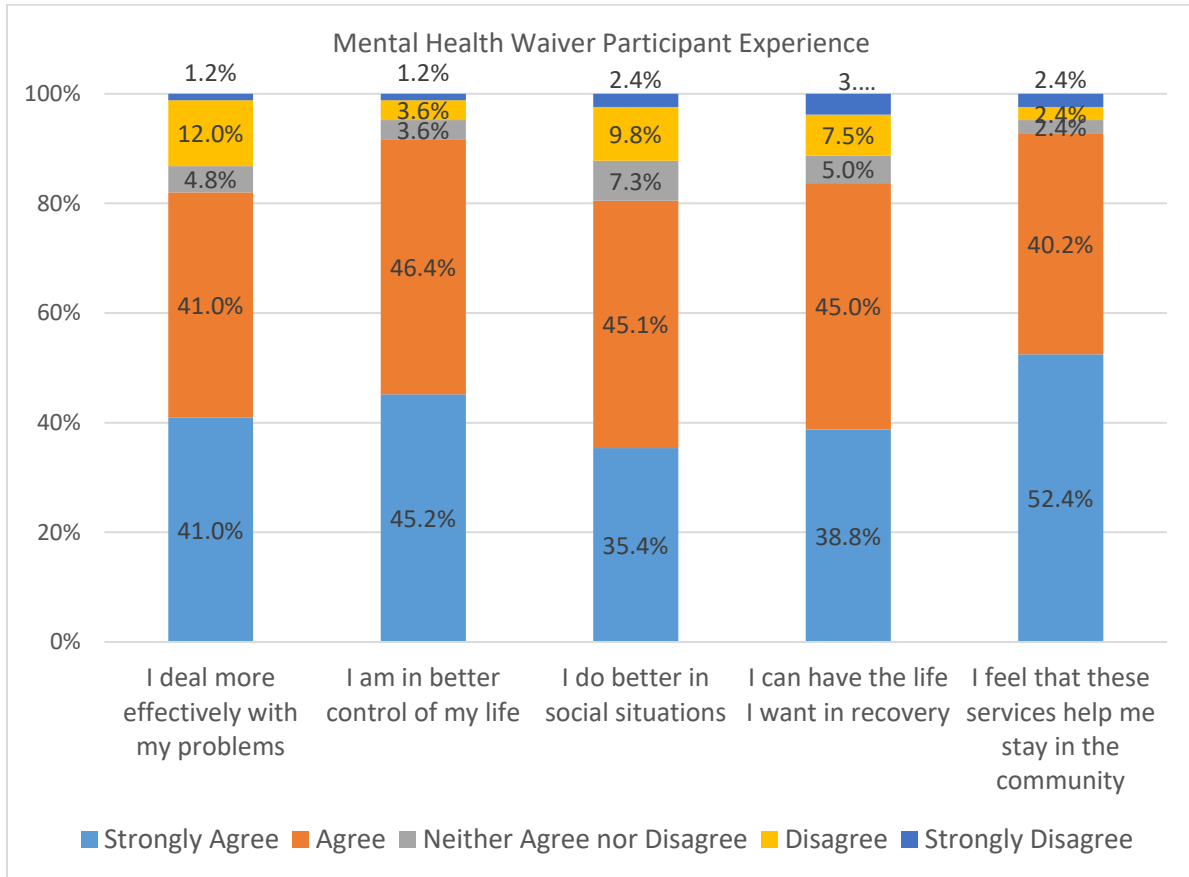
G. Mental Health Waiver Participant Questions

Provided by the MHW waiver program manager, five questions asked MHW waiver participants to what extent the services they receive through the Mental Health Waiver have affected their lives in five key areas (Figure 30). The questions asked participants how much they agreed or disagreed with each of the statements: “As a result of the services I have received through the Mental Health Waiver... I deal more effectively with my daily problems; I am better in control of my life; I do better in social situations; I can have the life I want in recovery; and I feel that these services help me stay in the community.”

Overall, participants gave positive responses – over 80 percent (81%-93%) either strongly agreed or agreed to all five questions. Participants especially agreed that the MHW waiver services help them

stay in the community (93% strongly agreed/agreed) and that with the waiver services they are in better control of their lives (92% strongly agreed/agreed). Participants were less sure about the effect of waiver services on their social skills. For example, about one-third (33%) strongly agreed that because of the waiver services they do better in social situations, compared to 52% who strongly agreed that the waiver services help them stay in the community. Additionally, 13% of participants disagreed/strongly disagreed that the MHW waiver services help them deal more effectively with their daily problems.

Figure 30. Mental Health Waiver Participant Experience



#### H. Comparison by Access Agency and Program

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 each key result: composite measures, global ratings, and overall recommendations.

Tables 15, 16, and 17 show the target number of surveys and the number of surveys completed for each program and agency. In this third year of implementation, all four Access Agencies, with the exception of AGENCY V, reached or exceeded the targeted number of surveys for each program they provided case management. AGENCY V missed their ABI 2 representative sample by one survey.

Table 15. Completed Surveys and Target Number by Program and Agency (CHCP)

Program	Agency & Region	Target number	Completed surveys N (%)
CHCP Category 1	AGENCY W	--	1
	AGENCY X	--	--
	AGENCY Y	--	--
	AGENCY Z	--	--
CHCP Category 2	AGENCY W	--	2
	AGENCY X	--	--
	AGENCY Y	--	--
	AGENCY Z	--	2
CHCP Category 3	AGENCY W	65	70 (>100)
	AGENCY X	209	214 (>100)
	AGENCY Y	70	75 (>100)
	AGENCY Z	29	31 (>100)
CHCP Category 4	AGENCY W	--	--
	AGENCY X	--	--
	AGENCY Y	--	1
	AGENCY Z	--	--
CHCP Category 5	AGENCY W	45	52 (>100)
	AGENCY X	140	157 (>100)
	AGENCY Y	9	9 (100.0)
	AGENCY Z	12	12 (100.0)

-- None required

Table 16. Completed Surveys and Target Number by Program and Agency (PCA)

