

2020 Annual Report:

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

Connecticut Community First Choice

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I. Introduction

Connecticut has seen a growth in use of Medicaid funded home and community-based services (HCBS). The Department of Social Services (DSS) administers six waivers, including the Connecticut Home Care Program, Personal Care Assistance, Acquired Brain Injury, 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). In 2015, a State Plan Amendment authorized a 1915k program, Community First Choice (CFC), as a self-directed HCBS option.

CFC provides a broad range of services, including personal attendant services, Support and Planning Coach services, environmental accessibility 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). As with the waiver programs, CFC participants must meet nursing facility level of care and certain financial requirements. Following a comprehensive assessment, a participant's budget is generated based on their level of need. The participant, either on their own or with assistance, creates a person-centered service plan which reflects what is important to the participant. One or more CFC services are incorporated into the service plan to support the participant's needs and goals, as allowed by their budget. To be eligible for funding under CFC, these services must either substitute for human assistance or increase the participant's independence as identified in their service plan. If eligible, CFC participants can also receive services from Medicaid waiver programs, providing the additional waiver services do not duplicate their CFC services.

Historically, these Medicaid programs have used diverse, program-specific methods to obtain the participant experience data required for quality assurance by the Centers for Medicare and Medicaid Services (CMS) and DSS. For example, DSS, DMHAS, and DDS have used several different annual participant surveys, which were not uniform across programs or even care management agencies. Annual program re-assessments can also provide some insight into a participant's overall satisfaction with their HBC services. However, re-assessment questions about the participant's experiences with their services are not standardized, and the information is not easily quantifiable. This lack of a standardized, universal instrument and quality assurance method has made it challenging to compare participant experiences across Medicaid HCBS programs.

Unlike surveys that assess satisfaction with services, the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS®) survey elicits program participant feedback on his/her daily experience with HCBS. For example, one item asks if a caregiver comes in on time. Reporting actual experiences across multiple domains is more conducive for measuring quality than satisfaction alone. As a standardized cross-disability instrument, the HCBS CAHPS® survey also allows for the comparison of various HCBS programs and case management providers, as individuals with different disabilities respond to the same questions. The HCBS CAHPS® survey provides Connecticut with one consistent approach to reward quality and facilitate reporting across waiver programs and care management provider agencies.

Other benefits of the HCBS CAHPS survey include its accessibility and person-centeredness. Participants can choose to do the survey by telephone or in-person, and a Spanish version is available. If a participant cannot answer the questions on his/her own, the survey allows for completion of the survey with assistance or by proxy. The HCBS CAHPS® survey also integrates alternately worded questions and responses. If the participant has difficulty using the typical four-part response options (never, sometimes, usually, or always), a standardized alternate question with a "mostly yes or mostly no" response is provided, making the survey more accessible for persons with cognitive or speech challenges. These more inclusive approaches means that Connecticut's data includes all participants' perspectives, regardless of disability.

To tailor the survey to the participant and HCBS program, HCBS waiver and program specific services and terms are integrated directly into the survey. For example, only ABI participants are asked about Independent Living Training Specialists. All participants are asked how they refer to their paid staff; these responses are then used throughout that individual’s survey.

II. Methods

A. HCBS CAHPS® Survey

The HCBS CAHPS® survey is composed of eleven sections: cognitive screen, identification of paid services, personal assistance and/or behavioral health staff services, homemaker services, case manager, choosing your services, transportation, personal safety, community inclusion and empowerment, demographics, and an employment module. A 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). This report does not include job coach or Mental Health Waiver community service provider results; for these, please see the September 2020 Annual HCBS CAHPS® survey report. The 2019-2020 HCBS CAHPS® survey, including the employment items asked of the PCA, ABI, Autism, DMHAS and CFC adult participants, is attached in Appendix B.

Table 1. HCBS Program Staff Services

	CHCP	PCA	ABI	Autism	Katie Beckett	Mental Health waiver	CFC
Personal care assistance/attendant	X	X	X	X			X
Behavioral health			X*	X**			
Recovery assistance						X	
Homemaking/companion services	X	X	X	X			
Case manager	X	X	X	X	X	X	
Support and Planning Coach							X

*Independent Living Skills Training (ILST)

**Life skills coach or community mentor

B. Survey Administration

In this third year of administration, the Connecticut Department of Social Services (DSS) implemented the HCBS CAHPS® in the DMHAS mental health waiver (DMHAS waiver). In December, 2019, the CFC program adopted the HCBS CAHPS® survey as part of its quality assurance strategy. In all, DSS used the HCBS CAHPS® to inform quality measurement in nine of its Medicaid programs in year three: CHCP Categories 3 and 5; the PCA, ABI 1, ABI 2, Autism, Katie Beckett, and DMHAS waivers; and CFC. All Access Agencies were required to complete surveys for their contracted programs (CHCP, PCA, ABI); DSS staff were responsible for completing surveys for the Katie Beckett and Autism waivers. DMHAS used administrative staff from one of its contracted case management agencies, Advanced Behavioral Health (ABH), as well as mental health waiver research staff from the University of Connecticut at Storrs to complete their surveys (hereafter collectively referred to as DMHAS quality assurance staff. The UConn Health Center on Aging (UConn) conducted surveys for people in the CFC program who did not also receive waiver services (CFC Only).

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

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

C. Sampling Methodology

i. CFC participants using waiver services

Using client enrollment numbers as of 6/30/2019, DSS determined the target number of surveys for each Access Agency, DSS, and DMHAS to complete in order to reach a representative sample in each of their programs. Using random sampling, Access Agency, DSS, and DMHAS quality assurance staff contacted waiver participants from their client lists and invited them to do the survey. Surveys were completed between July 1, 2019 to June 30, 2020. 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. For all HCBS CAHPS® surveys, if there were a legal guardian or conservator of person, quality assurance staff contacted them first before contacting the participant.

Of the 1400 HCBS CAHPS® surveys completed from July 1, 2019 to June 30, 2020, 339 of these participants were identified through administrative data as also on CFC. This CFC Plus Waiver group includes participants from each of the waivers that use the HCBS CAHPS® survey.

ii. CFC participants not using waiver services

DSS provided the UConn research team a list of CFC participants who had a CFC services claim from January, 2016 to November 16, 2019, but no other waiver claim during this time. Participants whose service plan was transmitted to the fiscal intermediary within less than three months were taken out in order to exclude participants who had not yet begun services. MFP participants were excluded as well. 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 intended sample was to reflect this target population distribution: 25% DD, 50% PD, and 25% OA. Due to the small number of older adults, the initial sample comprised 25% DD (n=50), 60% PD (n=120), and 15% OA (n=30) participants, for a total sample of 200 participants. Subsequently, in order to complete enough surveys with older adults, the remaining 22 OA participants from the original sample were added.

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 with these participants from December 4, 2019 to February 7, 2020 with a goal of completing 100 surveys. In all, 102 surveys were completed with CFC Only participants.

D. Measures

Key results are presented using established HCBS CAHPS® composite and other key measures (see Table 2). Individual items not covered by these measures are also reported.

Each composite scale comprised three to twelve individual questions (see Appendix A). Most of these questions had four response options: never, sometimes, usually, and always. Each response was given a

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

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

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

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

Table 2. Key Measures

Composites	Staff are reliable and helpful
	Staff listen and communicate well
	Case manager is helpful
	Choosing services that matter to you
	Transportation to medical appointments
	Personal safety and respect
	Planning your time and activities
Global ratings	Personal care/Recovery assistance/Behavioral health staff
	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).

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 2020 Annual Report Sample

Participant program	Surveys completed (N)
CFC Only	102
CFC Plus Waiver	339
Total CFC participants	441

Table 4. Waiver composition of CFC Plus Waiver sample

Waiver Program	Surveys completed (N)
CHCPE	9
PCA	243
ABI	49
Autism	1
Katie Beckett	24
DMHAS	13
Total CFC plus waiver	339

Most CFC surveys were completed by the consumer or the consumer with assistance (Table 5). A larger percentage of CFC Plus Waiver participants completed the survey by themselves, compared to CFC Only participants (69% vs. 61%, respectively). For assisted interviews, the person assisting most often helped by answering some of the questions for the consumer or prompting the consumer. Most proxy respondents were related to the consumer (84.9%). Almost all surveys were completed by telephone (99.5%); 7.0% were completed in Spanish.

Table 5. Survey Respondents

	CFC Only n (%)	CFC Plus Waiver n (%)	CFC All n (%)
By self	62 (60.8)	233 (68.7)	295 (66.9)
With assistance	8 (7.8)	12 (3.5)	20 (4.5)
By proxy	32 (31.4)	94 (27.7)	126 (28.6)

B. Consumer Demographics

Consumer demographics by program are presented in Table 6. There are some noticeable differences between the CFC Only participants and the CFC Plus Waiver participants. For example, the CFC Only group has a larger cohort under age 25 than the CFC Plus Waiver (17% vs. 9%). Almost three times as many CFC Only participants identify as Latino/Latina (33% vs. 13%), and a larger portion of CFC Only participants speak primarily Spanish (15% vs. <1%). Finally, the majority of CFC Only participants are female, compared to CFC Plus Waiver participants (71% vs 51%).

