

Money Follows the Person Rebalancing Demonstration

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

2021 Survey Results

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I. Introduction, Methods, and Analysis

As part of the comprehensive Money Follows the Person program (MFP) quality management strategy, the Connecticut directly interviews participants or their representatives asking about their experiences in the year after transition. Since January 2019, consumers are interviewed at 1 month and 12 months post-transition to identify the quality of care and services each consumer experiences over the entirety of their time in the MFP program using the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS®) survey. This report uses MFP HCBS CAHPS survey results as well as data from MyCommunityChoices.com to explore the experiences of various groups of MFP participants, including those with 1 month surveys completed in 2021 and the 1 and 12 month surveys for the cohort of consumers who transitioned in 2020.

A. Money Follows the Person HCBS CAHPS® Survey

The HCBS CAHPS survey comprises eleven sections: cognitive screen, identification of paid services, personal assistance and/or behavioral health staff services, homemaker services, case manager services, choosing your services, transportation, personal safety, community inclusion and empowerment, demographics, and employment. To provide more focused feedback about a participant's experience with their paid staff, the HCBS CAHPS survey has separate sections to ask about the staff who provide different types of services. Different sections cover personal assistance and behavioral health services, homemaking services, care management services, and supported employment services. A participant's waiver or program determines which types of staff or services to ask about and what terms to use to refer to these services. The consumer then identifies if they have received this service. Additional questions were added to the MFP HCBS CAHPS survey to further assess use of assistive devices and home modifications, self-direction, health care service use, depressive symptoms, finances, global satisfaction, and informal support. Consumers residing in a facility at the time of their survey answer about their experience with facility staff, as well as most of the other items covered in the full survey. The 2019-2020 MFP HCBS CAHPS Community and Institutional surveys are attached in Appendices A and B.

B. Survey Administration

MFP consumers are interviewed two times after transition: first at 1 month and again at 12 months post-transition. Surveys are completed with consumers residing in either a community or an institutional setting. Consumers completing 1 month interviews are asked to consider their experiences since their transition from a facility. At the 12 month survey, consumers consider the past 3 months prior to the survey. Please see the 2019 MFP HCBS CAHPS report for more details on methods and survey administration.

C. Analysis

Key results are presented using established HCBS CAHPS composite and other key measures (Table 1). Individual items not included in these measures are also reported. Each composite scale comprises three to twelve individual questions (see Appendix C). Most of these questions have four response options: never, sometimes, usually, and always. A composite's final score is generated by combining the answers from each question. For global ratings, participants are asked to rate the help they get from each type of staff based on a scale from 0 to 10, or alternatively, using a scale worded from poor to excellent. Recommendations are based on a four-point scale asking if the participant would recommend the person using one of the following responses: definitely no, probably no, probably yes, or definitely yes.

This report displays the percentage of participants who gave the most positive or highest composite score, global rating, or recommendation. To produce the highest composite scores, responses are divided into two groups: the most positive and all other responses. Likewise, each global rating is

categorized as either the highest score (a 9 or 10, or verbal rating of excellent), versus all other responses. Highest recommendation is determined similarly – only “definitely yes” is given the highest score, while the other three responses are grouped together.

Descriptive results for all other survey questions are presented as frequencies and percentages.

Table 1. 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

*See Appendix C for a list of the questions which compose each composite measure.

II. Results

Results are divided into five sections:

➤ Section 1: Survey and Respondent Characteristics for Surveys Completed in 2021

A total of 754 HCBS CAHPS surveys were completed with MFP participants in 2021: 364 1 month and 390 12 month surveys. Notable differences in survey characteristics and demographics by time point and setting are described.

➤ Section 2: 1 Month Community Surveys Completed in 2021

This section presents select results from the 341 1 month surveys completed in 2021 with consumers residing in the community. HCBS CAHPS key results and areas of interest from the previous 2020 MFP HCBS CAHPS report, in particular case manager, health, and assistive devices, are shown.

➤ Section 3: Community Experiences from 1 Month to 12 Months Post-transition for Consumers Who Transitioned in 2020

The full set of both 1 month and 12 month MFP HCBS CAHPS surveys are available for consumers who transitioned in 2020. With a focus on consumers in the community, this section explores questions such as, what are these consumers' lives like one year after transition compared to one month after leaving the facility? What are their experiences with their home and community-based services (HCBS) paid supports early and later in their post-transition journey?

➤ Section 4: Experiences of Waiver and Non-waiver Consumers from 1 Month to 12 Months Post-transition

Using the cohort of community-based consumers from Section 3, this part of the report separates them by waiver use, and looks at differences between consumers on a waiver and those using state plan services.

➤ Section 5: Community Experiences by Service Type: Agency-based vs. Self-directed Services Over Time

Section 5 examines the community-based cohort from Section 3 by type of service use, comparing consumers using agency-based versus self-directed supports.

➤ Section 6. The Reinstitutionalization Effect

This section examines the history and effect of readmission to a facility by following consumers from transition through their 1 or 12 month survey. First, the cohort of the 610 consumers who transitioned in 2020 is used to describe any history of reinstitutionalization up to one year post-transition. A Sankey diagram provides a visual representation of the reinstitutionalization pattern including movement in or out of an institution. Select results from consumers reinstitutionalized at the time they completed their 12 month survey are also presented.

Next, the experience of reinstitutionalization is examined for consumers who transitioned in 2021 and were reinstitutionalized, long-term or temporarily, by the time of their 1 month survey. Health, mental health, and service use items compare consumers who were never reinstitutionalized with those who experienced even temporary reinstitutionalization before 1 month post-transition. Qualitative analysis is then used to explore the circumstances leading up to readmission, considering questions such as, what happened within those four to six weeks that sent the participant back to a facility? What have their experiences been? Are there lessons to be learned? The goal is to obtain a detailed look at the user experience from their initial transition to the point of completing their 1 month interview.

Section 1. Survey and Respondent Characteristics for Surveys Completed in 2021

A total of 754 HCBS CAHPS surveys were completed with MFP participants in 2021: 364 1 month and 390 12 month surveys. While overall the majority of participants (91%) resided in the community at the time of their survey, 12% participants who completed a survey were in a facility at 12 months, slightly more than the 10% in 2020 (Table 1.1).