Program	Agency & Region	Target number	Completed surveys	
			N	(%)
PCA	AGENCY W	67	70	(>100)
	AGENCY X	147	148	(>100)
	AGENCY Y	42	43	(>100)
	AGENCY Z	19	21	(>100)

Table 17. Completed Surveys and Target Number by Program and Agency (ABI)

Program	Agency & Region	Target number	Completed surveys	
			N	(%)
ABI 1	AGENCY T	132	137	(>100)
	AGENCY U	45	46	(>100)
	AGENCY V	12	12	(100.0)
ABI 2	AGENCY T	79	80	(>100)
	AGENCY U	38	38	(100.0)
	AGENCY V	12	11	(91.7)

i. CHCP programs

CHCP scores were universally high across agencies for all but three of the key composite measures: Case manager is helpful, medical transportation, and planning your time and activities (Figure 31). Percentage of participants who gave the highest scores for case manager is helpful showed the greatest agency variation, ranging from 71% (AGENCY B) to 95% (AGENCY D). There was also notable agency variation in transportation to medical appointments, ranging from 70% (AGENCY C) to 82% (AGENCY D). Although all agencies had high scores for staff listen and communicate well, the scores differed from a low of 86% (AGENCY C) to a high of 96% (AGENCY A). All agencies had low scores for planning your time and activities.

Global ratings for CHCP personal assistants, homemakers, and case managers all showed variation across agencies (Figure 32). The percentage of participants who would rate their personal assistance staff a 9 or 10 varied from 79% (AGENCY B) to 90% (AGENCY D). Likewise, 77% of AGENCY C participants rated their care managers a 9 or 10, compared to 88% of AGENCY D participants

Overall, the majority of CHCP participants from each agency would “definitely” recommend their staff (Figure 33). Personal assistant staff recommendations showed the greatest variation: 72% of participants at AGENCY B would definitely recommend their personal assistant staff, compared to 85-86% of participants at the other three agencies. Case manager and homemaker recommendations also showed agency differences. Percentage of participants who would definitely recommend their homemaker ranged from 79% (AGENCY B) to 89% (AGENCY C); 73% of participants at AGENCY C would definitely recommend their case manager, compared to 83% at AGENCY D.

Figure 31. CHCP Composite Measures by Agency: Percentage with Highest Score

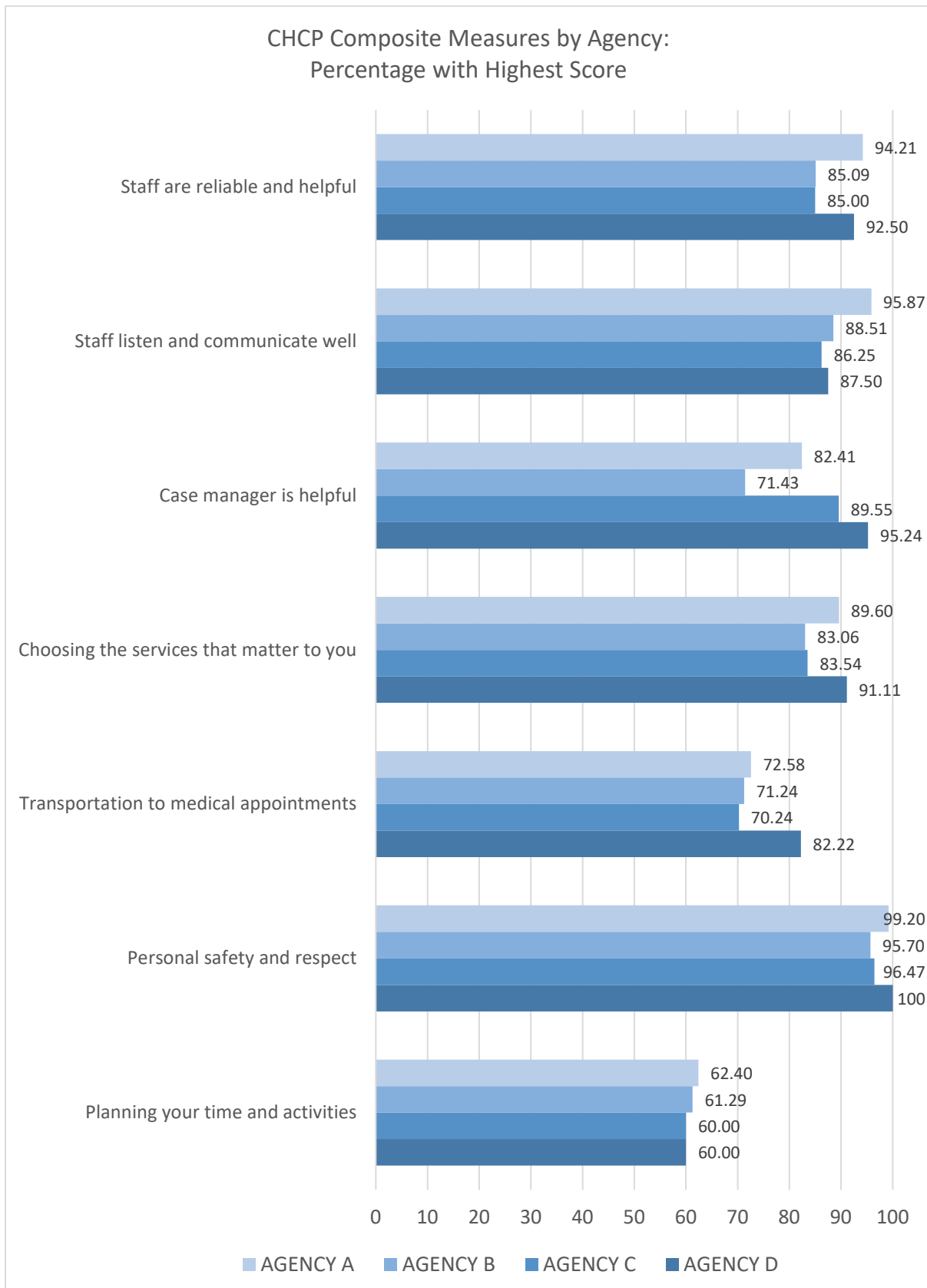


Figure 32. CHCP Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”

