

2023 Annual Report:

Consumer Assessment of Healthcare Providers  
and Systems Home and Community-Based  
Services (HCBS CAHPS<sup>®</sup>) Survey Results:  
Connecticut Community First Choice

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## I. Introduction

Connecticut has seen a growth in the use of Medicaid funded home and community-based services (HCBS) over the past 15 years. According to data provided by the Connecticut Office of Policy and Management, in 2009 53% of Connecticut residents using Medicaid long-term services and supports (LTSS) received these services in the community, and 47% received them in a facility. By 2022, 69% of residents using LTSS received them in the community (*Connecticut Money Follows the Person Report: Quarter 3: July 1 - September 30, 2023*). (2023). UConn Health Center on Aging. Prepared for the Connecticut Department of Social Services). HCBS are provided through various state plan programs and Medicaid waivers. Ten waivers are operated by the Department of Social Services (DSS), including the Connecticut Home Care Program, Personal Care Assistance, Acquired Brain Injury 1 and 2, Katie Beckett, and Autism waivers. Additional waivers are operated by the Department of Mental Health and Addiction Services (DMHAS) and the Department of Developmental Services (DDS). Connecticut state plan HCBS include Community First Choice (CFC), a self-directed 1915k program begun in 2015. CFC provides a broad range of services, including personal attendant services, support and planning coach services, environmental adaptations, assistive technology, electronic back-up systems, and home-delivered meals (Connecticut Department of Social Services (2015) State Plan Amendment 18-U: Community First Choice State Plan Option Pursuant to Social Security Act, 42 U.S.C. § 1915k). If eligible, CFC participants can also receive services from Medicaid waiver programs, providing the additional waiver services do not duplicate their CFC services. Medicaid waiver participants can also receive personal care assistance services utilizing CFC, again providing there is no duplication of CFC and waiver services.

Historically, Connecticut's different HCBS programs have used diverse, program-specific instruments to obtain the participant experience data required for quality assurance by the Centers for Medicare and Medicaid Services (CMS) and DSS. To improve the quality of the data and inform program comparison, Connecticut first implemented the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS®) survey in 2017 in the CHCP, PCA, and ABI waivers. The HCBS CAHPS survey is a standardized, cross-disability tool used to assess and improve HCBS program quality. Using the HCBS CAHPS survey allows for the comparison of various HCBS programs, as individuals with different disabilities respond to the same questions. Connecticut now uses the HCBS CAHPS survey in eight of its Medicaid programs: Connecticut Home Care Program (CHCP) Categories 3 and 5, CFC, and the Personal Care Assistant (PCA), Acquired Brain Injury 1 and 2 (ABI), Autism, and Katie Beckett waivers. In 2022, DMHAS began using a modified version of the HCBS CAHPS survey as its Mental Health Waiver participant survey. Connecticut also uses the survey for program evaluation and quality for additional HCBS programs such as Money Follows the Person. The HCBS CAHPS survey provides Connecticut with one consistent approach to assess quality and facilitate reporting across waiver programs and care management provider agencies. For more information about the HCBS CAHPS survey and its implementation with the waiver programs, please see the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS) Survey Results: Connecticut HCBS Programs Report, 2023.

## II. Methods

### A. HCBS CAHPS Survey

The HCBS CAHPS survey is composed of eleven sections: cognitive screen, identification of paid services, personal assistance and/or behavioral health staff services, homemaker services, case manager services, choosing your services, transportation, personal safety, community inclusion and empowerment, demographics, and an employment module. A participant's waiver or HCBS program determines which staff services to ask about and what terms to use to refer to these services (see Table 1). The HCBS CAHPS survey is attached in Appendix B.

Table 1. HCBS Program Staff Services

	CHCP	PCA	ABI	Autism	Katie Beckett	Mental Health waiver	CFC Only
Personal care assistance/attendant	X	X	X	X			X
Behavioral health			X*	X**			
Recovery assistance						X	
Homemaking or companion services	X	X	X	X			
Case manager	X	X	X	X	X	X	
Support and planning coach							X
Community service provider						X	
Job coach services			X	X		X	

\*Independent Living Skills Training (ILST)

\*\*Life skills coach or community mentor

### B. Survey Administration

Quality assurance staff from CHCP, PCA, and ABI care management Access Agencies complete HCBS CAHPS surveys with a representative sample of their CHCP, PCA, and ABI clients. DSS administers the Autism and Katie Beckett HCBS CAHPS surveys. Beginning in 2019, the UConn Health Center on Aging (UConn) annually conducts surveys with CFC program participants who are not on a waiver (CFC Only participants). DMHAS quality assurance staff administer the Mental Health waiver (MHW) participant survey. Because this survey does include only a small subset of HCBS CAHPS survey items, MHW surveys are not included in this analysis.

As the training and technical assistance provider, UConn provides ongoing training and technical assistance for the quality assurance staff and supervisors from all four Access Agencies, DSS, and DMHAS. UConn provides a secure online HCBS CAHPS platform with program specific surveys. Computer assisted telephone and in-person interviewing programming is used to direct the interviewer to the correct question and accurately follow the skip patterns for each type of survey.

### C. Sampling Methodology

#### i. CFC participants using waiver services

Using client enrollment numbers as of 7/1/2022, DSS determined the target number of surveys for each Access Agency and DSS to reach a representative sample in each of their programs. Using random sampling, Access Agency and DSS quality assurance staff contacted waiver participants from their client lists and invited them to do the survey. Surveys were completed between July 1, 2022 to June 30, 2023. The waiver program random samples included both waiver participants who only use waiver services and waiver participants who use CFC services in addition to the waiver services. Of the 1470 HCBS CAHPS® surveys completed from July 1, 2022 to June 30, 2023, 271 of these participants were identified through administrative data as also on CFC. Collectively, these participants are referred to as the CFC Plus Waiver group. This group includes participants from any waiver who completed the HCBS CAHPS survey and accessed CFC services.

#### ii. CFC participants not using waiver services

To obtain the sample of CFC participants not using waiver services, DSS provided the UConn research team with a list of CFC participants who had a CFC service claim from January 1, 2022 to August 1, 2022, but no waiver claim during this time. MFP participants were excluded, as were participants whose service plan was transmitted to the fiscal intermediary within less than three months to exclude participants who had not yet begun services. Due to limitations in obtaining claims information, the list

included people who were on a waiver. Using information from the Connecticut MyCommunityChoices website, UConn removed participants whose records indicated they were likely using waiver services and assigned the remaining participants into one of three target populations: Developmental Disability (DD), physical disability under 65 (PD), or older adult (OA). Each group was independently randomized. The completed survey sample was to include 25% DD, 50% PD, and 25% OA surveys.

UConn sent notification letters with information about the survey to potential participants. Within two weeks of sending the letter, UConn contacted participants and invited them to do the survey. If there were a conservator or legal guardian listed, UConn sent the notification letter to the conservator/legal guardian and contacted them first before contacting the participant. Surveys were conducted from October 25, 2022 to December 27, 2022. These CFC participants not receiving waiver services compose the CFC Only group.

#### D. Measures

Key results are presented using established HCBS CAHPS® composite and other key measures (see Table 2). Each composite scale comprises three to twelve individual questions (see Appendix A). Additional key results include staff global rating, staff recommendation, unmet need for services, and physical safety. This report also presents results from individual items not covered by these measures.

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 often highlights which programs are delivering the highest quality service. For more information about the HCBS CAHPS key results including their scoring, please see the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS) Survey Results: Connecticut HCBS Programs Report, 2023.

Table 2. Key Measures

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

### III. Results

#### A. Respondent Sample

This report examines three groups of respondents:

- i. Participants who use only CFC services (CFC Only),
- ii. Waiver participants who also use CFC services (CFC Plus Waiver), and
- iii. Participants in both groups combined (CFC All).

Data in figures and tables is presented as CFC Only, CFC Plus Waiver, and CFC All to easily highlight differences between the CFC Only and CFC Plus Waiver groups. Table 3 shows the total sample size for each of the three groups analyzed in this report. See Table 4 for the waiver composition of the CFC Plus Waiver participants.

Table 3. CFC 2023 Annual Report Sample

Participant program	Surveys completed (N)
CFC Only	101
CFC Plus Waiver	271
Total CFC participants	372

Table 4. Waiver composition of CFC Plus Waiver sample

Waiver Program	Surveys completed (N)
CHCPE	20
PCA	166
ABI	72
Katie Beckett	13
Total CFC plus waiver	271

Over 60% of both CFC Only and CFC Plus Waiver surveys were completed by the consumer, with another 31-32% completed by proxy (Table 5). For assisted interviews, the person assisting most often helped by answering some of the questions for the consumer or prompting the consumer.

Table 5. Survey Respondents

	CFC Only n (%)	CFC Plus Waiver n (%)	CFC All n (%)
By self	64 (63.4)	164 (60.5)	228 (61.3)
With assistance	6 (5.9)	20 (7.4)	26 (7.0)
By proxy	31 (30.7)	87 (32.1)	118 (31.7)

#### B. Consumer Demographics

Consumer demographics by program are presented in Table 6. There are noticeable differences between the CFC Only participants and the CFC Plus Waiver participants in every type of demographic data collected. For example, compared to the CFC Plus Waiver group, the CFC Only group has both a larger cohort under age 25 (15% CFC Only vs. 6% CFC Plus Waiver) and a larger percentage of consumers 65 and older (27% CFC Only vs. 14% CFC Plus Waiver). More than three times as many CFC Only

participants identify as Latino (45% vs. 14%), and a larger portion of CFC Only participants speak primarily Spanish (13% vs. 2%). On the other hand, CFC Plus waiver participants are more likely to be female, identify as white race, and have at least some college education.

Table 6. Consumer Demographics\*

		CFC Only %	CFC Plus Waiver %	CFC All %
Age		N=101	N=271	N=372
	<18	8.9	3.0	4.6
	18-24	5.9	3.0	3.8
	25-34	9.9	7.0	7.8
	35-44	8.9	14.8	13.2
	45-54	7.9	19.2	16.1
	55-64	31.7	39.1	37.1
	65-74	23.8	10.0	13.7
	75+	3.0	4.1	3.8
Language		N=100	N=271	N=371
	English Only	55.0	79.7	73.0
	Spanish Only	13.0	1.5	4.6
	Multilingual/ Other	32.0	18.8	22.4
Race		N=99	N=266	N=365
	White	48.5	65.4	60.8
	Black	25.3	27.4	26.8
	Other	26.3	7.1	12.3
Ethnicity		N=101	N=270	N=371
	Non-Hispanic	55.4	85.9	77.6
	Hispanic	44.6	14.1	22.4
Education Level		N=97	N=268	N=365
	< 8th Grade	20.6	4.1	8.5
	Some high school	22.7	11.6	14.5
	High school degree	40.2	49.3	46.9
	Some college	13.4	27.6	23.8
	4-year college	3.1	6.0	5.2
	More than 4 year degree	0.0	1.5	1.1
Gender		N=101	N=271	N=372
	Male	39.6	49.4	46.8
	Female	60.4	50.6	53.2

\*The percentages listed for each item are based on the total number of valid responses to that question (N). Missing data not reported.