Table 1.1. Surveys Completed in 2021 by Setting

	Community n (%)	Institution n (%)
1 Month	341 (93.7)	23 (6.3)
12 Month	342 (87.7)	48 (12.3)
All 2021 Surveys	683 (90.6)	71 (9.4)

One month surveys were attempted to be completed between 30 and 45 days post-transition. On average, 1 month surveys were completed 41 days post-transition, and 12 month surveys were completed an average of 11.4 months post-transition (Table 1.2).

Table 1.2. Time From Transition to Survey Completion in 2021: 1 Month and 12 Month Surveys

	Minimum	Maximum	Mean	Standard Deviation
1 Month Survey (Days)	22	89	40.99	10.247
12 Month Survey (Months)	10	14	11.35	0.532

Table 1.3 shows survey participants' home and community-based program at transition and at 1 and 12 months post-transition. Where the consumer is residing when the 1 month and 12 month surveys were completed are also specified. At each time point and setting, the greatest percentage of consumers transitioned with the Connecticut Home Care Program for Elders using agency-based services (CHCPE-AB). This was followed by consumers using state plan or residential care home (RCH) services. Altogether, over half of consumers (58%) transitioned on one of these programs.

Table 1.3. Home and Community-Based Program at Transition*

	At Transition n (%)	1 Month Community n (%)	1 Month Institution n (%)	12 Month Community n (%)	12 Month Institution n (%)
ABI waivers	20 (2.7)	5 (1.5)	0 (0)	14 (4.1)	1 (2.1)
CHCPE-AB	265 (35.1)	126 (37.0)	11 (47.8)	105 (30.7)	23 (47.9)
CHCPE-SD	29 (3.8)	7 (2.1)	2 (8.7)	19 (5.6)	1 (2.1)
DDS waivers	26 (3.4)	14 (4.1)	1 (4.3)	10 (2.9)	1 (2.1)
Katie Beckett	2 (<1.0)	1 (<1.0)	0 (0)	1 (<1.0)	0 (0)
Mental Health waiver	25 (3.3)	9 (2.6)	0 (0)	14 (4.1)	2 (4.2)
PCA-AB	98 (13.0)	60 (17.6)	3 (13.0)	29 (8.5)	6 (12.5)
PCA-SD	116 (15.4)	45 (13.2)	2 (8.7)	62 (18.1)	7 (14.6)
State Plan/RCH	173 (22.9)	74 (21.7)	4 (17.4)	88 (25.7)	7 (14.6)

*See Appendix D for a complete list of acronyms

Table 1.4 shows survey and respondent characteristics for surveys completed in 2021. Due to the continued COVID 19 pandemic, all but two surveys were completed by telephone. This single survey mode increased the number of surveys completed by a proxy on behalf of the participant, as in-person surveys are often done to accommodate consumers with a communication/hearing impairment or those who are in an institution. In all, proxies completed 27% of surveys in 2021, 4% greater than in 2020.

Table 1.4. Respondent and Survey Characteristics – Completed in 2021 by Time Point and Setting

		1 Month Community N=341 n (%)	1 Month Institution N=23 n (%)	12 Month Community N=342 n (%)	12 Month Institution N=48 n (%)
Survey Respondent					
	By self	229 (67.2)	12 (52.2)	237 (69.3)	28 (58.3)
	With assistance	33 (9.7)	1 (4.3)	14 (4.1)	0 (0.0)
	By proxy	79 (23.2)	10 (43.5)	91 (26.6)	20 (41.7)
Assistant Relationship					
	Spouse/partner	8 (24.2)	1 (100.0)	2 (14.3)	0 (0)
	Adult child	13 (39.4)	0 (0)	4 (28.6)	0 (0)
	Parent	3 (9.1)	0 (0)	3 (21.4)	0 (0)
	Attorney or legal representative	0 (0)	0 (0)	0 (0)	0 (0)
	Paid staff person	0 (0)	0 (0)	1 (7.1)	0 (0)
	Other	9 (27.3)	0 (0)	4 (28.6)	0 (0)
Proxy Relationship					
	Spouse/partner	7 (8.9)	1 (10.0)	16 (17.6)	3 (15.0)
	Adult child	31 (39.2)	4 (40.0)	35 (38.5)	6 (30.0)
	Parent	14 (17.7)	1 (10.0)	14 (15.4)	1 (5.0)
	Attorney or legal representative	7 (8.9)	1 (10.0)	4 (4.4)	3 (15.0)
	Paid staff person	0 (0)	0 (0)	0 (0)	0 (0)
	Other	20 (25.3)	3 (30.0)	22 (24.2)	7 (35.0)
How Person Assisted*					
	Answered some questions	32 (97.0)	1 (100.0)	14 (100.0)	0 (0)
	Restated/reminded/prompted for questions	14 (42.4)	0 (0)	5 (35.7)	0 (0)
	Translated questions	4 (12.1)	0 (0)	2 (14.3)	0 (0)
	Helped with use of assistive or communication equipment	0 (0)	0 (0)	0 (0)	0 (0)
	Other help provided	0 (0)	0 (0)	1 (7.1)	0 (0)
Survey mode					
	Telephone	341 (100.0)	21 (91.3)	341 (99.7)	48 (100.0)
	In-person	0 (0)	2 (8.7)	0 (0)	0 (0)
	Mail	0 (0)	0 (0)	1 (0.3)	0 (0)
Survey used					
	English	329 (96.5)	23 (100.0)	315 (92.1)	46 (95.8)
	Spanish	12 (3.5)	0 (0)	27 (7.9)	2 (4.2)

*Could assist in one or more ways

Demographics among the four groups showed some differences between survey setting and time point (Table 1.5). Some notable differences are the increase in percentage of institutionalized participants who were White, from 70% at 1 month to 90% at 12 months. Similar to national trends, participants who identified as White or non-Hispanic were more likely to reside in an institution, compared to Black or Hispanic respondents (Travers et al., 2021).