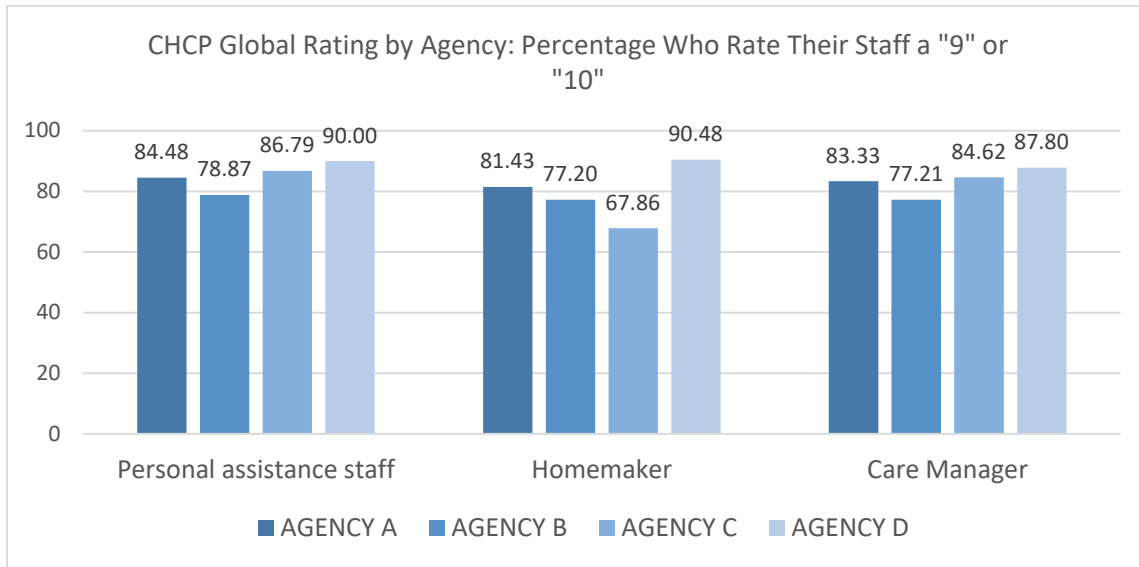
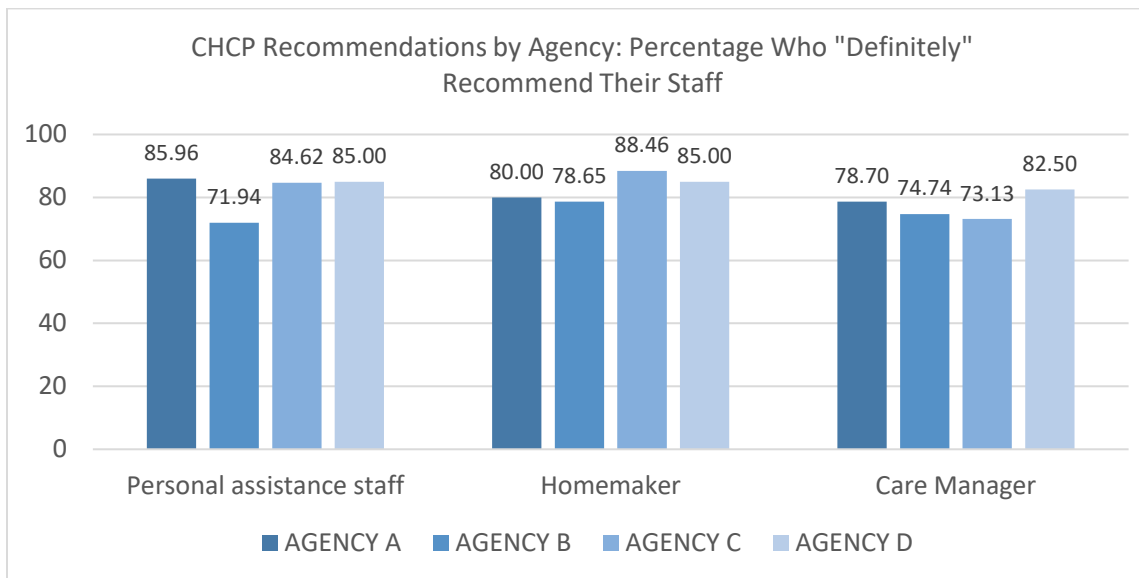


Figure 33. CHCP Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff



ii. PCA waiver

PCA composite results also showed more interagency differences (Figure 34). Among the composites, the percentage of participants who gave the highest scores for choosing the services that matter to you varied by 22% (78% AGENCY C to 100% AGENCY D), and the percentage with highest score for the composite case manager is helpful varied by 16% (84% AGENCY B to 96% AGENCY A). Global ratings and recommendations for case managers showed marked agency variation (Figures 35 and 36). Global ratings of PCA case managers varied by 30%, and case manager recommendations varied by 33%. Compared to participants from other agencies, a lower percentage of AGENCY B PCA participants rated their case managers a “9” or “10” or “definitely” recommended their case managers. Agency homemaker ratings and recommendations scores cannot be compared, as three agencies had one or no PCA participants with homemaking services.