### C. Program Service Use

Participants reported using a variety of program services to accommodate their needs in the three months prior to completing the survey (see Table 7). Although 90% of CFC Only consumers reported they used homemaking services, the great majority of these staff providing homemaking support also provided personal care services. Only 8 CFC Only consumers had a staff person they used exclusively for homemaking activities. Despite this small number, the experiences of these 8 CFC Only consumers with their homemaking staff is reported.

CFC Only consumers do not get case management, but they do have the option of hiring a support and planning coach. The case management questions were used to ask CFC Only consumers about their experiences with this type of staff. Support and planning coaches can assist the consumer in many ways, including budgeting for services, implementing the service plan, and hiring, training, and managing staff. Support and planning coach services were enhanced in fiscal year 2020 to expand their services with respect to training and managing staff.

When asked if they knew who their support and planning coach was, defined as “the person who helps make sure you have the services you need,” just 10% (n=10) of CFC Only consumers said they did. Support and planning coaches are most often used for a short time at start of services, so it is not unexpected that few CFC Only consumers used this service in the last three months. These participants then identified various staff who helped them this way. However, based on how these participants often identified their support and planning coaches, for example as a case manager, social worker, or by name, it is difficult to know if that person was hired by the consumer as a support and planning coach. Despite these limitations, what CFC Only consumers reported about their experience in the last three months with these service providers is presented.

Table 7. Program Service Use

	CFC Only %	CFC Plus Waiver %	CFC All %
	N=101	N=271	N=372
Personal care assistant/attendant services	92.1	86.3	87.9
Behavioral health services*		21.4	15.6
Homemaking or Companion services**	7.9	5.5	6.2
Case manager	0	84.1	61.3
Support and planning coach	10.0	0	2.7

\*Independent Living Skills Training (ILST) services (ABI); Life skills coach or community mentor services (Autism)

\*\*These numbers exclude homemaking staff who also provide PCA services.



#### D. Key Results

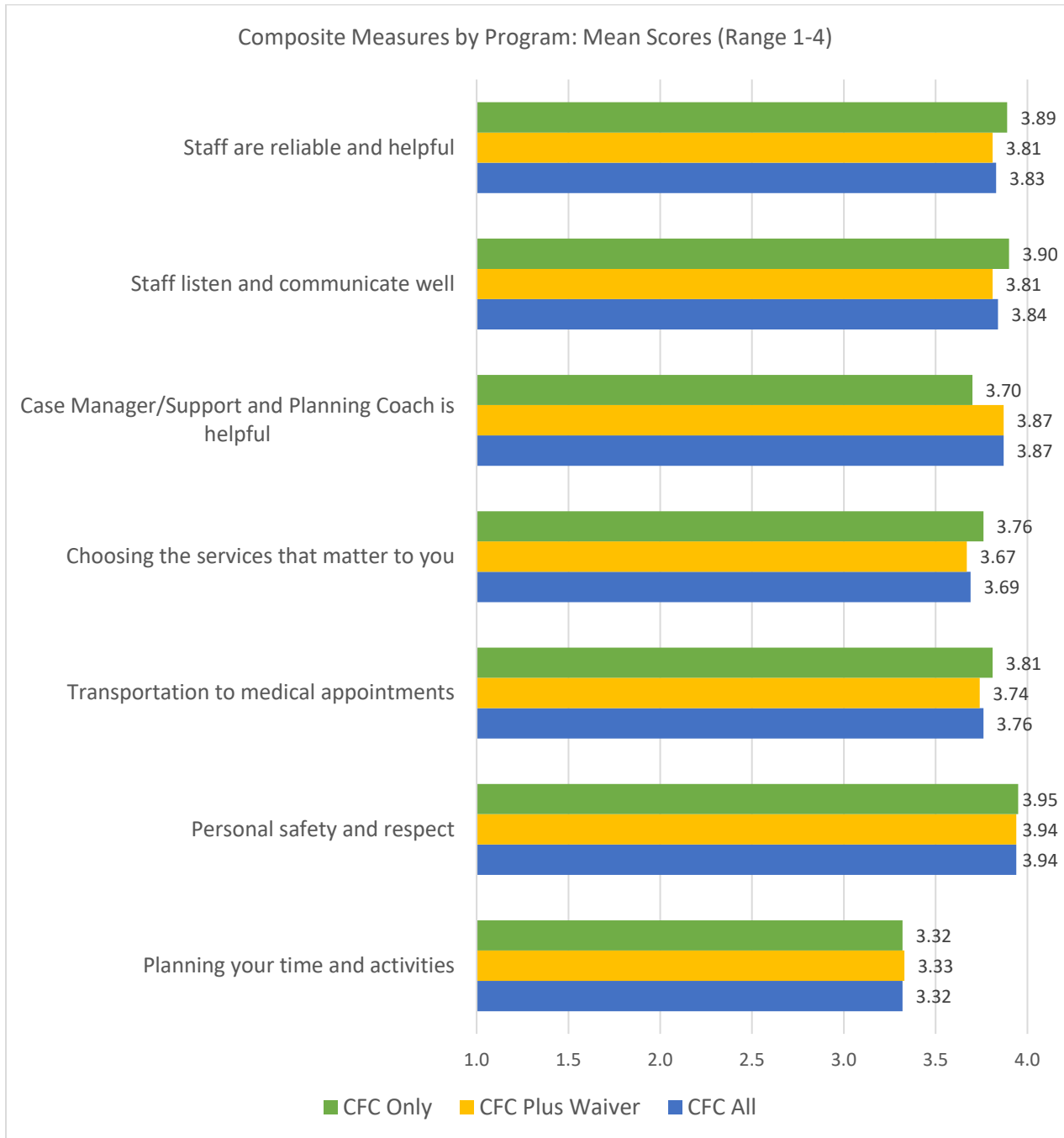
All the key measures (composites and staff global ratings and recommendation) show results for the three groups separately. The composite measures, global ratings, and recommendations by program are displayed two ways: the mean score and the percentage reporting the highest score. As described above, it should be noted that in many instances, the number of CFC Only respondents is considerably smaller compared to the CFC Plus Waiver, which makes some comparisons difficult.

##### i. Composite measures by program

Overall, mean scores for most composite measures were high for both CFC Only and CFC Plus Waiver groups (Figure 1). Following the trends seen in previous HCBS CAHPS reports, participants in both groups reported highest scores for personal safety and respect and lowest scores for planning your time and activities. CFC Only consumers reported better communication with their staff, but reported lower mean scores for the composite Care manager/Support and Planning Coach is Helpful compared to CFC Plus Waiver participants. The CFC Only mean score for the Support and Planning Coach is Helpful composite did increase substantially over the last two years (3.38 in 2022 to 3.70 in 2023).

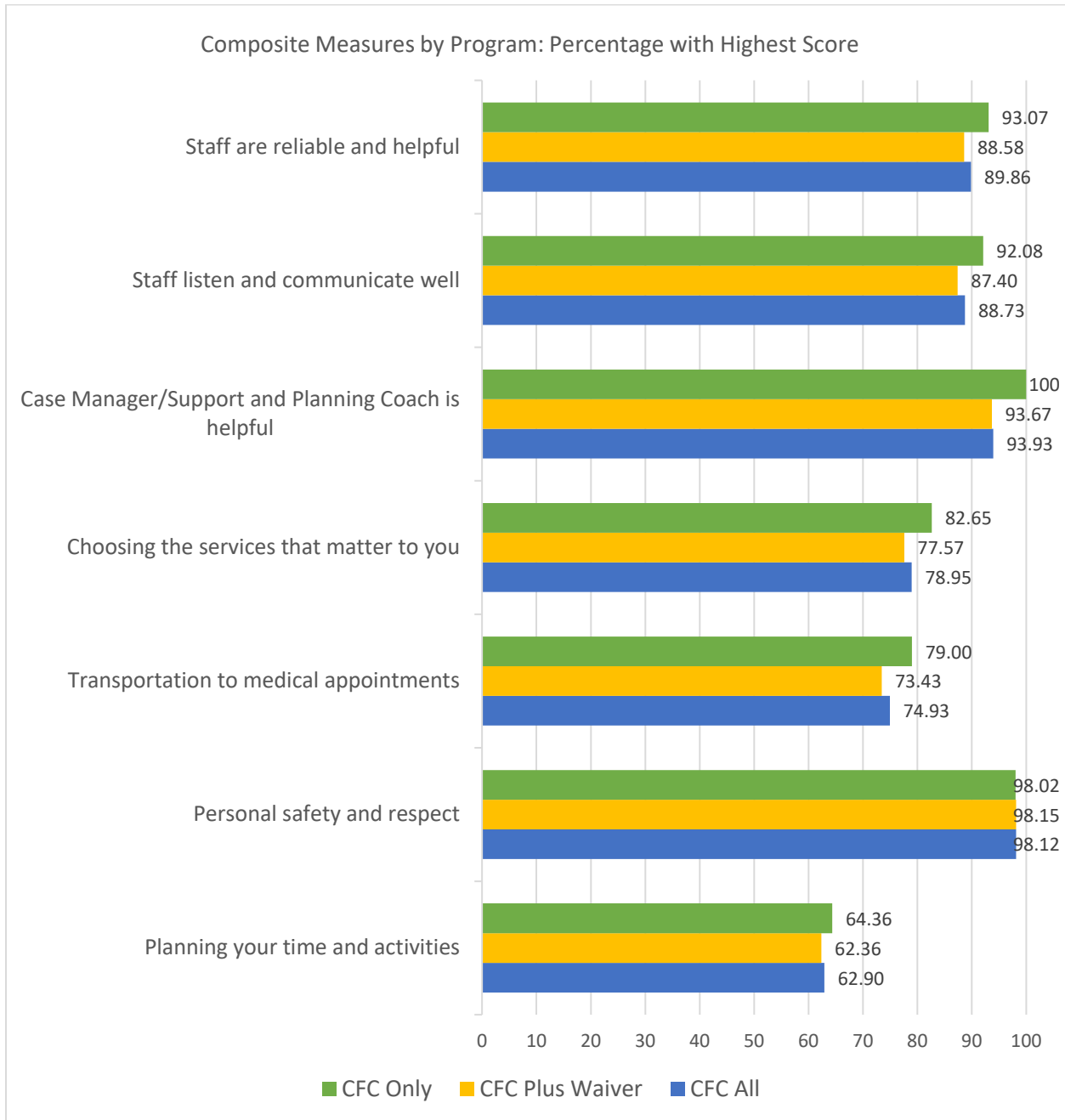
Figure 2 shows the percentage of participants in each program who gave the most positive answer for each composite item – a nine or ten, on a scale from zero to ten. This method usually highlights any differences across composites and populations more clearly. A greater percentage of CFC Only participants gave the highest score for the composites covering staff communication and reliability, transportation to medical appointments, and case manager/support and planning coach helpfulness compared to CFC Plus Waiver consumers. Unfortunately, the small number of CFC Only participants with support and planning coaches makes using the highest score for the care manager/support and planning coach composite less useful than the mean score.

