

2025 Annual Report:

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

Access Agencies De-Identified

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I. Introduction

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

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

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

II. Methods

A. HCBS CAHPS Survey

The HCBS CAHPS survey is composed of eleven sections: cognitive screen, identification of paid services, personal assistance and/or behavioral health staff services, homemaking services, case manager, choosing your services, transportation, personal safety, community inclusion and empowerment, demographics, and employment. Although the Department of Mental Health and Addiction services (DMHAS) used the standard HCBS CAHPS survey for the first three years, in state fiscal year (SFY) 2023 DMHAS revised the HCBS CAHPS survey in order to tailor it for the population they serve. The revised MHW HCBS survey follows a similar structure as the standard HCBS CAHPS, but uses a select subset of the HCBS CAHPS questions. In particular, the MHW HCBS survey does not ask about clinical case management services, limits the questions about MHW staff, and does not include the employment section. As in previous years, the MHW survey includes additional specific questions for overall MHW services. The full HCBS CAHPS survey is attached in Appendix B; the MHW HCBS survey is in Appendix C.

The HCBS CAHPS survey tailors the survey for each participant and waiver program by integrating waiver specific services and terms into the survey. For example, only ABI participants are asked about Independent Living Skills Training Specialists (ILSTs). Participants are asked how they refer to their paid staff; these responses are then used throughout that individual's survey. A participant's waiver program determines which services to ask about and what terms to use to refer to these services (see Table 1).

Table 1. Program Services

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

*Independent Living Skills Training (ILST)

**Life skills coach or community mentor

***Homemaking services include household tasks complete by any type of waiver staff

B. Survey Administration

Contracted case management agencies, or Access Agencies, are required to complete surveys for the CHCP, PCA, and ABI waivers. Quality assurance staff or staff who are not waiver case managers complete the surveys by telephone. This fiscal year, UConn Center on Aging (UConn) research staff were responsible for completing surveys for the Katie Beckett and Autism waivers. These were previously completed by staff at the Connecticut Department of Social Services (DSS). DMHAS uses staff from one of its case management provider agencies and research staff from the University of Connecticut to complete any MHW telephone surveys. Hereafter, all staff who complete surveys will be collectively referred to as quality assurance staff. Using client enrollment numbers as of 7/1/2024, DSS determined the target number of surveys for each Access Agency, DSS, and DMHAS to complete between July 1, 2024 to July 31, 2025 (SFY 2025) in order to reach their representative sample sizes.

This year's survey cycle went from July 1, 2024 to July 31, 2025. Beginning in January 2026, the annual HCBS CAHPS will follow a calendar year cycle. The CHCP, PCA, ABI, Autism and Katie Beckett annual surveys will begin again on January 1, 2026. The Access Agencies will no longer be completing annual HCBS CAHPS surveys. Instead UConn will be completing these surveys; DMHAS quality assurance staff will continue to complete the MHW surveys.

Using random sampling, Access Agency quality assurance staff contact waiver participants from their client lists and invite them to do the survey. If there is a legal guardian or conservator of person, the quality assurance staff contact them first before contacting the waiver participant. Although not required, some of the Access Agencies sent notification letters to their waiver participants and/or legal representative to increase their response rate. UConn acquired the Autism and Katie Beckett participant list and contact information from the Autism and Katie Beckett waiver program managers, along with any parent or legal guardian contact information. UConn then sent notification letters to all parents/legal guardians before contacting them. Both the Autism and Katie Beckett waiver notification letters included the name and work telephone of an Autism or Katie Beckett waiver staff for recipients to call if they had concerns about the survey or its legitimacy. Following HCBS CAHPS protocol, all the Access Agency and UConn surveys were completed with an interviewer. All waiver participants are encouraged to complete the survey on their own with the interviewer (by self) or with the interviewer and another person (with assistance). If the participant cannot take part in the survey process at all, then the survey is completed by a proxy on behalf of the participant. Proxies can be a family member, legal representative, or friend who knows the participant well, but not a paid staff person.

To increase the participation of MHW clients, the MHW survey includes a survey option to complete the survey without an interviewer. The self-administered survey can be completed either online using a unique login or with a paper survey. All MHW participants are called a month before their annual reassessment and given the option to do the survey by telephone with an interviewer. If the participant is unable to be reached, then their care manager or Community Service Provider delivers a paper survey and self-addressed, postage paid envelope to the participant at their next visit. A letter accompanying the paper survey also describes the survey and provides instructions to complete the survey online. Although delivered to the MHW participant, the self-administered survey can be completed with assistance or by proxy.

As the training and technical assistance provider, UConn provides ongoing training for the quality assurance staff and supervisors from all four Access Agencies and DMHAS. Using role playing, hands-on practice, and didactic teaching, the training covers the purpose of the HCBS CAHPS survey, a question by question survey review, participant recruitment, survey administration, and use of the online telephone and in-person survey platforms. UConn provides and manages secure online HCBS CAHPS platforms with program specific surveys, including programming to insert program and participant specific terms. Computer assisted telephone-personal interviewing programming is used to direct the interviewer to the correct question and accurately follow the skip patterns for each type of survey. The MHW HCBS CAHPS uses a REDCap platform which utilizes branching logic to direct the interviewer to the next appropriate question.

C. Measures

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

Each composite scale comprises three to twelve individual questions (see Appendix A). Most of these questions have four response options: never, sometimes, usually, always. Each response is coded with a number from one to four, with one indicating the most negative and four the most positive response. A composite's final score is generated by combining the answers from each question, producing one number ranging from one to four. All scores are rounded to the first decimal point.

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

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

Following CAHPS protocol, this report presents the composites, global ratings, and recommendations in two ways: the mean or average score, and the percentage with the highest score. The latter is especially helpful when comparing services or providers, as it highlights which providers are delivering the highest quality service. To produce the highest composite scores, responses are divided into two groups: the most positive (scores of 4 only) and all other responses (scores of 1, 2, or 3). Each item is scored individually, and the mean across the items in that composite is used. Highest recommendation is

determined similarly – only “definitely yes” is given the highest score, while the other three responses are grouped together. Likewise, each global rating is categorized as the highest score (rating of a 5), versus all other responses (any number less than five). This report displays the percentage of participants who gave the most positive or highest score, rating, or recommendation.

Table 2. Key Measures

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

III. Results

After overall respondent sample and demographics, results are presented as follows: Key results by program, Access Agency performance benchmarks, additional findings by program, comparisons by agency, and additional MHW findings.

A. Respondent Sample

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

The statewide representative sample size was met for CHCP Category 3, PCA, ABI 2, and Katie Beckett waivers. CHCP Category 5, ABI 1, Autism, and the Mental Health waivers did not reach their representative sample sizes. However, the statewide CHCP Category 5 completion rate increased this year from 85% in 2024 to 91% in 2025. ABI 1 reached 99%, and Autism reached 96%. Despite using the

same survey strategies as the previous year, the MHW representative sample size completion rate fell this year, from 94% in 2024 to 84% in 2025. The Katie Beckett and Autism waivers experienced the most substantial increase in participation rate over any year that these surveys have been administered. Katie Beckett reached 100% of their representative sample size, compared to just 42% last year, and Autism reached 96% of their representative sample size, compared to just 44% in the previous year. These high response rates likely reflect UConn's multipronged approach to recruitment, combining multiple notification letters, making calls not only during the day but also the evening, flexibility to accommodate the respondent's schedule, sending emails when appropriate, and having several Spanish bilingual research staff. Including the name and direct work number of an Autism or Katie Beckett waiver staff person in the notification letter, with a sentence encouraging participants to call if they had any questions about the survey, very likely increased survey participation as well. In addition, Autism care managers provided support by looking up updated contact information for some participants or their parents/legal guardians.

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 (%)
CHCP programs				
CHCP Category 3	14947	377	383	>100
CHCP Category 5	159	135	123	91.1
Total CHCP Surveys	15106	512	506	98.8
PCA	1059	282	288	>100
ABI waivers				
ABI 1	278	167	165	98.8
ABI 2	252	151	155	>100
Total ABI Surveys	530	318	320	>100
Autism	264	150	144	96.0
Katie Beckett	327	177	181	>100
MHW	558	228	192	84.2
Total surveys completed, any program			1439	

All but five of the CHCP, PCA, ABI, Autism and KBW surveys were completed by telephone. Five percent of these participants used the Spanish survey. Fifty-five (29%) of the MHW surveys were completed as online surveys. However, all paper surveys were entered by DMHAS staff as telephone surveys. This made it difficult to accurately know how many of the remaining 71% (n=137) MHW surveys were completed with an interviewer and how many were completed as paper surveys without the assistance of an interviewer.

All surveys, including the paper and online MHW survey formats, asked if the survey was completed by the consumer alone, the consumer with assistance, or by someone other than the consumer (by proxy). Apart from ABI, KBW, and Autism, most surveys were completed by the consumer or the consumer with

assistance (Table 4). For assisted interviews, the person assisting most often restated some of the questions or prompted the consumer.

Table 4. Survey Respondents

	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)	KBW n (%)	MHW N (%)	Total n (%)
By self	355 (70.2)	255 (88.5)	131 (40.9)	32 (22.2)	0 (0)	164 (85.4)	937 (57.5)
With assistance	11 (2.2)	6 (2.1)	26 (8.1)	18 (12.5)	1 (0.55)	24 (12.5)	86 (5.3)
By proxy	140 (27.7)	27 (9.4)	163 (50.9)	94 (65.3)	180 (99.5)	3 (1.6)	607 (37.2)

B. Consumer Demographics

Consumer demographics by program are presented in Table 5.

Table 5. Consumer Demographics*

	CHCP %	PCA %	ABI %	Autism %	KBW %**	MHW %
Age	N=506	N=288	N=320	N=144	N=181	N=184
<18	0	0	0	9.7	71.3	0
18-24	0	<1.0	<1.0	17.4	28.7	0
25-34	0	8.3	9.4	39.6	0	10.9
35-44	0	16.3	19.1	27.1	0	10.3
45-54	0	22.9	21.3	2.8	0	16.3
55-64	0	48.3	30.3	2.1	0	34.8
65-74	30.2	3.1	18.1	1.4	0	27.2
75+	69.8	<1.0	1.3	0	0	<1.0
Language	N=506	N=285	N=319	N=144	N=177	
English	65.6	84.2	90.0	93.1	85.3	
Spanish only	10.5	<1.0	1.3	0	0	
Multi-lingual	23.9	15.4	8.8	6.9	14.7	
Race	N=491	N=276	N=318	N=141	N=176	N=191
White	52.3	61.2	78.3	85.1	83.0	75.9
Black	22.0	28.6	16.4	7.1	8.0	14.1
Other	25.7	10.1	5.3	7.8	9.0	5.2
Ethnicity	N=501	N=282	N=319	N=142	N=177	N=180
Non-Hispanic	77.2	80.9	90.9	86.6	84.7	92.2
Hispanic	22.8	19.1	9.1	13.4	15.3	7.8

Table 5. Consumer Demographics* - *continued*

	CHCP %	PCA %	ABI %	Autism %	KBW %**	MHW %
Education Level	N=490	N=285	N=314	N=143	N=177	
< 8th Grade	22.2	1.8	3.2	3.5	57.1	
Some high school	13.9	11.6	9.6	13.3	29.9	
High school diploma	37.1	47.0	48.4	55.9	10.7	
Some college	12.9	27.7	25.8	18.2	1.7	
4-year college	10.0	10.9	10.8	8.4	<1.0	
> 4 year college	3.9	1.1	2.2	<1.0	0.0	
Gender	N=506	N=285	N=319	N=144	N=177	N=184
Male	10.5	<1.0	1.3	0	0	44.0
Female	23.9	15.4	8.8	6.9	14.7	55.4
Non-binary						<1.0

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

** MHW survey does not ask language or education.

C. Service Use by Program

Participants reported using a variety of program services in the three months prior to completing the survey (see Table 6). Reported use of ABI personal care assistance services decreased significantly from the previous year, as did homemaking service use for CHCP, PCA, and ABI waivers.

Table 6. Program Service Use

	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)	KBW n (%)	MHW n (%)
Personal care assistance	278 (54.9)	278 (96.5)	137 (42.8)	27 (19.0)		
Behavioral health services			281 (90.1)*	104 (73.2)**		
Recovery assistance (RA)						179 (93.7)
Homemaker/companion or Homemaking services ***	321 (63.4)	46 (16.0)	91 (28.9)	18 (12.8)		
Case manager or Clinical case manager	431 (87.2)	234 (83.0)	313 (98.4)	112 (82.4)	100 (56.5)	
Job coach			19 (70.4)	20 (37.7)		
Community service provider (CSP)						175 (92.6)

*Independent Living Skills Training (ILST) services

**Life skills coach or community mentor services

***Homemaking services include household tasks complete by any type of waiver staff

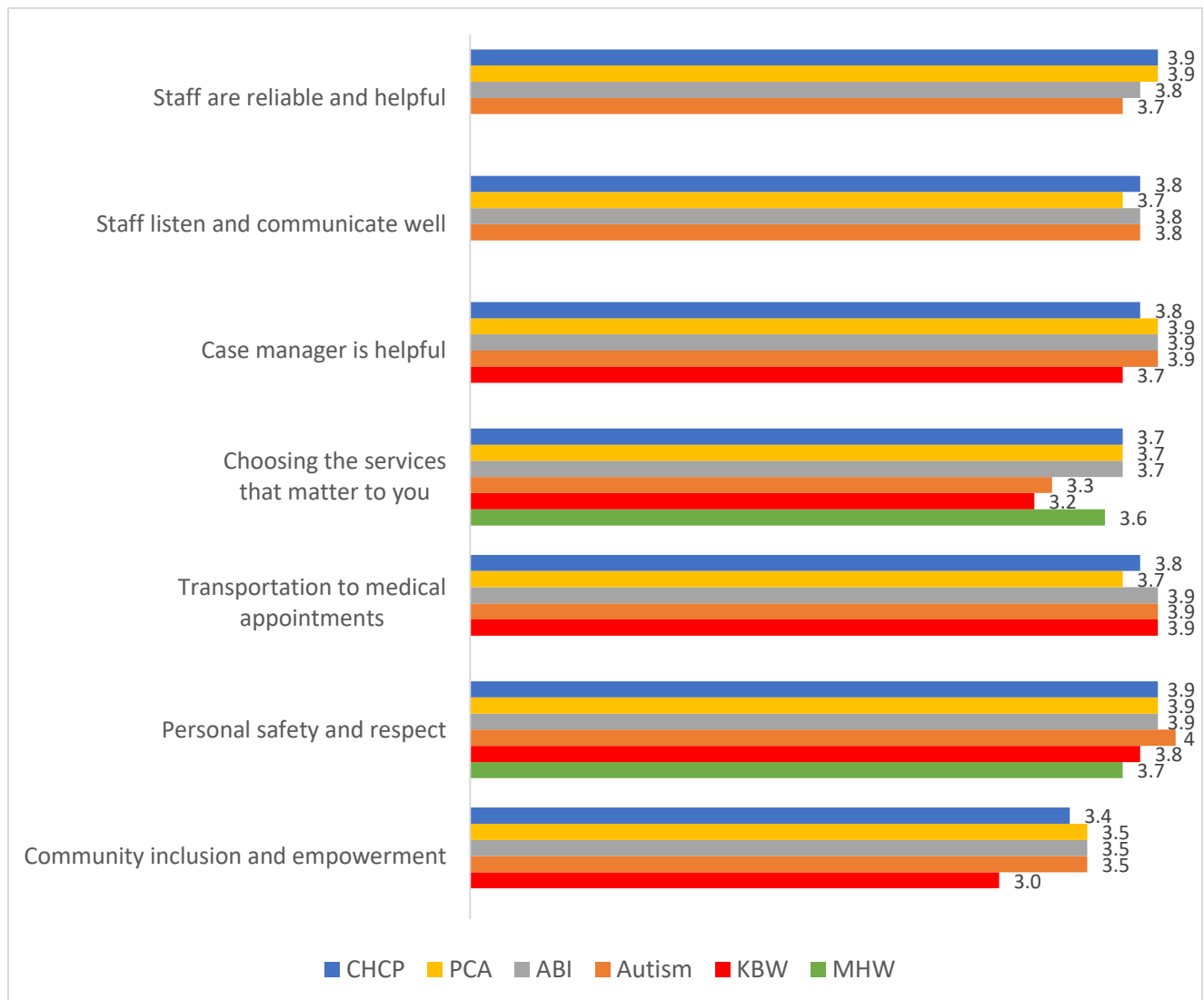
D. HCBS CAHPS Key Results by Program

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

i. Composite measures by program

Figure 1 shows mean scores for the 7 composite measures by program. The MHW survey included the full questions for only 2 of the composites, limiting the ability to compare the MHW across other programs. Overall, mean scores were high for most of the composite measures. As reported in previous years, participants across all programs reported lower scores for the composite community inclusion and empowerment, with KBW participants reported the lowest scores for this composite. Compared to the other waivers, Autism and KBW participants also reported lower scores for the composite choosing the services that matter to you. Both of these composites speak to consumer choice and control and represent opportunities for improvement.

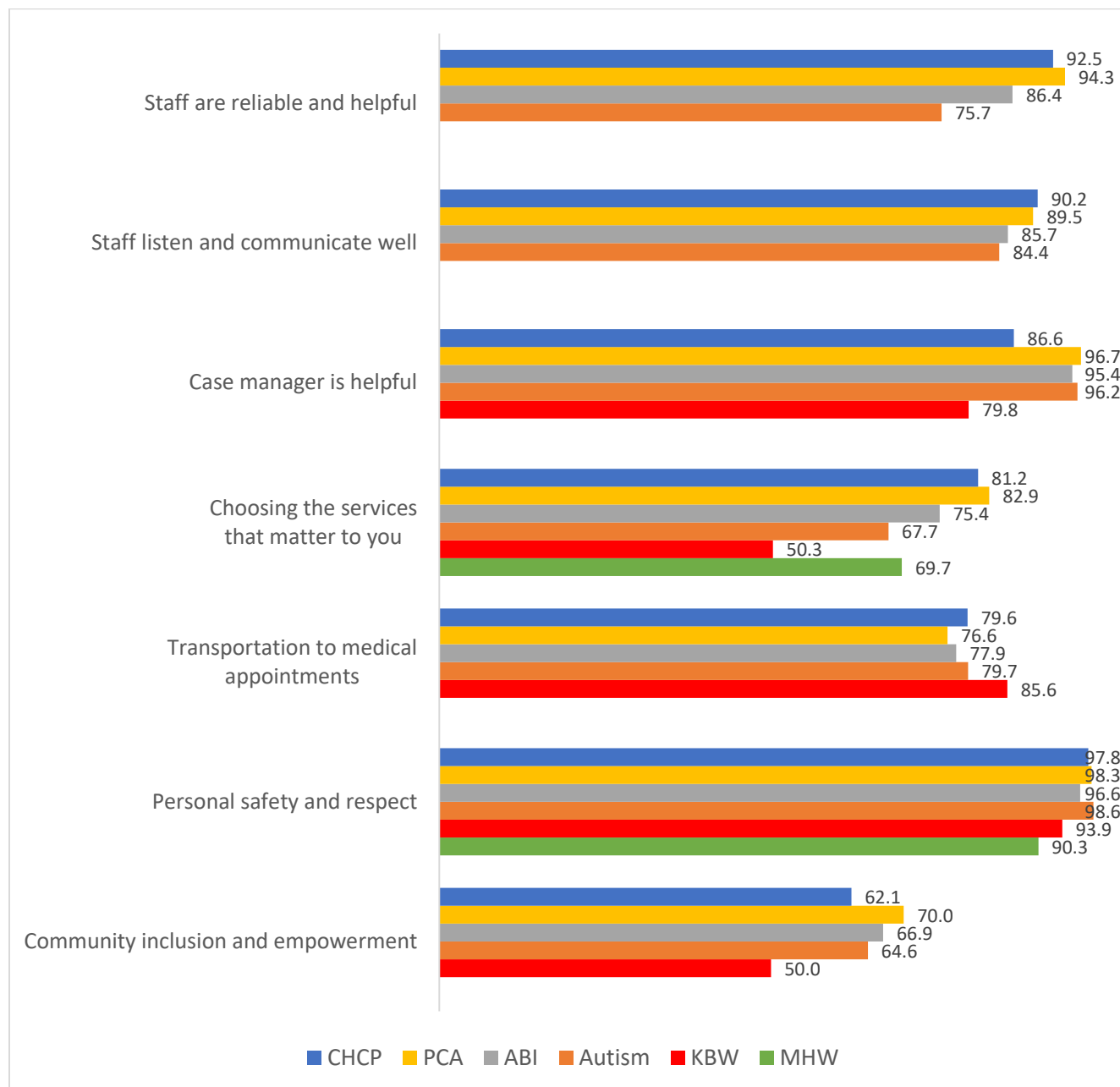
Figure 1. Composite Measures by Program: Mean Scores (Range 1-4)*



*In Figures 1 and 2 composite measures, “Staff” combines all PCA, ILST, RA, CSP, homemaking, companion, life skills coach, and community mentor staff.

Figure 2 shows the percentage of participants in each program who gave the most positive answer for each composite item. This method highlights any program differences more clearly. For example, while mean scores for the composite case manager is helpful showed only slight differences (range 3.7 to 3.9), when analyzed using the percentage highest scores, these differences become more apparent – 97% of PCA participants gave this composite item the highest scores, compared to 80% of KBW participants. Using this method also shows that Autism participants were less likely to find their staff reliable and helpful, even though the mean scores did not differ much from the other waivers. This method also highlights and reaffirms the need to improve choice and control among all programs.