Table 6. Consumer Demographics*

		CFC Only %	CFC Plus Waiver %	CFC All %
Age		N=102	N=336	N=438
	<18	4.9	4.5	4.6
	18-24	11.8	3.3	5.3
	25-34	11.8	8.6	9.4
	35-44	6.9	14.6	12.8
	45-54	18.6	25.9	24.2
	55-64	28.4	37.5	35.4
	65-74	12.7	3.9	5.9
	75+	4.9	1.8	2.5
Language		N=102	N=335	N=437
	English	61.8	78.2	74.4
	Spanish	14.7	<1.0	4.1
	Multilingual/ Other	23.5	20.9	21.5
Race		N=97	N=332	N=429
	White	66.0	69.9	69.0
	Black	20.6	25.0	24.0
	Other	13.4	5.1	7.0
Ethnicity		N=102	N=334	N=436
	Non-Hispanic	66.7	87.4	82.6
	Hispanic	33.3	12.6	17.4
Education Level		N=100	N=314	N=414
	< 8th Grade	16.0	4.5	7.3
	Some high school	22.0	16.9	18.1
	High school degree	31.0	36.9	35.5
	Some college	21.0	32.2	29.5
	4-year college	6.0	7.6	7.3
	More than 4 year degree	4.0	1.9	2.4
Gender		N=102	N=315	N=417
	Male	29.4	48.6	43.9
	Female	70.6	51.4	56.1

*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 in the three months prior to completing the survey (see Table 7). Three CFC Only participants indicated they used CFC staff for household chores or homemaking tasks.

Table 7. Program Service Use

	CFC Only %	CFC Plus Waiver %	CFC All %
	N=102	N=339	N=441
Personal care assistant/attendant services	95.1	82.3	85.3
Behavioral health services*		10.3	7.9
Recovery assistance services		3.2	2.5
Homemaking or Companion services	2.9	74.3	73.9
Case manager	0	92.3	71.0
Support and Planning Coach	14.7	0	3.4

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

D. Key Results

Most of the key measures (composites and staff global ratings and recommendations) show results for the three groups separately. Homemaker items show all CFC participants given the small number of CFC Only participants who use their staff for homemaking activities. Case manager items only use data from CFC Plus Waiver participants since CFC Only participants do not receive case management.

CFC Only participants were asked about any Support and Planning Coach services, and 15 said they used this service. These participants subsequently described a mix of providers who likely were not all Support and Planning Coaches as defined by the CFC program (e.g., universal assessors) making these results unreliable for describing any experiences specific to Support and Planning Coaches. Therefore, this data is not reported.

Additional findings in the rest of the report present the results for all the CFC participants. The data for all three groups are shown only if there were notable differences between the CFC Only and the CFC Plus Waiver groups.

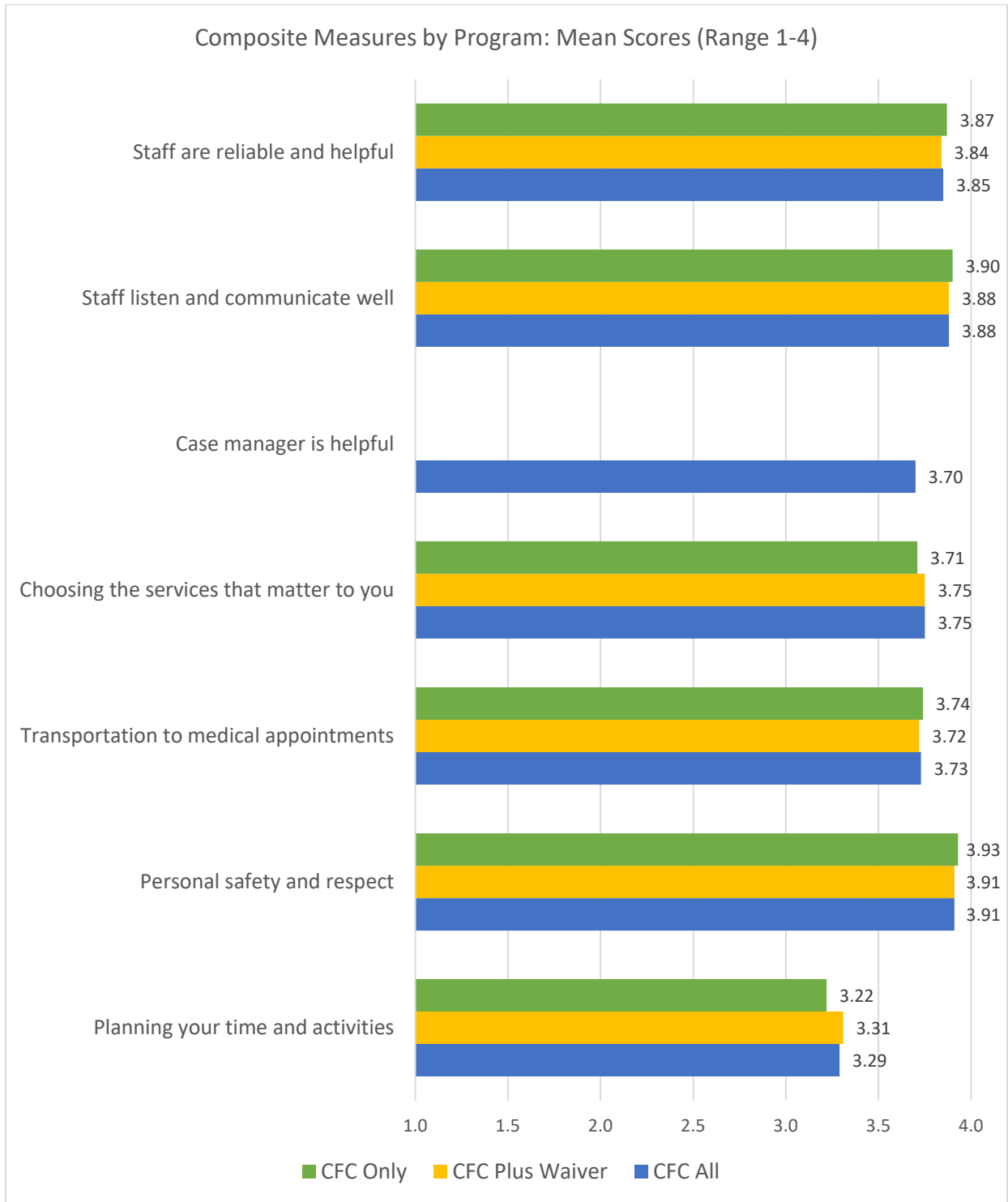
Composite measures, global ratings, and recommendations by program are displayed two ways: the mean score and the percentage reporting the highest score.

i. Composite measures by program

Overall, when examined by group (CFC Plus Waiver, CFC Only and CFC All), mean scores for most composite measures were high (Figure 1). Across all groups, participants reported higher scores for personal safety and respect, and lower scores (<3.5) for planning your time and activities. There was very little difference between the mean scores reported between the two groups.

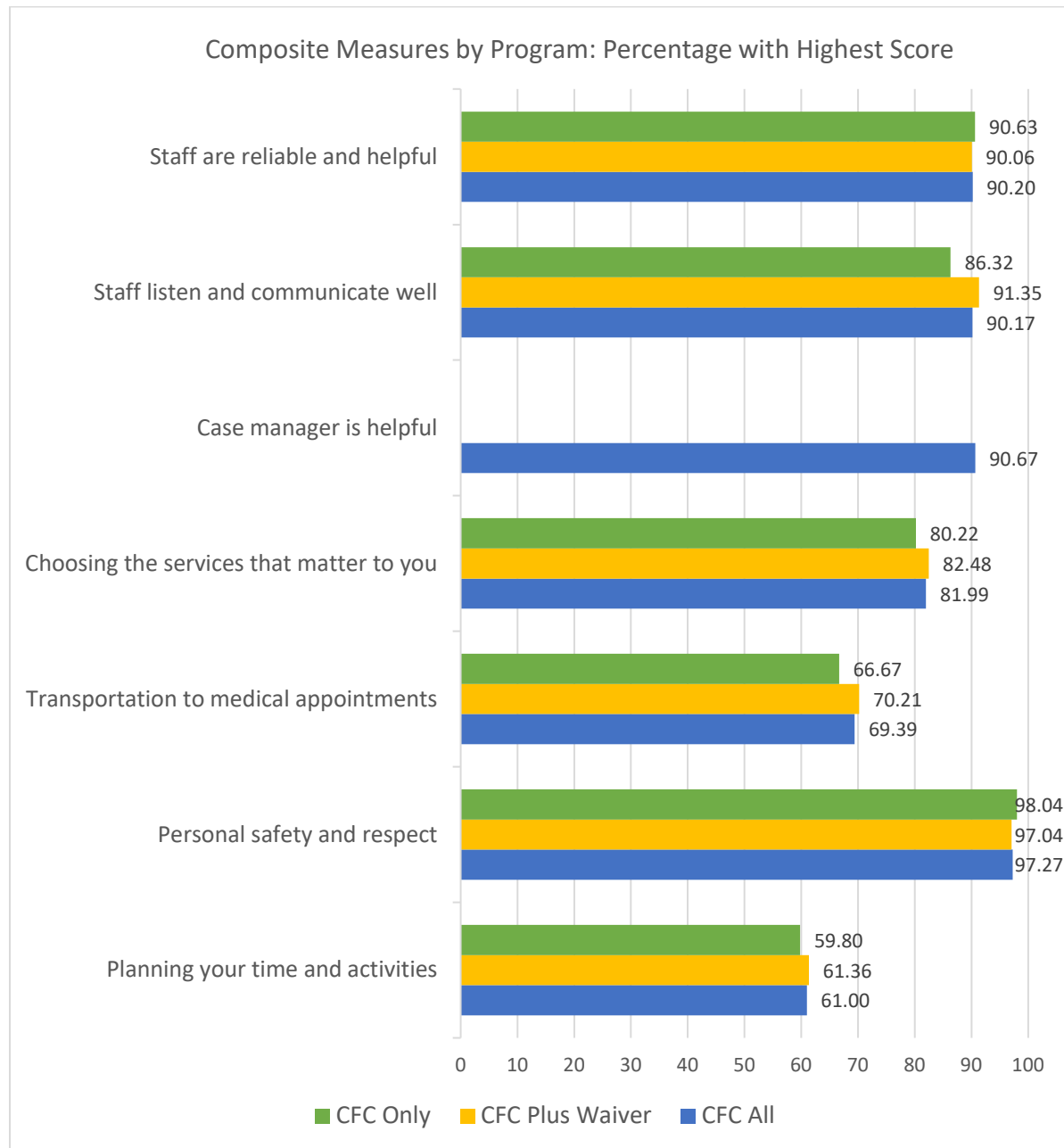
Figure 2 shows the percentage of participants in each program who gave the most positive answer for each composite item. This method highlights any differences more clearly.