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



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

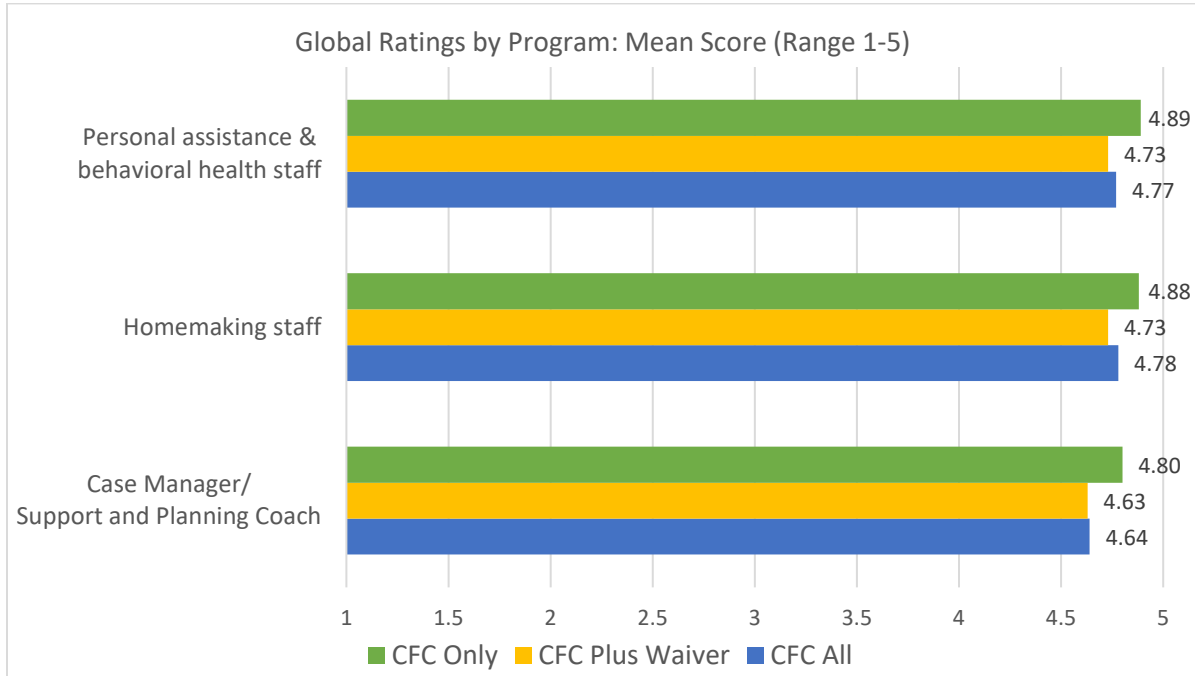
Figure 2. Composite Measures by Program: Percentage with Highest Score



ii. Global ratings by program

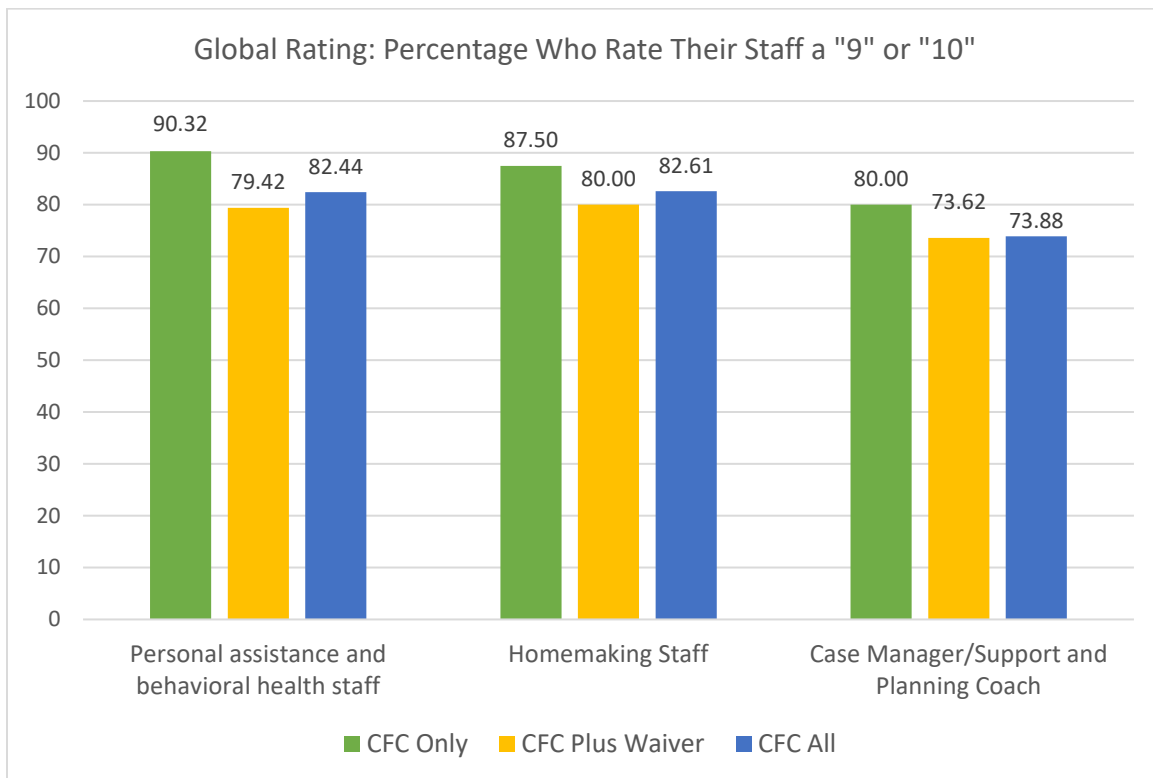
While both groups of CFC participants rated their staff highly, CFC Only participants gave their staff higher mean scores than their CFC Plus Waiver counterparts (Figure 3). Figure 4 presents the percentage of participants in each program who gave their staff the highest rating possible. Compared to 2022, the percentage of CFC participants in both groups who rated their homemaking staff this highly rose notably this year, although the trend of CFC Only participants giving higher scores to their staff was consistent across years.

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



\*In Figures 3, 4, 5, and 6, “Personal assistance & behavioral health staff” combines all PCA, ILST, life skills coach, and community mentor staff. “Homemaking staff” only includes staff who assist exclusively with homemaking tasks or household chores and do not provide personal care.

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



iii. Recommendations by program

When asked if they would recommend their personal care staff, homemaking staff, or case manager/support and planning coach, CFC Only participants recommended their staff more highly than CFC Plus Waiver participants (Figures 5 and 6). For example, CFC Only participants showed strong favorability towards their PCAs, with 99% reporting that they would “definitely” recommend their PCA staff, compared to 78% of CFC Plus Waiver participants (Figure 6).

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

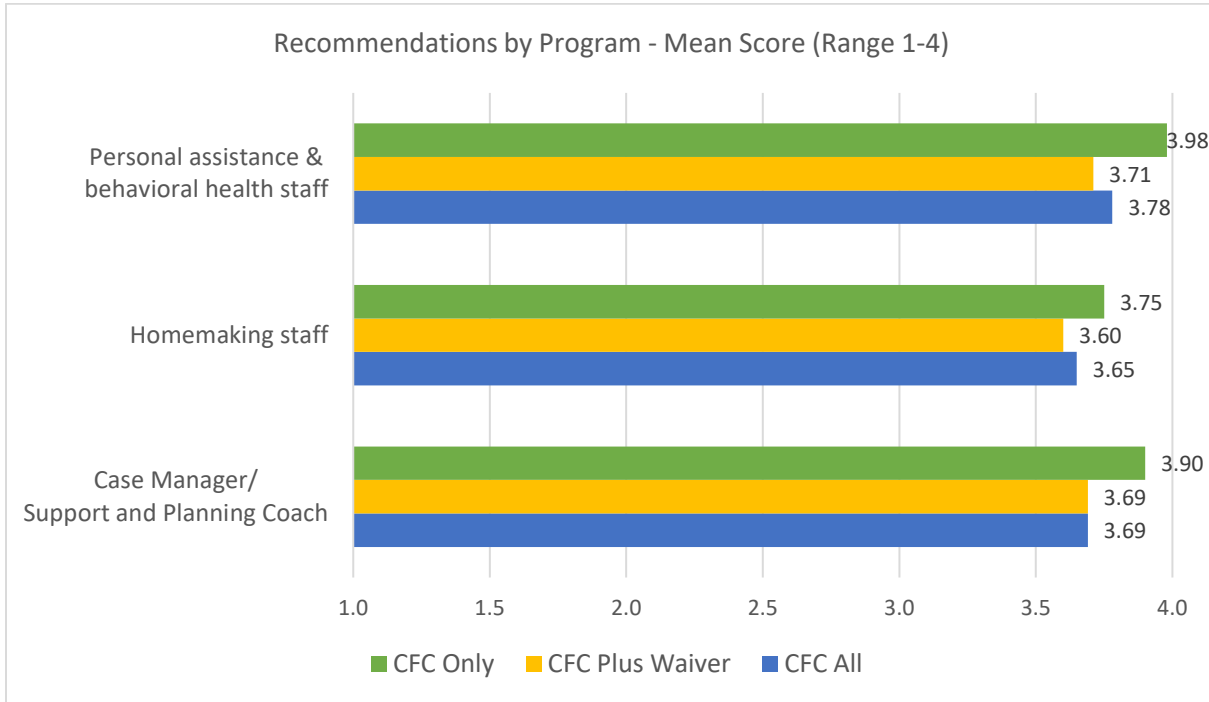
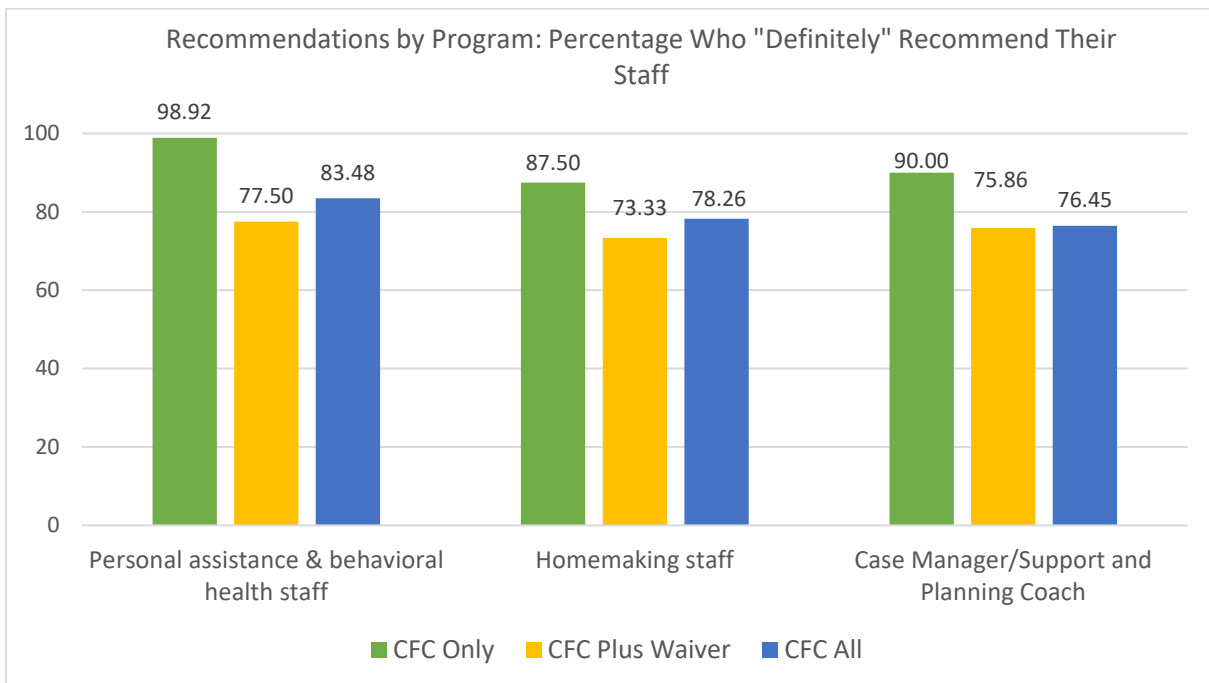