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



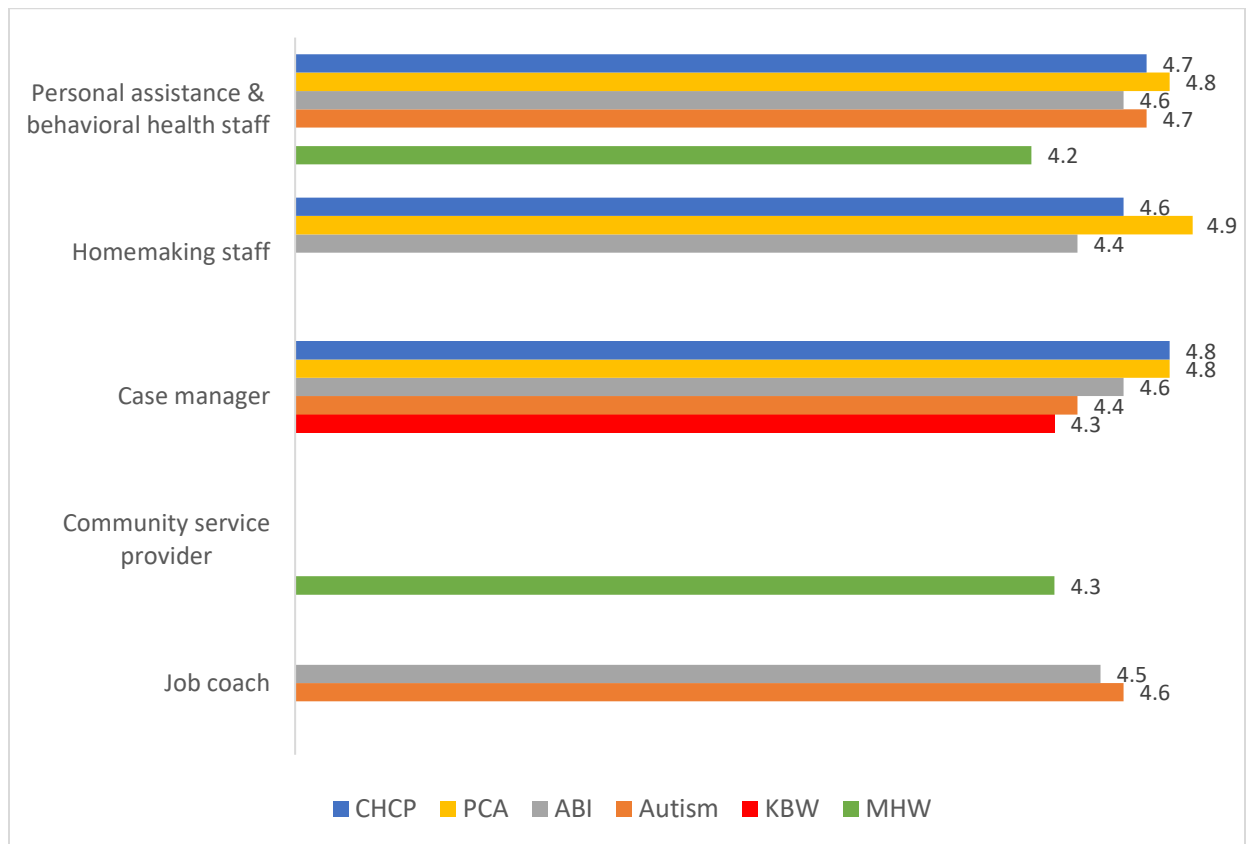
*In Figures 1 and 2 composite measure, “Staff” combines all PCA, ILST, RA, CSP, homemaking, companion, life skills coach, and community mentor staff.

ii. Staff global ratings by program

Using a scale from 1 to 5, mean global rating scores varied somewhat across programs for all types of staff and case managers (Figure 3). The majority of programs had staff and case managers scores of 4.5 or higher. MHW staff and KBW case managers received lower ratings. The mean score for Autism job coaches increased from 3.8 to 4.6 from 2024 to 2025, making the Autism job coach rating comparable to that of the ABI waiver.

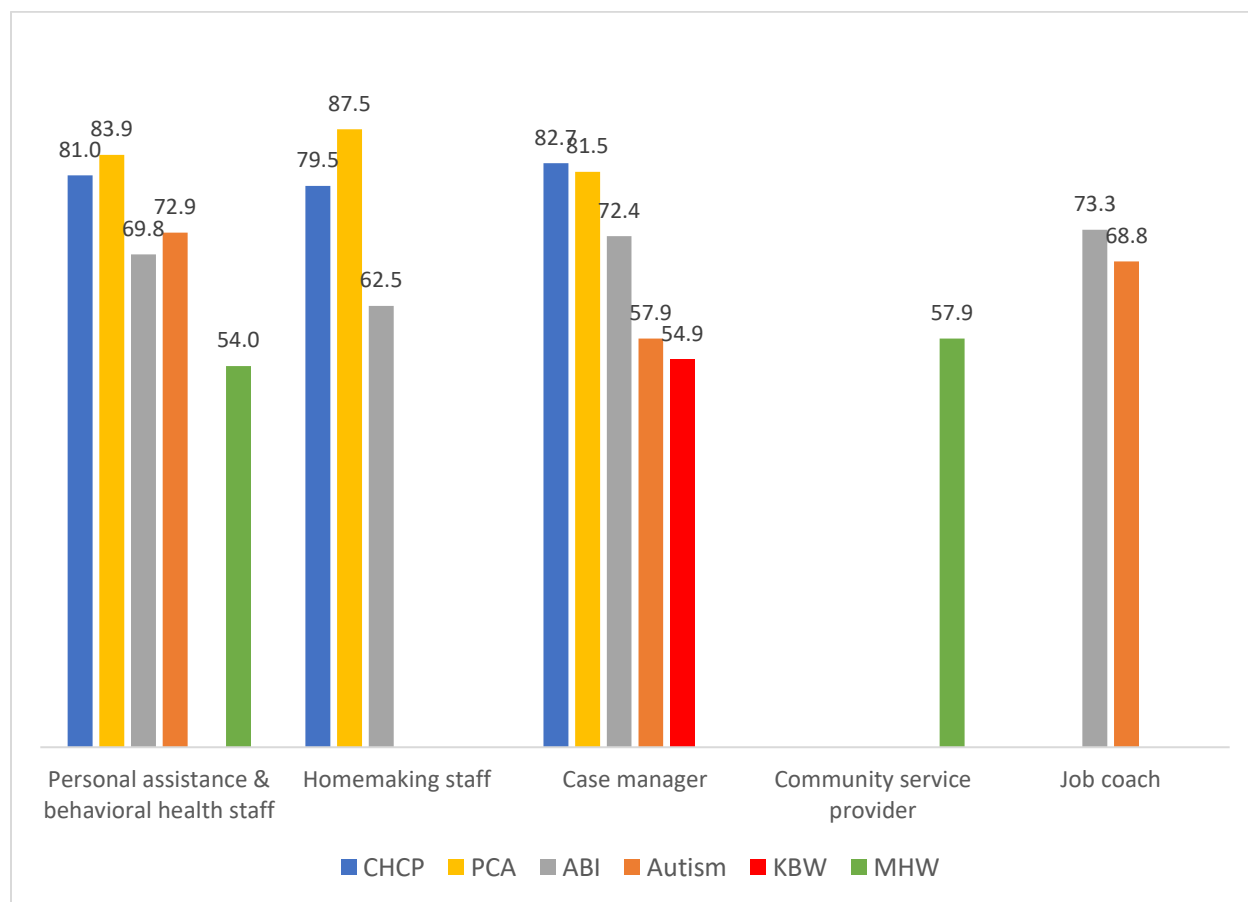
Figure 4 presents the percentage of participants in each program who gave their staff or case managers the highest rating possible, a 9 or 10 (range 0-10). When shown this way, the program differences become more apparent. For example, although the mean global personal assistance staff ratings did not differ much between ABI and PCA participants (4.6, 4.8 respectively), 84% of PCA participants gave their PCAs a 9 or 10, compared to just 70% of ABI participants. Compared to 2024, global ratings for ABI homemaking staff decreased by 21 percentage points, while global ratings for PCA homemaking staff increased by 13 percentage points.

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



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

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



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

iii. Staff recommendations by program

Staff recommendations were based on a four point scale, asking if the participant would recommend their staff from “Definitely No” (score 1) to “Definitely Yes” (score 4). Figure 5 shows the mean recommendation score, while Figure 6 shows the percentage of respondents who would “definitely” recommend their staff or services. Mean recommendation scores showed only slight variation among waivers (range 3.5 to 3.9). However, differences among recommendations become more apparent when one considers the percentage of respondents who would “definitely” recommend their staff (Figure 6). Notable differences from last year include a 29 percentage point decrease in KBW participants who would “definitely” recommend their case manager, while Autism waiver participants had a 20 percentage point increase in “definitely” recommending their Job Coach.

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

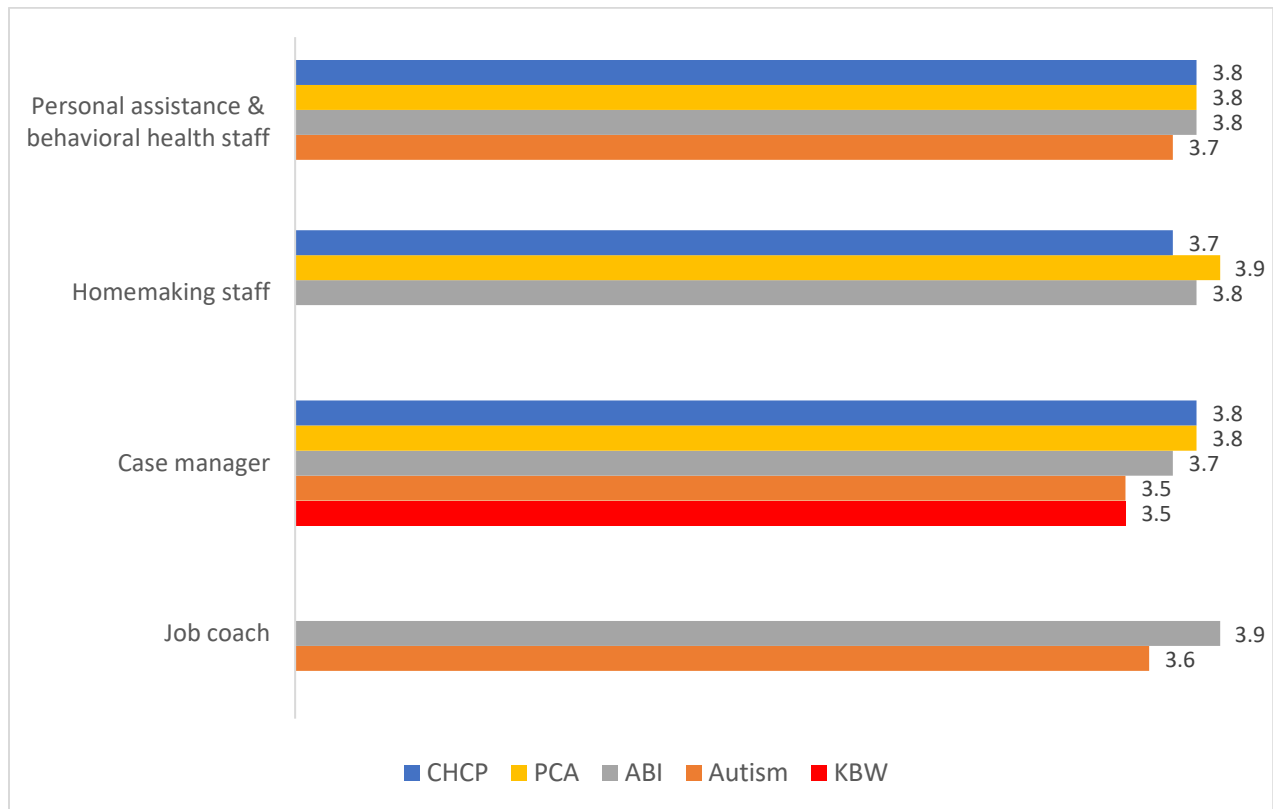
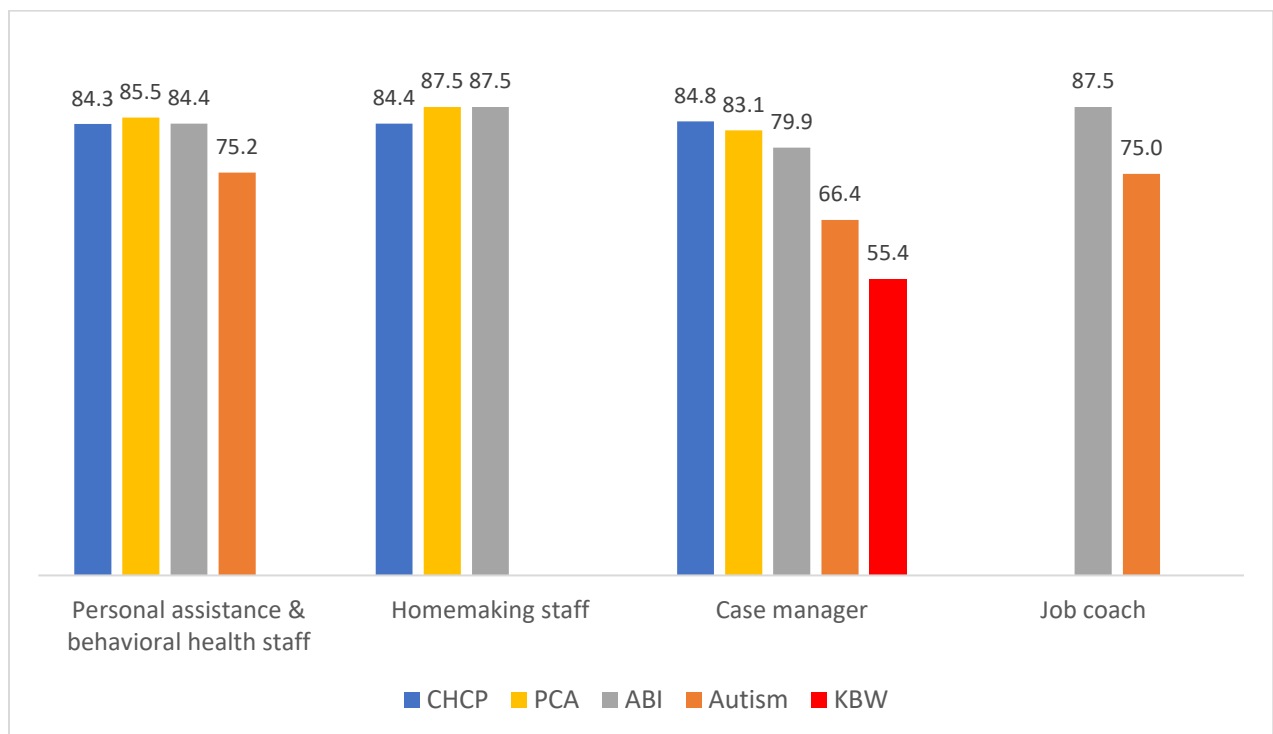


Figure 6. Staff Recommendations by Program: Percentage Who “Definitely” Recommend Staff



iv. Unmet needs by program

CHCP, PCA, ABI, and Autism participants who reported receiving some type of personal care assistance were asked if they needed help from their personal assistants with four everyday activities (Table 7). Similar to last year, PCA participants were more likely to need assistance with making meals/eating and using the toilet than any other waiver program. Meanwhile, all waivers reported receiving less assistance with taking medications than in 2024. One important consideration when considering assistance with meals is that the percentage of CHCP consumers who need this assistance may be underrepresented, as many CHCP participants receive this assistance from their homemakers, but meals are asked about in the PCA section.

To determine unmet need, participants who received personal care assistance were asked if an activity did not occur because they had no staff to assist them. Twenty-two participants reported any unmet need: 7 PCA, 6 CHCP, 6 ABI and 3 Autism. The most frequently mentioned unmet need was someone to help with using the toilet, followed by help with bathing and dressing (data not shown). Note that this describes unmet needs for consumers who reported using PCA services. It is possible that some consumers who do not have PCA services also need, but do not have, assistance in these areas.

Table 7. Self-reported Assistance with Everyday Activities

Needs assistance with:	CHCP n (%)	PCA n (%)	ABI n (%)	Autism n (%)
Dressing or bathing	231 (83.1)	240 (87.0)	165 (53.6)	8 (7.6)
Meals or eating	233 (84.1)	260 (93.5)	245 (80.1)	58 (55.2)
Taking medications	179 (65.1)	161 (57.9)	214 (69.7)	16 (15.5)
Using the toilet	114 (41.3)	179 (64.4)	114 (36.9)	2 (1.9)

v. Physical safety by program

Physical safety is assessed by the question, “In the last 3 months, did any staff hit you or hurt you?” Two MHW, one PCA, and one CHCP participant reported that a staff person hit them or hurt them in the past three months. The MHW and PCA participants reported that someone was working with them to resolve the problem.

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

The HCBS CAHPS provides DSS with a standard instrument to measure quality and performance among the Access Agencies which provide DSS waiver case management: Agency G, Agency S, Agency A, and Agency M. 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 are used to examine case management services: case manager global rating, case manager recommendation, and three composites (case manager is helpful, choosing the services which matter to you, and personal safety and respect). These five items measure HCBS participant experiences which a case manager could directly impact. More positive scores on these measures indicate higher quality case management. DSS established mean scores required to meet the performance benchmarks in each of the five measures based on CHCP data from initial survey testing: 3.5 for each composite measure (range 1-4), 4.5 for case manager global rating (range 1-5), and 3.5 for case manager recommendation (range 1-4). In each of the following figures, the performance benchmark score is indicated by a bold black line.

i. CHCP programs

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

Table 8 shows the representative sample size for CHCP Categories 3 and 5 by agency, the number of surveys completed, and the percentage of the representative sample which was completed. In FY 2025, all Access Agencies met or exceeded their required sample sizes for CHCP Category 3. Three agencies did not meet their Category 5 representative sample sizes, most notably AASCC. All agencies faced difficulties with their active Category 5 client count decreasing after the representative sample was determined at the start of the fiscal year. This especially makes a difference in less populated areas which begin with a small number of active clients. At the same time, some agencies did not start completing their Category 5 surveys until halfway through the fiscal year, in particular WCAAA and AASCC. AASCC, which reached only 46% of its Category 5 representative sample, completed only 2 Category 5 surveys in 2024, starting back up in February 2025. *To have the best chance at completing the representative sample sizes, it is essential to actively start call attempts once the new fiscal year begins.*

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

Program	Agency & Region	Representative sample size	Completed surveys	N (%)
CHCP Category 3	AASCC	71	72	(>100)
	CCC - E	33	33	(100)
	CCC - NC	141	143	(>100)
	CCC - NW	37	37	(100)
	SWCAA	69	69	(100)
	WCAAA	27	29	(>100)
CHCP Category 5	AASCC	22	10	(45.5)
	CCC - E	7	7	(100)
	CCC - NC	80	78	(97.5)
	CCC - NW	5	8	(>100)
	SWCAA	13	13	(100)
	WCAAA	8	7	(87.5)

Three of the Access Agencies, Agency S, Agency A, and Agency M, met the performance benchmark score of 3.5 for all three of the CHCP composite measures (Figure 7). Agency G scored notably below the benchmark (3.10 vs. 3.5) on case manager is helpful. All four Access Agencies met the benchmark score for CHCP case manager global rating (Figure 8). Similar to the composites, three of the four Access Agencies met the case manager recommendation benchmark – Agency S, Agency A, and Agency M – while Agency G was just below the benchmark (3.47 vs. 3.5) (Figure 9).

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

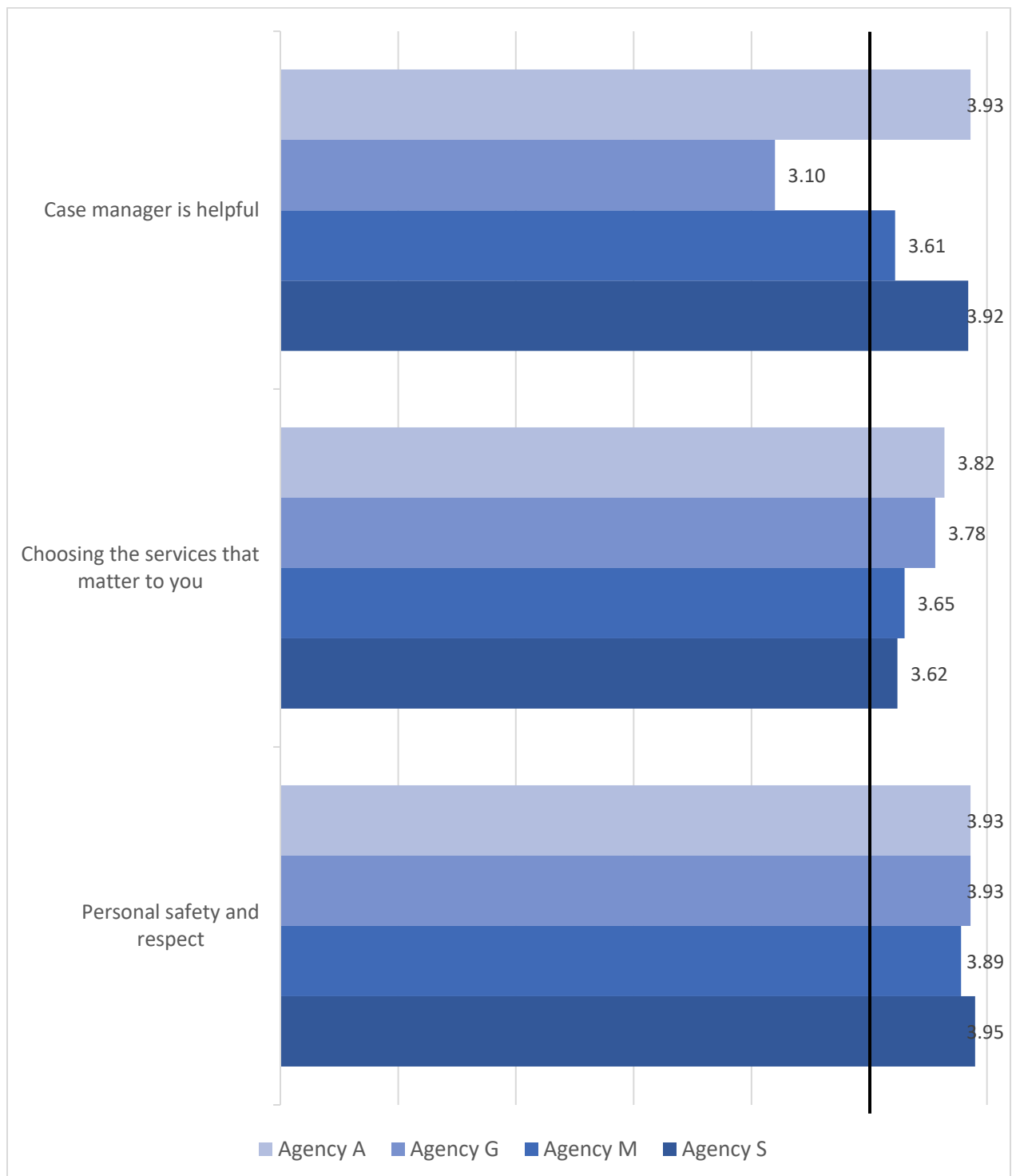


Figure 8. CHCP Performance Benchmarks by Agency: Case Manager Global Rating (Mean Score, Range 1-5)