Table 1.5. Demographics – Surveys Completed in 2021 by Time Point and Setting

		1 Month		12 Month	
		Community	Institution	Community	Institution
		%	%	%	%
Age		N=341	N=23	N=342	N=48
	<18	2.1	0.0	1.5	0.0
	18-44	8.5	13.0	11.1	4.2
	45-54	15.5	4.3	14.3	2.1
	55-64	29.6	26.1	31.6	37.5
	65-74	27.3	26.1	22.2	39.6
	75+	17.0	30.4	19.3	16.7
Language		N=339	N=23	N=338	N=48
	English	82.6	87.0	75.4	87.5
	Spanish	2.7	0.0	4.7	10.4
	Multilingual/Other	14.7	13.0	19.8	2.1
Race		N=337	N=23	N=333	N=48
	White	67.1	69.6	65.8	89.6
	Black	26.7	26.1	26.1	4.2
	Other	6.2	4.3	8.1	6.3
Ethnicity		N=339	N=23	N=336	N=48
	Non-Hispanic	89.4	91.3	83.0	89.6
	Hispanic	10.6	8.7	17.0	10.4
Education Level		N=330	N=23	N=330	N=48
	< 8th Grade	9.7	13.0	13.3	4.2
	Some high school	12.7	17.4	12.4	14.6
	High school degree	42.4	39.1	42.1	43.8
	Some college	24.5	17.4	24.2	20.8
	4 year college	6.7	8.7	5.5	10.4
	> 4 year degree	3.9	4.3	2.4	6.3
Gender		N=340	N=23	N=339	N=48
	Male	51.8	65.2	52.8	54.2
	Female	48.2	34.8	47.2	45.8

Section 2. 1 Month Community Surveys Completed in 2021

This section presents select results from the 341 1 month surveys completed in 2021 with consumers residing in the community. Results include areas of interest from the 2020 report, in particular HCBS CAHPS key results, direct care staff, physical/mental health, assistive devices, and home modification items. Although not shown, similar data from the 23 1 month institutional surveys is available for any specific questions.

Consumers reported using a number of program services at 1 month after transition, especially care management services (74%) and personal care assistance (PCA) (68%) (Table 2.1). While most service

use is similar to that reported at 1 month in 2020, use of homemaking services increased from 52% in 2020 to 59% in 2021, and case management service use increased by 5% in 2021. “Case manager” is an inclusive term, defined as “the person who helps make sure you have the services you need.” At 1 month post-transition, MFP consumers are most likely referencing their Transition Coordinator (TC) or Specialized Care Manager (SCM). Recovery assistance (RA) and Community service Provider (CSP) services are only used by participants in the Mental Health Waiver (MHW). At one month post-transition, just over half (56%) of MHW participants reported using RA services and 22% reported using CSP services.

The percentage of consumers reporting that they used none of the listed services dropped from 13% in 2020 to 7% in 2021. It is possible that by 2021 consumers were becoming more comfortable letting people who do not live with them into their homes.

Table 2.1. Self-reported Home and Community-Based Services Use*

	Community n (%)
Personal care assistant/attendant services	225 (67.8)
Behavioral health services	4 (1.2)
Homemaking services or Homemaker-Companion**	197 (59.3)
Care management services***	252 (73.9)
Job coach or vocational supports	0 (0)
Recovery assistance services (MHW only)	5 (55.6)
Community Service Provider (MHW only)	2 (22.2)
None of these services	23 (6.7)

* Consumers can use more than one service

**Homemaking tasks can be provided by PCA or separate homemaking staff

***Care management services can include TC, SCM, or other case management services as identified by the respondent

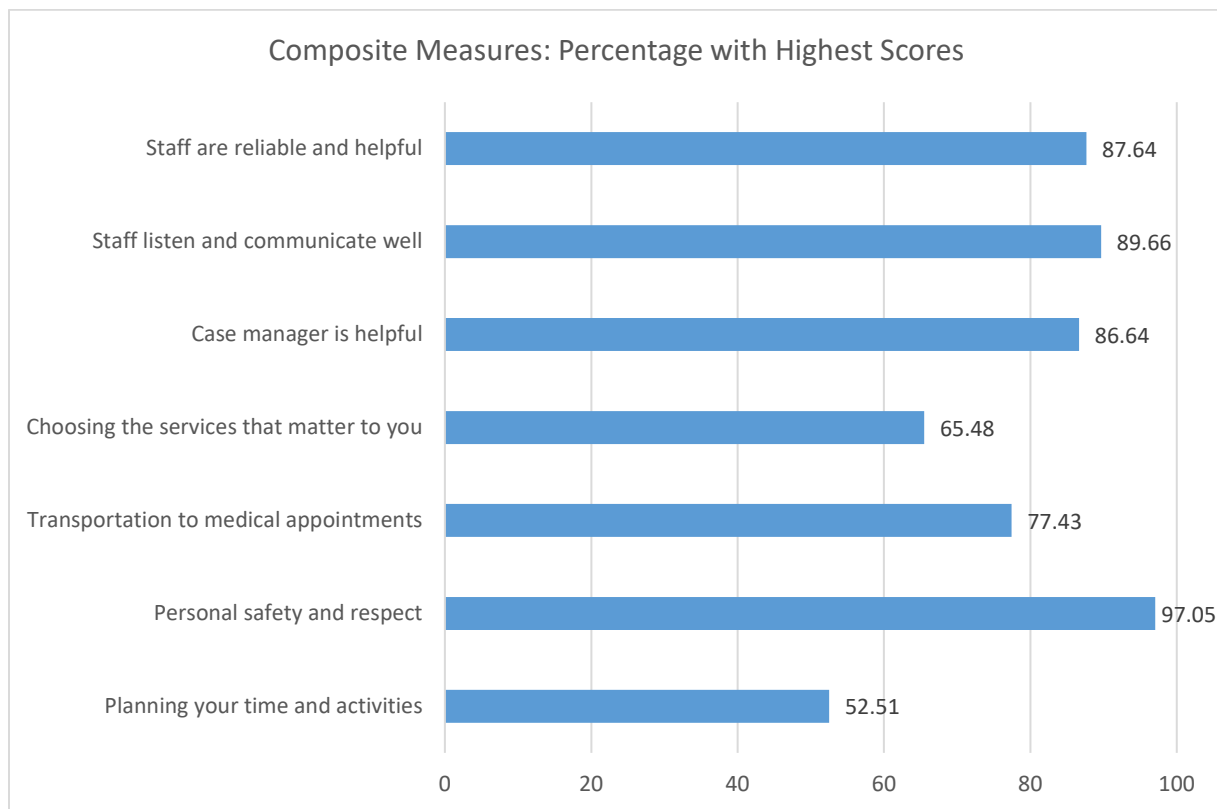
HCBS CAHPS Key Results

The next three figures show the HCBS CAHPS composite measures, staff global ratings, and staff recommendations. Each is shown as the percentage of consumers who gave the highest score to that composite or item. As shown in Figure 2.1, the composite measure “planning your time and activities” received a markedly lower score than the other composites. Just 53% of respondents gave this measure the highest score, which continues a downward trend seen over the past three years, from 68% in 2019 to 58% in 2020. Respondents also gave a noticeably lower score for the composite “choosing the services which matter to you” (66%), and transportation to medical appointments (77%), especially when compared to the high scores given to the staff, care manager, and personal safety composites (range 87% to 97%).