Figure 34. PCA Composite Measures by Agency: Percentage with Highest Score

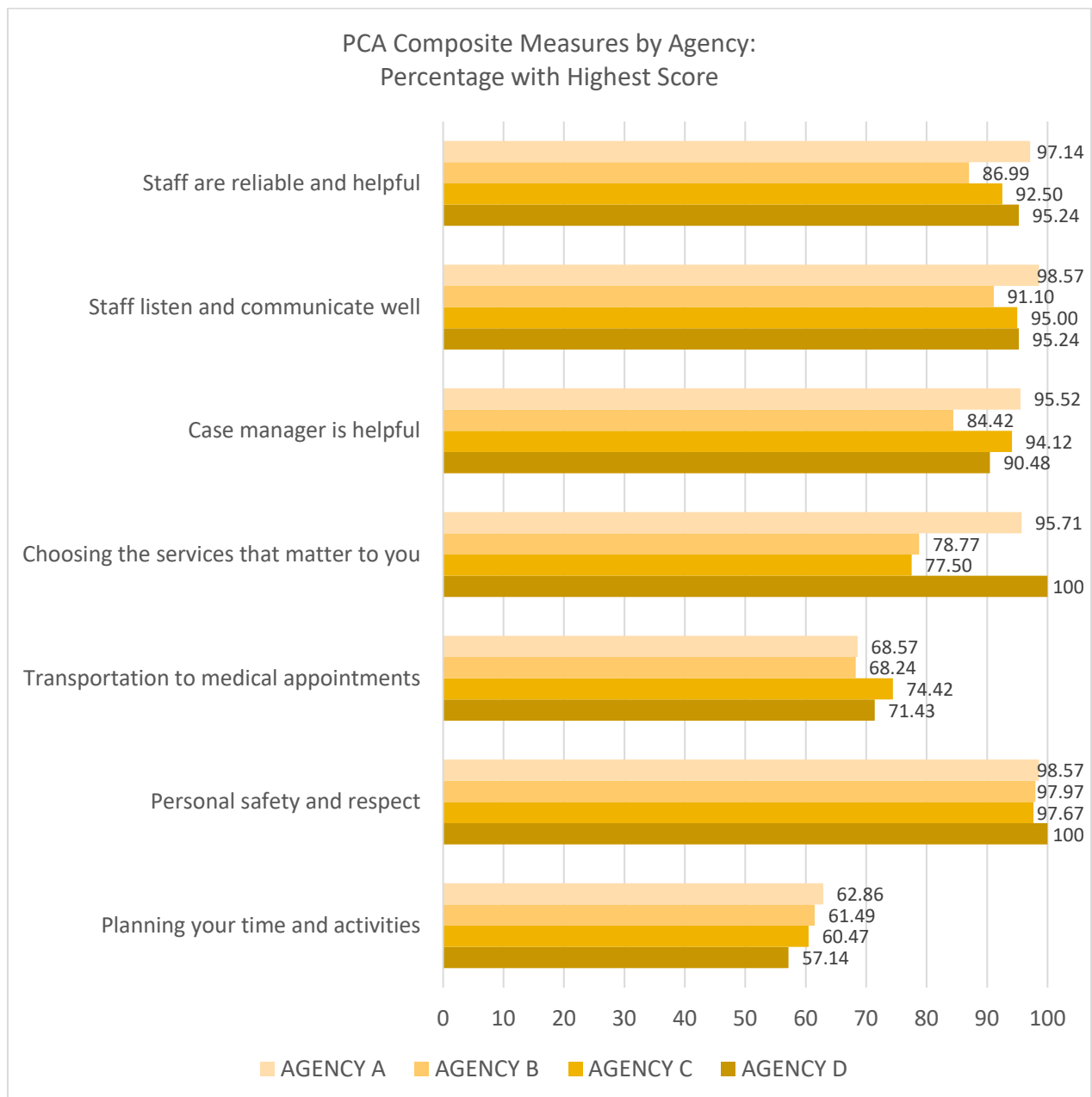


Figure 35. PCA Global Ratings by Agency: Percentage Who Rate Their Staff a “9” or “10”

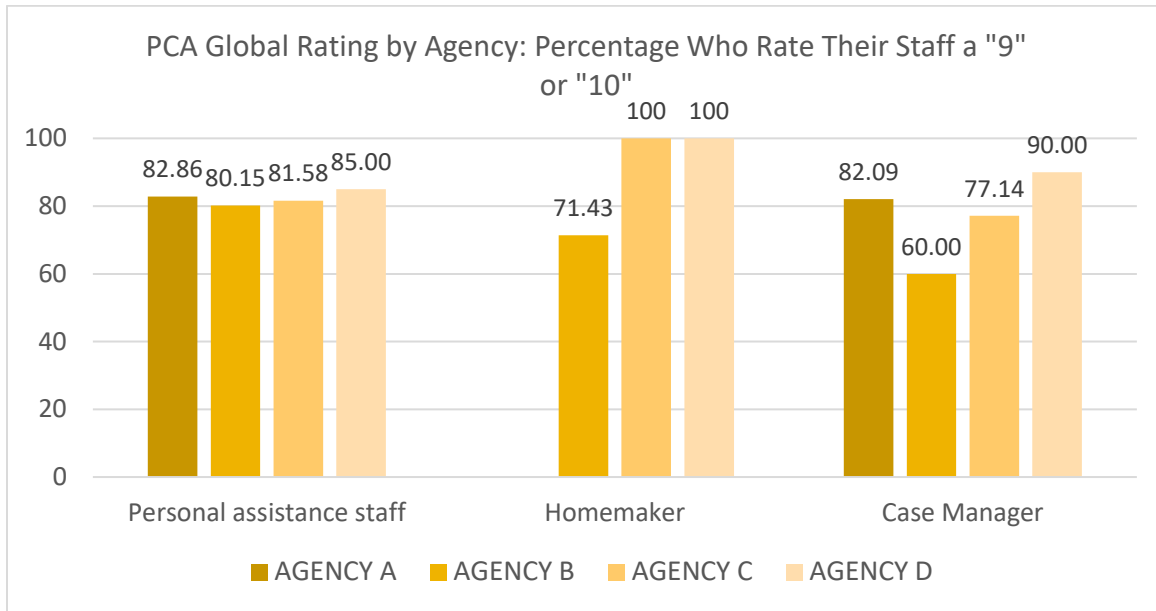
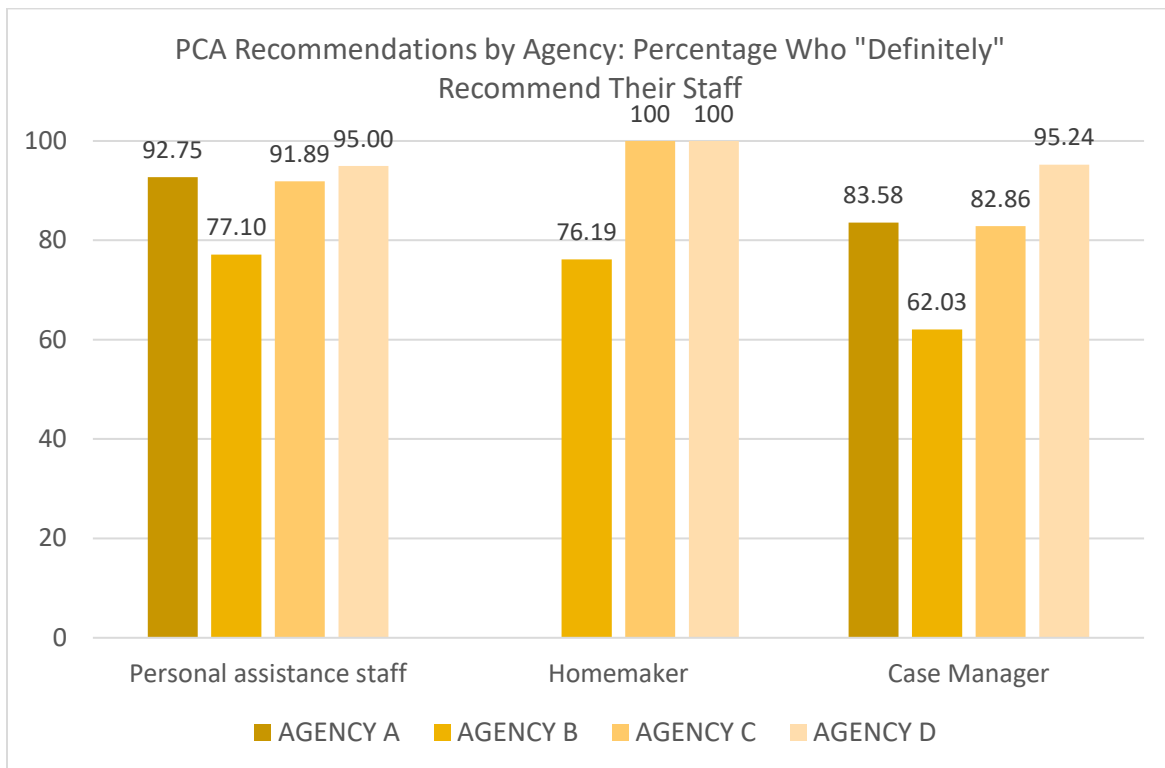