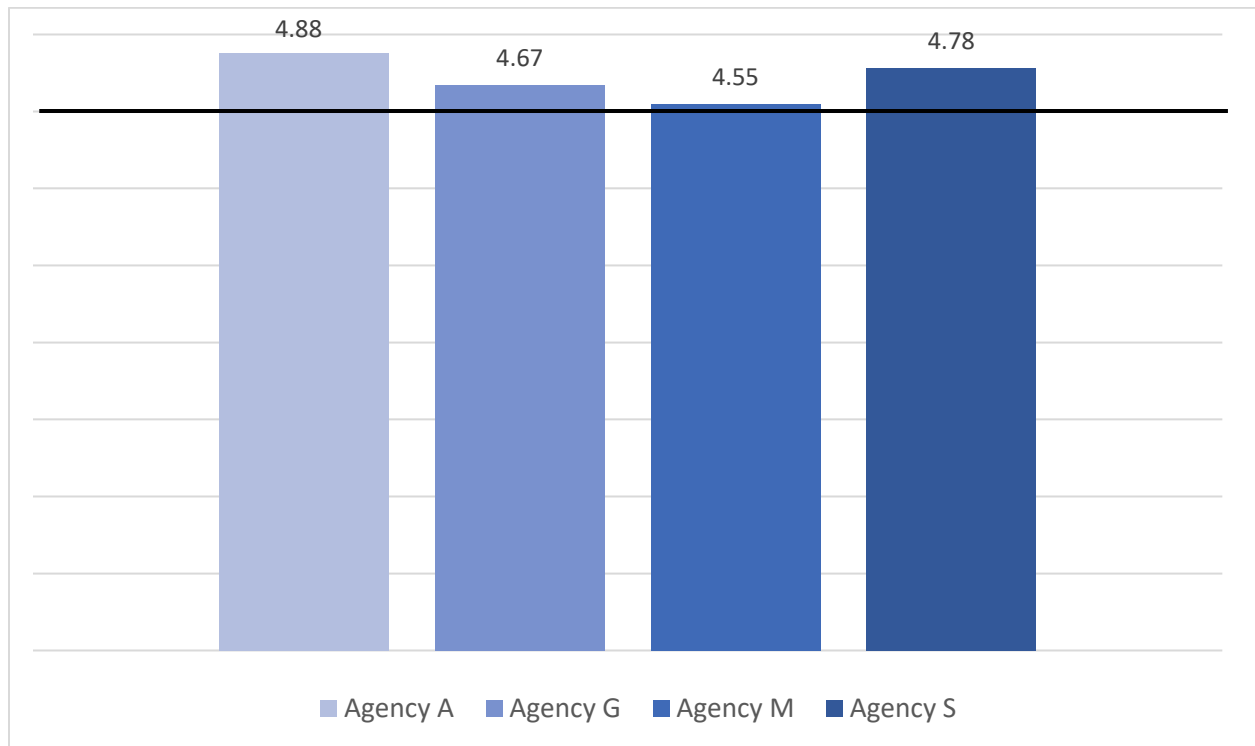
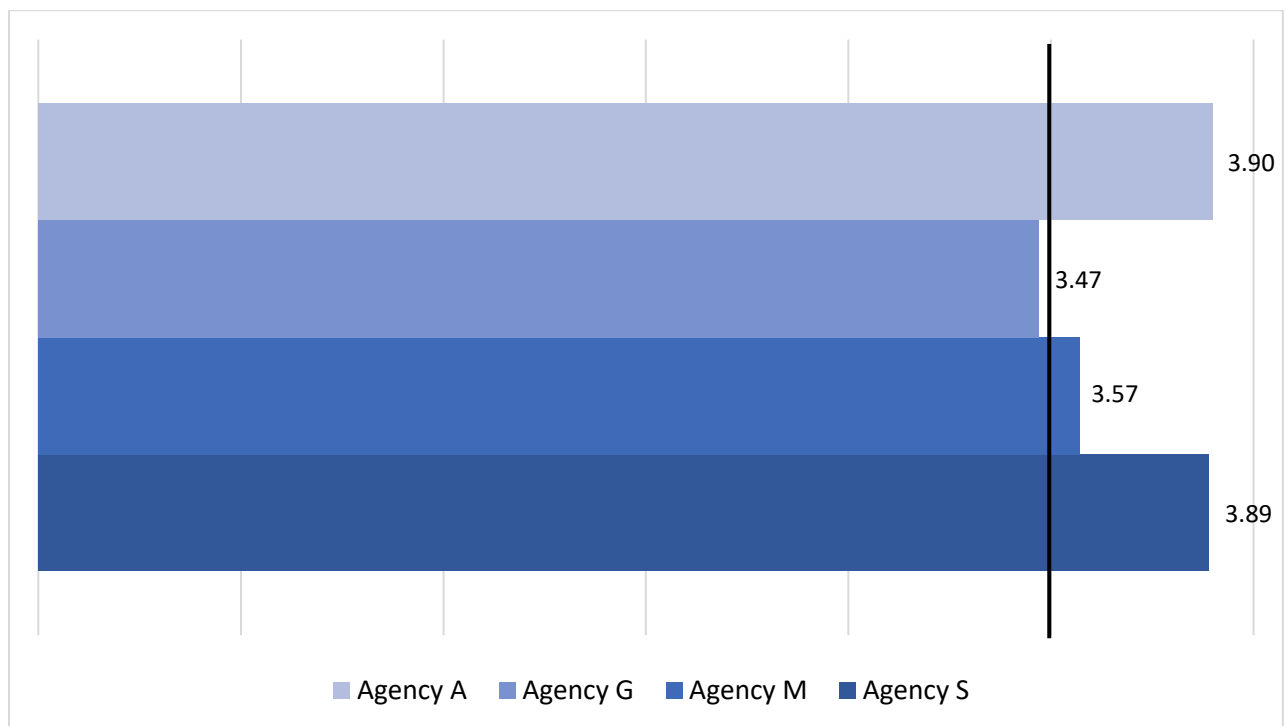


Figure 9. CHCP Performance Benchmarks by Agency: Case Manager Recommendation (Mean Score, Range 1-4)



ii. PCA waiver

All four Access Agencies met or exceeded the number of completed surveys required to meet their PCA waiver representative sample size (Table 9).

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

Program	Agency & Region	Representative sample size	Completed surveys N (%)
PCA	AASCC	76	79 (>100)
	CCC - E	36	38 (>100)
	CCC - NC	87	88 (>100)
	CCC - NW	30	30 (100)
	SWCAA	40	40 (100)
	WCAAA	13	13 (100)

Performance benchmark measures for the PCA waiver are shown in Figures 10, 11, and 12. All four Access Agencies met the benchmark for the three PCA composite measures (Figure 10). Agency M did not meet the benchmark for either PCA case manager global rating (4.38 vs. 4.5) or PCA case manager recommendation (3.23 vs. 3.5). Agency G, Agency S, and Agency A all met both of these PCA case manager benchmarks.

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

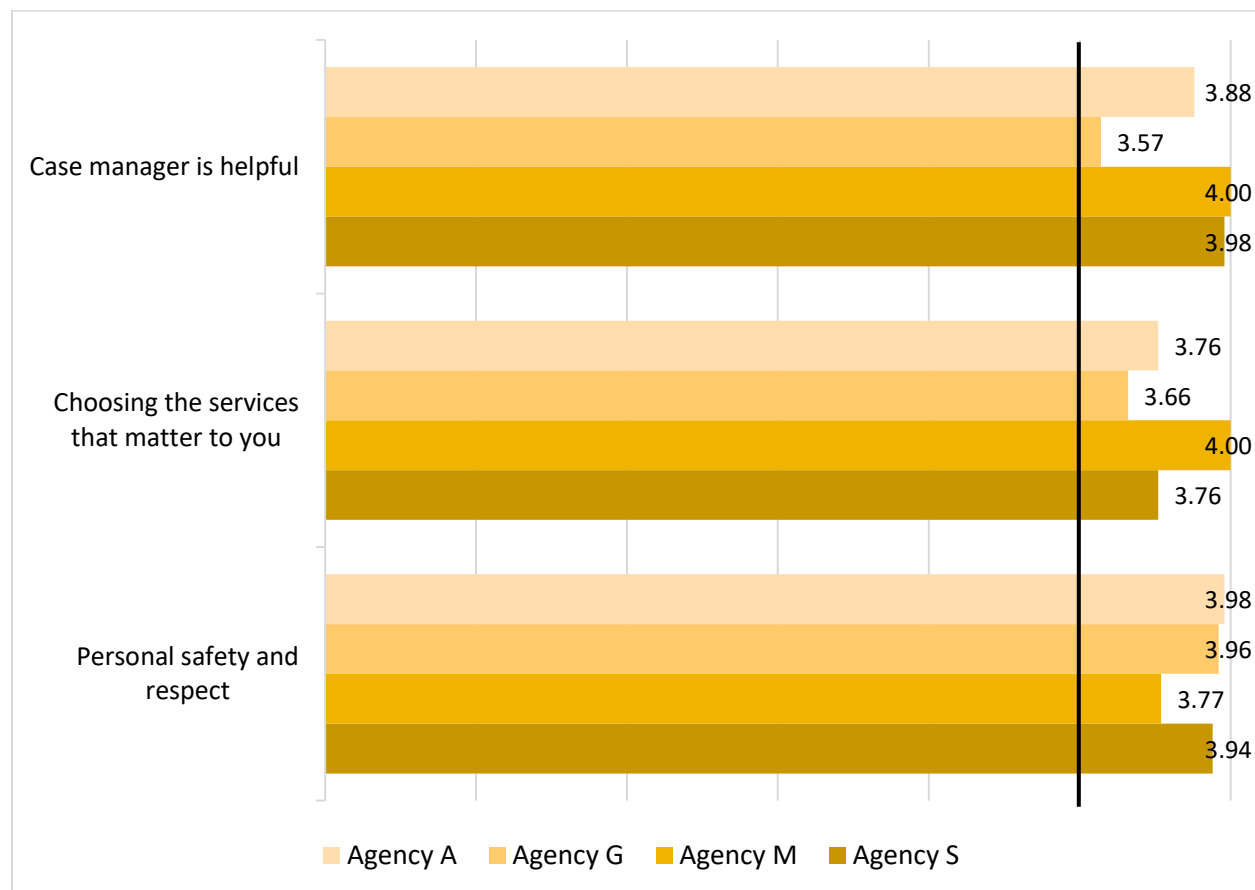


Figure 11. PCA Performance Benchmarks by Agency: Case Manager Global Rating (Mean Score, Range 1-5)

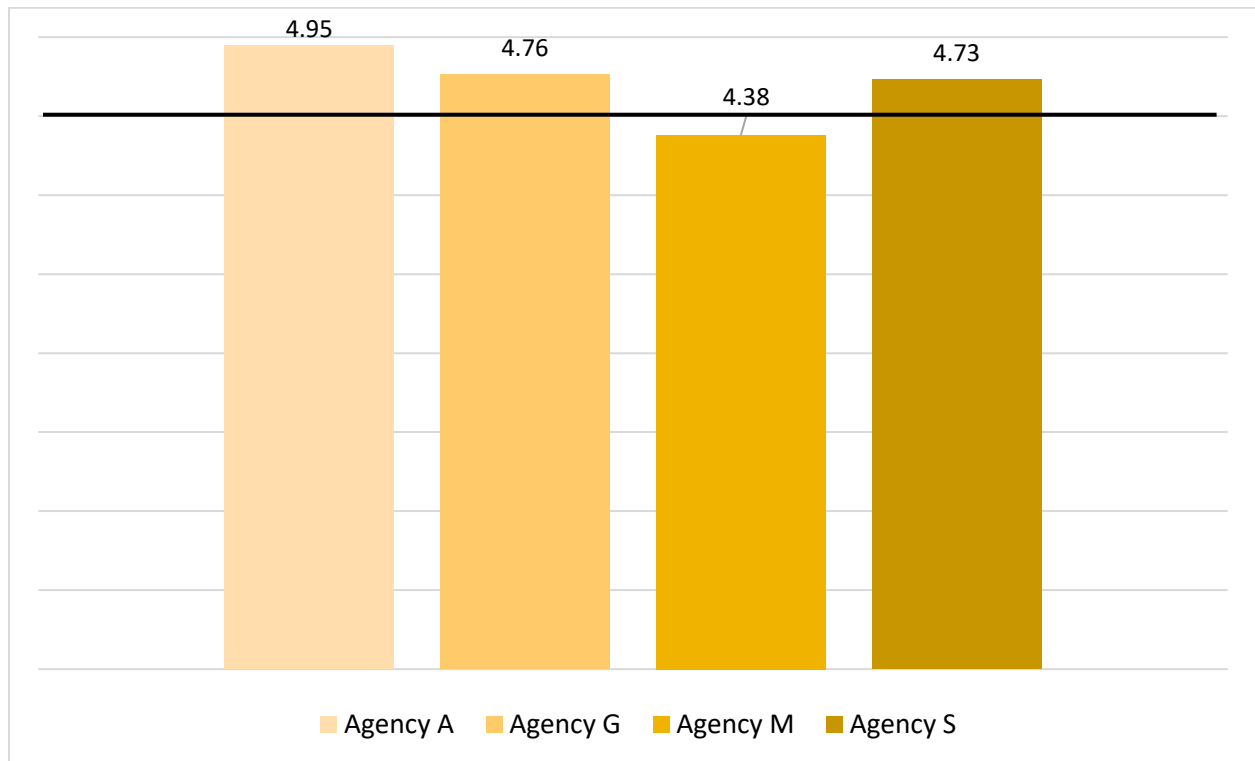
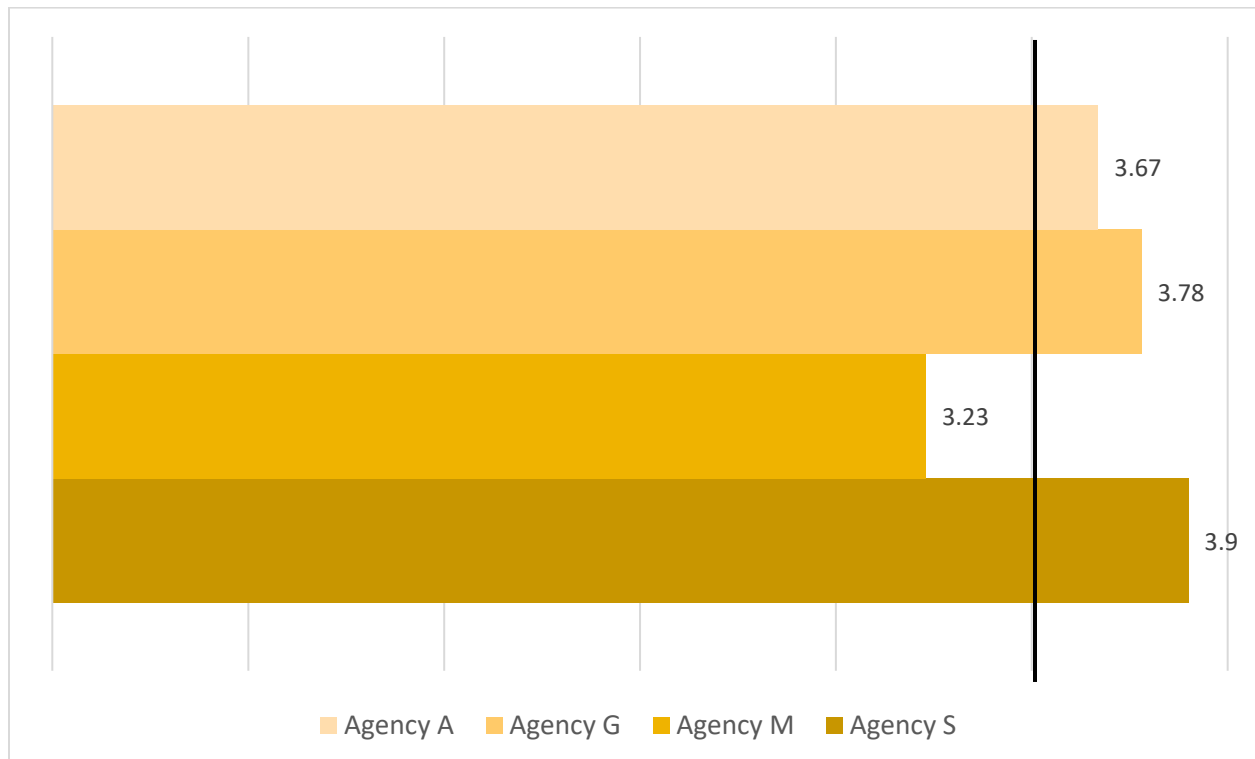


Figure 12. PCA Performance Benchmarks by Agency: Case Manager Recommendation (Mean Score, Range 1-4)



iii. ABI waivers

Three Access Agencies provide case management for the ABI waiver: CCC, SWCAA, and WCAAA. Table 10 shows that CCC and SWCAA met the number of surveys required to meet the ABI 1 representative sample, while WCAAA was one survey shy of meeting their ABI 1 numbers. All three Access Agencies completed enough ABI 2 surveys to meet or exceed their representative sample sizes.

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

Program	Agency & Region	Representative sample size	Completed surveys	N (%)
ABI 1	CCC - E	31	31	(100)
	CCC - NC	55	55	(100)
	CCC - NW	31	31	(100)
	SWCAA	35	35	(100)
	WCAAA	14	13	(92.9)
ABI 2	CCC - E	16	16	(100)
	CCC - NC	56	58	(>100)
	CCC - NW	20	20	(100)
	SWCAA	49	50	(>100)
	WCAAA	10	11	(>100)

All three Access Agencies met the performance benchmark score for the three ABI composite measures (Figure 13). Agency E fell slightly below the threshold for ABI case manager global rating (4.48 vs 4.5; Figure 14). All three Access Agencies met the benchmark for ABI case manager recommendation (Figure 15).

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



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

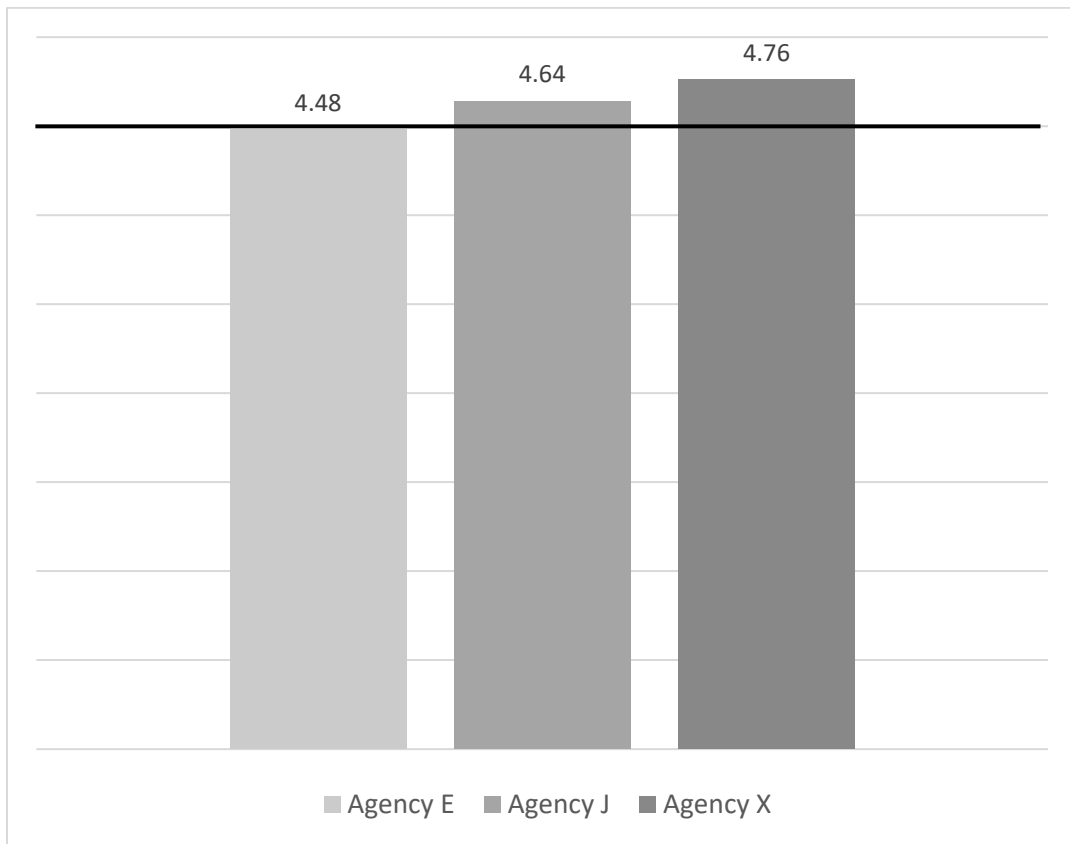
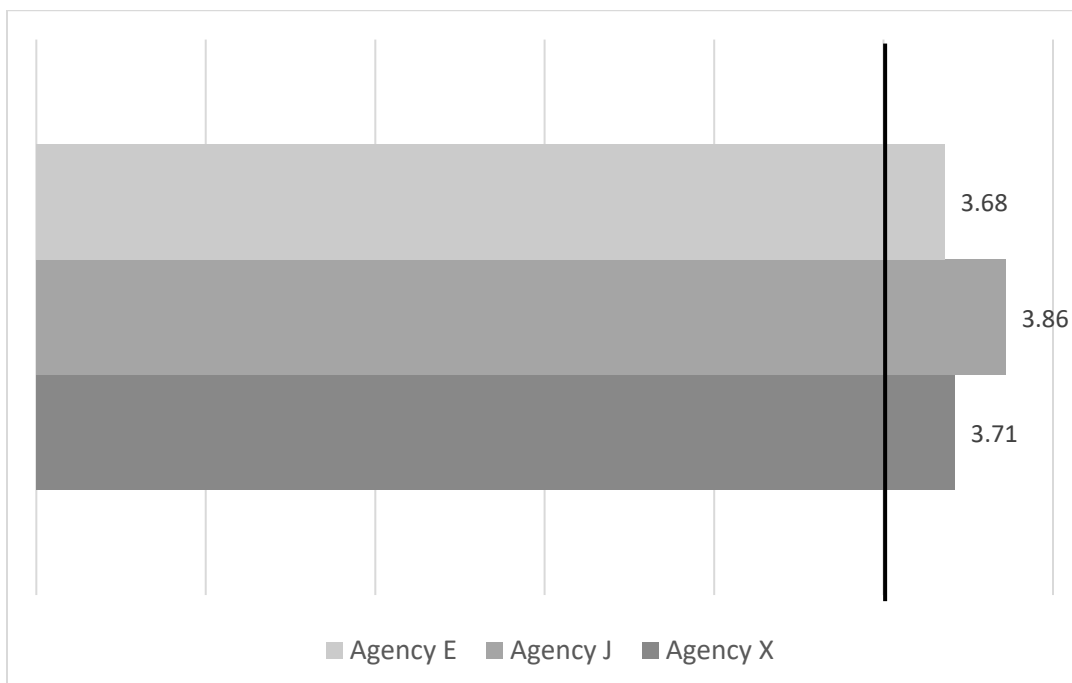


Figure 15. ABI Performance Benchmarks by Agency: Case Manager Recommendation (Mean Score, Range 1-4)

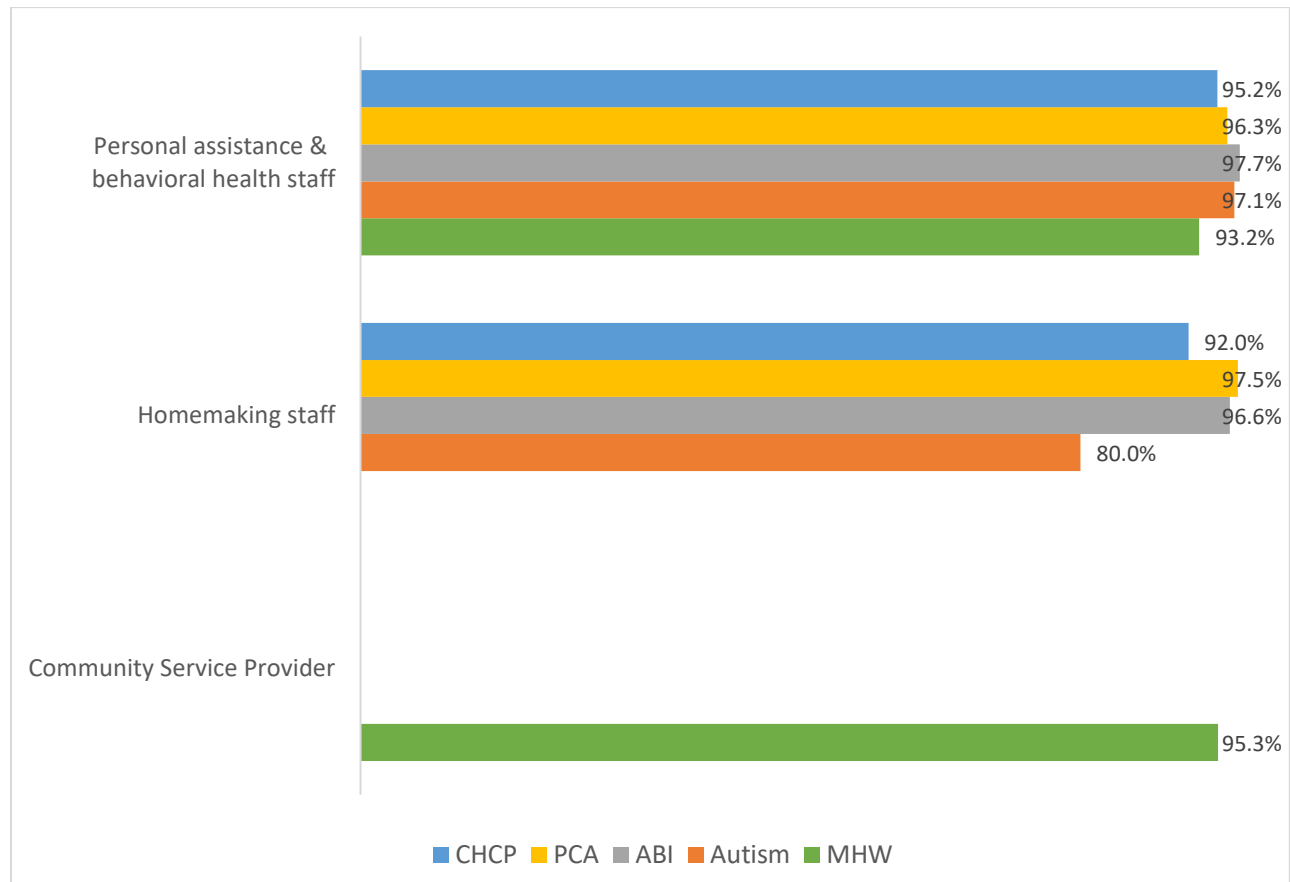


F. Additional Findings by Program

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

Participants with personal care, RA, behavioral health, homemaking, or CSP services were asked, “Did {staff} encourage you to do things for yourself if you could?” Similar to the previous year, the great majority of participants from most of the waivers reported their staff encouraged them in this way (Figure 16). The only notable difference among programs was for Autism homemaking staff – 80% of Autism respondents said their homemaking staff encouraged them to do things for themselves, compared to 92-98% of the other waiver programs.