There were multiple unsatisfactory comments about the transportation contractor, VEYO, such as this consumer who commented:

I cannot physically go into my physician’s office. ... VEYO, which I stopped using, was not sending the appropriate [wheelchair accessible] transportation to bring me to my doctor’s office. I feel like my recovery process is on hold because I don't have the appropriate transportation.

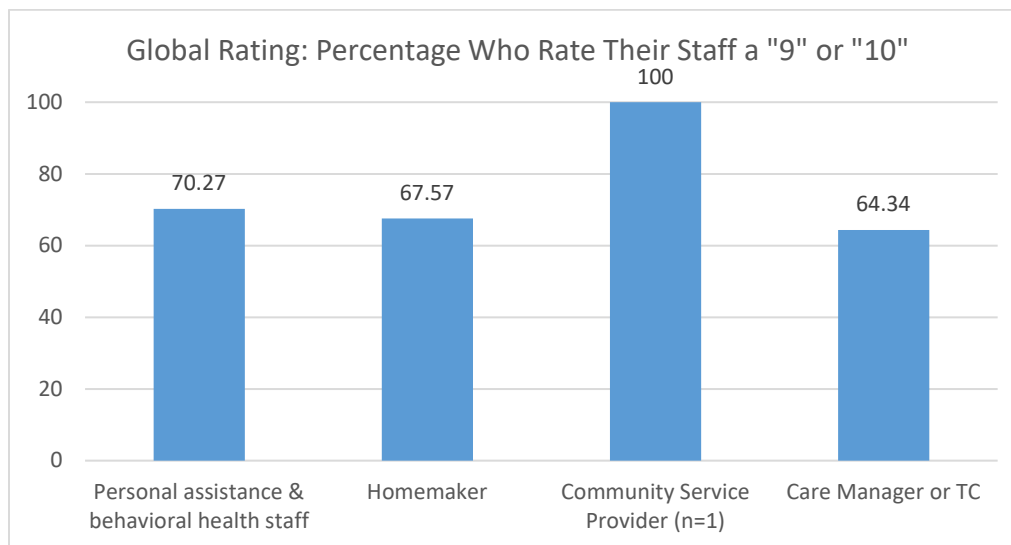
Figure 2.1. Composite Measures: Percentage with Highest Score*



*In all HCBS CAHPS composite figures, “staff” in the community data combines all personal care attendant (PCA), Independent Living Skills Trainer (ILST), recovery assistant (RA), community service provider, homemaking, companion, life skills coach, and community mentor staff.

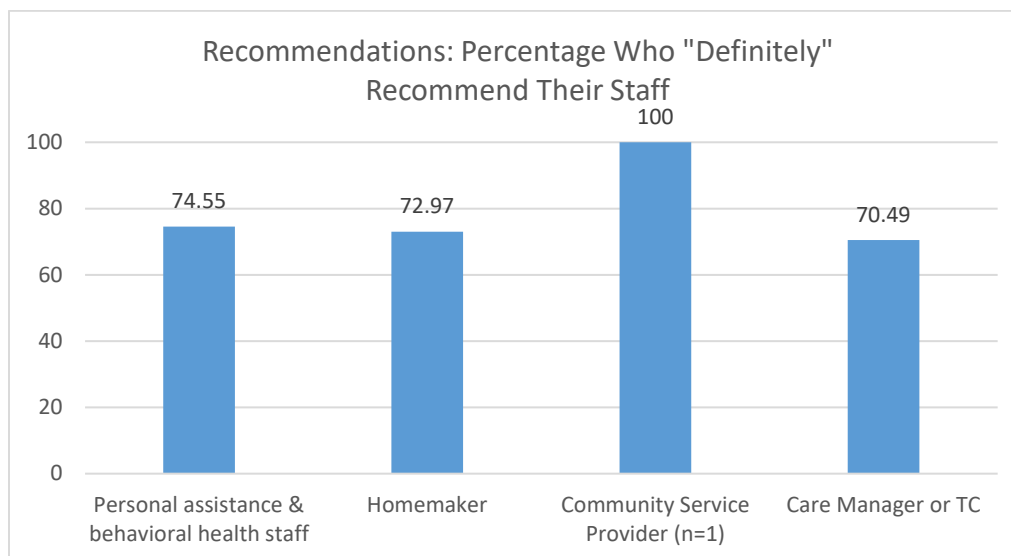
Figure 2.2 presents the percentage of consumers in the community who gave their staff the highest rating possible – a nine or ten, on a scale from zero to ten. Participants were more likely to give their personal assistant/behavioral health or homemaking staff a 9 or 10 (70%, 68% respectively) than their care manager/TC (64%). This trend continues in Figure 2.3, which shows the percentage of consumer who would “definitely” recommend their staff person.

Figure 2.2. Global Rating: Percentage Who Rate Their Staff a “9” or “10” (Range 0 to 10)*



*For all HCBS CAHPS community staff rating and recommendation figures, “personal assistance & behavioral health staff” combines all community PCA, ILST, RA, life skills coach, and community mentor staff. The term “Homemaker” is used to describe any type of staff who assists with homemaking tasks or household chores. “Care Manager/TC” comprises any staff identified by the participant as providing case management services.

Figure 2.3. Recommendation: Percentage Who “Definitely” Recommend Their Staff



Care manager

When asked about their care manager at 1 month, most participants (81%) knew who their care manager was, and 91% could contact them when needed (Table 2.2). On the other hand, some people found that having multiple program and agency staff was confusing:

It is confusing that there are so many people. I don't know who is my direct contact for all of the services.

Table 2.2. Care Manager Contact

Care Manager	Yes n (%)	No n (%)
Know who care manager is	256 (80.8)	61 (19.2)
Able to contact care manager when need to	224 (90.7)	23 (9.3)

Direct care staff

As shown above, at 1 month post transition, the majority of consumers would “definitely” recommend either their PCA/behavioral health/RA staff or their homemaking staff. Comments included:

I am very happy where I am. I am getting to my appointments. I love the [recovery assistant] who comes here.

It's been a great sense of relief to have my mother back home and to have found a great live-in caregiver. My mother says “she is a gem.”