Figure 36. PCA Recommendations by Agency: Percentage Who “Definitely” Recommend Their Staff





iii. ABI waivers

The ABI composite results showed notable interagency differences in four of the composites: staff listen and communicate well, case manager is helpful, choosing the services that matter to you, and medical transportation (Figure 37). Choosing the services that matter to you varied by 24%, from 72% (AGENCY F) to 96% (AGENCY G), while staff listen and communicate well varied from 74% (AGENCY F) to 95% (AGENCY G). However, there was no identifiable trend. As with the CHCP and PCA waivers, all agencies had low scores for planning your time and activities.

Staff ratings and recommendations also varied noticeably among the agencies (Figures 38 and 39). All of the ABI participants surveyed at AGENCY G rated their case managers a “9” or a “10,” compared to 82% of AGENCY F participants and 65% of AGENCY E participants. The percentage of ABI participants who would “definitely” recommend their PCA/ILST staff varied among the three agencies by 15%, from 57% (AGENCY F) to 72% (AGENCY E). Although agency homemaker and job coach ratings and recommendations also differed by agency, comparison of the data is difficult given two agencies had four or fewer ABI participants with either homemakers or job coaches.

Figure 37. ABI Composite Measures by Agency: Percentage with Highest Score

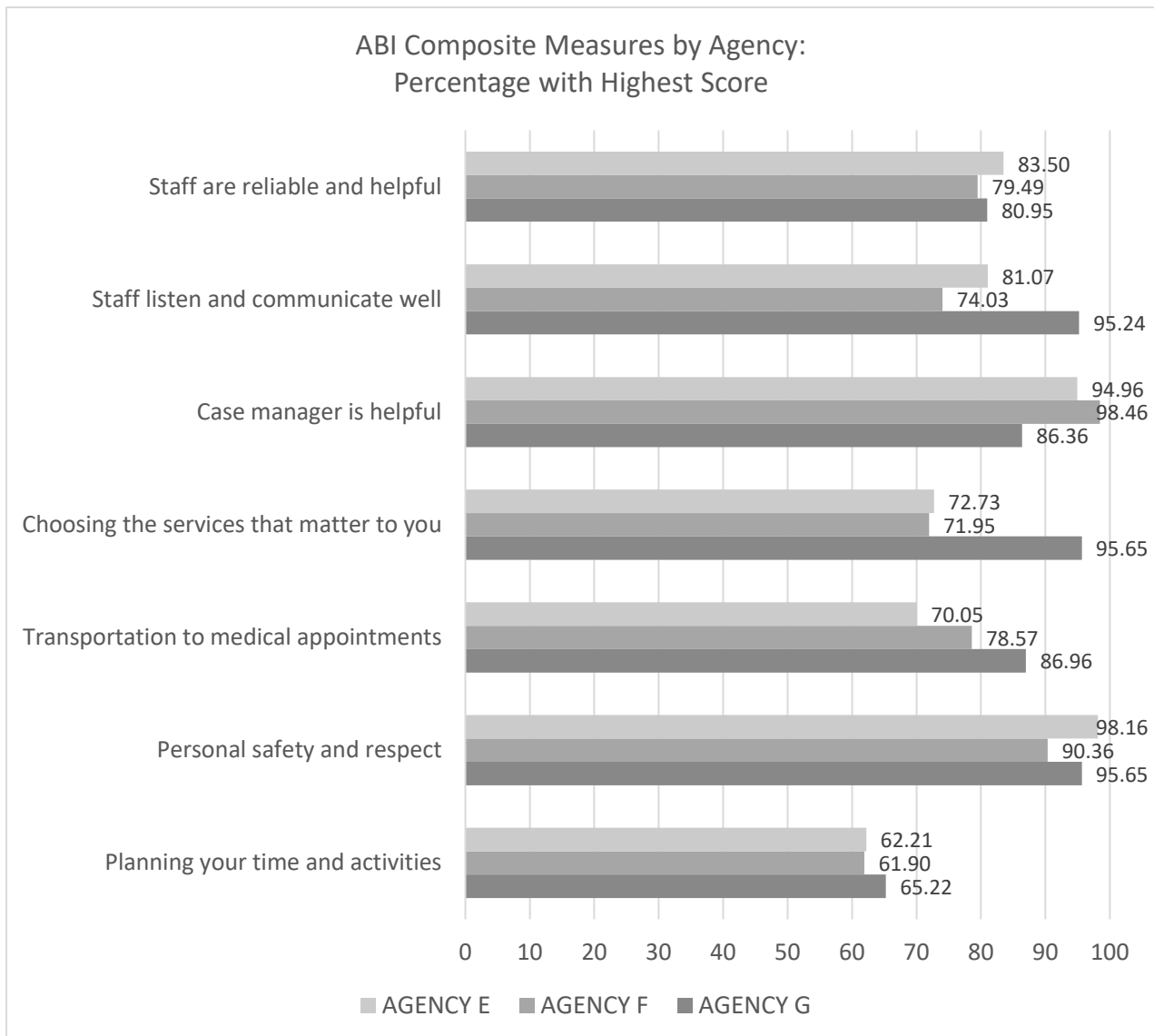


Figure 38. ABI Global Ratings by Agency: Percentage Who Rate Their Staff a "9" or "10"

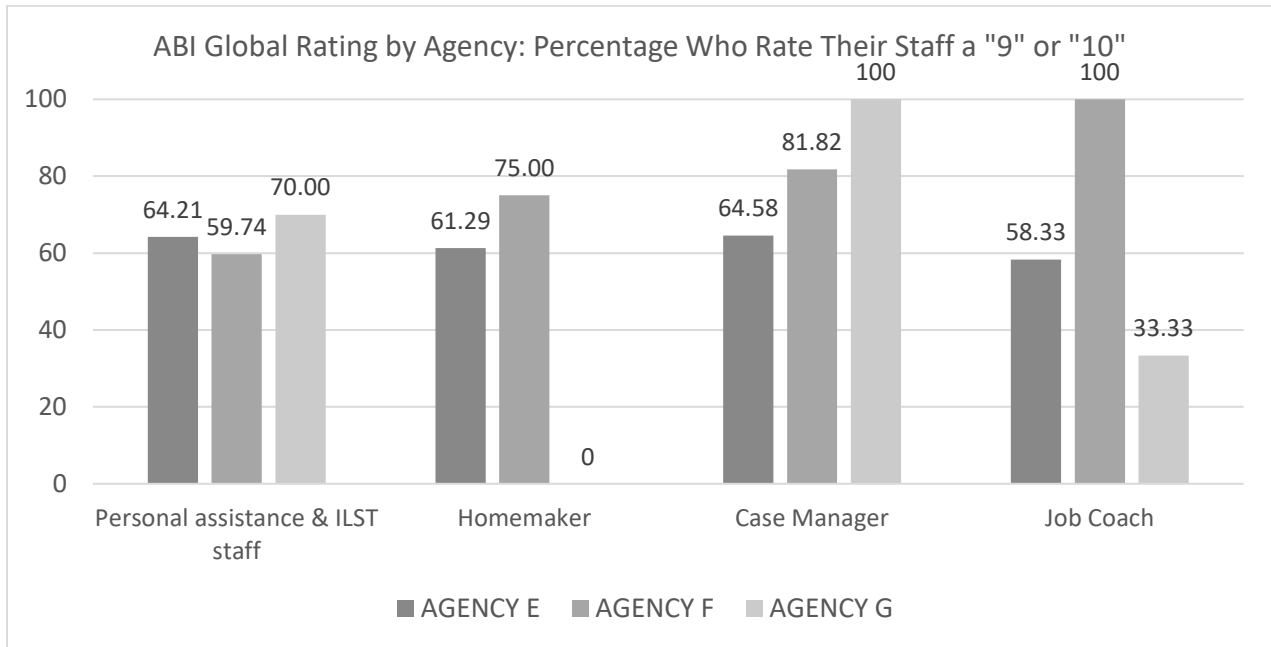
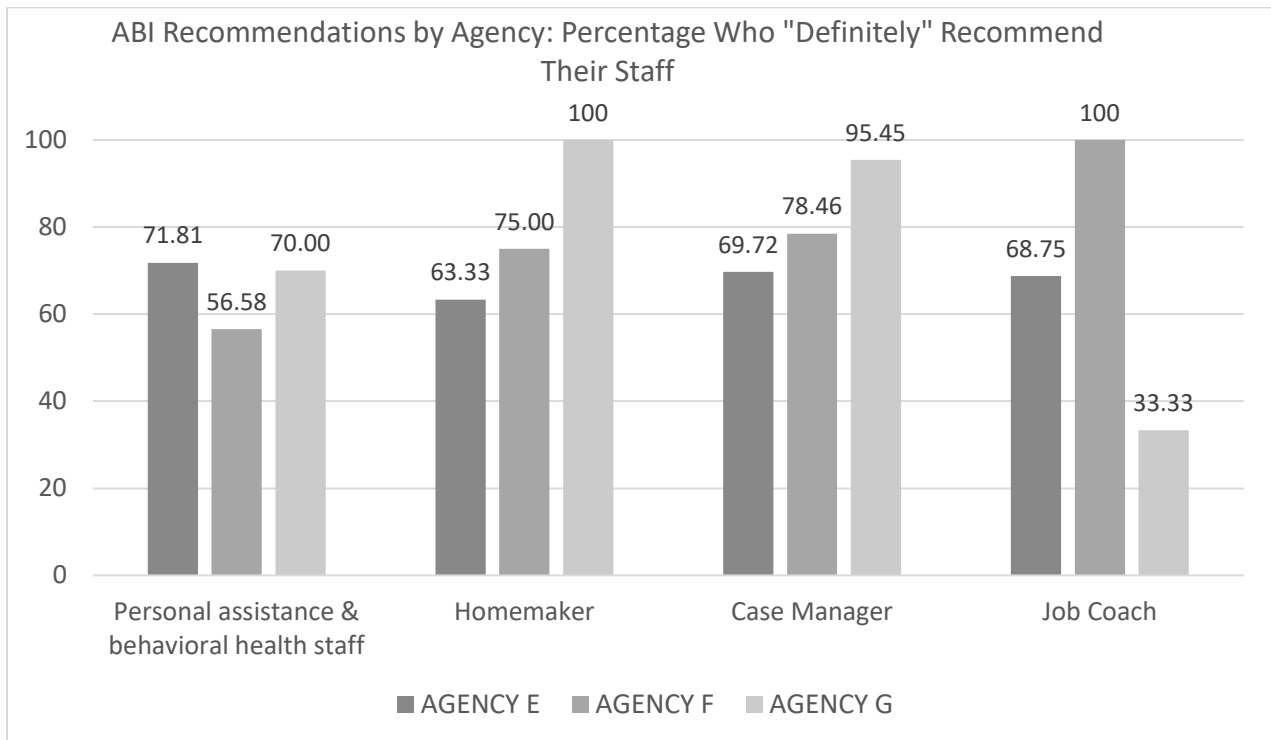