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



There was a notable increase in the percentage of ABI participants who knew who their case manager was (91% 2024, 98% 2025); the remainder of waiver program participants showed little to no change compared to the previous year. It is concerning that only 84% of CHCP participants know who their case manager is, considering the regular case manager contact required by the waiver. This represents an area for improvement for the agencies which provide this case management. KBW participants are consistently the least likely to know who their case manager is. One likely contributing factor is that even though the KBW provides a nurse case manager from a home health agency, the waiver does not provide other HCBS. Any other services the participant receives, such as PCA services from Community First Choice, must be obtained and managed directly by the parents or legal guardians, without assistance from the KBW nurse case manager.

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

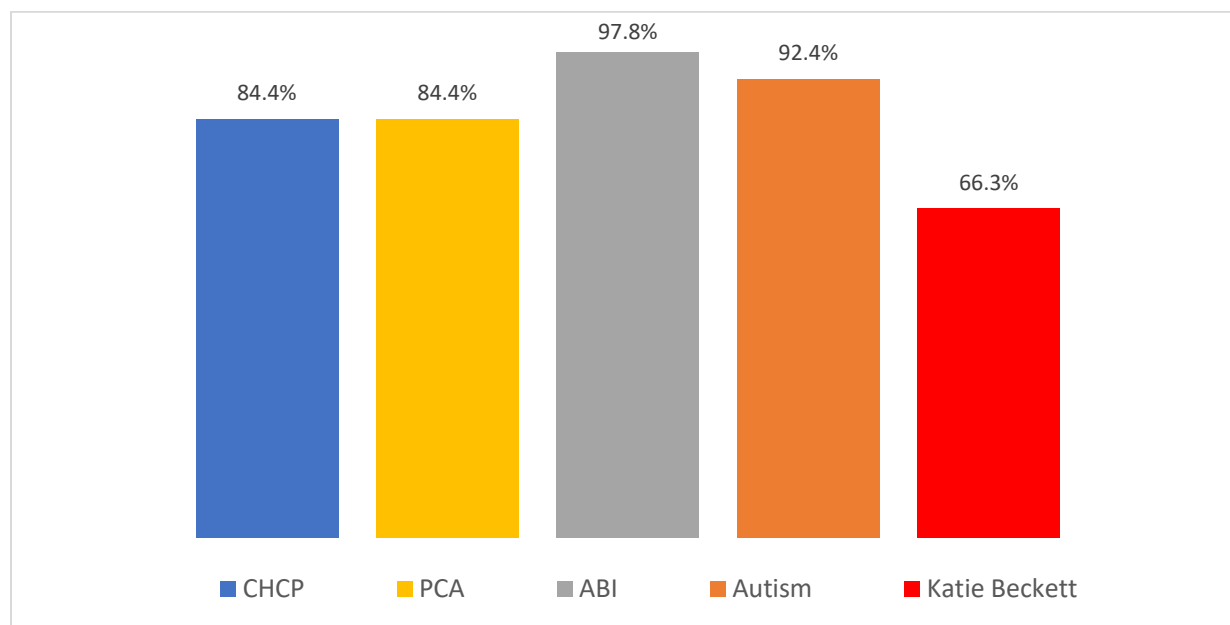
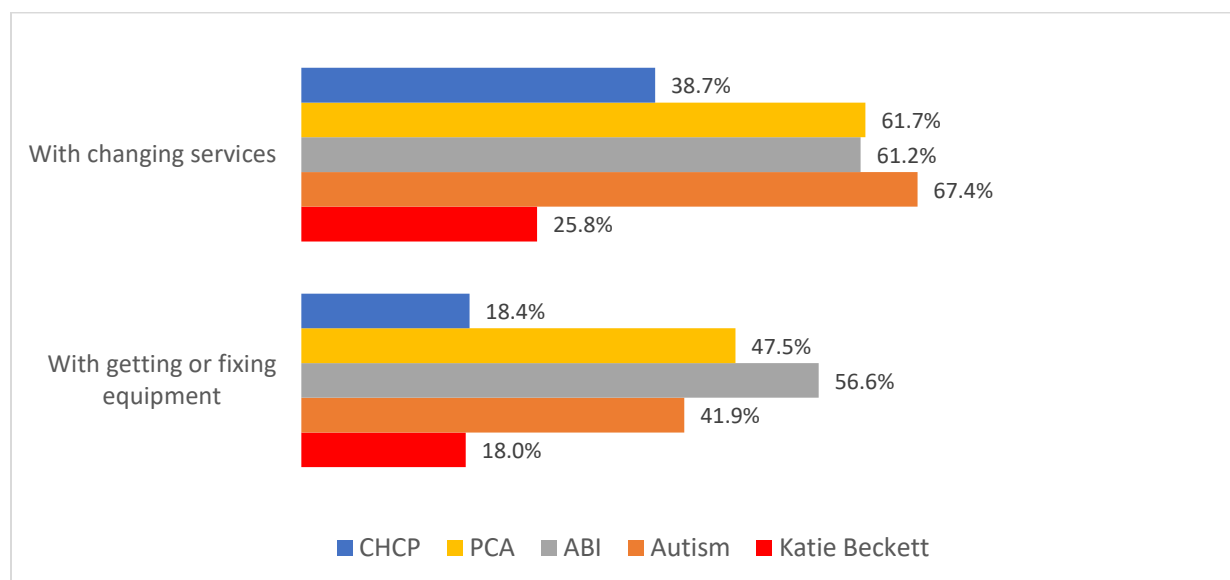


Figure 18 shows the wide variation between programs for how often respondents asked their case manager for help with changing services or with getting or fixing equipment. With the exception of CHCP, most waivers showed notable increases over last year in the percentage of respondents asking for help from their case managers. Most notably, PCA respondents were much more likely to ask their case managers for help with changing services (25% 2024, 62% 2025) or getting or fixing equipment (16% 2024, 48% 2025).

Figure 18. Asked Case Manager for Assistance with Services/Equipment – Percentage Positive Responses



The great majority of CHCP, PCA, ABI, and Autism participants said they knew someone to talk to if they wanted to change their care plan/service plan (Figure 19). When asked to name the person they would talk to, the majority of the waiver participants in these waivers said they would speak to their case manager (Table 11). Historically, KBW participants are less likely to know someone to talk to about their

services. This difference was stronger this year – just 78% of KBW participants knew someone to talk to if they wanted to change their care/service plan, and only 33% would talk to their case managers about this. Although not shown on Table 11, 44% of KBW respondents who knew someone to talk to would talk to their doctor or other health care provider to change their care plan.

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

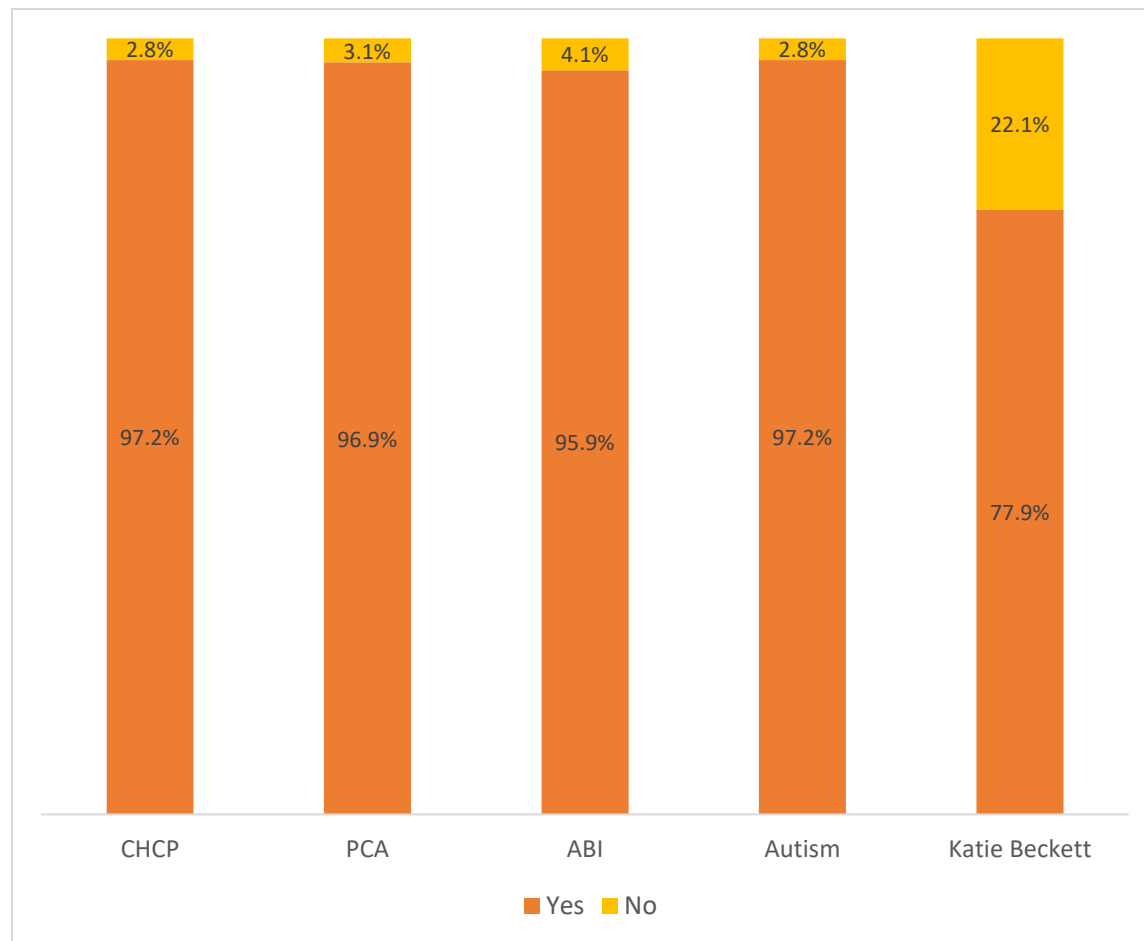


Table 11. Who Would You Talk to if You Wanted to Change Your Care Plan?*

	CHCP N=502 n (%)	PCA N=288 n (%)	ABI N=314 n (%)	Autism N=144 n (%)	KBW N=178 n (%)
Case manager or social worker	412 (82.1)	258 (89.6)	234 (74.5)	102 (70.8)	59 (33.1)
Other staff or home care agency/provider	39 (7.8)	21 (7.3)	50 (15.9)	32 (22.2)	42 (23.6)
Family/friends	108 (21.5)	25 (8.7)	116 (36.9)	37 (25.7)	18 (10.1)
Someone else	4 (0.8)	2 (0.7)	14 (4.5)	11 (7.6)	57 (32.0)
Do not know who to talk to	10 (2.0)	9 (3.1)	7 (2.2)	4 (2.8)	37 (20.8)

*Multiple choice, select all that apply

ii. Living situation and social support

Similar to previous years, a large majority of MHW participants (87%) lived alone or without other adults, as did 60 to 63% of CHCP, PCA, and ABI participants (Table 12). Participants in the MHW also had fewer family who lived nearby compared to all other waivers. Compared to the other programs, ABI participants were the least likely to live with family but were the most likely to live with people unrelated to them.

Table 12. Living Situation and Social Support*

	CHCP	PCA	ABI	Autism	KBW	MHW
	%	%	%	%	%	%
Number of adults living in household	N=505	N=286	N=319	N=144	N=179	N=133
1	60.2	62.6	62.7	21.5	6.7	87.2
2-3	36.0	34.6	34.2	60.4	79.9	12.0
4+	3.8	2.8	3.1	18.1	13.4	0.8
Lives with family^	N=201	N=107	N=120	N=113	N=167	
Yes	81.1	82.2	67.5	94.7	96.4	
No	18.9	17.8	32.5	5.3	3.6	
Lives with non-family^	N=201	N=107	N=119	N=113	N=167	
Yes	18.9	23.4	34.5	8.0	0.6	
No	81.1	76.6	65.6	92.0	99.4	
Family live nearby	N=503	N=287	N=320	N=144	N=180	N=140
Yes	78.3	77.0	82.5	69.4	77.2	66.4
No	21.7	23.0	17.5	30.6	22.8	33.6
Friend/s live nearby	N=501	N=286	N=316	N=144	N=175	N=140
Yes	61.7	73.1	51.3	45.1	51.4	65.7
No	38.3	26.9	48.7	54.9	48.6	34.3

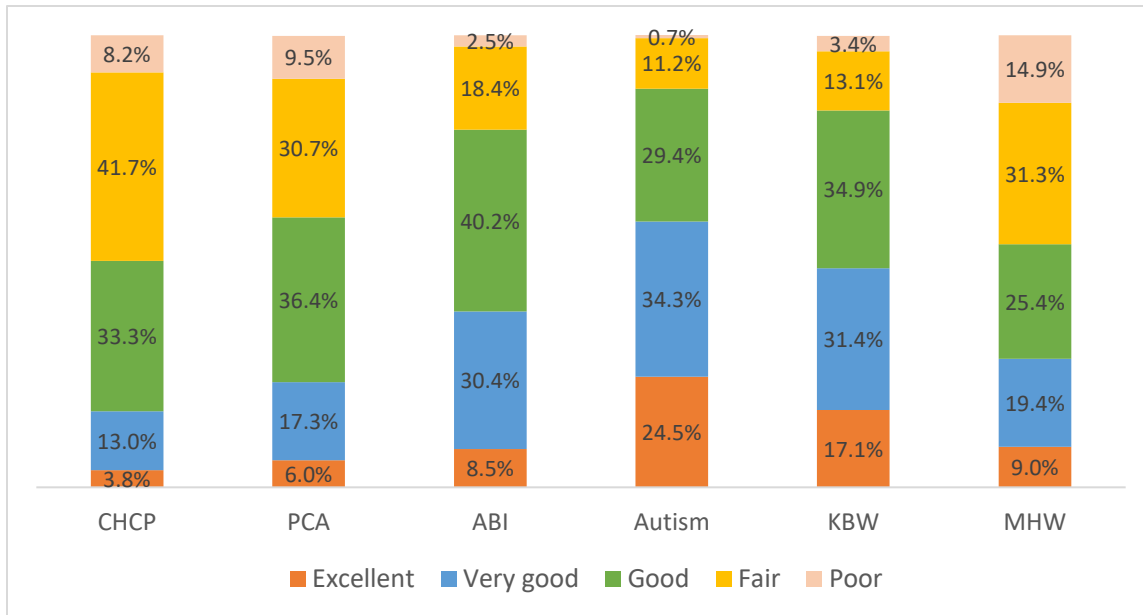
*Percentages listed for each item are based on the total number of valid responses to that question (N)

^Item not asked on MHW survey

iii. Physical and mental health

Two separate questions asked respondents to rate their physical health and their mental or emotional health, with response choices from excellent to poor. About half of both MHW (46%) and CHCP (50%) participants rated their physical health as fair or poor, as did 40% of PCA participants (Figure 20).

Figure 20. Self-Reported Physical Health



Autism, MHW, and PCA participants rated their mental or emotional health more positively this year (Figure 21). Forty-four percent of Autism, 35% of MHW, and 32% of PCA reported very good or excellent mental health, representing an increase by 9 percentage points for each of these waivers compared to 2024. Not surprisingly, MHW participants (35%) were the most likely to report fair or poor mental health, as did 21-25% of Autism, ABI, PCA, and CHCPE.

Figure 21. Self-Reported Mental or Emotional Health



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

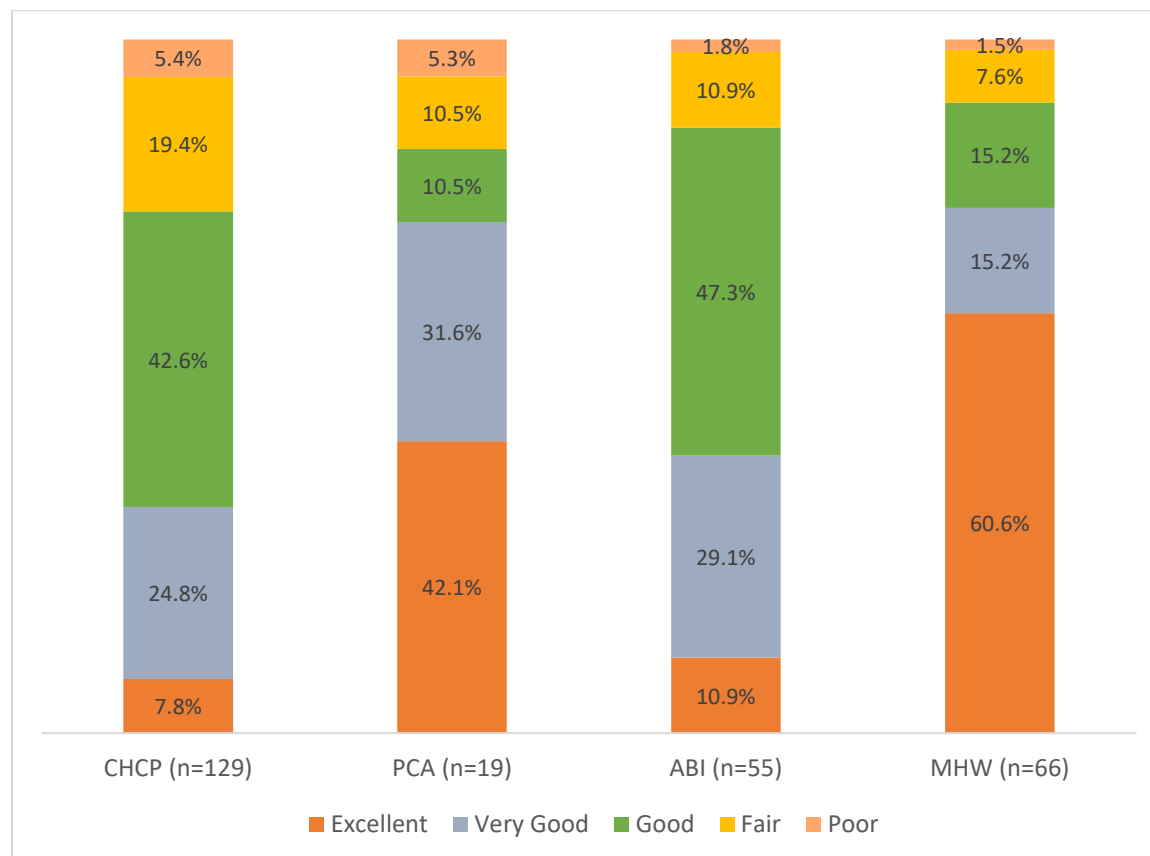
Compared to last year, PCA waiver participants increased their use of a van or transportation service (43% 2024, 59% 2025), while transportation use by other waiver participants did not show much change (Table 13).

Table 13. Use of Van or Transportation Service

	CHCP N=503 %	PCA N=288 %	ABI N=314 %	Autism N=143 %	KBW N=181 %
Yes	64.9	71.3	73.9	93.0	81.4
No	1.0	4.9	7.1	7.0	0

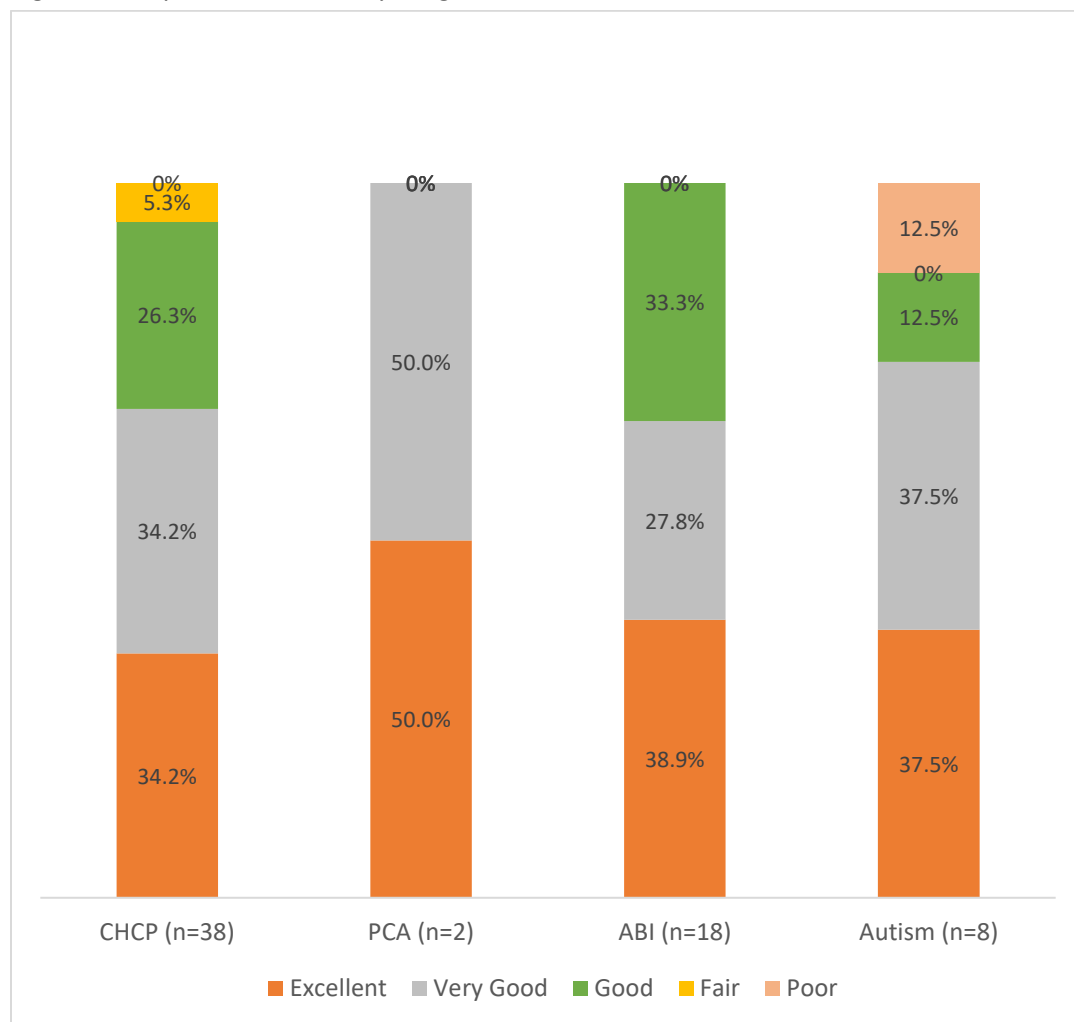
A total of 269 participants (19%) reported using a home delivered meal service, including 25% of MHW participants (Figure 22). While most participants rated their meal service as good or better, MHW participants rated theirs even higher, with 61% reporting their meal service was excellent. CHCP participants were the least happy with their meal service – 25% said it was fair or poor.