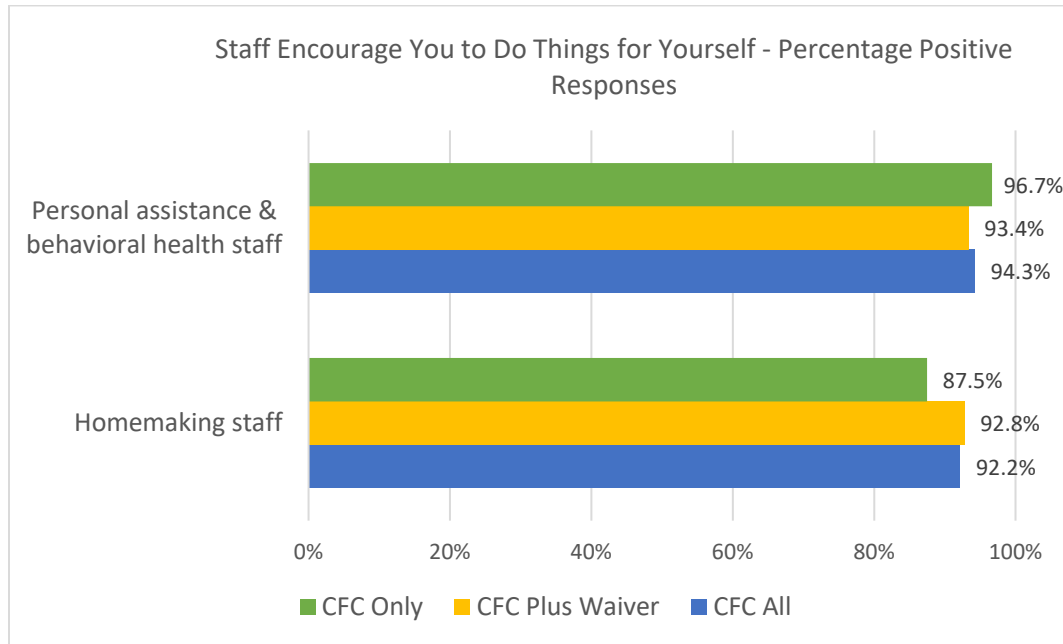
Figure 6. Recommendations by Program: Percentage Who “Definitely” Recommend Staff



iv. Additional staff and case manager measures

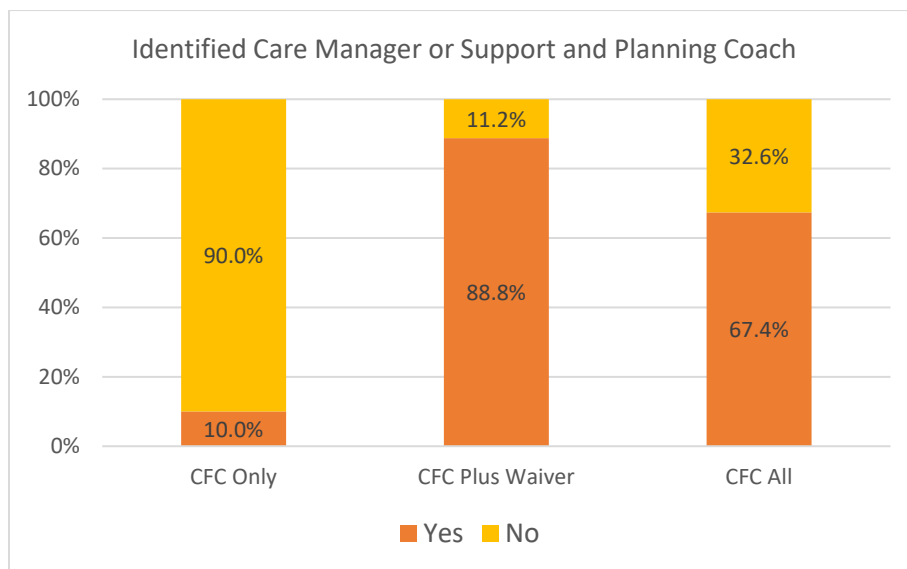
Participants with personal care, behavioral health, or homemaking services were asked, “Did [staff] encourage you to do things for yourself if you could?” As shown in Figure 7, CFC Plus Waiver participants were more likely to report that their homemaking staff encouraged them to do things for themselves if they could.

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



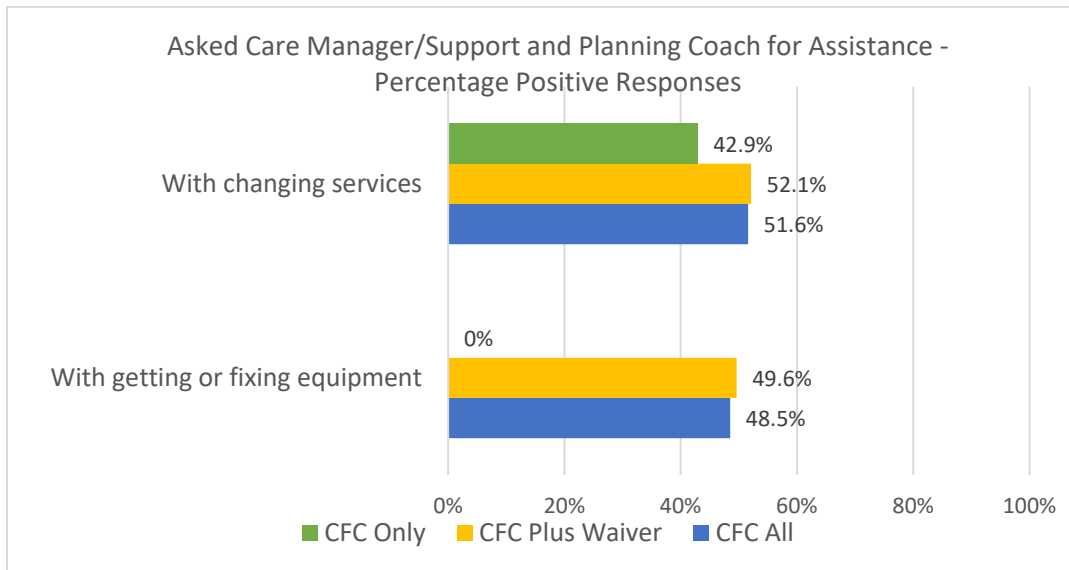
Consistent with previous reports, when asked if they knew who their care manager or support and planning coach was, most (89%) CFC Plus Waiver participants knew their case manager, while only 10% of CFC Only participants identified someone as their support and planning coach (Figure 8). The small use of this service is likely influenced by a variety of factors, including availability of support and planning coaches across the state, that it is an optional service which must be included in the total budget for services, and that support and planning coaches are most often used at the start of CFC Only services but may not be continued.

Figure 8. Identified a Care Manager or Support and Planning Coach



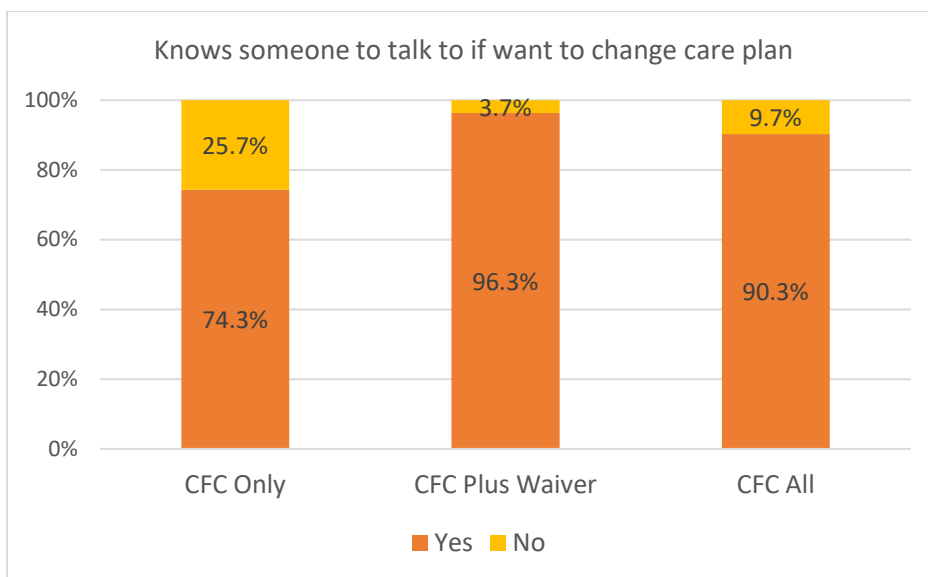
CFC Only participants with a support and planning coach were less likely to ask this staff for help with changing services or for getting equipment compared to CFC Plus Waiver participants with a care manager (Figure 9). Although there are similarities between a care manager for CFC participants on a waiver and a support and planning coach for CFC Only participants, the level of involvement and help navigating services which CFC Only participants are likely to experience from a support and planning coach may be less intensive than what CFC Plus Waiver consumers receive from their waiver care managers.

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



When asked, “In the last 3 months, who would you have talked to if you wanted to change your care plan/service plan?” almost all (96%) CFC Plus Waiver participants knew someone to contact, compared to 74% of CFC Only (Figure 10).