My PCA is excellent - she is terrific. She does what she's supposed to do and then some. I would like to see her agency do a follow up with me about how she is doing.

I wish my PCA could drive, then I would give her a 10 instead of a 9, but she's really good so I don't want to risk finding someone else that can drive but that isn't as good.

However, other comments indicated that at 1 month post-transition, respondents do not always have good experiences with their PCAs or other HCBS staff. Consumers found staffing consistency, including no shows, to be especially problematic. New or fill-in staff sent were not familiar with the consumer, making it difficult to provide personalized, trained assistance. Staff turnover can also make it difficult to establish rapport and trust. Communication with staff and agencies was also a problem. Comments indicated that staffing issues were hard on both the consumer and their family, who often had to fill in as best they could:

We have a great PCA Monday through Friday, but the weekends are a different story. They just can't seem to find a consistent person.

I love the goal of the program, but the agency that was supposed to provide PCA hours was not staffed for our case, and therefore family members are now caring.

I wish that the Recovery Assistant could come on time. She hasn't been able to give her a set schedule yet. Sometimes they give her weekly schedules. [I've had] 5 different people so far that switch back and forth.

There have been staffing issues that make this very difficult. The agency doesn't have enough people hired and if someone can't come in, they often don't have someone to cover. The hardest part is staffing.

Comments also indicated that the first month post-transition also meant adjusting to having different people assisting them and coming into their homes. Consumers found that every day activities, such as scheduling a doctor's appointment or going somewhere, often depended on their PCAs' schedules. Finding the right fit with a PCA was also important to mental and well as physical health.

I didn't [realize] that I have to set up appointments around my aide. I cannot make an appointment if she has to leave early.

PCAs really can control your progress and life, because if they do not work out you are stuck.

Physical and Mental Health

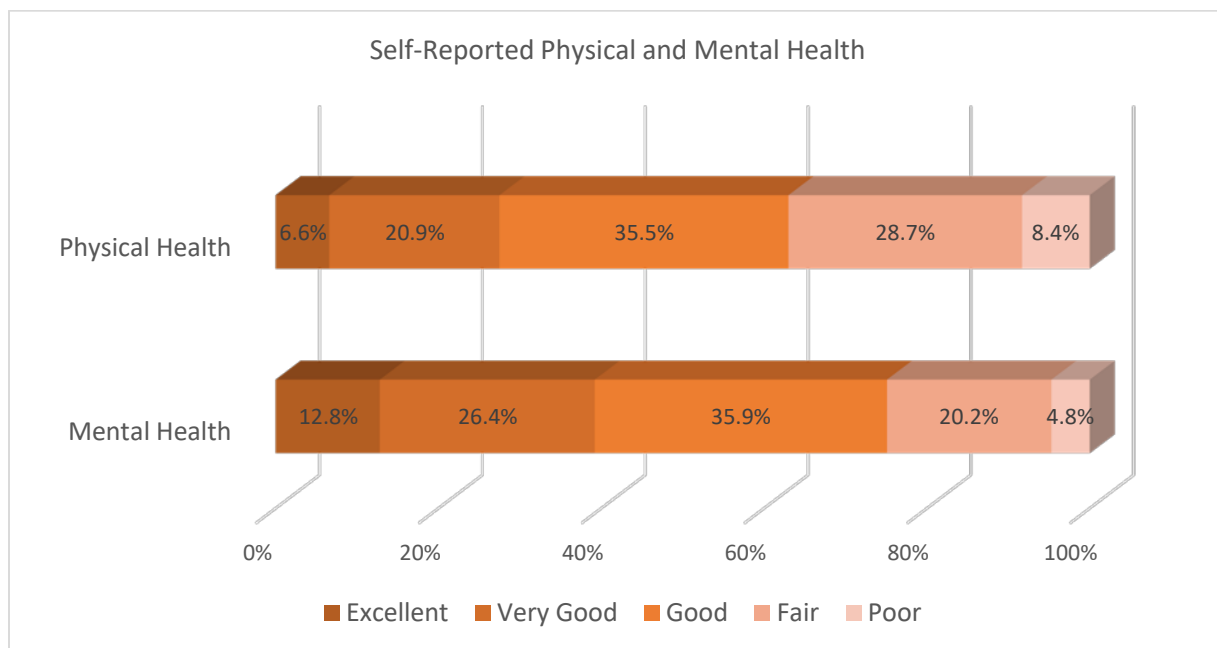
Figure 2.4 shows that the majority of consumers rated their physical and mental health as good or better (63% and 75% respectively). Still, more than one-third of consumers (37%) reported their physical health as fair or poor, and 25% said their mental health was fair or poor. Similar to 2020, 29% of consumers residing in the community at 1 month reported depressive symptoms. One consumer acknowledged that while adjusting to being on their own has been difficult emotionally, things are getting better:

I've been waiting for this since 2016, and I'm finally in my own apartment. It was a little rough at first. I found myself alone, and thinking of who I have and not have in my life. But I'm getting better.

At 1 month post-transition, 14% of consumers reported falling since transition, and slightly more than one-quarter (27%) of consumers had used the emergency room. One consumer attributed this to their “rushed” transition:

My transition was rushed. I left without high blood pressure and pain medications and mental health counseling. I had to go the ER several times and one of those times, my blood pressure was so high, they admitted me.

Figure 2.4. Self-Reported Physical and Mental Health

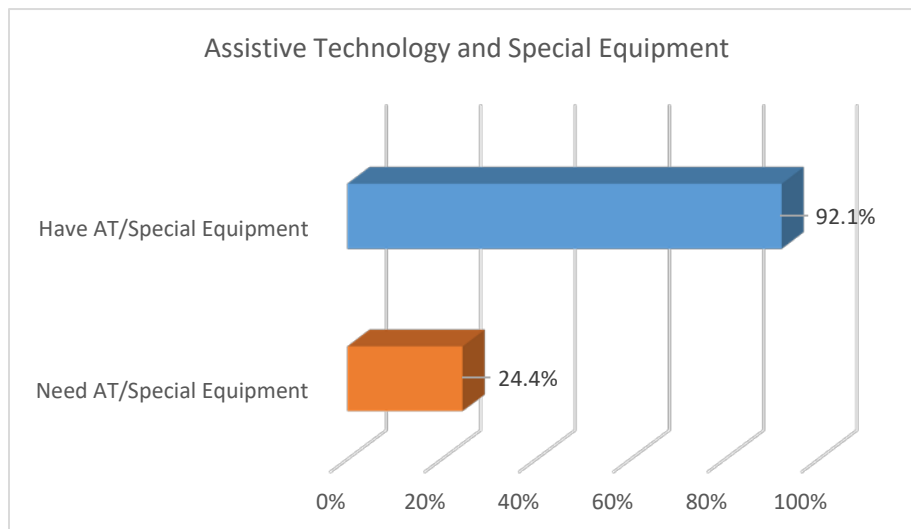


Assistive Technology and Special Equipment

MFP provides consumers with different types of assistive devices, special equipment, and modifications to enhance the consumer’s independence as long as it is needed because of a disability or health condition, is in their HCBS program services, and fits within their care plan budget. Consumers residing in the community were asked if they had different types of assistive devices, home modifications, or special equipment. If the consumer did not, a follow-up question asked if the consumer needed that device or equipment.