Figure 22. Experience with Home Delivered Meal Services



Just 66 participants (5%) reported receiving day program services. PCA respondents were much more satisfied with their day programs than respondents in the other waivers – 100% of PCA respondents rated their day program as very good or excellent (Figure 23).

Figure 23. Experiences with Day Program Services



v. Personal safety and respect follow-up

Twenty-nine participants (1% of all participants) said that their staff had taken their money or things without permission: 9 MHW, 10 ABI, 7 CHCP, and 3 PCA. Seventeen of these participants said someone was working with them to fix the problem. Twenty-eight participants said that their staff had yelled or cursed at them: 12 MHW, 7 ABI, 4 CHCP, 4 PCA, and 1 Katie Beckett. Twenty-one of these consumers said someone was working with them to fix the problem.

vi. Emergency contact

An open-ended question asked consumers who they would contact in case of an emergency (Table 14). Neither the survey nor the interviewers defined what an emergency meant, and participants could identify more than one person. Responses show that family and friends play a large role in consumer emergency plans. Similar to previous years, the majority of participants in each program would contact their family or friends in case of an emergency, followed by 911.

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

	CHCP N=501 %	PCA N=286 %	ABI N=310 %	Autism N=142 %	KBW N=161 %
Family/friend	64.9	71.3	73.9	93.0	81.4
Case manager	1.0	4.9	7.1	7.0	0
Home care agency or staff	4.6	4.9	20.7	9.2	1.2
PERS/Lifeline	24.2	7.0	10.0	0.7	0.6
911	47.1	50.7	31.9	19.7	24.2
Someone else	1.8	1.4	2.6	6.3	13.7

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

vii. Self-directed employment of paid assistants

To measure use of consumer employer self-direction, consumers were asked if their caregivers come from an agency or if they or a family member find and hire their caregivers. PCA and Katie Beckett waiver participants were most likely to hire their own staff (65%, 62% respectively), while only 12% of CHCP participants said they hired their own staff (Table 15). Self-directing consumers were then asked if they employed family members as staff. Although only a small percentage of CHCP participants self-directed their services, 67% of them hired family members, as did 52% of KBW respondents. Participants or their families most frequently employed adult children, siblings, or parents as staff.

Table 15. Self-Direction

	CHCP %	PCA %	ABI %	Autism %	KBW %
How hire staff	N=490	N=287	N=312	N=106	N=68
Agency	87.6	34.8	68.6	68.9	38.2
Self-hire	12.4	65.2	31.4	31.1	61.8
Employs family members	N=60	N=185	N=98	N=33	N=42
Yes	66.7	50.3	26.5	18.2	52.4
No	33.3	49.7	73.5	81.8	47.6

G. Employment

PCA, ABI, and Autism participants were asked the HCBS CAHPS employment module, which covers work status, goals, and assistance finding a job.

i. Employment status

Figures 24 and 25 show employment status and goals. Similar to previous years, there was a striking difference with respect to rate of employment among the three waivers, with Autism respondents much more likely to be employed. Over half of unemployed Autism participants would like to work, as would 23% of unemployed ABI participants.

Although the percentage of unemployed PCA participants who would like to work has continued to decrease over the past several years – 27% in 2022, 14% in 2023, and 9% in 2024, there was an increase in 2025 to 14% of PCA respondents who would like to be employed.

Figure 24. Employment Status

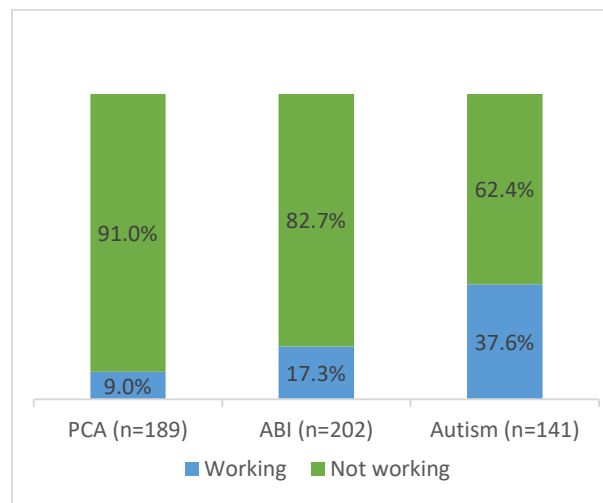
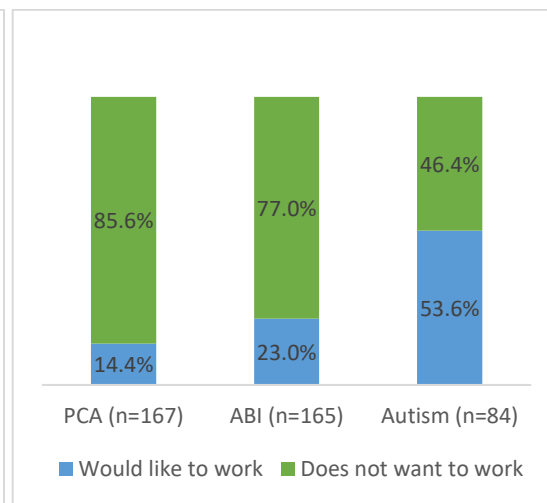


Figure 25. Employment Goal



Unemployed PCA and ABI respondents who wanted to work most often cited physical disability, physical health, or mental health related concerns as a reason for not working (Table 16). Eighty-six percent of unemployed PCA participants who did not want to work said health or disability related concerns were holding them back from wanting to work, representing a continual increase from 2023 (52%) to 2025.

Table 16. Most Common Reasons for Not Working*

<i>Participants who do want to work</i>	PCA N=24 n (%)	ABI N=36 n (%)	Autism N=45 n (%)
Benefits	1 (4.2)	3 (8.3)	2 (4.4)
Physical or mental health/disability	18 (75.0)	20 (55.6)	16 (35.6)
Don't know about job resources	2 (8.3)	4 (11.1)	8 (17.8)
Advice from others	1 (4.2)	1 (2.8)	0 (0.0)
Training/education needed	3 (12.5)	1 (2.8)	12 (26.7)
Looking for but cannot find work	6 (25.0)	9 (25.0)	11 (24.4)
Transportation	4 (16.7)	1 (2.8)	4 (8.9)
Other	3 (12.5)	2 (5.6)	18 (40.0)
Nothing is holding me back	0 (0.0)	3 (8.3)	1 (2.2)
<i>Participants who don't want to work</i>	PCA N=142 n (%)	ABI N=125 n (%)	Autism N=37 n (%)
Physical or mental health/disability	122 (85.9)	59 (47.2)	17 (45.9)
Nothing is holding me back	17 (12.0)	59 (47.2)	16 (43.2)

*Multiple choice, select all that apply

Approximately 50 percent of unemployed Autism participants who wanted to work had asked for assistance with finding a job, as did 35% of ABI and 38% of PCA participants (Figure 26). This is a large increase for PCA respondents – in 2024 only 8% of unemployed PCA participants who wanted to work asked for help with finding a job. The majority of unemployed ABI and Autism participants who did not ask for help knew that employment assistance was available. The percentage of unemployed PCA waiver participants who knew that employment assistance was available also showed a large increase, from 35% in 2024 to 57% in 2025 (Figure 27).

Figure 26. Sought Out Employment Assistance

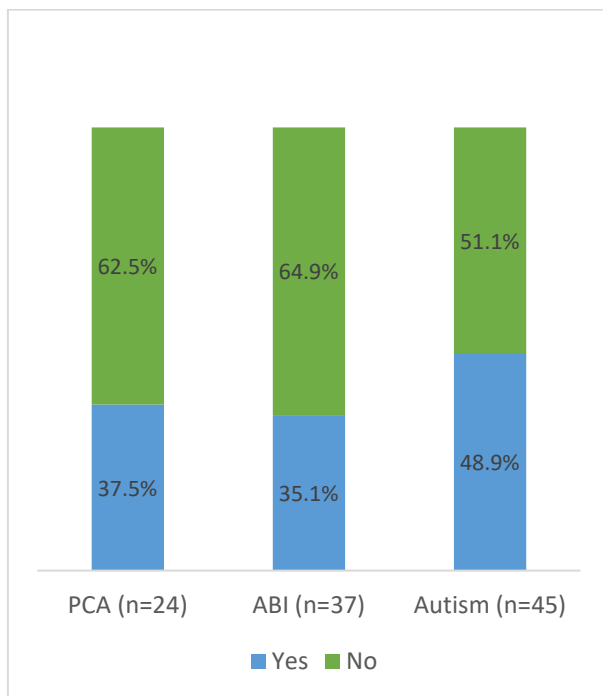
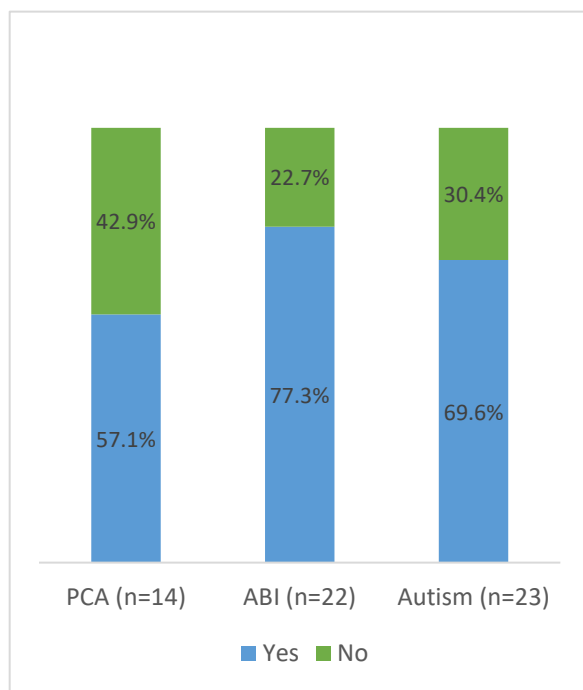


Figure 27. Aware of Employment Assistance



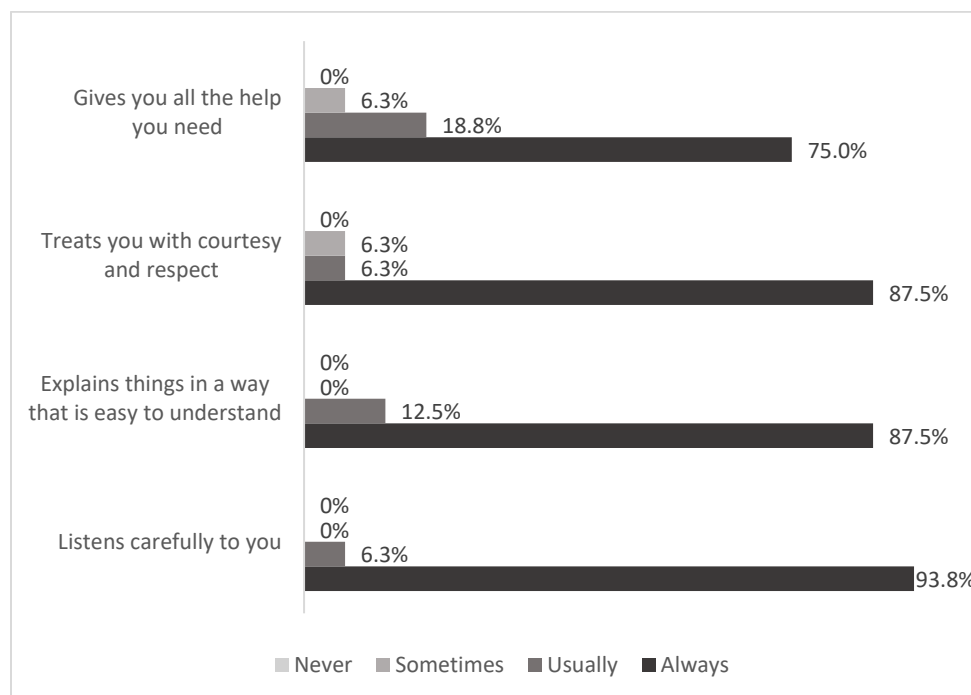
ii. ABI and Autism Employment Experiences

The ABI and Autism waivers provide various employment services for participants including job coach services. When employed ABI and Autism participants were asked who helped them find their current job, both ABI and Autism participants most often found their jobs using waiver/vocational staff. A majority of both ABI and Autism participants said they helped choose their job.

ABI Job Coach

Seventeen percent (n=35) of ABI participants were employed. Nineteen (70%) of these employed ABI participants reported someone was paid to help them with their job; 16 answered job coach questions. Almost all of them (94%) said that their job coaches encouraged them to do things for themselves, and the great majority reported positive experiences with their job support staff (Figure 28). As reported earlier in Figures 3 and 5, ABI participants as a whole gave their job coaches very good ratings (mean score 4.5 out of 5) and recommendations (mean score 3.9 out of 4).

Figure 28. ABI Job Coach Items



Autism Job Coach

Thirty-eight percent (n=53) of Autism participants were employed. Twenty (41%) of these employed Autism participants said someone was paid to help them with their job; 17 answered at least some of the job coach questions. Most of these participants reported that their job coach usually or always gave them the help they needed, treated them with courtesy and respect, explained things in a way that was easy to understand, and listened carefully to them. All of them also reported receiving encouragement from their job coach to do things for themselves if they could.

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

This section presents CHCP, PCA, and ABI key results by each Access Agency. Figures show the percentage of participants who gave the most positive answer for the three case manager related composite measures, case manager global rating, and case manager recommendation.

i. CHCP programs

Two of the three CHCP composite scores showed variation among the agencies (Figure 29). Scores for the composite case manager is helpful varied widely among the agencies, 78% (Agency G) to 98% (Agency A) of CHCP respondents gave this composite the highest score, a marked difference from 2024 when 94% or more of all agencies reported the highest score. Scores for choosing services which matter to you also varied among agencies, from 77% (Agency S) to 88% (Agency G and Agency A). CHCP participants gave consistently high scores for the composite personal safety and respect.

Case manager highest ratings and recommendations also varied among agencies (Figures 30 and 31). The percentage of CHCP participants who would rate their case manager a 9 or 10 ranged from 55% (Agency M) to 91% (Agency A). Both Agency G (53%) and Agency M (57%) had much lower percentages of CHCP participants who would definitely recommend their case manager, compared to over 90% of both Agency S and Agency A participants.

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

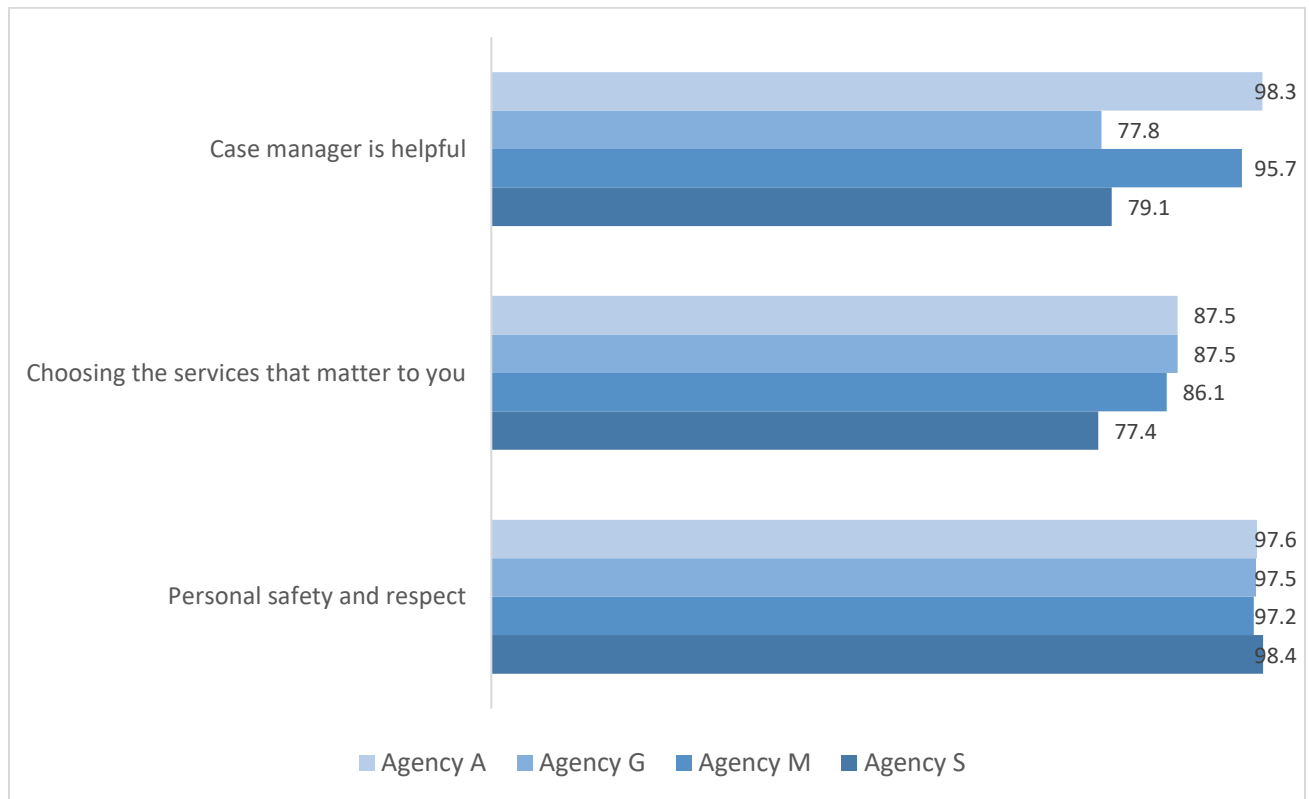


Figure 30. CHCP Global Ratings by Agency: Percentage Who Rate Their Case Manager a “9” or “10”

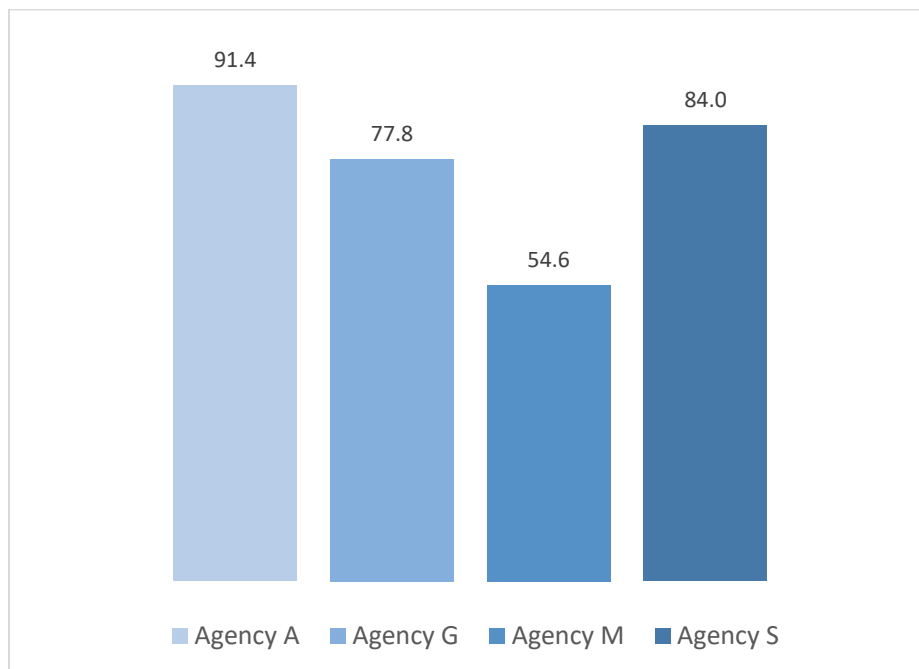
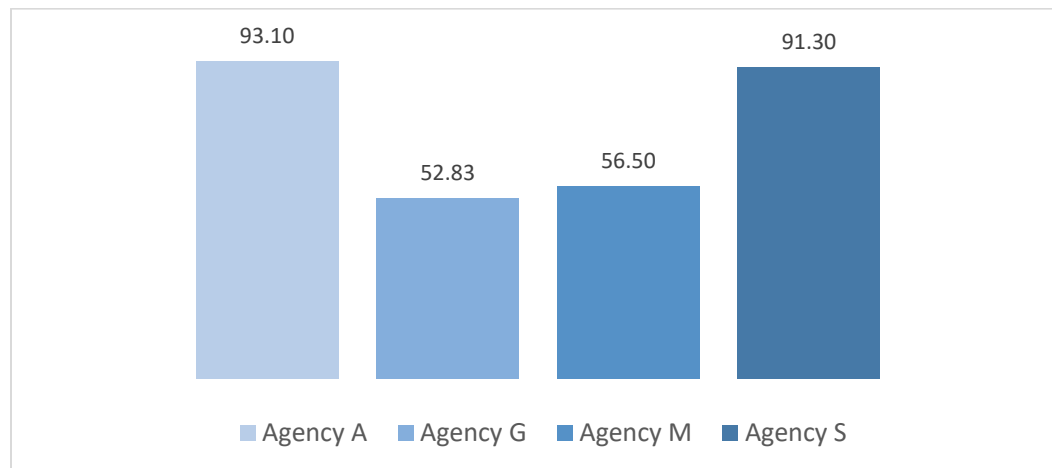


Figure 31. CHCP Recommendations by Agency: Percentage Who “Definitely” Recommend Their Case Manager



ii. PCA waiver

Similar to the CHCP composite measures, there was notable interagency variation across two of the PCA composite measures (Figure 32). Percentage with the highest scores for case manager is helpful varied from 58% (Agency G) to 99-100% (Agency S and Agency A, respectively). Choosing services that matter to you also differed, with percentage of highest scores ranging from 81% (Agency S) to 100% (Agency M). PCA percentage highest scores for the composite personal safety and respect were all high, ranging from 92% -100%.

PCA case manager global rating and recommendations showed marked interagency variation (Figures 33 and 34). The percentage of PCA participants who rated their case manager a 9 or 10 ranged from 46% (Agency M) to 97% (Agency A). Meanwhile percentage of PCA participants who would definitely recommend their case manager varied from a low of 31% (Agency M) to a high of 92% (Agency S).