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



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

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

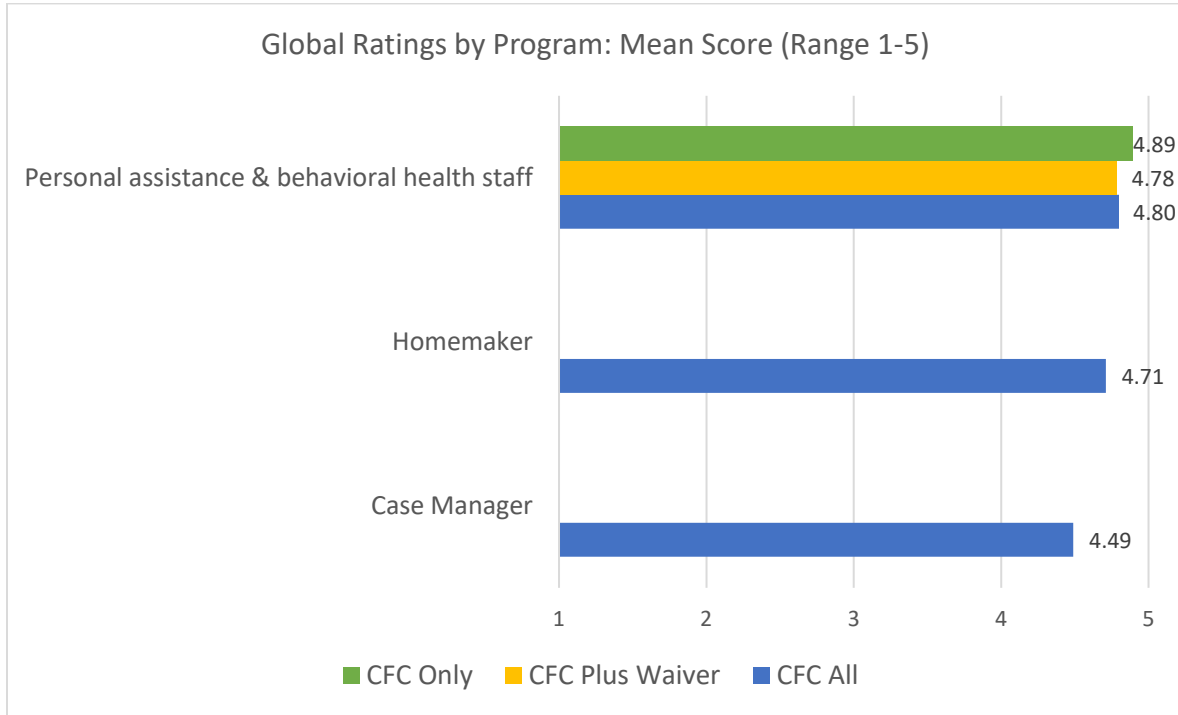


ii. Global ratings by program

When examined using mean scores, the majority of CFC participants gave their staff,* such as personal care and behavioral health staff, homemaker services, and case managers, high scores – between 4.5 to 4.9, on a scale from one to five (Figure 3). As with other care manager items, these figures only report data from CFC participants who have a case manager.

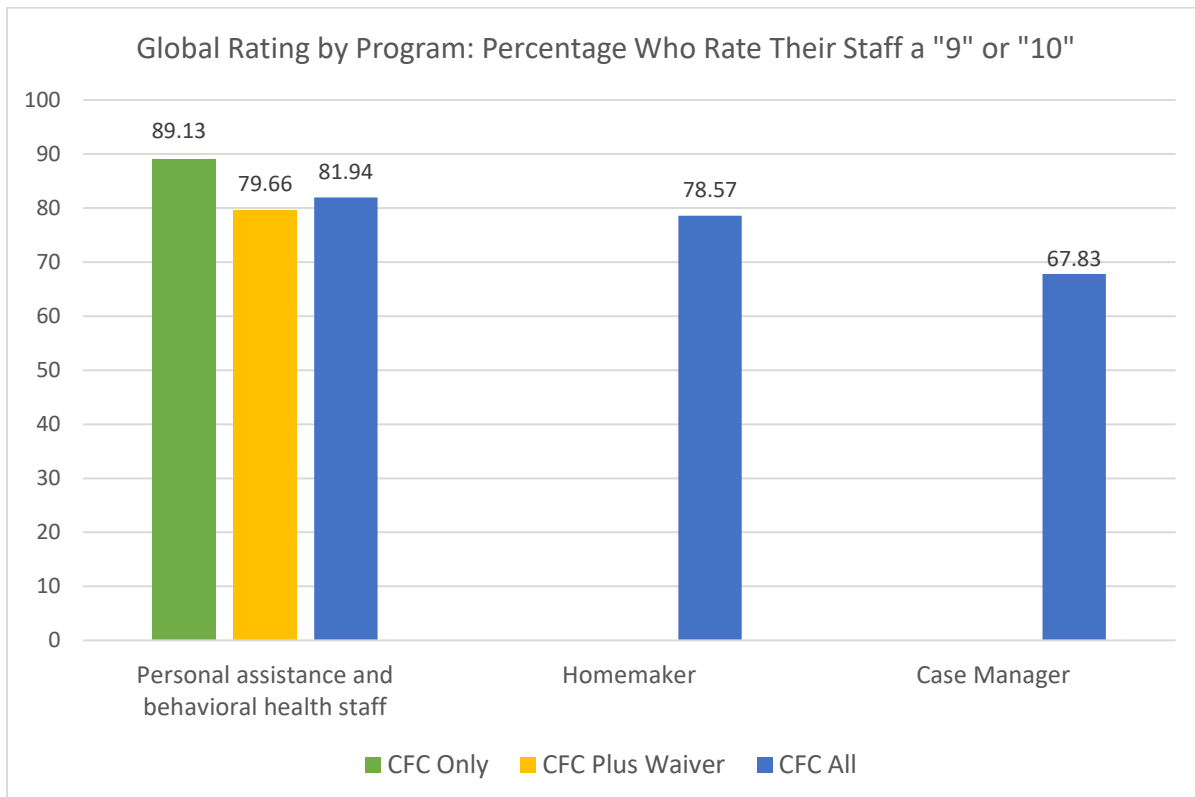
Figure 4 presents the percentage of participants in each program who gave their staff the highest rating possible – a nine or ten, on a scale from zero to ten. CFC Only rated their personal care staff more highly: 89% of CFC Only participants rated their PCAs a nine or ten, compared to 80% of CFC participants on a waiver. CFC participants gave their care managers lower ratings – only two-thirds (68%) of CFC participants rated their case manager a “9” or “10.”

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, recovery assistant, life skills coach, and community mentor staff. The term "Homemaker" is used to describe any type of staff who assist with homemaking tasks or household chores.

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, homemaker services, or case managers, all CFC participants gave their staff high mean recommendations – greater than 3.5 on a scale of one to four (Figure 5). Figure 6 shows the percentage of respondents who would “definitely” recommend their staff or services. This figure shows the differences in recommendations more clearly. CFC Only participants showed strong favorability towards their PCAs, with 91% reporting that they would “definitely” recommend their staff, compared to 80% of CFC participants on a waiver.