While over 90% of consumers reported having at least one type of assistive device or special equipment, 24% of consumers reported lacking some type of assistive device, equipment, or home modification needed for community living at the 1 month survey (Figure 2.5). This number is much lower than in 2020, when 31% reported a need for some type of device or modification 1 month post-transition.

Figure 2.5. Have or Need any Type of Assistive Devices, Home Modifications, or Special Equipment



Consumers most often reported having mobility equipment (81%), special medical equipment, (72%), or home modifications (69%) (Figure 2.6). When asked if they needed certain equipment, 10% of consumers still needed some type of home modification, a decrease from 14% in 2020. Another 10% needed a PERS, and 8% needed some type of special medical equipment. Comments included:

Everything is good for the most part, I'm just a little disappointed with the apartment. It's not very wheelchair accessible. I can't use my wheelchair to get into the bathroom, the aide has to help me. There is also a lot of carpet which they told me there wouldn't be, because it's harder to use my chair.

When I left the nursing rehab I didn't have any of my equipment that I needed for the house, I was missing the grab bars, shower chair and a recliner.

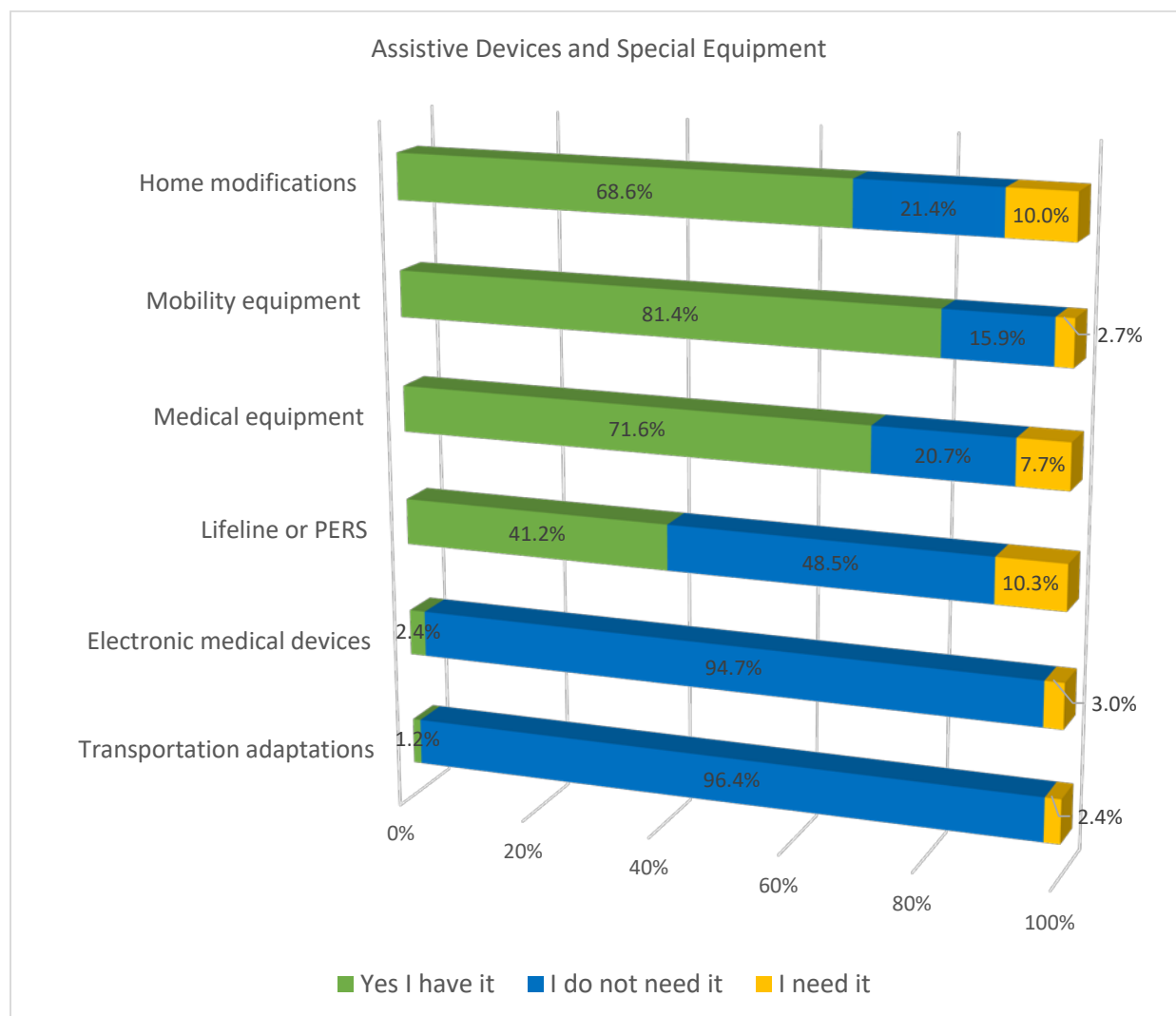
It's frustrating because when I got home, I have stepped backwards instead of forward. I need changes done to my toilet seat in the bathroom so that I can do my necessities in the bathroom not in my bed. I do not have an appropriate wheelchair or motorized chair to give me mobility in the home or outside in the community.

On the other hand, consumers who had received their needed equipment or home modifications were very appreciative:

I was away from my home for 9 1/2 months straight, I was very surprised that the house was set up to accommodate my needs.

My apartment is completely handicap accessible. I love it here.

Figure 2.6. Assistive Devices, Home Modifications, and Special Equipment Items*



*Examples of all categories are found in the MFP HCBS CAHPS community survey in Appendix A.