Figure 39. ABI Recommendations by Agency: Percentage Who "Definitely" Recommend Their Staff



#### IV. Conclusions

In July, 2017, DSS implemented the HCBS CAHPS survey to measure quality and performance across DSS Medicaid waivers or programs which provide case management. As of 2019, this survey is now used in eight different programs or waivers: CHCP Categories 3 and 5 and the PCA, ABI 1, ABI 2, Autism, Katie Beckett and MH waivers. This report presented results from HCBS CAHPS surveys completed in the third year of implementation, from July 1, 2019 to June 30, 2020.

##### A. Survey Completion Rates

HCBS CAHPS survey completion rates in each program were relatively the same as in 2020. Each of the Access Agencies completed 100% or more of the number of surveys required by each agency to obtain a representative sample size for the CHCP, PCA, and ABI populations, with the exception of AGENCY D ABI 2 waiver (92% complete). Approximately 72% of the required number of Katie Beckett surveys, 37% of MHW surveys, and 62% of the required number of Autism surveys were completed.

##### B. Key Results by Program

The composite items showed more variation this year, both among the composites and the programs. As in last year, CHCP and PCA participants reported higher scores for choosing services that matter to you than the other four programs. Autism and MHW participants reported lower scores for staff reliability and helpfulness compared to CHCP, PCA, or ABI participants. The composite case manager is helpful showed the greatest program differences, with Autism and ABI participants reporting the highest scores, and MHW participants the lowest scores. Similar to previous years, participants from all programs reported high scores for personal safety and respect, and the lowest scores for the composite measure planning your time and activities. This composite includes items which assess the participant's ability to choose and control his/her social interactions, community engagement, and daily activities, and represents an opportunity for improvement across all programs.

CHCP and PCA participants were once again more likely than participants from other programs to highly rate their personal care or homemaker services. Eighty-five percent of PCA participants would also "definitely" recommend their PCAs, while only 68% of ABI participants would do so for their PCAs and ILSTs. PCA, MHW and CHCP participants were much happier with their day program services than were ABI participants. Overall, fewer CHCP and MHW participants reported that their PCAs or RAs encouraged them to do things for themselves, compared to participants with PCAs or behavioral health staff in other waivers.

Eighty percent of CHCP participants gave their case manager the highest rating, compared to 58-73% of participants in the other programs. However, approximately three-quarters of CHCP, PCA, ABI, and Autism participants would definitely recommend their case managers. All Autism participants said they knew who their care manager was, compared to 73-83% of PCA, ABI, and CHCP, 65% of Katie Beckett, and 51% of MHW participants. Most participants in each program said they would contact their care manager if they wanted to change their service or care plan. However, nearly one out of ten ABI participants said they did not know who they would talk to if they wanted to change their care plan.

Although few participants reported any unmet personal care needs (n=16), proportionately more MHW participants (7%, n=6) reported this. While less than 2% of all participants reported staff stole from them, and only 2% said staff had yelled or cursed at them, proportionately more ABI participants reported both of these issues. Four participants reported being hit/hurt by staff (2 PCA and 2 ABI).

Not surprisingly, nearly all CHCP and MHW participants, as well as the majority of ABI and Autism participants uses an agency for their caregivers and staff, while nine out of ten of PCA participants reported they hired their own staff, as did over half of Katie Beckett participants. Forty-four percent (n=109) of self-directing PCA and 20% (n=98) of self-directing ABI participants employed family members.

Similar to last year, mental health is an area of potential concern for the three largest waiver programs. Approximately one out of every three CHCP, PCA, and ABI participants rated their overall mental or emotional health as fair or poor; as did one-third of MHW participants this year. The great majority of MHW participants (86%) live alone or without other adults, and compared to the other programs, MHW participants had considerably less nearby social support. The Governor's "Stay Safe, Stay Home" Executive Order enacted March 24, 2020 noticeably affected MHW participants' ability to see their nearby family as often as they wanted, and ABI participants' ability to see their friends as often as they liked. Helping participants find ways to connect with other people, even with COVID 19, is another focus area which could improve participants' lives.

Forty percent of Autism and 30% of ABI participants were working, compared to less than 5% of either PCA or MHW participants. However, about one-quarter of unemployed PCA and MHW participants, along with about one-third of unemployed Autism and ABI participants, would like to work. Health and disability related concerns were most frequently cited as the reason for not working for PCA, ABI, and MHW participants. MHW participants who did not want to work were also noticeably more concerned about losing their benefits and reported that they did not know about job resources. Facilitating employment, including providing support through the employment process, represents an area of potential improvement. MHW participants might also benefit from exploring ways to address the concerns commonly expressed by MHW participants in the HCBS CAHPS surveys.