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

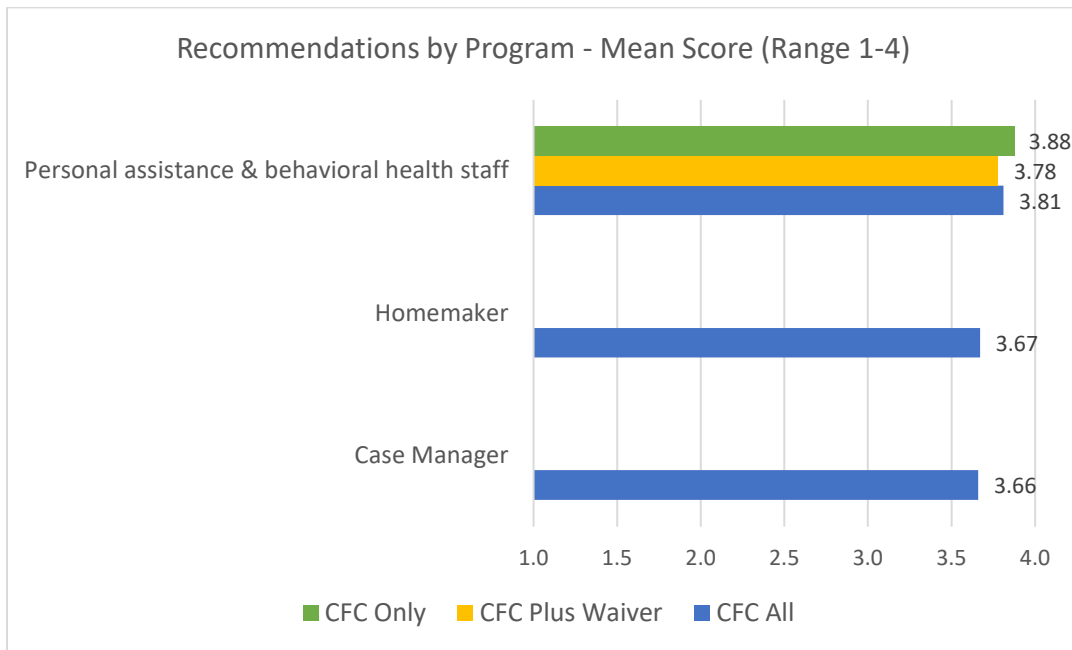
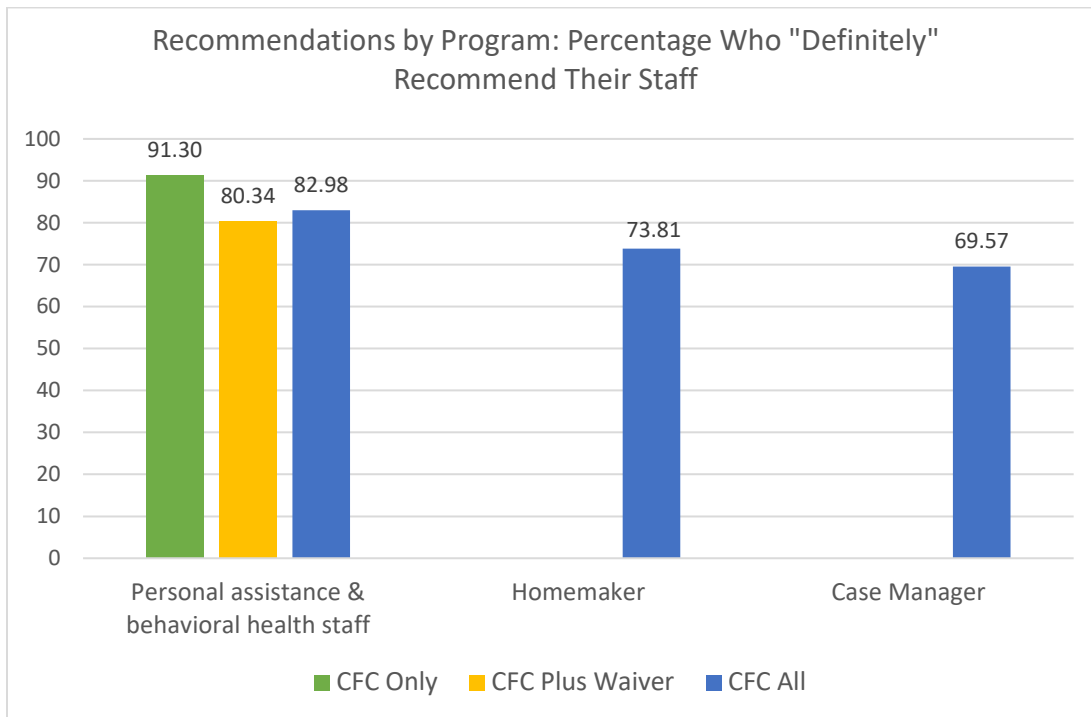


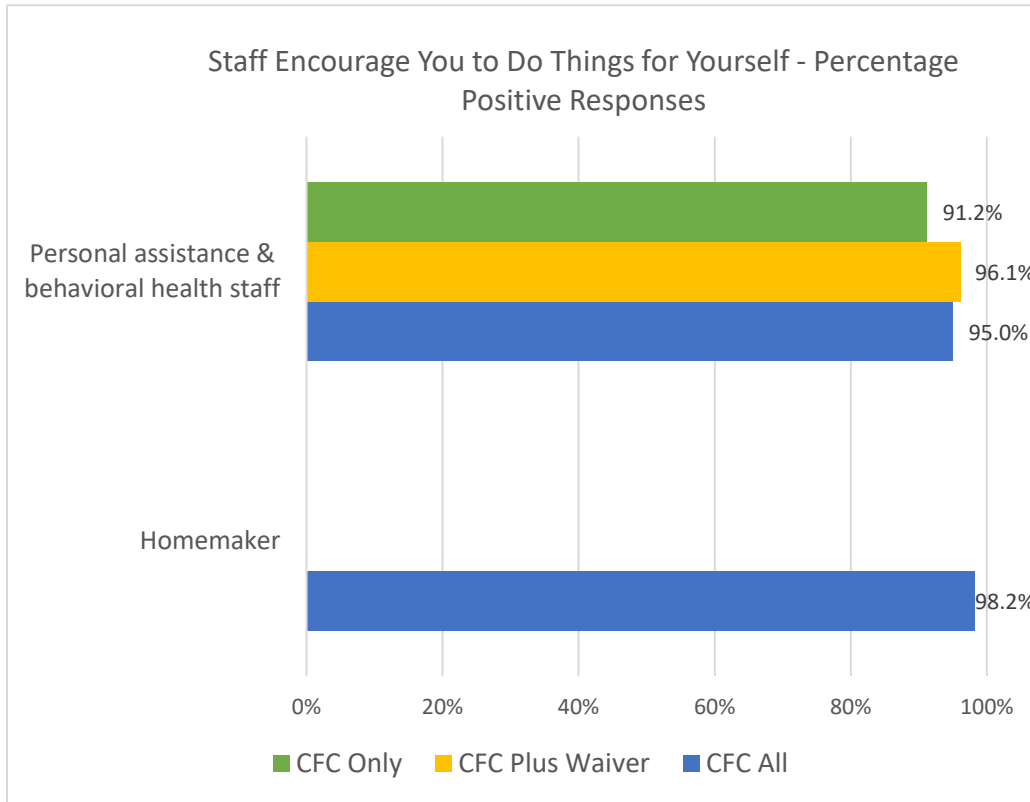
Figure 6. Recommendations by Program: Percentage Who “Definitely” Recommend Staff



iv. Additional staff and case manager measures

Participants with personal care, behavioral health, or homemaker services were asked, “Did [staff] encourage you to do things for yourself if you could?” As shown in Figure 7, 96% of CFC Plus Waiver participants and 91% of CFC Only participants reported that their personal assistance/behavioral health staff encouraged them to do things for themselves. When asked if their homemakers encouraged them to do things for themselves, almost all participants (98%) reported this to be true.

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



When asked if they knew who their care manager was, almost one-third (31%) of CFC participants on a waiver said they did not know, although all the waivers included case management as a service (Figure 8). About one-fifth of these respondents had asked their care manager for help with changing their services (22%) or getting or fixing equipment (21%) (Figure 9).