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



When asked to name the person they would talk to, the great majority (90%) of CFC Plus Waiver participants said their case manager (Table 8). Meanwhile, about one-third (32%) of CFC Only participants said they would talk to a person who they identified in various ways, including a social worker or support and planning coach. On the other hand, CFC Only participants would turn to family and friends to a greater extent than CFC Plus Waiver (37% CFC Only, 14% CFC Plus Waiver). Although not shown on the table, 26% of CFC Only participants did not know who they would talk to in order to change their service plan, compared to just 3% of CFC Plus Waiver participants.

Table 8. Who Would You Talk to if You Wanted to Change Your Care Plan?\*

	CFC Only N=75 n (%)	CFC Plus Waiver N=261 n (%)	CFC All N=336 n (%)
Waiver case manager	0 (0)	234 (89.7)	234 (69.6)
Support & planning coach, assessor, or social worker (CFC Only)	24 (32.0)	0 (0)	24 (7.1)
Other staff or home care agency/provider	13 (17.3)	16 (6.1)	29 (8.6)
Family/friends	28 (37.3)	36 (13.8)	64 (19.0)
Someone else	12 (16.0)	16 (6.1)	28 (8.3)

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

v. Unmet needs

CFC Only and CFC Plus Waiver participants who reported receiving some type of personal care, behavioral health, or homemaking paid assistance were further asked if they needed help with five everyday activities (Table 9). Noticeably more CFC Only participants reported a need for assistance with personal care and using the toilet.

Table 9. Self-reported Assistance with Everyday Activities

Needs assistance with:	CFC Only n (%)	CFC Plus Waiver n (%)	CFC All n (%)
Personal care	89 (95.7)	211 (86.8)	300 (89.3)
Meals or eating	92 (98.9)	228 (93.8)	320 (95.2)
Taking medications	76 (81.7)	192 (79.0)	268 (79.8)
Using the toilet	64 (68.8)	142 (58.4)	206 (61.3)
Housekeeping or laundry	87 (95.6)	68 (98.6)	155 (96.9)

To determine unmet need in these areas, participants who needed assistance with these activities were asked if they did not do the activity in the past three months specifically due to a lack of staff to assist them. Eight of CFC All participants indicated any unmet need: 3 for personal care, 2 for household tasks, 1 for medications, 1 for toileting, and 1 for meals or eating (separate items, can report more than one).

vi. Physical safety

Participants were asked, "In the last 3 months, did any {staff} hit you or hurt you?" to determine if any physical abuse took place. One CFC Plus Waiver participant reported being hit by a staff person in the last 3 months, and stated that a family member or friend was working with them to fix the problem.



E. Additional Findings

i. Living situation and social support

As shown in Table 10, CFC Plus Waiver participants were more likely to live alone or without other adults (55% CFC Plus Waiver vs. 38% CFC Only). For CFC participants who lived with others, CFC Only participants were more likely to live with family (92%) compared to CFC Plus Waiver participants (83%). On the other hand, proportionately more CFC Plus Waiver participants had either family or friends who lived nearby. About 71% of either group reported they could “usually” or “always” see their nearby family when they wanted to.

Table 10. Living Situation and Social Support\*

		CFC Only %	CFC Plus Waiver %	CFC All %
Number of adults living in household		N=100	N=270	N=370
	1	38.0	54.8	50.3
	2-3	53.0	40.7	44.0
	4+	9.0	4.5	5.7
Lives with family member/s		N=63	N=123	N=186
	Yes	92.1	82.9	86.0
	No	7.9	17.1	14.0
Lives with non-family		N=63	N=123	N=186
	Yes	15.9	19.5	18.3
	No	84.1	80.5	81.7
Family member/s live nearby		N=99	N=272	N=370
	Yes	70.7	79.7	77.3
	No	29.3	20.3	2.7
Friend/s live nearby		N=99	N=270	N=369
	Yes	47.5	59.3	56.1
	No	52.5	40.7	43.9

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

ii. Physical and mental health

Consistent with findings in previous years, a larger percentage of CFC Only participants reported fair or poor physical health than CFC participants on a waiver (53% vs. 46%, respectively) (Figure 11). There was not much difference between the groups with respect to self-reported mental health (Figure 12). When asked to rate their mental or emotional health, one third (34%) of all CFC participants said their mental health was either fair or poor (Figure 12).

Figure 11. Self-Reported Physical Health

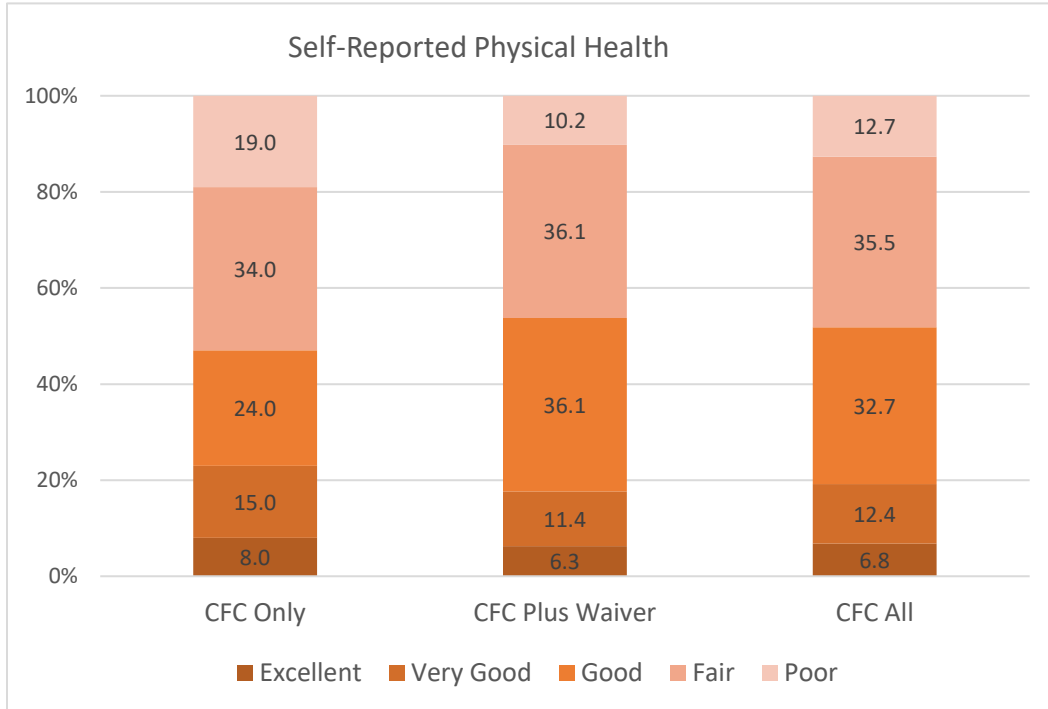
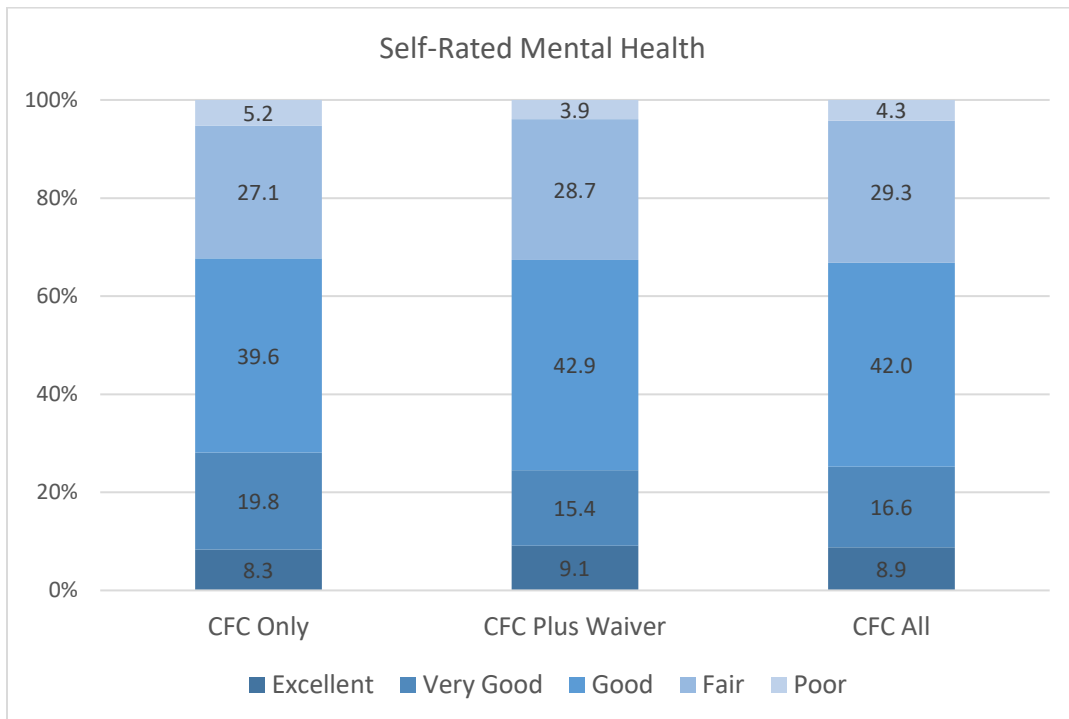