Figure 32. PCA Composite Measures by Agency: Percentage with Highest Score

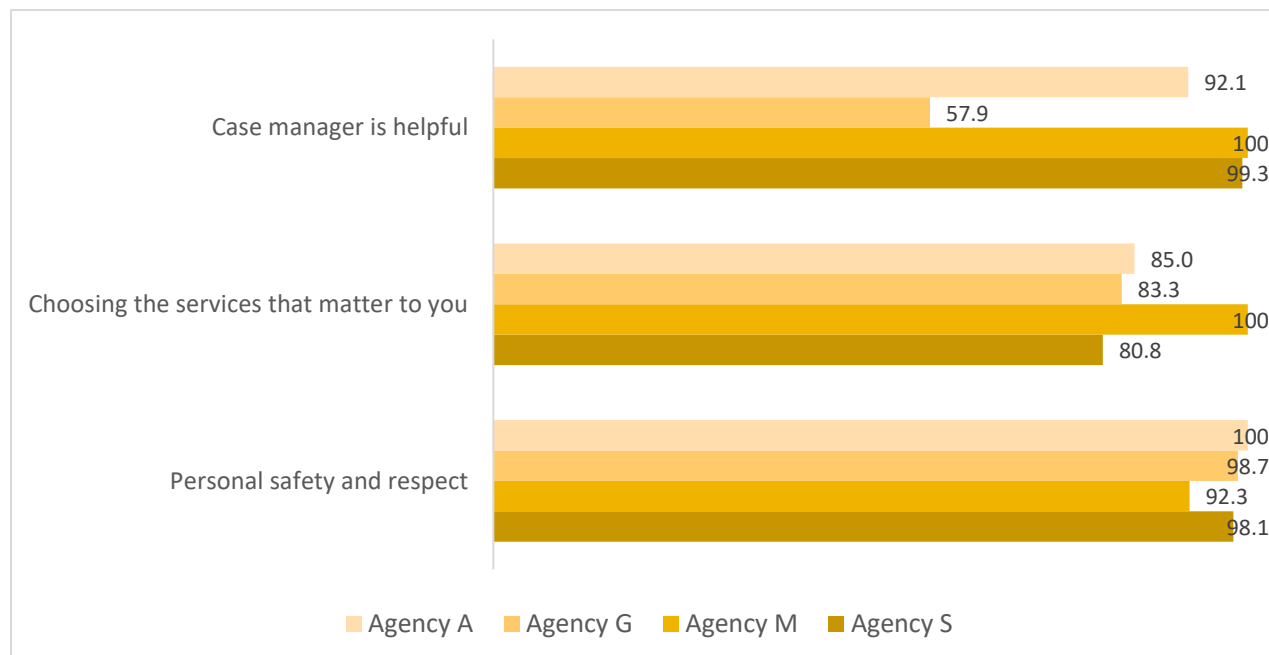


Figure 33. PCA Global Ratings by Agency: Percentage Who Rate Their Case Manager a “9” or “10”

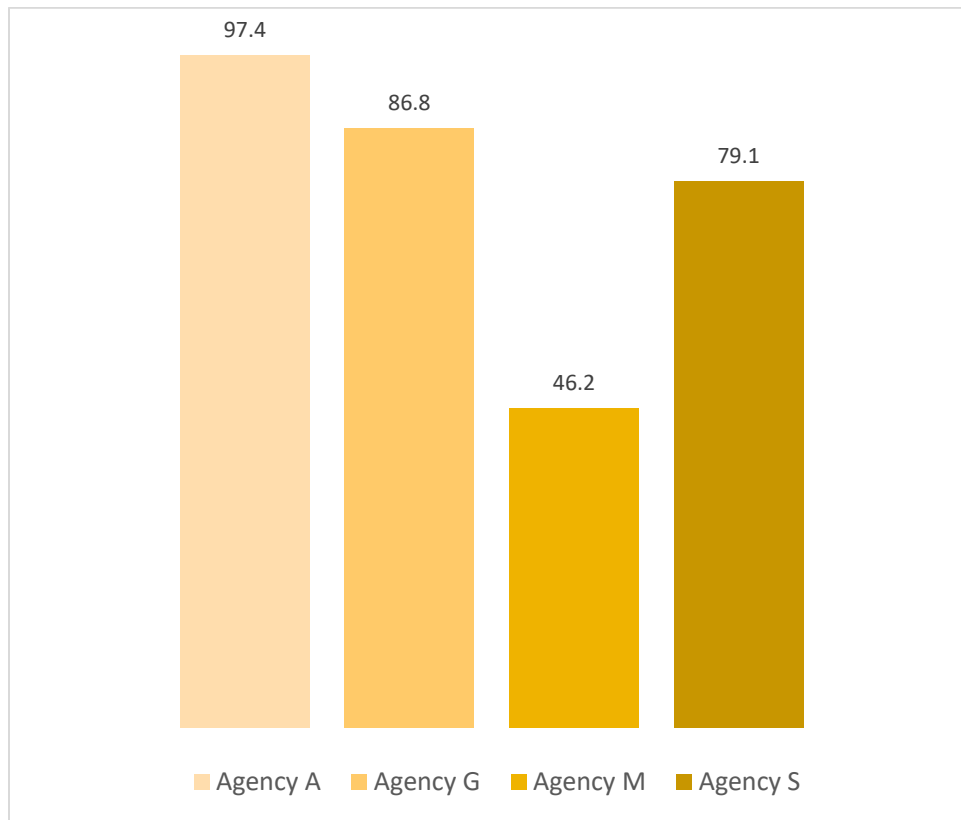
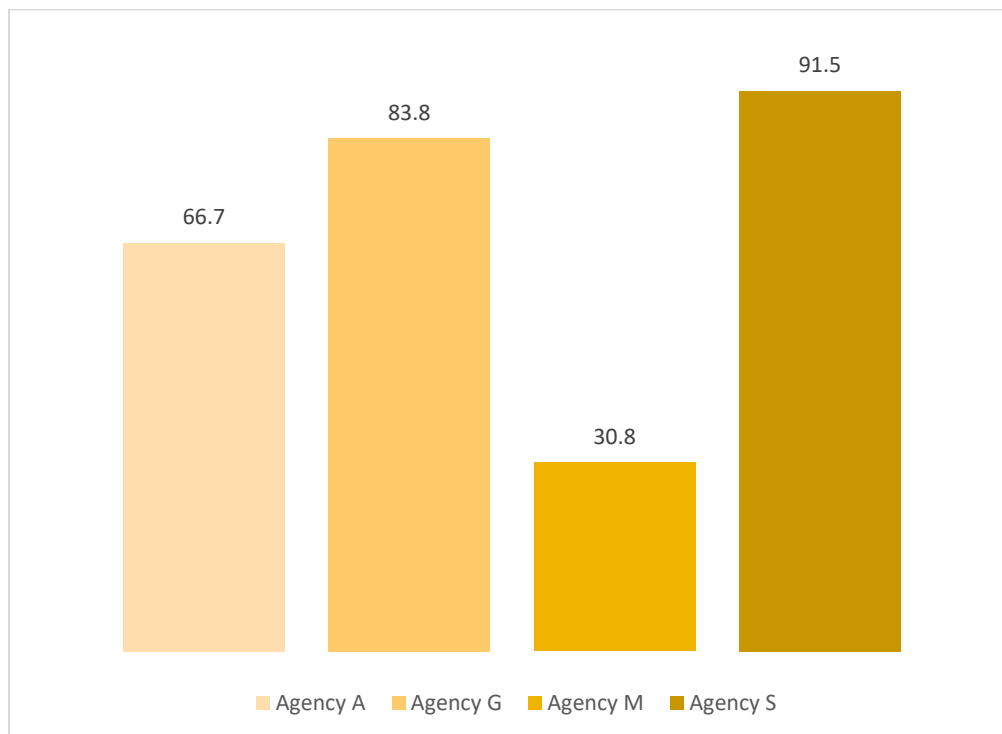


Figure 34. PCA Recommendations by Agency: Percentage Who “Definitely” Recommend Their Case Manager



iii. ABI waivers

One ABI composite score, as well as case manager global rating and recommendation, showed variation across the three ABI case management agencies (Figures 35, 36, and 37). Scores for the composite case manager is helpful were all high, ranging from 95% (Agency E) to 100% (Agency J), as were scores for personal safety and respect, ranging from 93% (Agency X) to 100% (Agency J). Meanwhile between 73% (Agency E) and 88% (Agency J) of ABI participants gave the highest score for choosing the services that matter to you. The percentage of ABI participants who rated their case managers a 9 or 10 also varied, from 68% (Agency J) to 79% (Agency X), while between 73% (Agency X) and 86% (Agency J) of ABI participants would definitely recommend their case manager.

Figure 35. ABI Composite Measures by Agency: Percentage with Highest Score

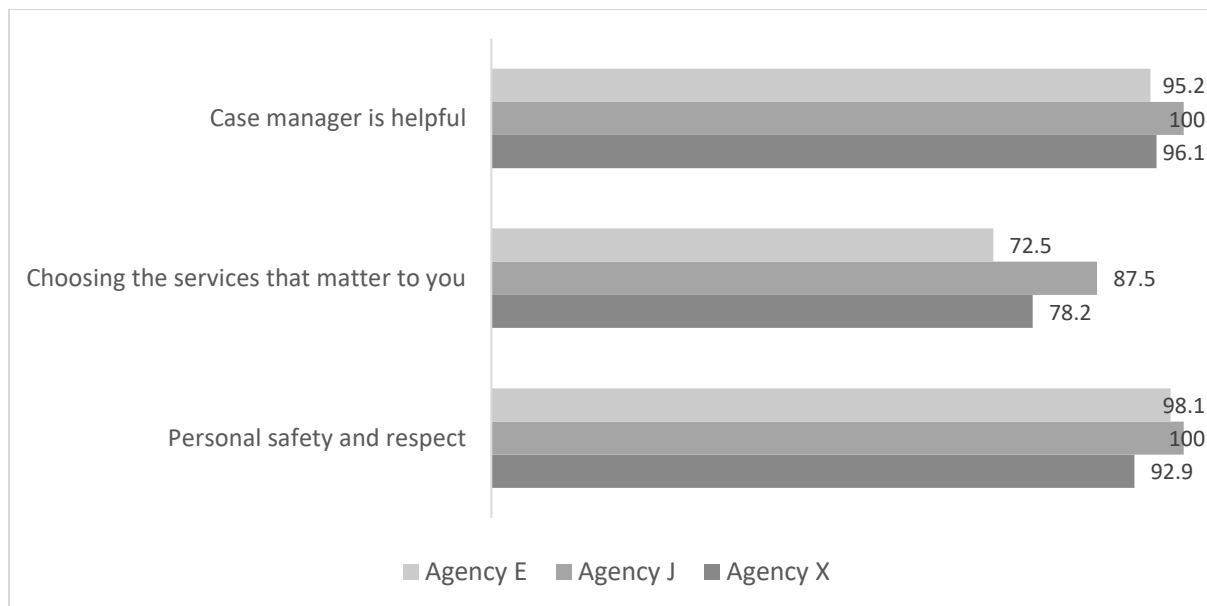


Figure 36. ABI Global Ratings by Agency: Percentage Who Rate Their Case Manager a “9” or “10”

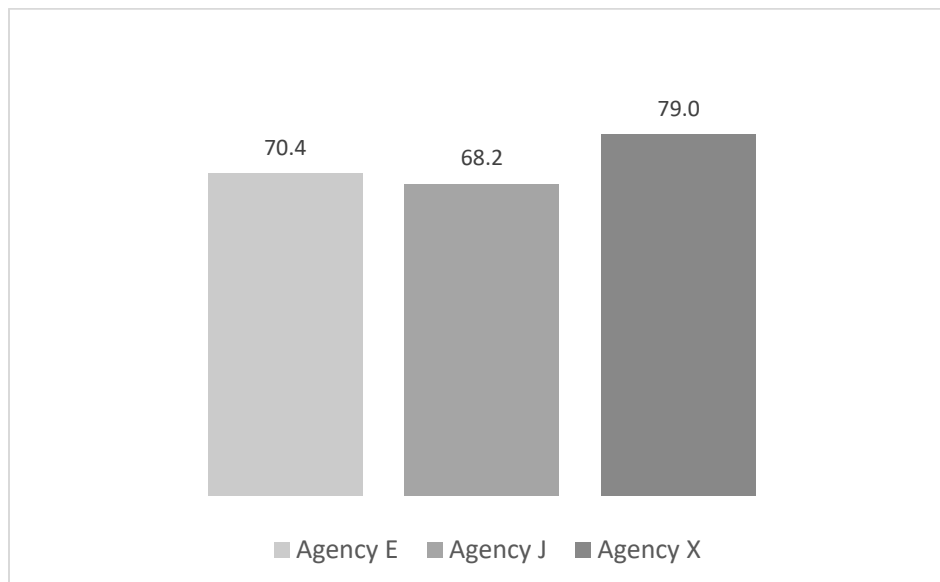
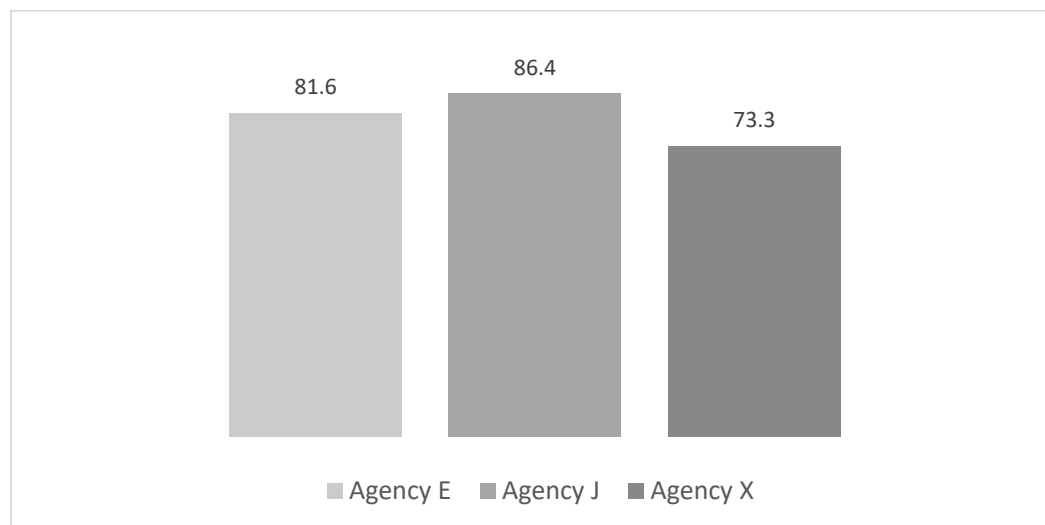


Figure 37. ABI Recommendations by Agency: Percentage Who “Definitely” Recommend Their Case Manager



I. Mental Health Waiver Consumer Experience

This section shows the collective experience of the 192 MHW clients who completed a MHW participant survey in FY 2025 (Table 17). Results from items either unique to the MHW survey or which do not represent a full HCBS CAHPS composite are presented. See Section D for MHW HCBS CAHPS composite, global ratings, and recommendation results. Although the unique MHW survey methods used to improve the response rate for these waiver participants have been effective, one limitation of this approach is its possible effect on the validity of survey responses. The validity of the HCBS CAHPS survey was established by asking all the applicable items in a specific order and having an interviewer administer the survey. In addition, with the online and paper surveys there is no way to determine the presence of a paid provider. The use of a subset of questions also limits the ability to compare the experience of MHW participants to participants in other waivers, most notably the CHCP, PCA and ABI programs.

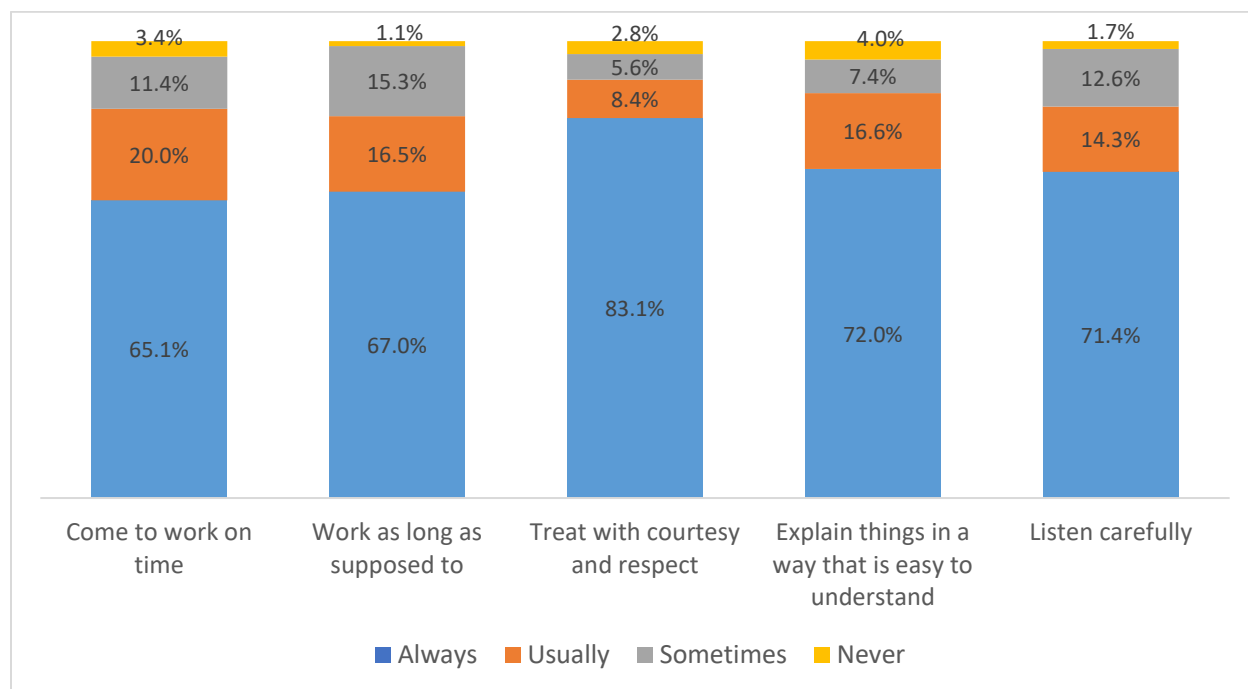
Table 17. MHW Interview Type

Survey Completed by:	MHW n (%)
Either Paper or Telephone	137 (71.4)
Online	55 (28.6)
Total	192 (100)

i. Recovery Assistants

The vast majority (94%) of MHW participants received RA assistance in the 3 months prior to completing the survey. Overall, MHW participants reported positive experiences with their RAs. From 84-92% of MHW clients responded always or usually in response to each RA experience question (Figure 38). In addition, 92% percent of MHW participants felt that their RA knew what kind of help they needed with their everyday activities, and 93% said their RA encouraged them to do things for themselves if they could. Still, when asked to rate the help they get from their RA, only about half (54%) would rate them as excellent (Figure 4).

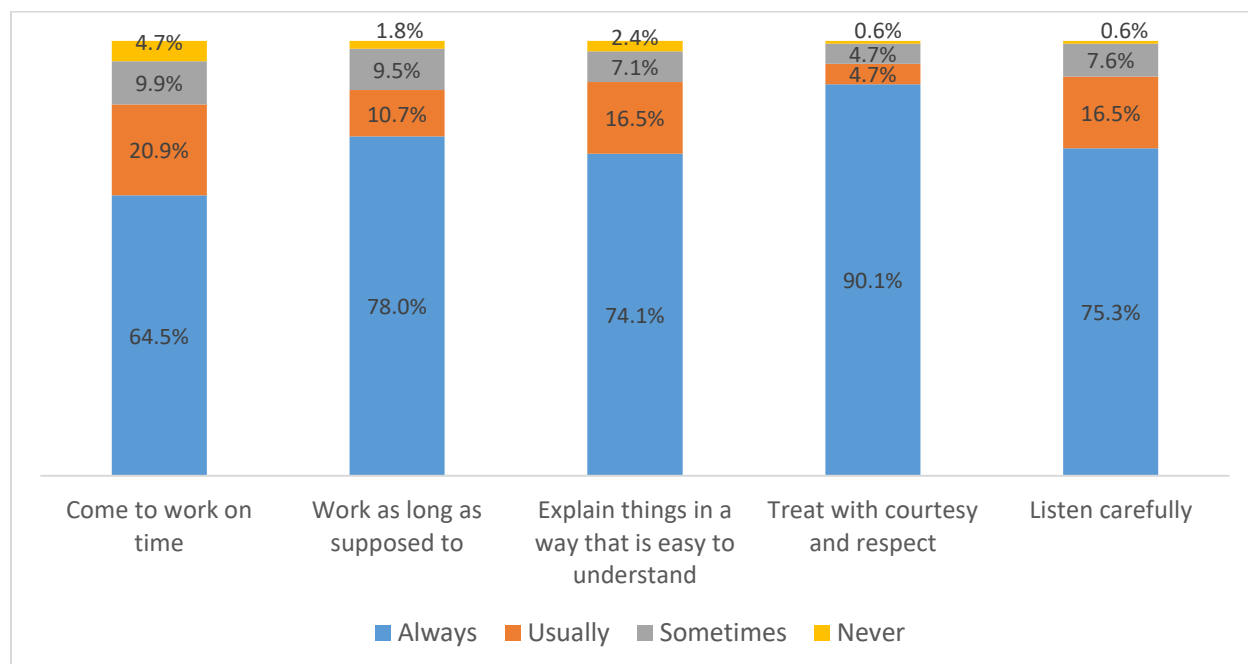
Figure 38. Recovery Assistant Experience



ii. Community Service Providers (CSP)

Similar to use of RA services, 93% of MHW participants received CSP services in the last 3 months. The majority of respondents (93%) felt their CSP knew what kind of help they needed, and between 85-95% of MHW participants responded always or usually in response to the other CSP experience questions (Figure 39). However, similar to RAs, when asked to rate their CSPs, just 58% of participants would rate them as excellent (Figure 4).

Figure 39. Community Service Provider Experience



The MHW survey asked just one of the four medical transportation items: How often did you have a way to get to your medical appointments? MHW participants were not asked about their use of or experience with a van service for medical appointments. Ninety percent said they usually or always had a way to get to their medical appointments (Table 18).

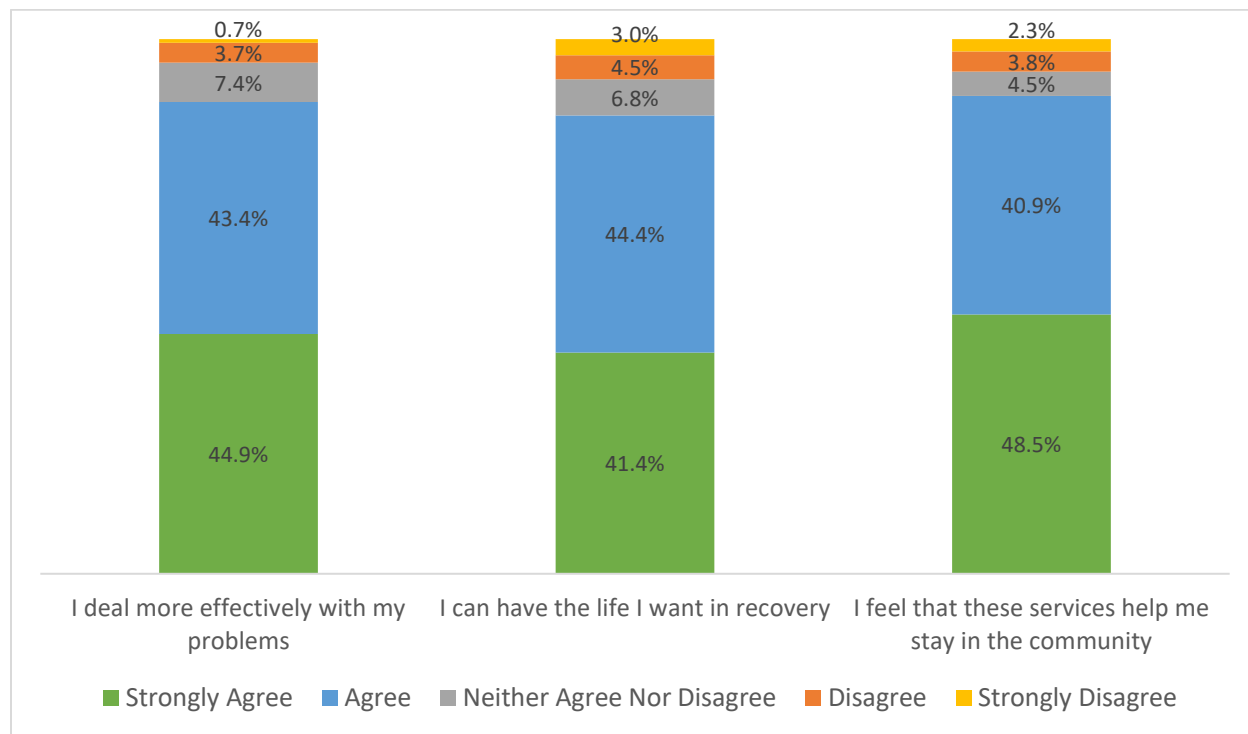
Table 18. Had a Way to Get to Medical Appointments (Positive responses)

N=136 n (%)	
Always	99 (72.8)
Usually	24 (17.6)
Sometimes	11 (8.1)
Never	2 (1.5)

iii. Mental Health Waiver Participant Experience

MHW participants were asked to what extent their MHW services affected their lives in three key areas (Figure 40). Overall, participants gave positive responses – 86% or more either agreed or strongly agreed with each statement. In particular, 89% of MHW respondents agreed or strongly agreed that the MHW services helped them stay in the community.