Figure 8. Knows Who Care Manager Is

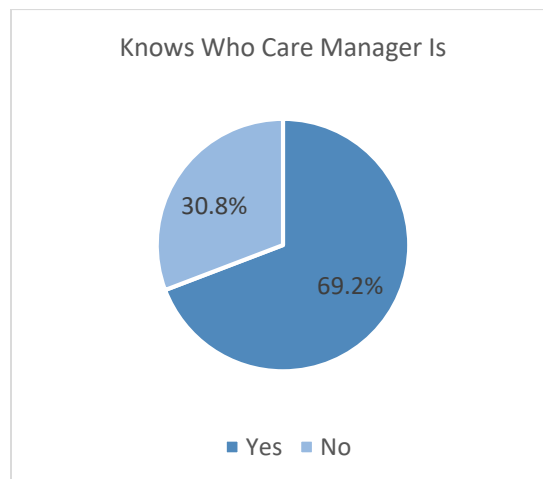
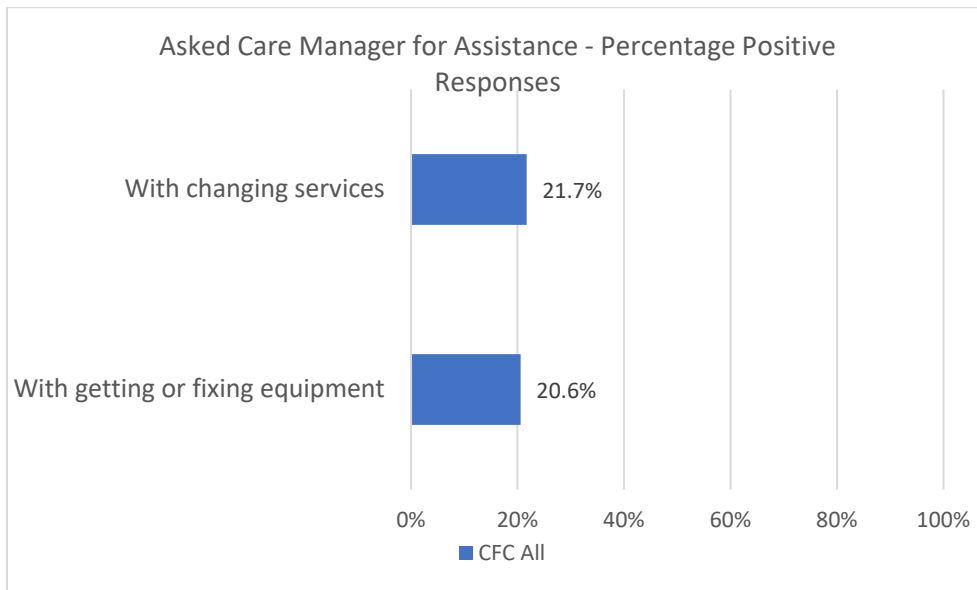
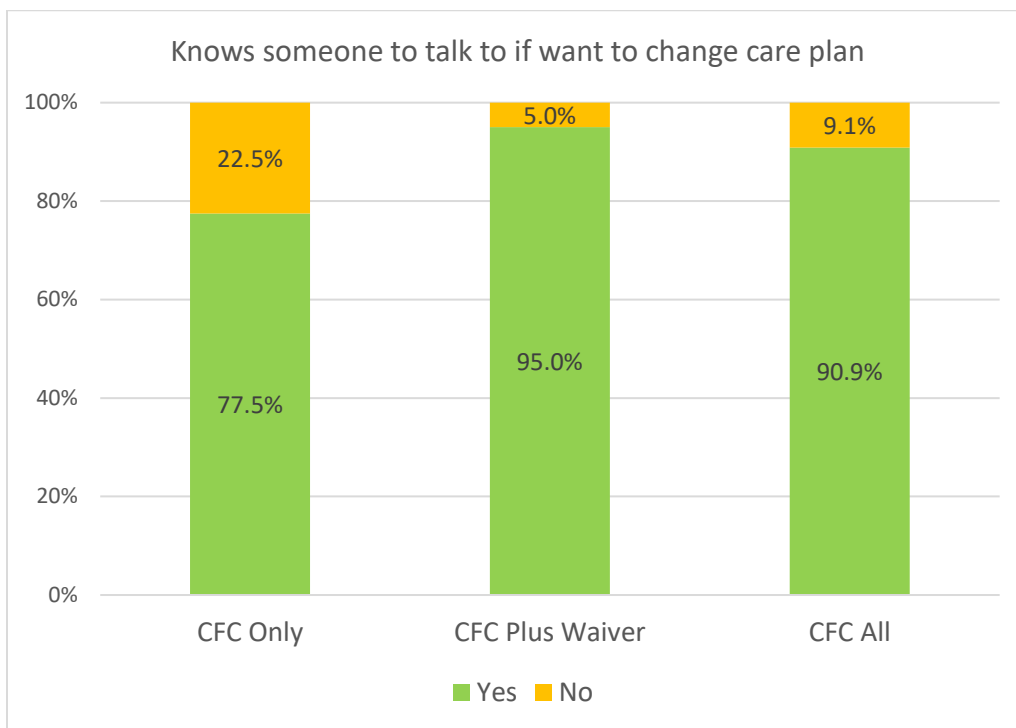


Figure 9. Asked Care Manager for Assistance with Changing Services or Equipment – Percentage Positive Responses



Participants were asked the open-ended question, “In the last 3 months, who would you have talked to if you wanted to change your [care plan, service plan]?” Almost all (95%) of CFC Plus Waiver participants reported they did have someone to talk to, while about one in four (23%) of CFC Only participants said they did not know who they would talk to about changing their care plan (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 (94%) of CFC Plus Waiver participants said they would talk to their case manager, and 39% of CFC Only participants said they would talk to their Universal Assessor (UA) or Support and Planning Coach (Table 8). CFC Only participants more often involved family or friends than CFC Plus Waiver (33% CFC Only, 9% CFC Plus Waiver). Although not shown on the table, 18 (5%) of all CFC participants said they would contact Allied, and another four (3 CFC Only; 1 PCA) said they would just “do it myself.”

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

	CFC Only N=79 n (%)	CFC Plus Waiver N=322 n (%)	CFC All N=401 n (%)
Waiver Case manager	0 (0)	304 (94.4)	304 (75.8)
UA or Support & Planning Coach	31 (39.2)	0 (0)	31 (7.7)
Other staff or home care agency/provider	9 (11.4)	13 (4.0)	22 (5.5)
Family/friends	26 (32.9)	30 (9.3)	56 (14.0)
Someone else	16 (20.3)	22 (6.8)	38 (9.5)

*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: personal care (dressing/bathing), meals, medications, toileting, and housekeeping (Table 9). The greatest need for assistance for all CFC participants was for meals (96%), followed by personal care (92%) and household chores (82%)

Table 9. Self-reported Assistance with Everyday Activities

Needs assistance with:	CFC Only n (%)	CFC Plus Waiver n (%)	CFC Combined n (%)
Personal care	81 (86.2)	273 (93.8)	354 (91.9)
Meals or eating	90 (95.7)	278 (95.5)	368 (95.6)
Taking medications	72 (77.4)	222 (76.0)	294 (76.4)
Using the toilet	55 (58.5)	187 (64.3)	242 (62.9)
Housekeeping or laundry	74 (73.3)	262 (84.5)	336 (81.8)

To determine unmet need in these areas, participants who needed assistance with a task were asked if they did not do the activity in the past three months specifically because of lack of staff to assist them. Six participants indicated an unmet need: 2 for taking medications, 2 for using the toilet, 1 for meals or eating, and 2 for housekeeping (separate items, can report more than one). No participant reported an unmet need with personal care.

vi. Physical safety

One CFC participant reported that a staff person had hit them or hurt them in the past three months. This participant reported that neighbors and friends were working with him/her to resolve the problem. No other participants from either of the groups reported being hit or hurt by a staff person.

E. Additional Findings

i. Living situation and social support

As shown in Table 10, CFC Plus Waiver participants were more likely than CFC Only to live alone or without other adults (47% CFC Plus Waiver vs. 31% CFC Only). This may in part reflect age cohort differences between the two groups – 17% of CFC Only participants were less than 25 years old compared to 8% of CFC Plus Waiver. On the other hand, proportionately more CFC Plus Waiver participants had friends who lived nearby (67% CFC Plus Waiver vs. 53% CFC Only). In addition, CFC Plus Waiver participants were also more likely to see their nearby friends – over half (54%) of CFC Plus Waiver participants could “usually” or “always” see their nearby friends when they wanted to, compared to only 42% of CFC Only participants.

The Governor’s “Stay Safe, Stay Home” Executive Order enacted March 24, 2020 in response to the coronavirus noticeably affected CFC participants’ ability to see their family or friends. Sixty-nine percent of all CFC participants could see their nearby family “usually” or “always” prior to March 25, 2020, compared to only 60% after that date. The ability of all CFC participants to “usually” or “always” see their nearby friends fell from 59% before March 25, 2020 to 52% after the “Stay Safe, Stay Home” order was enacted.

Table 10. Living Situation and Social Support*

		CFC Only %	CFC Plus Waiver %	CFC All %
Number of adults living in household		N=102	N=336	N=438
	1	31.4	46.7	43.2
	2-3	59.8	48.8	51.4
	4+	8.8	4.5	5.5
Lives with family member/s		N=70	N=179	N=249
	Yes	90.0	85.5	86.8
	No	10.0	14.5	13.3
Lives with non-family		N=70	N=179	N=249
	Yes	14.3	15.1	14.9
	No	85.7	84.9	85.1
Family member/s live nearby		N=102	N=339	N=441
	Yes	79.4	75.8	76.6
	No	20.6	24.2	23.4
Friend/s live nearby		N=102	N=337	N=439
	Yes	52.9	67.1	63.8
	No	47.1	32.9	36.2

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

ii. Physical and mental health

CFC Only participants reported themselves to be in worse physical health than CFC participants on a waiver. Over half (56%) of CFC Only participants said their health was fair or poor, compared to 48% of CFC participants on a waiver (Figure 11). When asked to rate their mental or emotional health, a substantial portion (38%) of all CFC participants said their mental health was either fair or poor (Figure 12). Katie Beckett waiver data is not included due to missing data.