Figure 12. Self-Reported Mental Health



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

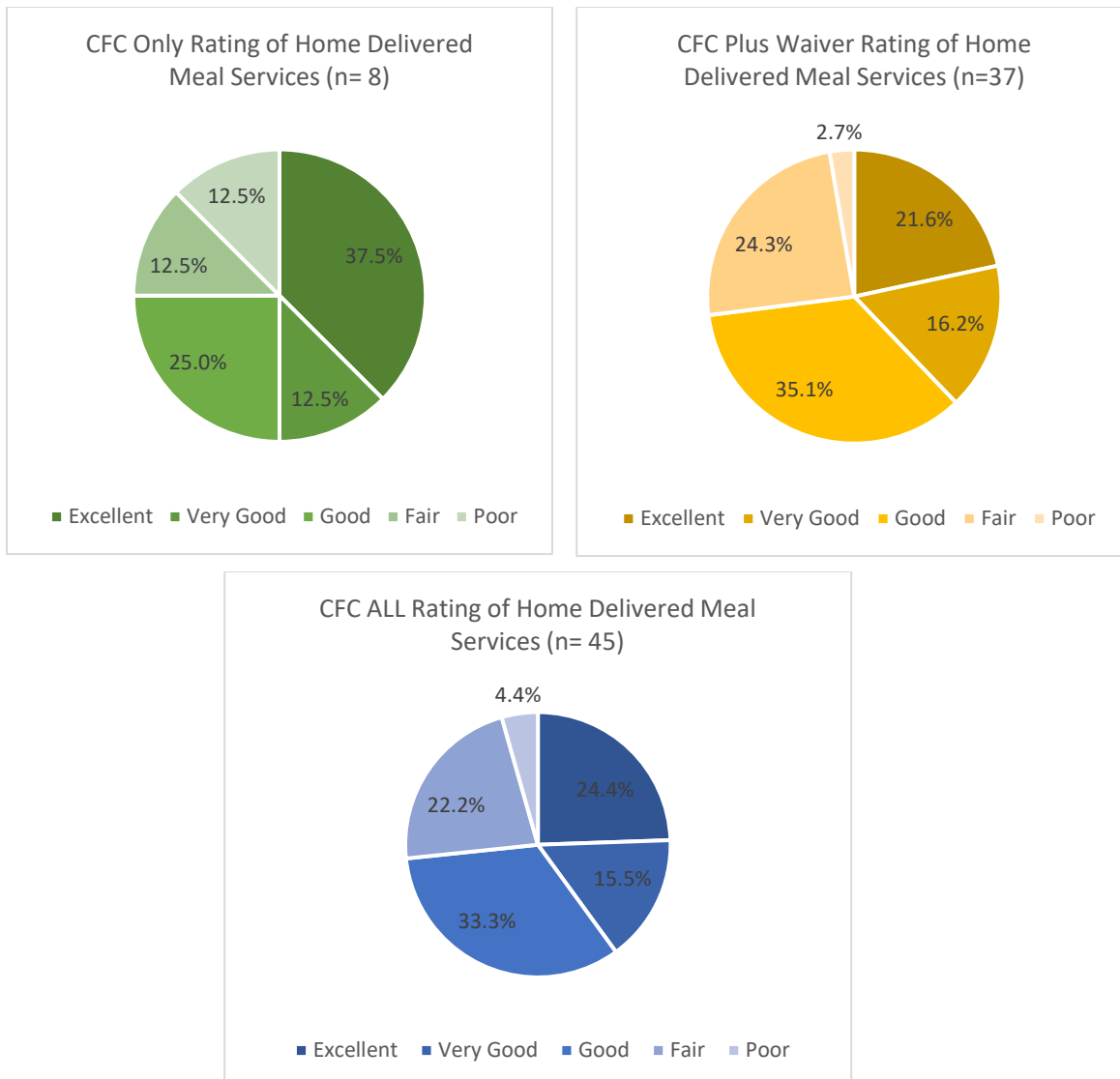
A much larger percentage of CFC Plus Waiver participants reported using a van or transportation service compared to CFC Only participants (43% vs. 20%, respectively) (Table 11). It is not clear why this is so, as both groups have access to Veyo Medicaid transportation service.

Table. 11. Use of a Van or Transportation Service

	CFC Only % N= 101	CFC Plus Waiver % N= 271	CFC All % N= 372
Yes	19.8	42.8	36.6
No	80.2	57.2	63.4

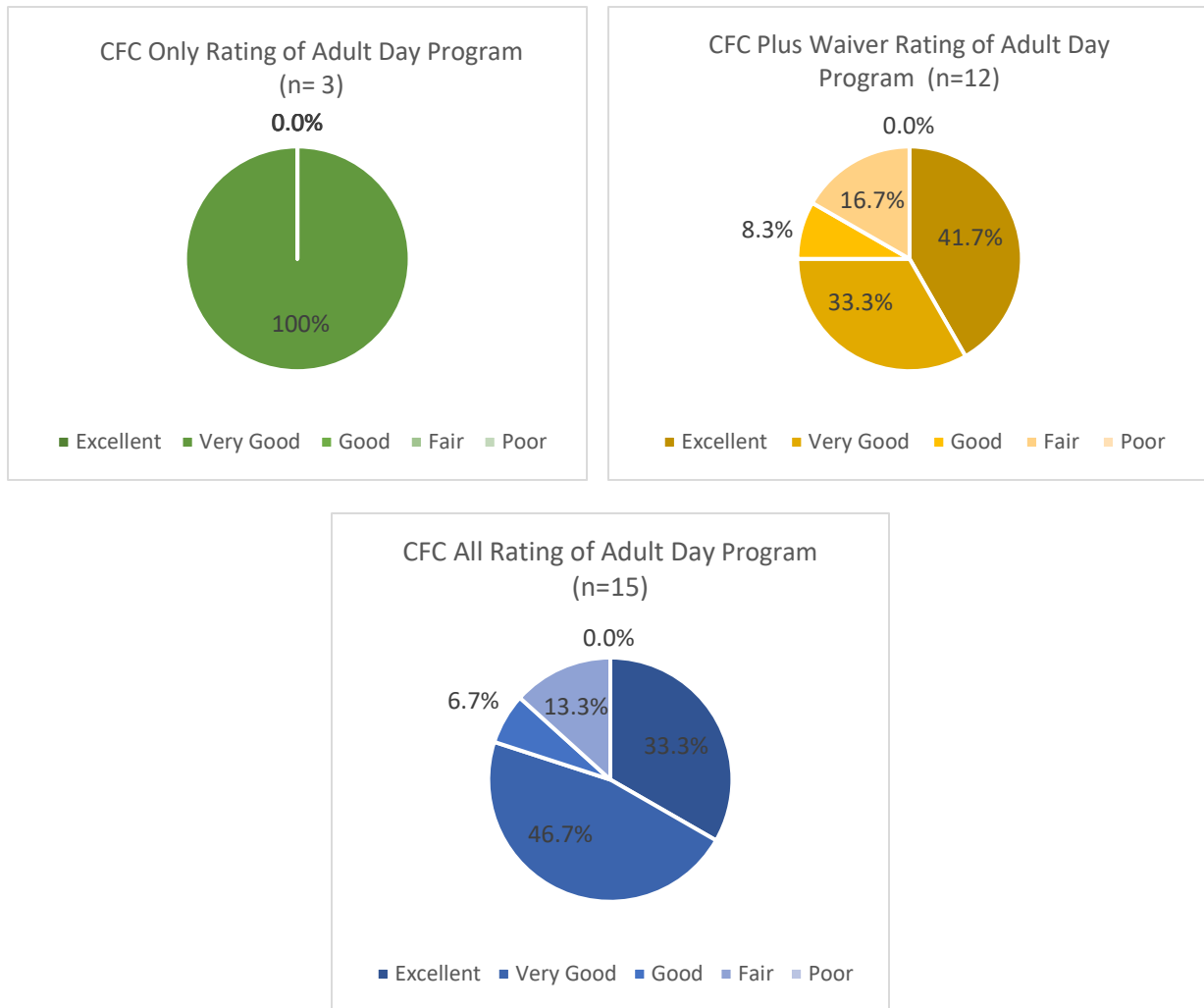
A total of 45 participants rated their home delivered meal service: 8 CFC Only participants and 37 CFC Plus Waiver participants. As shown in Figure 13, a much greater percentage of CFC Only participants were highly satisfied with their meal services.

Figure 13. Experience with Home Delivered Meal Services



Another 15 participants rated their adult day program services. As shown in Figure 14, 80% of all CFC participants rated their day program as either excellent or very good.

Figure 14. Experiences with Adult Day Program Services



iv. Personal safety and respect follow-up

Two participants (<1% of all CFC participants) said that one of their staff had taken their money or things without permission; both were CFC Plus Waiver. One received help from the agency providing the services, while the other received help from another aide to fix this problem. Four other participants said that one of their staff yelled or cursed at them: 1 CFC Only and 3 CFC Plus Waiver. Three of them were working with someone to fix the problem.

v. Emergency contact

Another open-ended question asked, “The next few questions ask about your personal safety. Who would you contact in case of an emergency?” Neither the survey nor the interviewers defined what “emergency” meant, and participants could identify more than one person. As seen in Table 12, CFC Only were more likely than CFC Plus Waiver participants to call family or friends (79% vs. 66%, respectively). On the other hand, CFC Plus Waiver were more likely to call 911 (39% CFC Plus Waiver vs. 21% CFC Only).

Table 12. Who would you contact in case of an emergency?\*

	CFC Only N= 98 n (%)	CFC Plus Waiver N= 266 n (%)	CFC All N=364 n (%)
Family/friend	77 (78.6)	176 (66.2)	253 (69.5)
Case manager/support and planning coach	0 (0)	8 (3.0)	8 (2.2)
HCBS agency or paid staff	10 (10.2)	20 (7.5)	30 (8.2)
PERS/Lifeline	5 (5.1)	30 (11.3)	35 (9.6)
911	21 (21.4)	104 (39.1)	125 (34.3)
Someone else	9 (9.2)	14 (5.3)	23 (6.3)

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

vi. Self-directed employment of paid assistants

To measure use of consumer employer self-direction, consumers were asked how their caregivers were hired, “Do your caregivers come from an agency, or do you or a family member find and hire your aides?” As expected, the great majority (82%) of CFC participants reported they hired their own staff (Table 13).

Consumers who reported hiring their own staff were asked if any of their family members were paid to assist them. There was a pronounced difference in hired family members between CFC Only (62%) and CFC Plus Waiver participants (49%). Overall, more than half (53%) of all CFC participants reported hiring a family member, most often employing their adult children, siblings, or parents as staff.

Table 13. Self-Direction\*

	CFC Only %	CFC Plus Waiver %	CFC All %
How hire staff	N= 99	N= 265	N= 364
Agency	8.1	21.1	17.6
Self-hire	91.9	78.9	82.4
Agency and Self-hire	0.0	0.0	0.0
Employ family member/s	N= 90	N= 209	N= 299
Yes	62.2	48.8	52.8
No	37.8	51.2	47.2

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

vii. Employment

CFC participants were asked about employment status, goals, and assistance finding employment (Figure 5). Overall, 5 percent of all CFC participants are currently working, with CFC Plus Waiver participants three times more likely than CFC Only participants to be employed. Slightly less than a quarter (22%) of all unemployed CFC participants would like to have a job (Figure 16).