Section 3. Community Experiences from 1 Month to 12 Months Post-transition of Consumers Who Transitioned in 2020

This section reports the experiences of consumers who transitioned in 2020 and were living in the community at the time of their 1 month or 12 month survey. It explores questions such as, what are these consumers' lives like at one year after transition compared to 1 month after leaving the facility? What are their experiences with their HCBS paid supports early and later in their post-transition journey? Sections 4 and 5 describe this group by waiver status and type of service to answer the questions: are there any notable differences between consumers on a waiver and those using state plan services? How do the experiences of consumers using agency-based services differ from those using self-directed supports?

Respondent sample

A total of 610 consumers transitioned in 2020. Altogether, they completed 894 HCBS CAHPS surveys: 499 1 month and 395 12 month surveys (Table 3.1). The majority (92%) of surveys were completed with consumers residing in the community, an increase of 2% from the previous year. This resulted in 476 1 month and 346 12 month community surveys completed for consumers transitioned in 2020. This section reports data from the 822 1 and 12 month community surveys. For the 1 month survey, consumers described their experience since transition; for the 12 month survey, consumers described their experience in the last 3 months.

Table 3.1. Surveys Completed for 2020 Transitions by Time Point and Survey Setting

	Community Surveys n (%)	Institution Surveys n (%)	Settings Combined n (%)
1 Month	476 (95.4)	23 (4.6)	499 (100.0)
12 Month	346 (87.6)	49 (12.4)	395 (100.0)
Both Time Points	822 (100.0)	72 (100.0)	894 (100.0)

Home and Community-Based Services Use

At the beginning of the survey, community-residing consumers self-reported if they received any of the services in Table 3.2 either “since transition” for the 1 month survey, or “in the past 3 months” for the 12 month survey. The HCBS CAHPS survey defines a case manager as “the person who helps make sure you have the services you need,” with the participant determining for themselves if they had someone who helped them in this way. All MFP consumers receive TC services for 6 months following transition and may receive short-term SCM services post-transition. A consumer might think of either of these transitional staff as their case manager post-transition, especially at the 1 month survey. Consistent with other MFP HCBS CAHPS reports, for purposes of analysis all staff identified as case managers by MFP consumers are combined into case management services.

Only use of care management services showed a noticeable difference from 1 month to 12 months, decreasing from 69% at 1 month to 58% at 12 months. This is not unexpected given MFP consumers may not have much case management support at 12 months after transition. After six months, MFP case management services are usually reduced to monthly check in calls by the TC.

Table 3.2. Self-reported Home and Community-Based Services Use*

	1 Month n (%)	12 Month n (%)
Personal care assistant/attendant services	319 (67.0)	222 (64.2)
Behavioral health services	8 (1.7)	5 (1.4)
Homemaking services or Homemaker-Companion	249 (52.3)	177 (51.2)
Care management services	326 (68.5)	200 (57.8)
Job coach or vocational supports	0 (0)	1 (<1)
Recovery assistance services (MHW only)	12 (85.7)	11 (78.6)
Community Service Provider (MHW only)	8 (57.1)	7 (50.0)
None of these services	57 (12.0)	65 (18.8)

* Consumers can use more than one service

A. HCBS CAHPS Key Results

The HCBS CAHPS survey key results include 7 composite measures, staff global ratings, staff recommendations, unmet need for services, and physical safety.

Composite measures

Figure 3.1 shows the percentage of participants at each time point who gave the most positive answer for each composite item. Notable differences from 1 to 12 months include the decrease in the transportation to medical appointments composite score from 1 month (78%) to 12 months (69%). Comments indicated multiple medical transportation issues, causing people to miss appointments, go without medications, and change doctors. Several consumers mentioned the 10 mile radius rule being a barrier. Others commented that Veyo would not give them transportation because they were on a bus line.

I'm having a really hard time with transportation. Veyo for my medical appointments has been really unreliable and I'm always getting there late, often resulting in having to miss the appointment and the office being on the brim of not letting me come back.

Difficulty setting up appointments with Veyo. I had 2 very important appointments cancelled by Veyo drivers with no notice. I then had to wait months to reschedule those appointments.

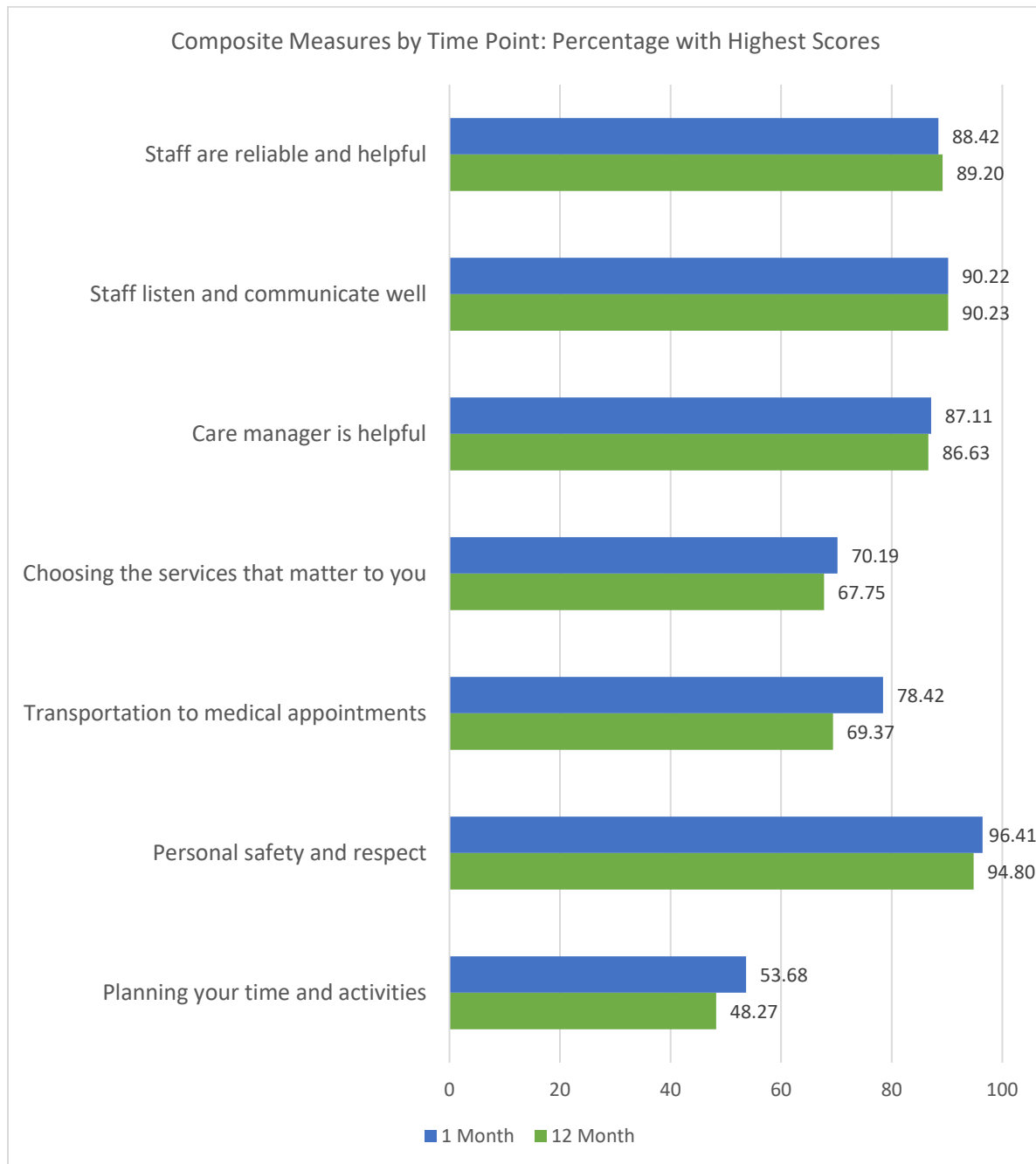
Also I've been without my pain meds for two months because Veyo won't bring me to the pain clinic and I can't get the meds anywhere else. There's no bus route to the clinic. I don't know what they expect me to do. Veyo says it's too many miles which is their excuse for everything.