Figure 40. Mental Health Waiver Participant Experience



IV. Conclusions

This is the eighth year Connecticut has used the HCBS CAHPS survey to inform quality measurement in seven of its Medicaid HCBS programs (CHCP Categories 3 and 5, PCA, ABI I and II, Autism, and KBW). As a standardized, cross-disability survey, the HCBS CAHPS provides Connecticut with the ability to compare participant experiences in the same domains across different waivers. The HCBS CAHPS survey is also

part of quality and performance assessment for the Access Agencies contracted to provide CHCP, PCA, and ABI case management services. This is the third year the MHW has used a subset of the HCBS CAHPS survey questions in a separate annual MHW survey. This report presents results from surveys conducted in FY 2025, from July 1, 2024 to July 31, 2025.

A. Survey Completion Rates

In FY 2025 each Access Agency met or exceeded their respective representative samples for CHCP Category 3, PCA, ABI 2 programs. Three agencies did not meet their sample size for CHCP Category 5. AASCC met just 46% of their representative sample, completing 10 of their 22 surveys. CCC Eastern Region was just two surveys shy of meeting their Category 5 representative sample, and WCAAA was just one survey away from meeting their Category 5 target.

In addition to Category 5, ABI 1 or ABI 2 consumer numbers can also be small, especially if the agency provides services to either a limited number of towns or to a more rural area. This makes reaching the representative sample size much more of a challenge as it requires a significantly higher response rate than for larger sample sizes. For the smaller programs in particular, client attrition over the course of the fiscal year can greatly affect the agency's ability to reach the representative sample size determined by the client numbers at the beginning of the fiscal year. For example, CHCP Category 5 can lose clients if they become eligible for Category 3. One recommendation is to redetermine the sample size needed halfway through the fiscal year to see if the number of clients in that program has decreased. Another suggestion is to combine Categories 3 and 5 into one CHCP program, and to consider combining ABI 1 and ABI 2 into one ABI program. Another possibility is to revise the calculation of the sample size especially for very small sample sizes, where as high as a 70% response rate is needed to reach the representative sample size.

For the first time since the implementation of these surveys, the Katie Beckett Waiver program met and exceeded their representative sample size. This year UConn Health Center on Aging (UConn) administered the Katie Beckett and Autism waiver surveys instead of DSS staff. As in previous years, the Autism and Mental Health waivers did not reach their representative sample sizes – Autism completed 96% (n=144), and MHW 84% (n=192) of their respective sample sizes. However, the response rate for Autism improved drastically over last year when just 44% of the Autism surveys were completed. Although the MHW did not reach its representative sample, it still maintains a relatively high response rate due to their revised survey and self-administration option. Results from all surveyed programs or waivers are presented, even those which did not reach 100% sample size, as these can still show program trends. Reaching the statistically derived representative sample, or close to this number, allows for a more accurate assessment of participants' experiences across waivers. UConn's multipronged approach to recruitment, beginning with sending DSS approved notification letters, likely helped lead to an improved response rate. This was followed by 5-10 call attempts made during the day and evening. UConn's greater flexibility to accommodate the participant's schedule also increased survey complete rates. The support and commitment of both the Katie Beckett and Autism waiver program managers and Autism case managers was also essential. In addition to providing the waiver participant lists including the contact information for any parent or legal guardians, both Katie Beckett and Autism program managers provided a designated waiver contact name and telephone number to include in the letter, encouraging participants or their parents/legal guardians to call if they had any questions about the survey or its legitimacy. Autism case managers also looked up contact information for some consumers whose letters were returned. Enhanced strategies, especially to reach the consumer by telephone, would likely further improve the MHW survey numbers. As the training and technical assistance provider, UConn is available to support the development of an enhanced recruitment strategy to increase the number of MHW surveys completed by telephone.

B. Key Results by Program

Composite measures

The composite item scores varied among the composites and the programs. Choosing the services that matter to you once again showed the greatest variation this year. KBW again stood out as having the lowest score for this composite, which is not surprising considering the limited services provided by this waiver.

Community inclusion and empowerment had lower scores across all the programs relative to the other composites, with KBW again having lowest score. All waivers reached high scores across the other composites. The MHW survey only included enough items for 2 of the 7 composites: personal safety and choosing services.

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

Choosing the services that matter to you assesses whether the consumer's care/service plan includes the things that are important to them and if their staff know what is on their care plan. These items speak to person-centered care as well as choice. CHCP, PCA, and ABI had higher scores in this composite compared to MHW, Autism, or KBW. Using standardized methods to elicit from each individual what is important to them (e.g., SMART goals), incorporating these into their care plan, and effectively communicating this to all staff would improve services for waiver participants. However, this can be difficult if the staff are not available to implement the care plan. Autism consumers in particular commented on the lack of staff or agencies which provide Autism services in their areas.

The respite and the assistive technology has been great. There are not a lot of service providers available where we live. It is hard to use the waiver opportunities when there aren't any available. Autism

- ***Community inclusion and empowerment***

The items in the composite community inclusion and empowerment assess the participant's ability to choose and control their social interactions, community engagement, and daily activities. As in previous years, consumers in all waiver programs gave this composite lower scores. Multiple issues may contribute to these low scores, including waivers not providing or supporting these opportunities, not having the assistance needed to participate, or a lack of nearby community activities. Lack of transportation to these activities can also be a problem, not just for community engagement but also increased personal autonomy. Meaningful community involvement, social engagement, and enhanced choice and control are all important elements of successful community living, and these areas represent an opportunity for improvement across all programs.

Case Manager Items

The majority of CHCP, PCA, ABI, and Autism consumers (84% to 98%) knew who their case manager was, compared to 66% of KBW respondents. KBW case management is currently provided by various home care agencies which confused some respondents and left others feeling like they were not getting the case management support they needed. As in previous years, CHCP participants gave their case managers the highest ratings and recommendations among all the programs. Eighty-three percent of CHCP participants gave their case manager the highest rating, and 85% would definitely recommend their case manager. Remarks indicated that consumers across programs highly valued case managers who responded to their calls in a timely manner and tried to address issues. Respondents also gave high scores for case managers who listened empathetically and made an effort to understand and not dismiss their concerns. Participants also appreciated case managers they could rely on.

I love the case manager. She is really good and she listens. She answers me anytime I talk to her.
Autism

Every time [my son] needs something [his case manager] helps us. ABI

Between 71-90% of PCA, CHCP, ABI, and Autism participants said they would contact their case manager if they wanted to change their service or care plan, compared to 33% of KBW respondents. Comments from participants in all waivers suggested that consumers had needs which case managers might be able to assist with, such as finding transportation, contacting home care agencies, getting food stamps, filling out paperwork, or accessing durable medical equipment. KBW parents in particular expressed the need for increased case manager support, often remarking that their sole contact with the nurse case manager was limited to their child's annual reassessment. Commented one KBW parent, "Quarterly check-ins from the case manager would be helpful."

The scores and comments about case managers also indicated that there is still room for improvement. In addition to providing a timely and empathetic response, Access Agency case managers, KBW nurse case managers, and DSS waiver program staff could improve communication by returning calls more quickly and effectively communicating any change in case managers.

Staff Ratings and Recommendations

Overall, PCA and CHCP participants were more likely than other program participants to highly rate their PCAs. Eighty-one percent of CHCP and 84% of PCA respondents would give their PCAs a 9 or 10, compared to 54%-73% of the other waiver programs. PCA and CHCP participants were also more likely to highly rate their homemaking staff. Meanwhile, only 54-58% of MHW participants gave their RAs or CSPs a 9 or 10. Positive comments about HCBS staff included:

Everything is great and both my caregiver and care manager are the best. CHCP

I'm happy with the case manager and the job skills coach. They are very respectful in the house, very respectful to my son, and I have no complaints. They always ask if there are any questions we need or help. Autism

My personal care agency is great, and I am happy with my caregivers and [case manager name].
CHCP

My PCAs are the best. CHCP

- ***Staffing issues***

Although many consumers had good experiences with their services, comments also pointed to systemic HCBS issues such as staff shortages, untrained staff, turnover, and low pay. Participants mentioned difficulties with consistency, reliability, and quality of staff, overall lack of HCBS staff, lack of agency supervision, staff coming late or not at all, and difficulties finding weekend and back-up staff.

[I had] issues with stand in PCAs while regular one was gone – issues with consistency and understanding of what live-in PCAs are required to do. PCA

[We were] approved for more services but every agency we've spoken to says there's no staff available. KBW

Los servicios que recibe están bien, pero con el cambio de agencia redujeron servicios que son necesario. [The services he receives are good, but with the change of agency they reduced services that are necessary.] ABI

I have been treated badly by the caregivers sent here, and they do not want to work – they just come to collect a check. CHCP

Another common theme was going through several staff before finding someone who provided quality, skilled care or who was the “right fit.” Participants across programs sometimes had to change agencies as well, often due to the agency not providing good quality, dependable, and reliable staff. Respondents also mentioned challenges such as an apparent lack of oversight or supervision by the agency for staff they provided.

I feel that there is not a lot of oversight in this program. We've had trouble in this area, we have gotten staff that don't know about Autism which leads to not good care for [consumer]. As a family member you get stuck because there is not a lot of providers, you have to manage with what you have. I don't know if the agency needs more funding or what, but I don't think the staff in our home get consistent oversight. We've definitely had a lot of problems in the past, but we really just have to pick and choose our battles. There's been times when I really wonder what the staff are doing when they are with him. I wish there was more consistency and we didn't have to have new or rotating staff all the time. Sometimes they tell us that they have to pull his staff person for the day because they're needed elsewhere – it makes it feel like others are more important than our needs. Autism

Having reliable and consistent staff is important to providing person-centered care, especially for individuals with medical concerns or who need specialized support. It can take time for a staff person to learn about the individual and how to best assist them. With each change in staff, the new staff person has to be trained or learn how to provide the best care for their new client.

Both self-directing consumers and those using agency-based services expressed the need for a better trained and qualified workforce, including working with specific populations. Increasing workforce training opportunities for agency-based and participant-employed HCBS staff would also help those working in this field to expand their skill sets and gain specialized skills. Comments indicated a need for the state to focus on workforce development – building a quality, trained, and well-staffed workforce – as well as focusing on improving person-centered care at the state and HCBS agency level.

- **Self-Direction**

PCA and KBW respondents were the most likely to hire their own staff, with 65% of PCA and 62% of KBW self-hiring. Consistent with previous years, a much smaller percentage of CHCP participants (12%) self-directed their services. However, these CHCP participants were the most likely to hire family members – 67% of self-directing CHCP hired family members compared to 50-52% of PCA and KBW. Benefits of self-direction include the ability to choose who works with you, determine the hours and tasks to be provided, manage staff directly, and hire family members. In addition, self-directing one's paid caregivers can build self-efficacy and self-empowerment. However, self-directing consumers still had difficulties finding appropriate primary and back-up staff. A regularly updated PCA and other HCBS staff directory, including descriptions of specialized skills such as dementia or life skills coach training, would be very helpful for self-directing consumers.

This reporting year marks over one year since the change of the state's fiscal intermediary from Allied to GT Independence. Despite expectations for improvement, much of the same feedback levelled against Allied was repeated regarding GT Independence. Although one ABI participant remarked that GT Independence, “Has made it easier to get people approved as an ILST,” other respondents consistently expressed challenges such as reaching someone at GTI, getting problems resolved, and getting payments processed.

I wouldn't do the self-hire program again because of GT independence. They have no idea what they're doing there. I had to call them so many times with no response or help. I'll never do it again. Autism

Well, I am really glad he has the Autism waiver program – they are helping him tremendously and he has excellent caregivers. None of which I found through the GT independence list or Allied list – I found them on my own. Anyone I found through the list was not worth having. Autism

Importance of Family and Informal Supports

Comments indicated the important role families play in providing unpaid care for their loved one. Often the waiver approved services or budget do not cover all the assistance the participant needs, such as transportation, specialized services, overnight care, or enough hours. Participants remarked on the support they received from their family members, such as the CHCP participant who said, “My aide is so good to me and does so much to help me. My daughter lives here and does so much too.” Some family members found providing unpaid care and support to their loved ones challenging – physically, emotionally, and financially. KBW parents especially remarked on the constant care they provide to their children on the waiver.

My daughter has lots of medical needs, and without a nurse she can't go in the community. For me it's hard to be with her all the time. At school, she has a nurse who helps her. She has a digestion problem, and she constantly needs help. When she goes to the community, like a park, I need to be with her or my husband. I can't work because I have to take care of her. Even at nighttime it is a little complicated, because I need to watch her every 2 hours and it's very hard.
KBW

At the same time, family caregivers acknowledged that their unpaid support allowed their loved one to live in the community. Many waivers include respite services, although finding staff and using it can be challenging. Expressed a family member of a PCA participant, “I wish there was easier access to respite care.” Some of the parents or family members were able to get paid for their assistance through Community First Choice or Adult Family Living. Providing more information on these options would be very helpful for participants and family members.

Transportation

Transportation to medical appointments often has mixed reviews based on consumer experience. Although the medical transportation provider changed in FY 2024, participants continued to face similar issues getting to medical appointments, such as rides not coming on time and overall lack of reliability. Commented one ABI participant, “Transportation is horrible.”

Challenges with transportation in general, not just to medical appointments, were mentioned repeatedly by participants across all waivers. Town provided transportation services often only cross town lines for medical appointments, not for social activities, volunteering, or work. Participants often rely on their family or PCAs for non-medical outings, such as errands, shopping, social activities, or work, as well as getting to medical appointments. It was clear from comments that the implementation of a low cost, accessible, nonmedical transportation service that would not be limited by town lines would have a strong positive impact for waiver participants.

I'd like to volunteer somewhere for a few hours per week, but I have no transportation to get there. CHCP

Transportation is a problem – lack of transportation and a lower income. ABI

We would love transportation for [consumer] to get to and from work. The Agency does not provide that service and the Autism waiver does not pay for that. Autism

I wish there was other transportation options for a wheelchair van that was not limited to medical appointments. ABI

Program Services

When asked for any additional comments, many consumers expressed that they were “satisfied” with their services, such as the ABI respondent who commented, “Overall we are satisfied and happy with the services he receives.” A few Autism participants were newly accepted to the Autism waiver. They were very happy to finally be on the waiver – “It’s like hitting the lottery.” Unfortunately, some of these participants ran up against lack of available staff or agencies when they tried to access services.

As I said, we waited over 10 years for a slot to open up. ... [The agency] came down and then they told me they couldn't find anyone to work with [my children]. I've heard, "Gee if only there were services in your area" since kindergarten. ... It's extremely frustrating since they need the help, they need a job mentor, they need a community mentor. The waiver says they provide that, but the state has had nobody in that position. It is hard to take it seriously when nothing is happening. Autism

Participants across all programs expressed the need for additional services, such as more hours or overnight care. A few comments indicated unmet needs for assistive technology, equipment, or home modifications.

I need more hours and a steady person. CHCP

[I am] satisfied [with services], but I need a walker and commode. CHCP

I'd love to get more services for my grandfather, at least a 24/7 due to his Alzheimer's. CHCP

We are waiting on the ramp to be approved and built to be able to get her out of the house and to her appointments. She can't get out of the house without the ramp. CHCP

Respondents also expressed a need for more information about waiver and other community-based services changes. Participants and their family members would benefit from DSS and case managers effectively communicating the services provided by the waiver, in addition to other community-based services they could take advantage of. This was especially true for KBW participants. While some KBW respondents were grateful for the waiver services they had, especially the medical equipment and supplies, many wanted to know what services were provided by the waiver.

The waiver is good for us because it pays for medical equipment like diapers or feeding tubes, which isn't covered by the primary insurance. KBW

I would like to have more information about what is included in the Katie Beckett waiver program. ... If once you get accepted, it would be great to get a list of the services that are included. All I know is someone comes in every 6 months for an evaluation and that's it – they leave. KBW

I think the program needs better communication and direction once you're in it. I never know if I'm calling the right person or if there is someone better I should contact. It would be nice if they provided some kind of clear cut outline of who to contact for what regarding the program, what the benefits are, etcetera. I don't know if I get all the benefits my son is entitled to. KBW

C. CHCP, PCA, and ABI Performance Benchmarks

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

mean scores and were determined using the CHCP data from initial survey testing. The benchmark scores to meet for each performance measure are:

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

CHCP programs

Agency S, Agency A, and Agency M met the performance benchmarks for three of the five performance measures. Agency G scored substantially below the benchmark for case manager is helpful (3.10 vs. 3.5) and fell just below the benchmark for case manager recommendation (3.47 vs. 3.5). The CHCP performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.10-3.93
- Choosing the service which matter to you composite: 3.62-3.82
- Personal safety and respect composite: 3.89-3.95
- Case manager global rating: 4.55-4.88
- Case manager recommendation: 3.47-3.90

PCA waiver

Three Access Agencies met the benchmark for all five of the PCA benchmarks – Agency G, Agency S, and Agency A. Agency M met the performance benchmarks for three of the measures, but scored below the benchmark for two measures: case manager global rating (4.38 vs. 4.5) and case manager recommendation (3.23 vs. 3.5). The PCA performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.57-4.00
- Choosing the service which matter to you composite: 3.66-4.00
- Personal safety and respect composite: 3.77-3.98
- Case manager global rating: 4.38-4.95
- Case manager recommendation: 3.23-3.90

ABI waiver

Three Access Agencies provide case management for the ABI waivers (Agency E, Agency X, and Agency J). All three agencies met the ABI performance benchmarks for four of the five ABI Benchmarks, while Agency E fell just below the threshold for case manager global rating (4.48 vs. 4.5). The ABI performance benchmark scores across all Access Agencies ranged from:

- Case manager is helpful composite: 3.84-4.00
- Choosing the service which matter to you composite: 3.65-3.85
- Personal safety and respect composite: 3.78-3.96
- Case manager global rating: 4.48-4.76
- Case manager recommendation: 3.68-3.86

D. Mental and Emotional Health

Despite the improvement shown by several waivers in 2025, mental health continues to be an area of concern in the majority of waiver programs. Twenty-one to 23 percent of Autism, ABI, PCA, and CHCP participants reported fair or poor mental or emotional health, as did 35% of MHW participants. Still, comments from MHW participants indicated the essential way this waiver supports them and positively impacts their lives.

I've been on the [Mental Health] waiver for a while, and my life has only progressed and gotten better. Without these programs, I wouldn't be alive today. I am so grateful. I have [had] no police contact, no court date, no affiliation with the judicial system at all for 10 years. I sincerely appreciate the programs; I wouldn't be alive today without them. MHW

Because of the access I have from the [MHW] program, I'm alive, well, and stable. The only reason was getting the formula right – treating mental health, treating alcohol and addiction. I am literally alive from the programs. Thank you. MHW

A large majority (87%) of MHW participants lived alone or without other adults, as did between 60-63% of PCA, ABI, and CHCP participants. Waiver sponsored volunteer programs across the state could be one way to increase social connections and at the same time expand employment skills. Another way to increase social engagement might be to strengthen organized peer supports, drawing upon experienced self-advocates and other stakeholders as facilitators. Another recommendation is for DSS to reach out directly to waiver participants and ask what would be helpful for them to increase their community engagement and socialization.

E. Employment

Similar to last year, 38% of all Autism participants reported being employed. The employment rate of ABI participants decreased by 4 percentage points this year to 17%. Unemployed Autism respondents were much more likely to want to work compared to unemployed ABI or PCA respondents.

Similar to previous years, unemployed respondents who wanted to work most often reported that physical health, mental health issues and disability related concerns prevented them from working. Working for pay can increase both social and financial well-being. The state could explore ways to encourage participant employment, such as learning from the experiences of other waiver participants who are successfully employed and coordinating more with the Bureau of Rehabilitation Services.

F. CHCP, PCA, ABI Additional Data by Agency

Additional CHCP, PCA, and ABI data by agency was given for the three case manager related composite measures, case manager global rating, and case manager recommendation using the percentage of participants who gave the highest or most positive score. Scores showed great variation among agencies, programs, and items.

Percentage of CHCP participants who gave the highest score for case manager is helpful composite varied widely across the agencies, from 78% (Agency G) to 98% (Agency A). Scores for choosing the services that matter to you also varied, from 77% (Agency S) to 88% (Agency G and Agency A). As might be expected from previous data, scores for personal safety and respect showed little differences across agencies (97-98%). Between 55% (Agency M) and 91% (Agency A) would rate their CHCP case manager a

9 or 10, while from 53% (Agency G) to 93% (Agency A) would definitely recommend their CHCP case manager.

Scores for most of the PCA composite, rating, and recommendation measures showed much variation across agencies. Highest scores for the composite case manager is helpful ranged from 58% (Agency G) to 100% (Agency M). Scores for choosing the services that matter to you varied from 81% (Agency S) to 100% (Agency M). Personal safety and respect scores varied much less, from 92% (Agency M) to 100% (Agency A). Percentage who would rate their PCA case manager a 9 or 10 showed great variation, from 46% (Agency M) to 97% (Agency A). At 31%, Agency M also had the lowest score for PCA case manager recommendation, while Agency S had the highest (92%).

Percentage of ABI participants who gave the highest score for case manager is helpful composite did not vary much, with scores from 95% (Agency E) to 100% (Agency J). ABI agency scores for choosing services that matter to you showed more variation, from 73% (Agency E) to 88% (Agency J). Personal safety and respect scores ranged from 93% (Agency X) to 100% (Agency J). Between 68% (Agency J) and 79% (Agency X) of participants would rate their ABI case manager a 9 or 10, while from 73% (Agency X) to 86% (Agency J) participants would definitely recommend their ABI case manager.