Figure 11. Self-Reported Physical Health

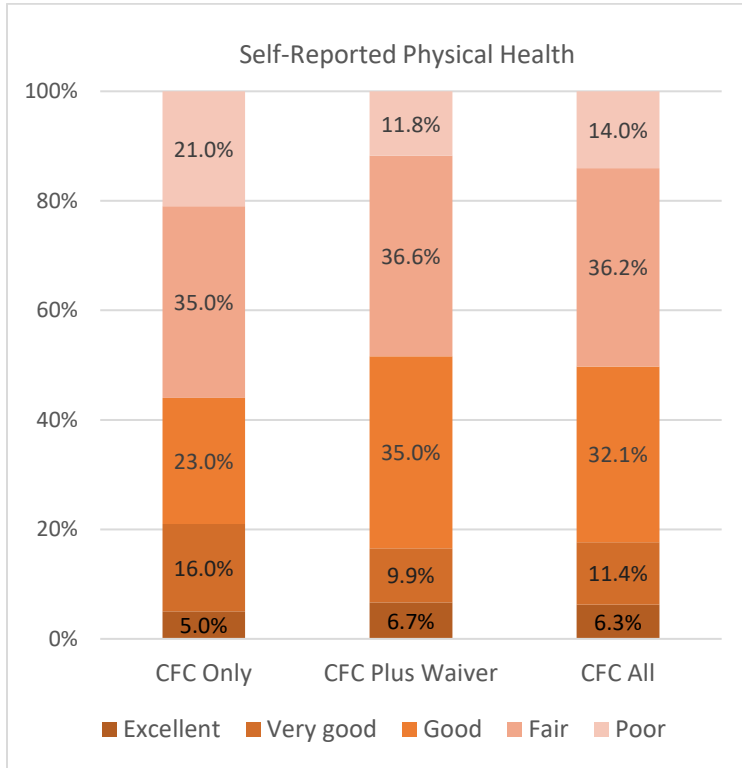
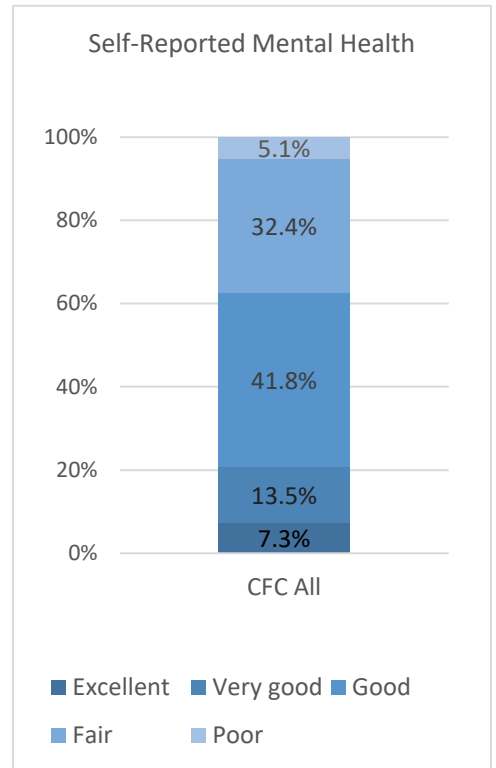


Figure 12. Self-Reported Mental Health



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

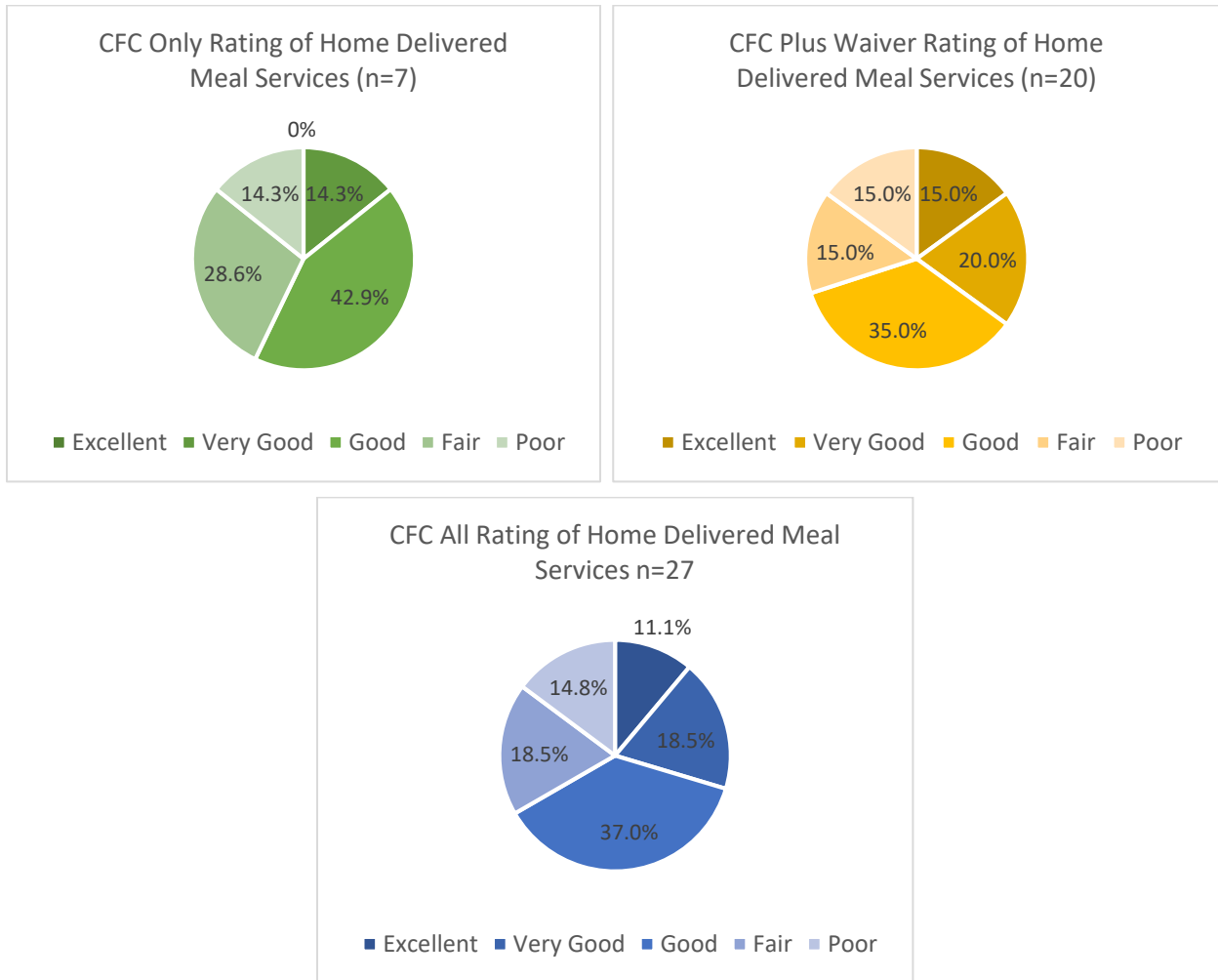
Over one-third (36%) of CFC Plus Waiver participants reported using a van or transportation service, while CFC Only participants (27%) used this type of service less frequently (Table 11).

Table. 11. Use of a Van or Transportation Service

	CFC Only % N=102	CFC Plus Waiver % N=338	CFC All % N=440
Yes	26.5	36.4	34.1
No	73.5	63.6	65.9

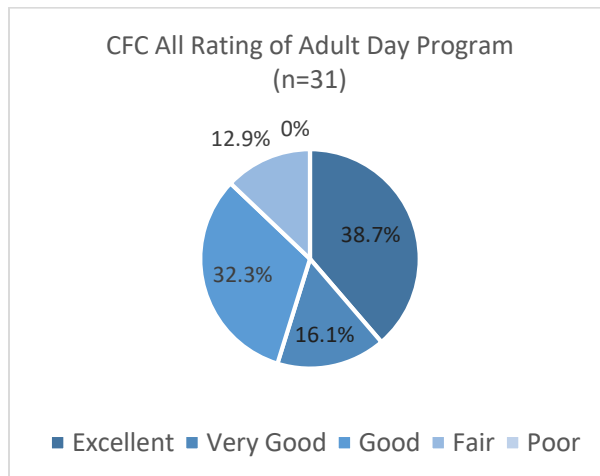
A total of 27 participants rated their home delivered meal service: 7 CFC Only participants and 20 CFC Plus Waiver participants. As shown in Figure 13, a much higher percentage of CFC Only participants were satisfied with their meal services. 57% of CFC Only participants rated their meal service as very good or excellent, compared to only 35% of CFC Plus Waiver participants.

Figure 13. Experience with Home Delivered Meal Services



Another 31 participants rated their day program services. As shown in Figure 14, 55% of all CFC participants rated their day program as either excellent or very good, and another 32% rated it as good.

Figure 14. Experiences with Day Program Services



iv. Personal safety and respect follow-up

Six participants (1.4% of all CFC participants) said that one of their staff had taken their money or things without permission: 1 CFC Only and 5 CFC Plus Waiver. Three of them had someone working with them to fix this problem. Eight participants (1.8% of all CFC participants) said that one of their staff had yelled or cursed at them: 1 CFC Only and 7 CFC Plus Waiver. Four of these participants said someone was working with them to fix the problem. Altogether, six of the 14 participants who were stolen from or yelled at said that someone was working with them to resolve these issues.

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. The majority (82%) of CFC participants would contact their family or friends in case of an emergency (Table 12). However, CFC Plus Waiver were more likely to call 911 (32% CFC Plus Waiver vs. 20% CFC Only) and were about four times as likely to use a Personal Emergency Response System (PERS) than CFC Only (11% vs. 3%, respectively). Although not shown in the table, six percent of CFC Only participants said they did not know who they would contact in an emergency, compared to one percent of CFC Plus Waiver participants.