Figure 15. Employment Status

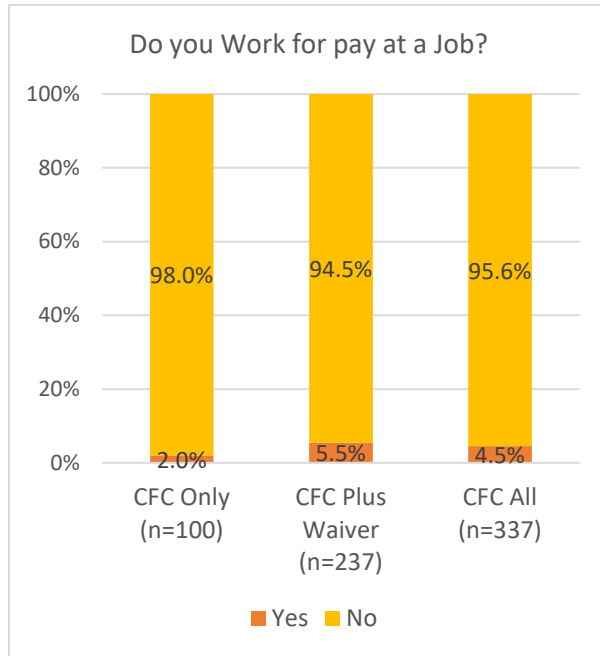
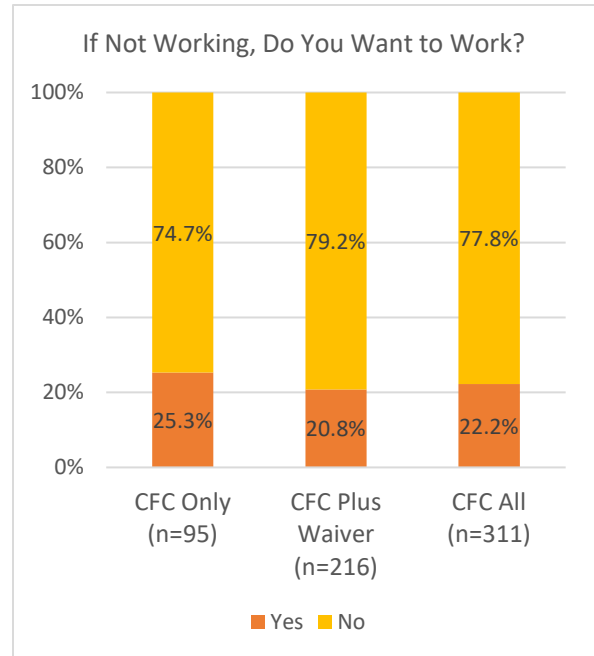


Figure 16. Employment Goal



As in previous years, health and disability related concerns were the most frequently reported reason for not working for both CFC participants who wanted to work and for those who did not want to work (Table 14). CFC Only participants especially felt this way – of participants who wanted to work, the majority (92%) of CFC Only participants said health or disability challenges prevented them from working, compared to 80% of CFC Plus Waiver participants. Very few CFC participants reported that other challenges such as training/education, transportation, looking but can't find work, or potential loss of benefits prevented them from working. On the other hand, nearly half (45%) of all CFC participants who did not want to work reported that nothing was holding them back from working.

Table 14. Most Common Reasons for Not Working\*

<i>Respondents who would like to work</i>			
	CFC Only N=24 n (%)	CFC Plus Waiver N=45 n (%)	CFC All N=69 n (%)
Health/disability	22 (91.7)	36 (80.0)	58 (84.1)
<i>Participants who do not want to work</i>			
	CFC Only N=71 n (%)	CFC Plus Waiver N=171 n (%)	CFC All N=242 n (%)
Health/disability	44 (62.0)	75 (43.9)	119 (49.2)
Nothing is holding me back	21 (29.6)	88 (51.5)	109 (45.0)

\*Multiple choice

Only 12 percent of unemployed CFC participants who wanted to work asked for help with finding a job (Figure 17). Fifty percent of unemployed CFC Only participants and 69% of unemployed CFC Plus Waiver participants knew that employment assistance was available, although they did not seek it out.

Figure 17. Sought Out Employment Assistance

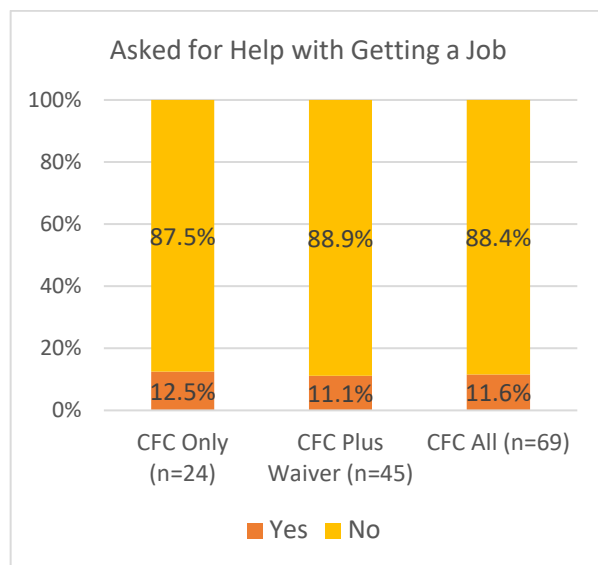
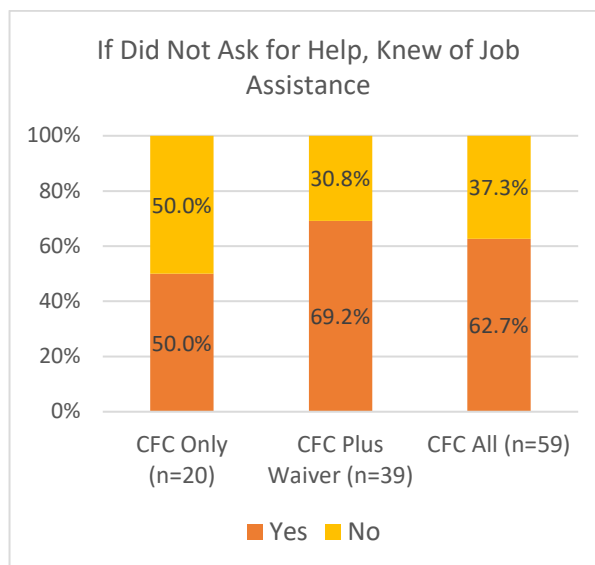


Figure 18. Aware of Employment Assistance



#### IV. Conclusions

##### A. Respondent Sample

From October 2022 to December 2022, UConn completed 101 HCBS CAHPS® surveys with CFC participants who were not receiving any waiver services (CFC Only). Of the 1470 HCBS CAHPS® surveys completed with waiver participants from July, 2022 to June 2023, 271 of those participants were also using CFC (CFC Plus Waiver). These were combined with the CFC Only surveys to produce a sample of 372 CFC participants for this report.

Compared to CFC participants on a waiver, CFC Only participants had a larger percentage of participants who were younger (<25: 15% CFC Only vs. 6% CFC Plus Waiver) and a larger percentage of older participants (≥65: 27% of CFC Only vs. 14% of CFC Plus Waiver). The latter most likely reflects the historic use of home care agencies to provide to provide CHCPE waiver services. Other demographic differences included ethnicity, race, gender, and education. CFC Only participants were much more likely to identify as Latino and/or speak primarily Spanish. On the other hand, CFC Plus Waiver participants were more likely to be female, identify as non-Latino white, and have at least some college education. The living situation between the two groups also differed, as CFC Plus Waiver participants were much more likely to live alone or without other adults compared to the CFC Only consumers.

##### B. Key Results

Mean scores for six of the seven composites were high for all CFC participants, with planning your time and activities receiving much lower scores. This composite includes items which assess the participant’s ability to choose and control his/her social interactions, community engagement, and daily activities. This finding is not unique to the CFC population and represents an opportunity for improvement in the DSS waiver programs as well as CFC.

Compared to CFC Plus Waiver participants, CFC Only consumers reported better communication with their staff and higher scores for choice of services. On the other hand, CFC Only consumers reported lower mean scores for the Care Manager/Support and Planning Coach is Helpful composite. The roles of the CFC support and planning coach and waiver care managers for CFC Plus waiver consumers are not

exactly the same, although both provide help with coordinating services and implementing the consumer's HCBS budget. The mean score for this composite for CFC Only participants increased substantially over the previous year (3.38 in 2022 to 3.70 in 2023). However, the small sample size of CFC Only consumers (n=10) who received services from a support and planning coach in the last 3 months creates some limitations for data interpretation.

CFC Only participants consistently rated and recommended their personal assistants and homemaking staff higher than CFC Plus waiver participants. In particular, CFC Only participants recommended their PCAs higher than CFC Plus Waiver participants (mean score 4.89 vs. 4.73; range 1-5). Interpretation of the homemaking staff results is limited by the small number of CFC Only participants (n=8) who reported having staff who provided homemaking services exclusively. CFC Only consumers gave higher rating and recommendation scores for their support and planning coaches compared to waiver care managers for CFC Plus Waiver consumers as well. This seems contradictory to the findings above, that CFC Only participants gave lower scores to the Case Manager/Support Coordinator is Helpful composite. These 3 key results measure slightly different aspects of these roles.

### C. Additional Findings

Most CFC participants (94%) reported that their personal assistant staff encouraged them to do things for themselves if they could. This highlights a core tenet of CFC, which places an emphasis on program services promoting the independence and resiliency of its clients. However, compared to CFC Plus Waiver consumers, CFC Only participants were less likely to report that their homemaking staff encouraged them in this way.

When asked who they would contact to change their service plan, 26% of CFC Only participants said they did not know. Almost all CFC Plus Waiver participants (96%) could name someone they would talk with about this, and most of them said they would contact their care manager. Having ongoing care management services could be a substantial benefit for CFC Only participants in the event they wanted to change their service plan. In addition, education and outreach to all CFC Only participants would be helpful regarding how to change their services.

A majority of all CFC participants used staff for preparing meals or eating (95%), personal care (89%), or taking medications (80%). Noticeably more CFC Only participants reported a need for assistance with personal care and using the toilet. Still, very few (n=8) CFC participants indicated any unmet care needs. Regarding personal safety and staff respect, less than 1% of CFC participants said that one of their staff had taken their money or things without permission, yelled or cursed at them, or hit or hurt them.

Consistent with previous years, a larger percentage of CFC Only participants reported fair or poor physical health than CFC participants on a waiver. Mental health is also a definite area of concern for CFC participants in both groups, approximately one-third of both CFC Only and CFC Plus Waiver participants rated their mental or emotional health as "fair" or "poor." While lower than the 39% reported last year, it is still a substantial portion of this population. Finding ways to support CFC participants' emotional health, such proactively connecting CFC participants to community or mental health services or encouraging community engagement, could improve CFC participants' mental or emotional health.

The majority (82%) of CFC participants reported they self-directed their services. The other 18% said an agency provided their staff, including 8% of CFC Only participants. It may be that these participants were confusing the role of the fiscal intermediary and/or were not clear about their role as employers. More than half of participants who hired their own staff employed a family member, which is a benefit of using CFC.

Few CFC participants (5%) were working for pay, although 22% of unemployed CFC participants would like a job. Most unemployed CFC participants reported that health and disability related issues prevented them from working. Unemployed CFC Plus Waiver participants who did not want to work



were more likely than their CFC Only counterparts to report that “nothing” was holding them back from wanting to work. Half of unemployed CFC Only participants knew about job assistance, compared to over two-thirds of CFC Plus Waiver participants. Unfortunately, although the majority of unemployed CFC participants knew that such employment assistance was available, they did not seek it out. Facilitating employment, including finding ways to address health concerns, and providing support through the employment process, represents another area of potential program improvement.