G. Mental Health Waiver Consumer Experience

Establishing a routine that enables independence in the community is one goal of the MHW. Recovery assistants work with MHW consumers to develop skills such as bill-paying, meal preparation, and other community skills. MHW participants rated their RAs very highly. From 84-92% of MHW clients responded usually or always to the RA experience questions, such as how often do your RAs listen carefully to you. MHW participants also rated their CSPs very highly. For example, 95% of participants agreed that their CSP encouraged them to do things for themselves if they could, while 93% felt their CSP knew what kind of help they needed. While there were numerous positive comments, some comments indicated room for improvement with their staff experiences. Examples of both experiences include:

[I am] pleased with my staff, my CSP is great, I love her so much. She is available for me to reach out to her if I need her. My clinician and CSP remind me they are both just a phone call away. I am extremely pleased with my staff. I'm hoping my tolerance level to being around people gets better so I can get RA services again. MHW

The recovery assistant had a problem with interrupting me while I was speaking. He also seemed to have personal issues, so he would act strangely at times, without warning and often times he would flake out on plans we had made. Later on he became very lax in his attendance. [The CSP] is always kind and courteous to me, and when I am speaking I feel that she listens with empathy and compassion. We get along well. Sometimes I wished that she could help me out with money matters when I was in a bind, but I understand there are only limited areas she is assigned to help. MHW

When asked to what extent their MHW services helped them deal more effectively with problems, have the life they want in recovery, or stay in the community, at least 86% of participants either agreed or strongly agreed with each statement. In particular, 89% of MHW respondents agreed or strongly agreed that the MHW services helped them stay in the community. Commented one MHW respondent, "The WISE (MHW) program changed my whole life. They made me into a better person and helped me to succeed. The program is great."

H. Final thoughts

Respondents expressed appreciation for their waiver services and commented on the impact of the waiver programs on their lives:

I want it known I'm very grateful and appreciative of my staff and they don't get paid enough. ABI

The program is very helpful to me, if they take it away I don't know what I will do. MHW

The services have been a great help to my mom giving her all she needs. CHCP

The positive part of this program is, and I cannot stress this enough, neither of my children would be independent and able to face the world without the help of the Autism Program. Whatever you need to put down to express that this is essential and necessary to their lives, you put it down. The workers have always treated them as family and humans and not just as their job for the day. They are attentive, and it is invaluable – not just for the kids but also for the parents. I can't be around forever to help, and when I pass away, at least I know that they will have the skills and tools for help. This program is like a safety net for them. Autism

I am happy with the ABI Waiver and my services I get. I have gotten much healthier and eat a very healthy diet. ABI

I value my RA and CSP time. I know a lot of these places are nonprofit and it's a struggle to keep up. I really feel they should be getting paid more. The last 3 months has been a definite improvement – quality of life, emotional life, overall life improvement. I feel like a real person, valued and cared about. Any chances for advocacy in the community, we would like to be a part of. MHW

Without this program it would be impossible to live. I am forever grateful for this company. PCA

The waiver is the best thing that happened to me. ABI

We are very happy and satisfied with the services. It opened up a lot of avenues for my son and he couldn't be more happy. All of the goals that he set for himself were achieved with the help of [his staff]. Autism

- **Moving forward**

As of August, 2025, the Access Agencies will no longer administer the CHCP, PCA, or ABI HCBS CAHPS surveys. UConn Center on Aging will be responsible for completing the CHCP, PCA, ABI, Autism, and Katie Beckett waiver surveys. Beginning in January 2026, the annual HCBS CAHPS will follow a calendar year cycle. Meanwhile, DMHAS staff plan to continue to complete the modified MHW HCBS CAHPS survey using both telephone and consumer self-administration. UConn Center on Aging will continue to provide training and technical assistance, including survey modifications, survey site administration, online platforms for survey entry, training, and other support.

V. Appendices

Appendix A. Composite Measures

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

Appendix C. Mental Health Waiver HCBS Survey – 2022

Appendix A. Composite Measures Items

Staff are reliable and helpful
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?*
Staff listen and communicate well
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?*
Case manager is helpful
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?
Choosing services that matter to you
In the last 3 months, did your [program-specific term for “service plan”] include . . .
In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what’s on your [program-specific term for “service plan”], including the things that are important to you?
Transportation to medical appointments
Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. In the last 3 months, how often did you have a way to get to your medical appointments?
In the last 3 months, were you able to get in and out of this ride easily?
In the last 3 months, how often did this ride arrive on time to pick you up?
Personal safety and respect
In the last 3 months, was there a person you could talk to if someone hurt you or did something to you that you didn’t like?
In the last 3 months, did any {personal assistance/behavioral health staff, homemakers, or your case managers} take your money or your things without asking you first?
In the last 3 months, did any {staff} yell, swear, or curse at you?
Planning your time and activities
In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby?
In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby?
In the last 3 months, when you wanted to, how often could you do things in the community that you like?
In the last 3 months, did you need more help than you get from {personal assistance/behavioral health staff} to do things in your community?
In the last 3 months, did you take part in deciding what you do with your time each day?
In the last 3 months, did you take part in deciding when you do things each day—for example, deciding when you get up, eat, or go to bed?

* Question added by Connecticut

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

Waivers-Programs:

- Acquired Brain Injury Waivers
- Autism Waiver
- Community First Choice
- Connecticut Home Care Program
- Katie Beckett Waiver
- Personal Care Assistance Waiver

CAHPS® Home- and Community-Based Services Survey

Version: 1.0

Population: Adult

Language: English

Connecticut version – 2019

Waivers – Programs

- Acquired Brain Injury Waivers
- Autism Waiver
- Community First Choice
- Connecticut Home Care Program
- Katie Beckett Waiver
- Personal Care Assistant Waiver



Instructions for Vendor

- The interview is intended as an
- File name: CAHPShcbs01192017SurvEng508
Last updated: January 19, 2017

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? [PROBE: Or does someone, like a case manager, social worker, or nurse, call you on the phone to check in with you about your services?]

¹ ☐ YES

² ☐ NO → GO TO [Interviewer - Screening Failed]

⁻¹ ☐ DON'T KNOW → GO TO [Interviewer - Screening Failed]

⁻² ☐ REFUSED → GO TO [Interviewer - Screening Failed]

⁻³ ☐ 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

⁻¹ ☐ DON'T KNOW → GO TO [Interviewer - Screening Failed]

⁻² ☐ REFUSED → GO TO [Interviewer - Screening Failed.]

⁻³ ☐ 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.)

⁻¹ ☐ DON'T KNOW → GO TO [Interviewer - Screening Failed.]

⁻² ☐ REFUSED → GO TO [Interviewer - Screening Failed.]

⁻³ ☐ UNCLEAR RESPONSE → GO TO [Interviewer - Screening Failed.]

[Interviewer - Screening Failed]

☐ Continue anyhow. [CHOOSE THIS IF PARTICIPANT GETS ANY TYPE OF SERVICES, EVEN NURSE CASE MANAGEMENT SERVICES] → GO TO Q4

☐ End Survey → Thank you for your time. Those are all the questions we have.

IDENTIFICATION QUESTIONS

KATIE BECKETT – SKIP TO QUESTION 11.

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

4. In the last 3 months, did you get *{program specific term for personal assistance}* at home?
- ¹ ☐ YES
- ² ☐ NO → GO TO Q6
- ⁻¹ ☐ DON'T KNOW → GO TO Q6
- ⁻² ☐ REFUSED → GO TO Q6
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO Q6
5. What do you call the person or people who gave you *{program-specific term for personal assistance}*? For example, do you call them *{program-specific term for personal assistance}*, staff, personal care attendants, PCAs, workers, or something else?

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

6. In the last 3 months, did you get *{program specific term for behavioral health specialist services}* at home?
- ¹ ☐ YES
- ² ☐ NO → GO TO Q8
- ⁻¹ ☐ DON'T KNOW → GO TO Q8
- ⁻² ☐ REFUSED → GO TO Q8
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO Q8
7. What do you call the person or people who gave you *{program specific term for behavioral health specialist services}*? For example, do you call them *{program-specific term for behavioral health specialists}*, counselors, peer supports, recovery assistants, or something else?

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

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

KATIE BECKETT – SKIP TO QUESTION 48.

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

KATIE BECKETT – SKIP TO QUESTION 48.

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

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

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

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

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

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

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

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

- ¹ ☐ Mostly yes or
² ☐ Mostly no?

- 1 ☐ DON'T KNOW
 -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?
- ¹ ☐ YES
² ☐ NO → GO TO Q26
⁻¹ ☐ DON'T KNOW → GO TO Q26
⁻² ☐ REFUSED → GO TO Q26
⁻³ ☐ UNCLEAR RESPONSE → GO TO Q26
24. In the last 3 months, did you **always** take your medicine when you were supposed to?
- ¹ ☐ YES → GO TO Q26
² ☐ NO
⁻¹ ☐ DON'T KNOW → GO TO Q26
⁻² ☐ REFUSED → GO TO Q26
⁻³ ☐ UNCLEAR RESPONSE → GO TO Q26
25. In the last 3 months, was this because there were no {*personal assistance/behavioral health staff*} to help you?
- ¹ ☐ YES
² ☐ NO
⁻¹ ☐ DON'T KNOW
⁻² ☐ REFUSED
⁻³ ☐ UNCLEAR RESPONSE
26. Help with toileting includes helping someone get on and off the toilet or help changing disposable briefs or pads. In the last 3 months, did you need help from {*personal assistance/behavioral health staff*} with toileting?
- ¹ ☐ YES
² ☐ NO → GO TO Q28
⁻¹ ☐ DON'T KNOW → GO TO Q28
⁻² ☐ REFUSED → GO TO Q28
⁻³ ☐ UNCLEAR RESPONSE → GO TO Q28
27. In the last 3 months, did you get all the help you needed with toileting from {*personal assistance/behavioral health staff*} when you needed it?
- ¹ ☐ YES

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

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

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

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

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

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

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

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

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

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

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

30. In the last 3 months, how often did {*personal assistance/behavioral health staff*} treat you the way you wanted them to? Would you say . . .

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

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

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

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

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

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

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

32. In the last 3 months, how often did {*personal assistance/behavioral health staff*} listen carefully to you? Would you say . . .

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

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

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

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

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

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

- ¹ ☐ YES

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

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

- __ 0 TO 10
 -1 ☐ DON'T KNOW
 -2 ☐ REFUSED
 -3 ☐ UNCLEAR RESPONSE

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

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

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

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

GETTING NEEDED SERVICES FROM HOMEMAKERS

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

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

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

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

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
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO Q55a

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

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

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

- ¹ ☐ YES
- ² ☐ NO → GO TO Q52
- ³ ☐ DON'T NEED → GO TO Q52
- ⁻¹ ☐ DON'T KNOW → GO TO Q52
- ⁻² ☐ REFUSED → GO TO Q52
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO Q52

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

- ¹ ☐ YES

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

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

- ¹ ☐ YES
² ☐ NO → GO TO 54
³ ☐ DON'T NEED → GO TO Q54
⁻¹ ☐ DON'T KNOW → GO TO Q54
⁻² ☐ REFUSED → GO TO Q54
⁻³ ☐ UNCLEAR RESPONSE → GO TO Q54

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

- ¹ ☐ YES
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
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO EM5

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

- ¹ ☐ BENEFITS → GO TO THE ABOUT YOU SECTION
- ² ☐ HEALTH CONCERNS → GO TO THE ABOUT YOU SECTION
- ³ ☐ DON'T KNOW ABOUT JOB RESOURCES → GO TO THE ABOUT YOU SECTION

- ⁴ ☐ ADVICE FROM OTHERS → GO TO THE ABOUT YOU SECTION
- ⁵ ☐ TRAINING/EDUCATION NEED → GO TO THE ABOUT YOU SECTION
- ⁶ ☐ LOOKING FOR AND CAN'T FIND WORK → GO TO THE ABOUT YOU SECTION
- ⁷ ☐ ISSUES WITH PREVIOUS EMPLOYMENT → GO TO THE GO TO THE ABOUT YOU SECTION
- ⁸ ☐ TRANSPORTATION → GO TO THE GO TO THE ABOUT YOU SECTION
- ⁹ ☐ CHILD CARE → GO TO THE ABOUT YOU SECTION
- ¹⁰ ☐ OTHER (_____) → GO TO THE ABOUT YOU SECTION
- ¹¹ ☐ NOTHING/DON'T WANT TO WORK → GO TO THE ABOUT YOU SECTION
- ⁻¹ ☐ DON'T KNOW → GO TO THE ABOUT YOU SECTION
- ⁻² ☐ REFUSED → GO TO THE ABOUT YOU SECTION
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

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

- ¹ ☐ YES → GO TO EM7
- ² ☐ NO
- ⁻¹ ☐ DON'T KNOW
- ⁻² ☐ REFUSED
- ⁻³ ☐ UNCLEAR RESPONSE

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

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

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

- ¹ ☐ YES → GO TO EM8
- ² ☐ NO → GO TO THE ABOUT YOU SECTION
- ⁻¹ ☐ DON'T KNOW → GO TO THE ABOUT YOU SECTION
- ⁻² ☐ REFUSED → GO TO THE ABOUT YOU SECTION
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

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

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

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

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

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

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

EM11. Sometimes people need help from other people to work at their jobs. For example, they may need help getting to or getting around at work, help getting their work done, or help getting along with other workers. In the last 3 months, was someone paid to help you with the job you have now?

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

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

[USE THIS TERM 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 . . .

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

- ⁻² ☐ REFUSED
⁻³ ☐ UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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

- ¹ ☐ YES
² ☐ NO
⁻¹ ☐ DON'T KNOW
⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

__ 0 TO 10

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

Would you say . . .

¹ ☐ Excellent,

² ☐ Very good,

³ ☐ Good,

⁴ ☐ Fair, or

⁵ ☐ Poor?

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ Definitely no,

² ☐ Probably no,

³ ☐ Probably yes, or

⁴ ☐ Definitely yes?

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

ABOUT YOU – THE WAIVER PARTICIPANT

INTERVIEWER: REMEMBER THAT THIS SECTION IS ABOUT THE WAIVER PARTICIPANT. IF A PROXY IS DOING THE SURVEY FOR THE WAIVER PARTICIPANT, USE THE WAIVER PARTICIPANT'S NAME, NOT "YOU."

Now I just have a few more questions about you.

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

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

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

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

84. What is your age?

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

ALTERNATE VERSION: In what year were you born?

_____ (YEAR)

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

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

- 1 ☐ MALE

- ² ☐ FEMALE
⁻¹ ☐ DON'T KNOW
⁻² ☐ REFUSED
⁻³ ☐ UNCLEAR RESPONSE

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

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

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

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

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

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

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

- ¹ ☐ White → GO TO Q92
² ☐ Black or African-American → GO TO Q92
³ ☐ Asian → GO TO Q90
⁴ ☐ Native Hawaiian or other Pacific Islander → GO TO Q91
⁵ ☐ American Indian or Alaska Native → GO TO Q92

- ⁶ ☐ OTHER → GO TO Q92
- ⁻¹ ☐ DON'T KNOW → GO TO Q92
- ⁻² ☐ REFUSED → GO TO Q92
- ⁻³ ☐ UNCLEAR RESPONSE → GO TO Q92

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

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

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

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

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

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

93. What is the language you speak at home?

- ¹ ☐ Spanish,
- ² ☐ Some other language → Which one? _____
- ⁻¹ ☐ DON'T KNOW
- ⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ 1 [JUST THE RESPONDENT] → END SURVEY

² ☐ 2 TO 3

³ ☐ 4 OR MORE

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ YES

² ☐ NO

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ YES

² ☐ NO

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

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

CCCI Eastern region: 860-885-2960

CCCI North Central region: 860-257-1503

CCCI Northwest region: 203-596-4800

SWCAA: 203-333-9288

WCAAA: 203-465-1000

Autism waiver: 860-424-5865

DMHAS: 866-548-0265

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?

¹ ☐ YES

² ☐ NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

¹ ☐ YES

² ☐ NO → GO TO END OF SURVEY

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

¹ ☐ SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT

² ☐ STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

¹ ☐ YES

² ☐ NO → GO TO END OF SURVEY

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

¹ ☐ ANSWERED **ALL** THE QUESTIONS FOR RESPONDENT

² ☐ ANSWERED **SOME** OF THE QUESTIONS FOR THE RESPONDENT

³ ☐ RESTATED THE QUESTIONS IN A DIFFERENT WAY OR REMINDED/PROMPTED THE RESPONDENT

⁴ ☐ TRANSLATED THE QUESTIONS OR ANSWERS INTO THE RESPONDENT'S LANGUAGE

⁵ ☐ HELPED WITH THE USE OF ASSISTIVE OR COMMUNICATION EQUIPMENT SO THAT THE RESPONDENT COULD ANSWER THE QUESTIONS

⁶ ☐ HELPED THE RESPONDENT IN ANOTHER WAY,
SPECIFY _____

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

¹ ☐ SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT

² ☐ STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

- F7. Relationship to participant:
- ☐ Spouse/partner
 - ☐ Adult child
 - ☐ Parent
 - ☐ Attorney or legal representative
 - ☐ 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
- ☐ Other: _____

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 – KBW and Autism, choose this
- ☐ 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. Connecticut HCBS Survey – Mental Health Waiver

Telephone Mental Health Waiver Participant Survey

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

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

GETTING NEEDED SERVICES FROM RECOVERY ASSISTANTS

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

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

3. In the last 3 months, how often did your recovery assistant work as long as they were supposed to?
 - ☐ Always
 - ☐ Usually
 - ☐ Sometimes
 - ☐ Never
 - ☐ Do not know
 - ☐ Refused

4. In the last 3 months, how often did your recovery assistant treat you with courtesy and respect?
- ☐ Always
 - ☐ Usually
 - ☐ Sometimes
 - ☐ Never
 - ☐ Do not know
 - ☐ Refused
5. In the last 3 months, how often did your recovery assistant explain things in a way that was easy to understand?
- ☐ Always
 - ☐ Usually
 - ☐ Sometimes
 - ☐ Never
 - ☐ Do not know
 - ☐ Refused
6. In the last 3 months, how often did your recovery assistant listen carefully to you?
- ☐ Always
 - ☐ Usually
 - ☐ Sometimes
 - ☐ Never
 - ☐ Do not know
 - ☐ Refused
7. In the last 3 months, did you feel your recovery assistant knew what kind of help **you** needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?
- ☐ Yes
 - ☐ No
 - ☐ Do not know
 - ☐ Refused
8. In the last 3 months, did your recovery assistant encourage you to do things for yourself if you could?
- ☐ Yes
 - ☐ No
 - ☐ Do not know
 - ☐ Refused

9. How would you rate the help you get from your recovery assistant?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Do not know
- ☐ Refused

GETTING NEEDED SERVICES FROM CSPs OR CSP CASE MANAGERS

10. In the last 3 months, did you get CSP, Community Service Provider, or CSP case management services? A CSP or CSP case manager helps you with things like benefits, paperwork, and budgeting.

- ☐ Yes → GO TO #11
- ☐ No → GO TO #19
- ☐ Do not know → GO TO #19
- ☐ Refused → GO TO #19

11. In the last 3 months, how often did your CSP come to work on time?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Do not know
- ☐ Refused

12. In the last 3 months, how often did your CSP work as long as they were supposed to?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Do not know
- ☐ Refused

13. In the last 3 months, how often did your CSP explain things in a way that was easy to understand?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Do not know
- ☐ Refused

14. In the last 3 months, did your CSP encourage you to do things for yourself if you could?

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

15. In the last 3 months, how often did your CSP treat you with courtesy and respect?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Do not know
- ☐ Refused

16. In the last 3 months, how often did your CSPs listen carefully to you?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Do not know
- ☐ Refused

17. In the last 3 months, did you feel your CSP knew what kind of help you needed?

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

18. How would you rate the help you get from your CSP?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Do not know
- ☐ Refused

HOME DELIVERED MEALS

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

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

CHOOSING YOUR SERVICES

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

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

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

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

TRANSPORTATION

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

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Do not know
- ☐ Refused

PERSONAL SAFETY

The next few questions ask if anyone paid to help you treated you badly in the last 3 months. This includes an RA, aide, or CSP case manager. We are asking everyone the next questions—not just you. I want to remind you that, although your answers are confidential, I have a responsibility to tell my supervisor if I hear something that makes me think you are being hurt or are in danger.

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

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

24. In the last 3 months, did **any** staff take your money or your things without asking you first?

- ☐ Yes → GO TO #24a
- ☐ No → GO TO #25
- ☐ Do not know → GO TO #25
- ☐ Refused → GO TO #25

24a. In the last 3 months, did someone work with you to fix this problem?

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

25. In the last 3 months, did **any** staff yell, swear, or curse at you?

- ☐ Yes → GO TO #25a
- ☐ No → GO TO #26
- ☐ Do not know → GO TO #26
- ☐ Refused → GO TO #26

25a. In the last 3 months, did someone work with you to fix this problem?

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

26. In the last 3 months, did **any** staff hit you or hurt you?

- ☐ Yes → GO TO #26a
- ☐ No → GO TO #27
- ☐ Do not know → GO TO #27
- ☐ Refused → GO TO #27

26a. In the last 3 months, did someone work with you to fix this problem?

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

COMMUNITY INCLUSION AND EMPOWERMENT

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

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

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

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

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

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Never
- ☐ Do not know
- ☐ Refused

30. In the last 3 months, did you need more help than you get from your staff to do things in your community?

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

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

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

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

- ☐ Yes
- ☐ No
- ☐ Do not know
- ☐ Refused

MENTAL HEALTH WAIVER QUESTIONS

How much do you Agree or Disagree with each statement?

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

☐ Strongly Agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly Disagree
☐ Do not know
☐ Refused

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

☐ Strongly Agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly Disagree
☐ Do not know
☐ Refused

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

☐ Strongly Agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly Disagree
☐ Do not know
☐ Refused

FINAL QUESTIONS

36. In general, how would you rate your overall health?

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Do not know
☐ Refused

37. In general, how would you rate your overall mental or emotional health?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Do not know
- ☐ Refused

38. How many adults live at your home, including you?

- ☐ 1 (Just the waiver participant)
- ☐ 2 to 3
- ☐ 4 or more
- ☐ Do not know
- ☐ Refused

39. What is your age?

- ☐ 18 to 24
- ☐ 25 to 34
- ☐ 35 to 44
- ☐ 45 to 54
- ☐ 55 to 64
- ☐ 65 to 74
- ☐ 75 or older
- ☐ Do not know
- ☐ Refused

40. Are you male or female?

- ☐ Male
- ☐ Female
- ☐ Non-binary (not exclusively male or female, or transgender)
- ☐ Other gender (specify) _____
- ☐ Do not know
- ☐ Refused

41. Are you of Hispanic, Latino/a, or Spanish origin?

- ☐ Yes, Hispanic, Latino/a, or Spanish
- ☐ No, Not Hispanic, Latino/a, or Spanish
- ☐ Other ethnicity (specify) _____
- ☐ Do not know
- ☐ Refused

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

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

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

Thank you for completing this interview with me.

**If you wish to contact Advanced Behavioral Health, Inc. (ABH),
the number is: 860-704-6186.**

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

44. Who completed this survey?

- ☐ The waiver participant on his/her own
- ☐ The waiver participant with assistance from another person
- ☐ A proxy – Someone else completed the survey for the waiver participant

45. Did a Recovery Assistant, Aide, CSP, Case manager, or any other Paid Staff person help the waiver participant complete this survey?

- ☐ Yes
- ☐ No

46. Interview done by:

- ☐ Telephone
- ☐ Video (for example, Zoom, MS Teams, etc.)
- ☐ In-person
- ☐ Other _____

Waiver Participant First Name: _____

Waiver Participant Last Name: _____

ABH Client ID: _____

Interviewer Name: _____

Date Interview Completed: _____