#### C. Mental Health Waiver Experience

Mental Health waiver participants were asked to what extent the services they receive through the Mental Health Waiver have affected their lives in five key areas: I deal more effectively with my daily problems; I am better in control of my life; I do better in social situations; I can have the life I want in recovery; and I feel that these services help me stay in the community. Overall, participants gave positive responses – over 80 percent (81%-93%) either strongly agreed or agreed to all five questions. Participants especially agreed that the MHW waiver services help them stay in the community and have more control of their lives. Participants were less sure about the effect of waiver services on their social skills, or on helping them deal more effectively with their daily problems.

#### D. 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 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).

All four Access Agencies met and exceeded the CHCP performance benchmark scores for CHCP case manager global rating, CHCP case manager recommendation, and each of the CHCP composites. CHCP mean scores for the composite case manager is helpful ranged from 3.73 to 3.93, choosing services varied from 3.63 to 3.87, and personal safety/respect ranged from 3.87 to 3.98 (scale 1-4; performance benchmark score for each composite: 3.5). CHCP case manager mean global rating scores ranged from 4.64 to 4.80 out of 5 (performance benchmark score: 4.5), and CHCP case manager mean recommendation scores ranged from 3.64 to 3.78 out of 4 (performance benchmark score: 3.5).

The PCA performance measures were not met by all the Access Agencies. As with last year, three of the four Access Agencies met the performance benchmark for PCA care manager global rating (range 4.31 to 4.90; benchmark score 4.5). All four agencies met the PCA case manager recommendation performance benchmark (range 3.62 to 3.95; benchmark score 3.5). All four agencies also met the PCA benchmark score (3.5) for all three composite measures: PCA care manager is helpful (range 3.57 to 3.80), choosing the services that matter to you (range 3.68 to 4.00), and personal safety/respect (range 3.91 to 4.00).

One performance benchmark was missed for the ABI waiver as well. Two of the three Access Agencies met the performance benchmark for ABI care manager global rating (range 4.45 to 5.00; benchmark score 4.5). All agencies met the ABI care manager recommendation performance benchmark (range 3.63 to 3.95; benchmark score 3.5). All agencies met the ABI composite benchmarks: mean scores for the composite measure case manager is helpful ranged from 3.75 to 3.88, choosing services from 3.54 to 3.93, and personal safety/respect from 3.73 to 3.94 (range 1-4; performance benchmark score for each composite: 3.5).

#### E. Comparisons by Access Agency and Program

CHCP scores were universally high across agencies for all but three of the key composite measures: case manager is helpful, medical transportation, and planning your time and activities. There were clear differences among the agencies, but no identifiable agency trends. The majority of CHCP participants in each agency highly rated and highly recommended their PCAs, homemakers, and case managers, with some variations across agencies. Overall, AGENCY B CHCP participants gave their PCA staff lower ratings than participants from other agencies.

PCA scores were high across agencies for all but three of the key composite measures: choosing the services that matter to you, medical transportation, and planning your time and activities. The PCA composites showed interagency differences, but no identifiable agency trends. Global ratings for PCA staff were high across all agencies, while case manager ratings and recommendations showed more agency variation. Overall, AGENCY B PCA participants gave their case managers lower ratings and lower recommendations, and gave their PCA staff lower recommendations, than the participants from other agencies.

ABI composite scores were high across all agencies for just two composite measures: case manager is helpful and personal safety and respect. As with the other waivers, all agencies received lower scores for planning your time and activities. Scores for the other four composites showed marked interagency differences, but with no discernable pattern. ABI staff and case manager ratings and recommendations also varied noticeably among the agencies. For these, a greater percentage of AGENCY G participants highly rated and highly recommended their PCAs/ILSTs and ABI case managers, compared to either AGENCY E or AGENCY F.

Quality assurance staff from the Access Agencies and DSS are currently in the fourth year of completing HCBS CAHPS surveys for the CHCP, PCA, ABI, Autism, Katie Beckett, and MHW programs. UConn Health Center on Aging continues to provide technical assistance, including survey site administration, training, and other support.

**V. Appendices**

Appendix A. Composite Measures Items

Appendix B. CAHPS® Home and Community-Based Services Survey – Connecticut version  
2019

Appendix C. CAHPS® Home and Community-Based Services Survey – Connecticut version  
Mental Health Waiver 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?

---

[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?

---

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

## IDENTIFICATION QUESTIONS

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

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

- <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?

---

[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?

---

[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?

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

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

[ADD RESPONSE WHEREVER IT SAYS “*homemaker*”]

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

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

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

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

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

---

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

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

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 . . .

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

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

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

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

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

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

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

- 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 . . .

- <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}* 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 *{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?

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

34. In the last 3 months, did *{personal assistance/behavioral health staff}* 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

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
- <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 {*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 HOME MAKERS

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?

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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 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?

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

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

\_\_ 0 TO 10

- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from your {job coach}?

Would you say . . .

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

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

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

## ABOUT YOU

Now I just have a few more questions about you.

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

- Excellent,
- Very good,

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

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

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

84. What is your age?

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

ALTERNATE VERSION: In what year were you born?

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

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

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

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

-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. . .

- <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

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?

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

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

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

22. In the last 3 months, was this because there were no *{recovery assistant 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

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?

- <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

- 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?

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

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

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

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

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

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

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

## HOW WELL CSPs COMMUNICATE AND TREAT YOU

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

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

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

- 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?

- YES  
 NO  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

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

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

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

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

## PERSONAL SAFETY

The next few questions ask about your personal safety.

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

- FAMILY MEMBER OR FRIEND  
 CASE MANAGER  
 AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES  
 PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)  
 9-1-1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)  
 SOMEONE ELSE, PLEASE SPECIFY \_\_\_\_\_  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

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?

- YES  
 NO  
 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?

---

[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

- NO  
 DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

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

\_\_ 0 TO 10

- DON'T KNOW  
 REFUSED  
 UNCLEAR RESPONSE

ALTERNATE VERSION: How would you rate the help you get from your *{job coach}*?  
 Would you say . . .

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

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

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