#### D. Looking Forward

HCBS CAHPS® surveys with CFC participants on a waiver are administered on an ongoing basis by the quality assurance staff from the Access Agencies and DSS. In 2023, UConn completed its third round of HCBS CAHPS® interviews with CFC participants who are not on a waiver. UConn also continues to provide technical assistance for Connecticut’s use of the HCBS CAHPS, including survey site administration, training, conducting surveys, data analysis and reporting, and other support.

**V. Appendices**

Appendix A. Composite Measures Items

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

## Appendix A. Composite Measures Items

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

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

\* Question added by Connecticut

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

### Waivers-Programs:

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

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# CAHPS® Home- and Community-Based Services Survey

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**Version: 1.0**

**Population: Adult**

**Language: English**

**Connecticut version – 2019**

Waivers-Programs

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



File name: CAHPSHcbs01192017SurvEng508  
Last updated: January 19, 2017

## Instructions for Vendor

- The interview is intended as an interviewer-administered survey; thus all text that appears in initial uppercase and lowercase letters should be read aloud. Text that appears in **bold, lowercase letters** should be emphasized.
- Text in *{italics and in braces}* will be provided by the HCBS program’s administrative data. However, if the interviewee provides another term, that term should be used in place of the program-specific term wherever indicated. For example, some interviewees may refer to their case manager by another title, which should be used instead throughout the survey.
- For response options of “never,” “sometimes,” “usually,” and “always,” if the respondent cannot use that scale, the alternate version of the survey with response options of “mostly yes” and “mostly no” should be used. These alternate response options are reserved for respondents who find the “never,” “sometimes,” “usually,” “always” response scale cognitively challenging.
- For response options of 0 to 10, if the respondent cannot use that scale, the alternate version of the survey with response options of “excellent,” “very good,” “good,” “fair,”

or “poor” should be used. These alternate response options are reserved for respondents who find the numeric scale cognitively challenging.

- All questions include a “REFUSED” response option. In this case, “refused” means the respondent did not provide any answer to the question.
  - All questions include a “DON’T KNOW” response option. This is used when the respondent indicates that he or she does not know the answer and cannot provide a response to the question.
  - All questions include an “UNCLEAR” response option. This should be used when a respondent answers, but the interviewer cannot clarify the meaning of the response even after minor probing or the response is completely unrelated to the question, (e.g., the response to “In the last 3 months, how often did your homemakers listen carefully to what you say?” is “I like to sit by Mary”).
  - Some responses have skip patterns, which are expressed as “→ GO TO Q#.” The interviewer should be advanced to the next appropriate item to ask the respondent.
  - Not all respondents receive all home and community-based services asked about in this instrument. Items Q4 through Q12 help to confirm which services a respondent receives. The table after it summarizes the logic of which items should be used.
  - Survey users may add questions to this survey before the “About You” section. A separate supplemental employment module can be added.
- Use singular/plural as needed. In most cases, questions are written assuming there is more than one staff person supporting a respondent or it is written without an indication of whether there is more than one staff person. Based on information collected from Q4 through Q12, it is possible to modify questions to be singular or plural as they relate to staff.
- Use program-specific terms. Where appropriate, add in the program-specific terms for staff (e.g., [*program-specific term for these types of staff*]) but allow the interviewer to modify the term based on the respondent’s choice of the word. It will be necessary to obtain information for program-specific terms. State administrative data should include the following information:
  - Agency name(s)
  - Titles of staff who provide care



## COGNITIVE SCREENING QUESTIONS

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

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

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

2. How do they help you?

---

[EXAMPLES OF CORRECT RESPONSES INCLUDE]

- HELPS ME GET READY EVERY DAY
  - CLEANS MY HOME
  - WORKS WITH ME AT MY JOB
  - HELPS ME DO THINGS
  - DRIVES ME AROUND
- <sup>-1</sup>  DON'T KNOW → END SURVEY  
<sup>-2</sup>  REFUSED → END SURVEY  
<sup>-3</sup>  UNCLEAR RESPONSE → END SURVEY

3. What do you call them?

---

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

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

[Interviewer - Screening Failed]

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

## IDENTIFICATION QUESTIONS

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

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q6
- <sup>-1</sup>  DON'T KNOW → GO TO Q6
- <sup>-2</sup>  REFUSED → GO TO Q6
- <sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q6

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

---

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

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

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

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

---

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

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

home?

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

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

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

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

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

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

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

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

---

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

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

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

**GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF**

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

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

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

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

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

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

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

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

- 2  REFUSED
- 3  UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

- 2  REFUSED
- 3  UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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

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

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

Would you say . . .

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

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

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

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

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

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

- \_\_ 0 TO 10
- <sup>-1</sup> DON'T KNOW
  - <sup>-2</sup> REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

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

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

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

## GETTING NEEDED SERVICES FROM HOME MAKERS

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

...

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

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

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

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

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

## HOW WELL HOME MAKERS COMMUNICATE WITH AND TREAT YOU

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

## YOUR CASE MANAGER

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

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

- 1  YES  
 2  NO → GO TO Q55a  
 -1  DON'T KNOW → GO TO Q55a  
 -2  REFUSED → GO TO Q55a

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

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

<sup>1</sup>  YES

<sup>2</sup>  NO

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

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  YES

<sup>2</sup>  NO → GO TO Q52

<sup>3</sup>  DON'T NEED → GO TO Q52

<sup>-1</sup>  DON'T KNOW → GO TO Q52

<sup>-2</sup>  REFUSED → GO TO Q52

<sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q52

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

<sup>1</sup>  YES

<sup>2</sup>  NO

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

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  YES

<sup>2</sup>  NO → GO TO 54

<sup>3</sup>  DON'T NEED → GO TO Q54

<sup>-1</sup>  DON'T KNOW → GO TO Q54

<sup>-2</sup>  REFUSED → GO TO Q54

<sup>-3</sup>  UNCLEAR RESPONSE → GO TO Q54

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

<sup>1</sup>  YES

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

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

\_\_ 0 TO 10

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

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

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

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

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

## HOME-DELIVERED MEALS, ADULT DAY PROGRAM

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

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

- 1  Excellent,
- 2  Very good,
- 3  Good,
- 4  Fair, or
- 5  Poor?
- 1  DON'T KNOW
- 2  REFUSED
- 3  UNCLEAR RESPONSE OR DID NOT USE A HOME-DELIVERED MEALS SERVICE

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

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

## CHOOSING YOUR SERVICES

56. In the last 3 months, did your [*program-specific term for "service plan"*] include . . .

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

57. In the last 3 months, did you feel {*personal assistance/behavioral health staff*} knew what's on your [*program-specific term for "service plan"*], including the things that are important to you?

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

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

Probes (Use only if respondent is unclear or does not know):

- How do you hire and pay your aides or caregivers?
- Do you work with Allied, Sunset Shores, or Advanced Behavioral Health/ABH to pay your aides?

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

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

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

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

- 1  CASE MANAGER  
 2  OTHER STAFF  
 3  FAMILY/FRIENDS  
 4  SOMEONE ELSE, PLEASE SPECIFY \_\_\_\_\_  
 -1  DON'T KNOW  
 -2  REFUSED  
 -3  UNCLEAR RESPONSE

## TRANSPORTATION

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

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

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

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

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

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

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

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

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

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

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

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

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

## PERSONAL SAFETY

The next few questions ask about your personal safety.

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

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

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

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

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

65. In the last 3 months, did **any** {*personal assistance/behavioral health staff, homemakers, or your case managers*} take your money or your things without asking you first?

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

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

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

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

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

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

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

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

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

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

- 1  FAMILY MEMBER OR FRIEND



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

71. In the last 3 months, did any {staff} hit you or hurt you?

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

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

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

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

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

## COMMUNITY INCLUSION AND EMPOWERMENT

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

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

- 1  YES
- 2  NO → GO TO Q76
- 1  DON'T KNOW → GO TO Q76

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

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

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

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

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

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

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

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

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

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

- 1  Mostly yes or
- 2  Mostly no?

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

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

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

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

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

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

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

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

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

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

- 1  YES
- 2  NO

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

**ABI, Autism, and PCA:** Ask Employment Module

**CHCP & Katie Beckett:** Skip to ABOUT YOU

### **EMPLOYMENT MODULE (ABI, Autism & PCA)**

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

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

\_\_ 0 TO 10

- DON'T KNOW
- REFUSED
- UNCLEAR RESPONSE

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

Would you say . . .

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

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

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

## ABOUT YOU

Now I just have a few more questions about you.

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

- Excellent,
- Very good,

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

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

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

84. What is your age?

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

ALTERNATE VERSION: In what year were you born?

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

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

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

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

-3  UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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

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

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

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

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

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

93. What is the language you speak at home?

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

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

- 1  1 [JUST THE RESPONDENT] → END SURVEY
- 2  2 TO 3
- 3  4 OR MORE

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

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

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

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

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

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

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**END OF QUESTIONS**

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

- AASCC: 203-752-3040
- CCC Eastern region: 860-885-2960
- CCC North Central region: 860-257-1503
- CCC Northwest region: 203-596-4800
- SWCAA: 203-333-9288
- WCAAA: 203-465-1000
- Autism waiver: 860-424-5865
- Katie Beckett waiver: 860-424-5582

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

**INTERVIEWER QUESTIONS**

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

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

Participant by his/herself

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

Participant with assistance from another person.

If Assisted

Contact information for person who assisted with interview:

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

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

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

A proxy - Someone else completed the survey for the participant

If Proxy:

**Proxy Contact Information:**

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

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

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

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

Spouse/partner

Adult child

Parent

Attorney or legal representative

Other: \_\_\_\_\_

P2. Is the proxy also a legal representative?

Yes

No

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

Yes → GO TO END OF SURVEY

No → GO TO END OF SURVEY

F1. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

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

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

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

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

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

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

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

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

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

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

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

F7. Relationship to participant:

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

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

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

**END OF SURVEY – INTERVIEWER COMPLETE FOR EVERYONE:**

Interview done by:

- Telephone
- In-person

Participant Information:

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

Middle name: \_\_\_\_\_

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

Medicaid ID: \_\_\_\_\_

Date of Birth (MM/DD/YYYY): \_\_\_\_\_

Town of residence: \_\_\_\_\_

ZIP code of residence: \_\_\_\_\_

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

- Yes
- No
- Do not know

Program:

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

If CHCP: CHCP Category:

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

If ABI waiver:

- ABI I



- ABI II
- Do not know

Community First Choice?

- Yes
- No
- Do not know

Access Agency:

- AASCC
- CCC
- DSS
- SWCAA
- WCAAA
- DMHAS

If CCC client: CCC Region:

- Eastern (Region 3)
- North Central (Region 4)
- Northwest (Region 5)
- Do not know

If SWCAA client: SWCAA Region:

- Bridgeport Proper
- Greater Bridgeport
- Norwalk
- Stamford
- Do not know

Date Interview Complete: \_\_\_\_\_

Interviewer: \_\_\_\_\_