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

	CFC Only N=96 n (%)	CFC Plus Waiver N=334 n (%)	CFC All N=430 n (%)
Family/friend	85 (88.5)	267 (79.9)	352 (81.9)
Case manager/UA	1 (1.0)	19 (5.7)	20 (4.7)
HCBS agency	0 (0)	11 (3.3)	11 (2.6)
PERS/Lifeline	3 (3.1)	37 (11.1)	40 (9.3)
911	19 (19.8)	107 (32.0)	126 (29.3)
Staff	6 (6.3)	18 (5.4)	24 (5.6)
Someone else	1 (1.0)	12 (3.6)	13 (3.0)

*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 (85%) of CFC participants reported they hired their own staff (Table 13). Surprisingly, 12 CFC Only participants reported an agency provided their staff.

Consumers who reported hiring their own staff were asked if any of their family members were paid to assist them. Approximately half (48%) 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=101	N=334	N=435
Agency	11.9	16.2	15.2
Self-hire	88.1	83.8	84.8
Agency and Self-hire	0.0	0.0	0.0
Employs family member/s	N=89	N=280	N=369
Yes	56.2	45.0	47.7
No	43.8	55.0	52.3

*The percentages listed for each item are based on the total number of valid responses to that question

vii. Employment

CFC participants were asked about employment status, goals, and assistance finding employment. As shown in Figure 15, CFC Only participants were twice as likely to be employed (14% CFC Only, 6% CFC Plus Waiver). Overall, 8 percent of all CFC participants are currently working. Almost 30 percent (29%, n=105) of all unemployed CFC participants would like to have a job (Figure 16).

Figure 15. Employment Status

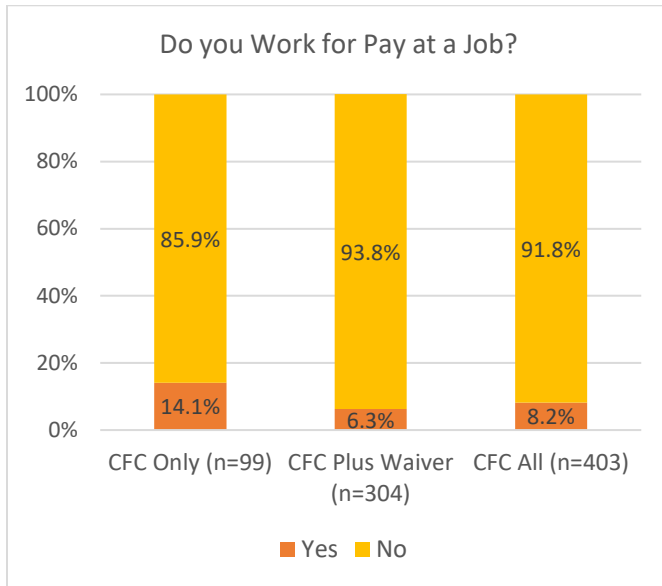
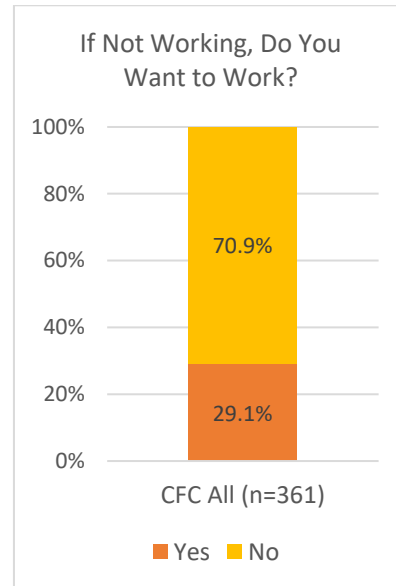


Figure 16. Employment Goal



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, almost all CFC Only participants (96%) said health or disability challenges prevented them from working, compared to 67% of CFC Plus Waiver participants. Few CFC participants reported that training/education, transportation, looking but can't find work, potential loss of benefits, or employment resources were challenges to employment – less than 10 participants reported any one of these reasons.

Unemployed CFC Plus Waiver participants showed one major difference from CFC Only participants. Only 18% of CFC Only participants who did not want to work reported that nothing was holding them back from working, compared to 27% of CFC Plus Waiver participants who reported that nothing was

holding them back. Overall, 25% of all CFC participants 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=27 n (%)	CFC Plus Waiver N=76 n (%)	CFC All N=103 n (%)
Health/disability	26 (96.3)	51 (67.1)	77 (74.8)
Nothing is holding me back	1 (3.7)	1 (1.3)	2 (1.9)
<i>Participants who do not want to work</i>			
	CFC Only N=57 n (%)	CFC Plus Waiver N=198 n (%)	CFC All N=255 n (%)
Health/disability	44 (77.2)	138 (69.7)	182 (71.4)
Nothing is holding me back	10 (17.5)	54 (27.3)	64 (25.1)

*Multiple choice

A small number (n=6) of unemployed CFC participants who wanted to work had asked for help with finding a job (Figure 17). About half (48%) of unemployed CFC Only participants knew about job assistance, compared to nearly two-thirds (63%) of CFC Plus Waiver participants (Figure 18). A majority (59%) of all unemployed CFC participants knew that such help was available, although they did not seek it out.

Figure 17. Sought Out Employment Assistance

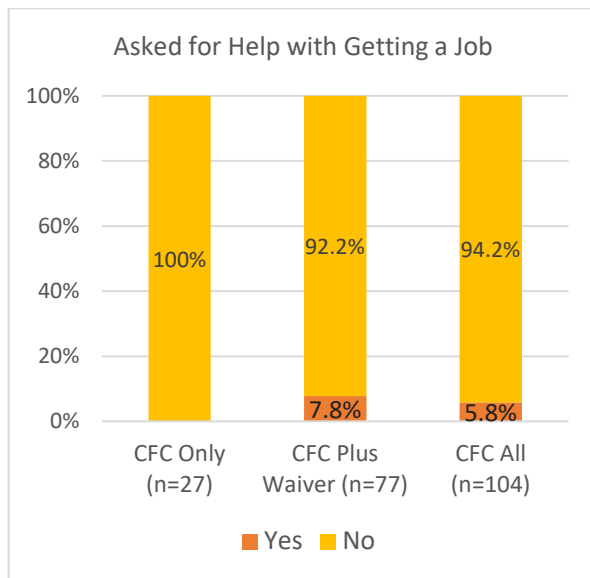
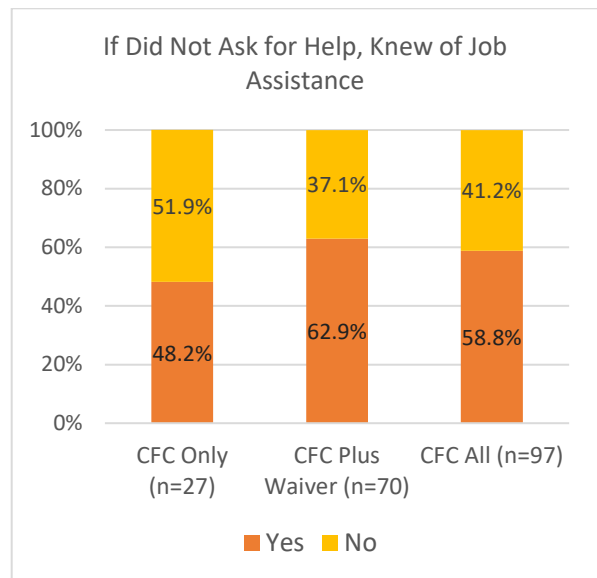


Figure 18. Aware of Employment Assistance



IV. Conclusions

In 2019, the HCBS CAHPS® survey was implemented in the Community First Choice program to measure the experiences of CFC participants with their self-directed HCBS. Although the HCBS CAHPS® surveys administered by waiver quality assurance staff included waiver participants using CFC, surveys had not been completed with participants solely on CFC who were not receiving additional waiver services.

A. Respondent Sample

From December 2019 to February 2020, UConn completed 102 HCBS CAHPS® surveys with CFC participants not receiving any waiver services (CFC Only). Of the 1400 HCBS CAHPS® surveys completed from July, 2019 to June 2020 with waiver participants, 339 of those participants were also using CFC (CFC Plus Waiver). These were combined with the CFC Only surveys to produce a sample of 441 CFC participants for this report.

CFC Only participants not on a waiver had a larger younger age cohort, with 17% of CFC Only participants less than age 25, compared to 8% of CFC Plus Waiver. There was also a larger percentage of older CFC Only participants – 18% of CFC Only participants were age 65 or older, compared to 6% of CFC Plus Waiver. This most likely reflects the long-term use of home care agencies to provide HCBS for CHCPE waiver participants, as self-direction was not part of that waiver. With the aging Baby Boomer generation, it will be interesting to see if this trend shifts and more CHCPE participants choose to self-direct. The two groups differed in ethnicity, as almost three times as many CFC Only participants identified as Latino/Latina (33% CFC Only vs. 13% CFC Plus Waiver), and a larger portion of CFC Only participants primarily spoke Spanish (15% CFC Only vs. <1% CFC Plus Waiver). There were gender differences as well, as the majority (71%) of CFC Only participants were female, compared to 51% of CFC Plus Waiver participants.

B. Key Results

The scores for six of the seven composites were high for all CFC participants, with the exception of planning your time and activities. This composite includes items which assess the participant's ability to choose and control his/her social interactions, community engagement, and daily activities. This finding is not unique to the CFC population and represents an opportunity for improvement in the DSS waiver programs as well as CFC. When looked at using the percentage who gave the highest score, participants gave their personal assistant and other staff high scores for reliability, helpfulness, and listening and communication skills. Medical transportation was not rated as highly when viewed this way, which may represent another area for improvement.

Mean global rating scores for personal assistant and behavioral health staff were all uniformly high. When looked at through the lens of the percentage who rated their staff a 9 or a 10, a difference emerged between the two CFC groups – a greater percentage of CFC Only participants (89%) compared to CFC Plus Waiver participants (80%) rated their staff that highly.

Mean recommendation scores were also high, especially for personal assistant and behavioral health staff. CFC Only participants were more likely to “definitely” recommend their personal assistants compared to CFC participants on a waiver (91% vs. 80%, respectively). As a whole, 83% of all CFC participants would “definitely” recommend their personal assistant and behavioral health staff.

C. Additional Findings

CFC participants reported positive experiences with their staff in other ways as well. Almost all (95% - 98%) CFC participants said their staff encouraged them to do things for themselves when they could. This finding underscores one of the core values in CFC, which is that program services should support and/or increase a participant's independence. CFC Plus Waiver participants all receive case management; however, 31% of these participants did not know who their care manager was, which indicates an area of improvement for waiver services.

Having a care manager, and knowing how to contact them, could make a difference for CFC participants in the event that they wanted to change their service plan. When asked who they would contact to change their service plan, 23% of CFC Only participants said they did not know. Almost all (95%) of CFC Plus Waiver participants could name someone they would talk with about this, and most of them said they would contact their care manager. Education and outreach to all CFC participants would be helpful regarding who to contact to change their services.

Almost all participants used staff for preparing meals or eating (96%) and for personal care (92%), following by housekeeping (82%). Very few (n=6) participants indicated they had any unmet needs for care. Less than 2% of participants reported staff stealing from them or yelling/cursing at them. One participant reported being physically abused; this participant indicated someone was helping him/her to resolve this issue.

The majority (85%) of CFC participants reported they self-directed their services. The other 15% said an agency provided their staff, including 12 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. Almost half of participants who hired their own staff employed a family member, which is a benefit of using CFC.

CFC Only participants reported themselves to be in worse physical health than CFC participants on a waiver. Mental health is also a definite area of concern for CFC participants in both groups – 38 percent of all CFC participants rated their mental or emotional health as “fair” or “poor.” In addition, the Governor’s “Stay Safe, Stay Home” Executive Order noticeably affected CFC participants’ ability to see their nearby family or friends as often as they would like. Finding ways to support participants’ emotional health, and helping participants find ways to connect with other people even with COVID 19, are two focus areas which could improve participants’ lives.

Only eight percent of CFC participants were working for pay. However, almost 30% of unemployed CFC participants would like to have a job. The majority of these participants reported that health and disability related issues prevented them from working. Over 70% of unemployed participants who did not want to work also cited health and disability related concerns; in addition, one-quarter of these participants said nothing was holding them back from working. Only a small number (n=6) of unemployed CFC participants who wanted to work had asked for help with finding a job. The majority (59%) of unemployed CFC participants knew that employment assistance was available, even though they did not seek it out. Facilitating employment, including finding ways to address health concerns and providing support through the employment process, represents an area of potential improvement.

D. Looking Forward

HCBS CAHPS® surveys with CFC participants on waiver are administered on an ongoing basis by the quality assurance staff from the Access Agencies and DSS. UConn is preparing to complete a second round of HCBS CAHPS® interviews with CFC participants who are not on a waiver in the fall of 2020. UConn continues to provide technical assistance, including survey site administration, training, and other support.

V. Appendices

Appendix A. Composite Measures Items

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

Appendix A. Composite Measures Items

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

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

* Question added by Connecticut

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

Waivers-Programs:

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

CAHPS® Home- and Community-Based Services Survey

Version: 1.0

Population: Adult

Language: English

Connecticut version – 2019

Waivers-Programs

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



File name: CAHPSHcbs01192017SurvEng508

Last updated: January 19, 2017

Instructions for Vendor

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

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

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

COGNITIVE SCREENING QUESTIONS

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

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

- ¹ YES
² NO → END SURVEY
⁻¹ DON'T KNOW → END SURVEY
⁻² REFUSED → END SURVEY
⁻³ UNCLEAR RESPONSE → END SURVEY

2. How do they help you?

[EXAMPLES OF CORRECT RESPONSES INCLUDE]

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

3. What do you call them?

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

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

[Interviewer - Screening Failed]

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

IDENTIFICATION QUESTIONS

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

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

- ¹ YES
- ² NO → GO TO Q6
- ⁻¹ DON'T KNOW → GO TO Q6
- ⁻² REFUSED → GO TO Q6
- ⁻³ UNCLEAR RESPONSE → GO TO Q6

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

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

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

- ¹ YES
- ² NO → GO TO Q8
- ⁻¹ DON'T KNOW → GO TO Q8
- ⁻² REFUSED → GO TO Q8
- ⁻³ UNCLEAR RESPONSE → GO TO Q8

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

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

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

home?

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

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

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

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

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

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

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

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

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

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 . . .

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

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

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

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

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

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

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

- 2 REFUSED
- 3 UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

- ¹ YES
- ² NO → GO TO Q28
- ⁻¹ DON'T KNOW → GO TO Q28
- ⁻² REFUSED → GO TO Q28
- ⁻³ UNCLEAR RESPONSE → GO TO Q28

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

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

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

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

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

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

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

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

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

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

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

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

- 2 REFUSED
- 3 UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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

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

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

Would you say . . .

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

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

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

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

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

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

- __ 0 TO 10
- 1 DON'T KNOW
 - 2 REFUSED

⁻³ UNCLEAR RESPONSE

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

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

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

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

GETTING NEEDED SERVICES FROM 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 . . .

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

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

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

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

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

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

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

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

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

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

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

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

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

...

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

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

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

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

- 1 YES → GO TO Q41
- 2 NO
- 1 DON'T KNOW → GO TO Q41
- 2 REFUSED → GO TO Q41
- 3 UNCLEAR RESPONSE → GO TO Q41

40. In the last 3 months, was this because there were no {*homemakers*} to help you? [ASK IF HOMEMAKER IS THE SAME AS PCA STAFF]

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

HOW WELL HOMEMAKERS COMMUNICATE WITH AND TREAT YOU

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

YOUR CASE MANAGER

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

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

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

⁻³ UNCLEAR RESPONSE → GO TO Q55a

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

¹ YES

² NO

⁻¹ DON'T KNOW

⁻² REFUSED

⁻³ UNCLEAR RESPONSE

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

¹ YES

² NO → GO TO Q52

³ DON'T NEED → GO TO Q52

⁻¹ DON'T KNOW → GO TO Q52

⁻² REFUSED → GO TO Q52

⁻³ UNCLEAR RESPONSE → GO TO Q52

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

¹ YES

² NO

⁻¹ DON'T KNOW

⁻² REFUSED

⁻³ UNCLEAR RESPONSE

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

¹ YES

² NO → GO TO 54

³ DON'T NEED → GO TO Q54

⁻¹ DON'T KNOW → GO TO Q54

⁻² REFUSED → GO TO Q54

⁻³ UNCLEAR RESPONSE → GO TO Q54

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

¹ YES

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

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

__ 0 TO 10

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

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

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

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

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

HOME-DELIVERED MEALS, ADULT DAY PROGRAM

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

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

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

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

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

CHOOSING YOUR SERVICES

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

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

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

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

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

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

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

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

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

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

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

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

TRANSPORTATION

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

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

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

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

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

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

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

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

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

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

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

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

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

PERSONAL SAFETY

The next few questions ask about your personal safety.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

- 1 FAMILY MEMBER OR FRIEND

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

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

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

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

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

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

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

COMMUNITY INCLUSION AND EMPOWERMENT

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

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

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

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

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

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

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

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

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

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

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

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

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

- 1 Mostly yes or
- 2 Mostly no?

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

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

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

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

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

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

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

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

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

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

- 1 YES
- 2 NO

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

ABI, Autism, and PCA: Ask Employment Module

CHCP & Katie Beckett: Skip to ABOUT YOU

EMPLOYMENT MODULE (ABI, Autism & PCA)

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

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

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

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

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

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

⁻³ UNCLEAR RESPONSE → GO TO EM5

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

__ 0 TO 10

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

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

Would you say . . .

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

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

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

ABOUT YOU

Now I just have a few more questions about you.

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

- ¹ Excellent,
- ² Very good,

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

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

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

84. What is your age?

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

ALTERNATE VERSION: In what year were you born?

_____ (YEAR)

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

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

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

-3 UNCLEAR RESPONSE

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

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

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

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

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

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

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

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

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

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

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

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

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

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

93. What is the language you speak at home?

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

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

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

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

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

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

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

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

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

END OF QUESTIONS

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

- AASCC: 203-752-3040
- 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?

- ¹ YES
- ² NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

- ¹ YES
- ² NO → GO TO END OF SURVEY

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

- ¹ SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- ² STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

- ¹ YES
- ² NO → GO TO END OF SURVEY

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

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

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

- ¹ SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT
- ² STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F7. Relationship to participant:

- Spouse/partner
- Adult child
- Parent
- Attorney or legal representative
- 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: _____