I also need transportation, I receive methadone treatment and I have missed many appointments because of transportation. I wished that Veyo would take me because of my condition but because I'm on the bus line, I'm not eligible. Now, I have to wait before the methadone clinic takes me again.

Similar to 2020, scores for the composite planning your time and activities also fell over time. At 1 month, just over half (54%) of consumers gave this composite the most positive score, and at 12 months this dropped to 48%. These scores were also lower than in 2020 (2020: 1 month 64%, 12 month 59%). This composite includes community participation items such as seeing friends and family, and having enough paid staff assistance to participate in community activities. A few consumers expressed how lack of support and/or transportation limited their ability to do things in the community that they enjoy:

[I'd like] transportation to places other than doctor's appointments, such as Walmart or friend's/family's house.

Figure 3.1. Composite Measures by Time Point: Percentage with Highest Score



Global Ratings

Global ratings for PCA staff, homemakers, and care managers stayed stable over time. Slightly more than three-quarters of participants residing in the community rated their homemakers a nine or ten both at 1 and 12 months, and 71-72% gave their PCAs/RAs/ILSTs the highest rating (Figure 3.2). A noticeably smaller percentage, 64%, gave their care managers the highest rating. MHW CSP highest ratings increased over time, from 67% to 100%, although the small CSP sample sizes make comparisons difficult (n=8 at 1 month; n=7 at 12 months). Positive comments about PCAs include:

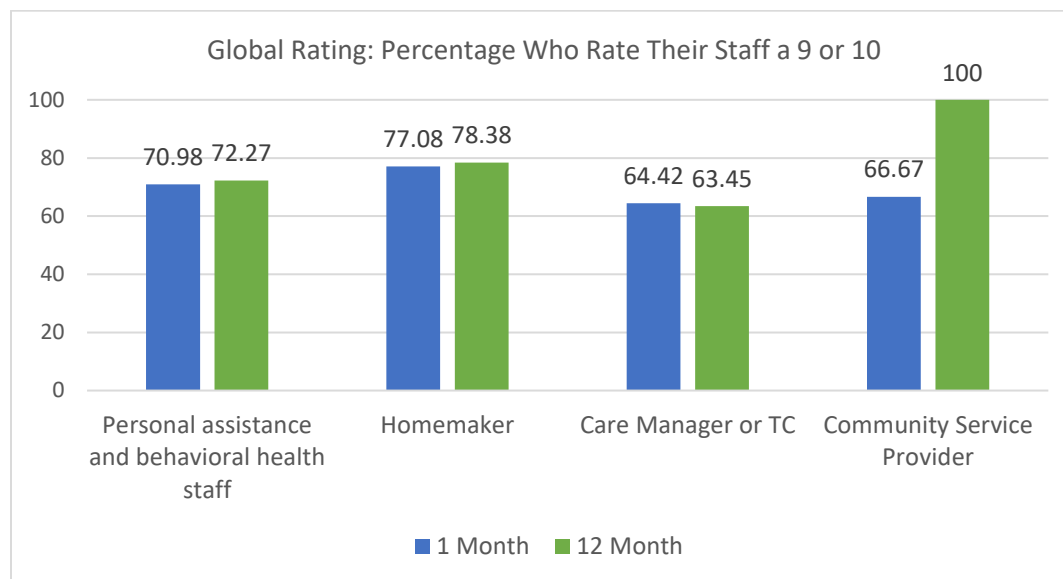
Everything has been wonderful. We have been so blessed. We got so lucky with the live-in – she works really well with my mom. I'm so thankful for everything and everyone who's helped us and continue to help us.

I am getting excellent care! My other substitute aide is also good by checking up on me. Overall we are very satisfied. My mother is in much better shape than a year ago.

[PCA 1] is wonderful – I will give her a 9 because she's competent and reliable. When she's around, I feel confident my son will be taken care of. That's not the case with [PCA 2], I'd give her a 3 because I am still trying to work with her. She's young and inexperienced, I am trying to give her a chance and work with her. It is hard to teach someone and also trying to keep my son safe. It has been a challenge with the aides, I am happy one has worked out great. Both [PCAs] get along well with my son and treat him well. I am just trying to help [PCA 2] have a better work ethic.

My caregivers are very good. The first one didn't work out, but now I have a mom and daughter duo and they're great.

Figure 3.2. Global Rating by Time point: Percentage Who Rate Their Staff a “9” or “10” (Scale 0-10)



At the same time, many consumers shared the multiple issues they have experienced with getting assistance, such as staffing turnover, lack of training, difficulty finding staff, issues with managing multiple staff, lack of home care agency communication, and needing more assistance. Unlike in 2020, in 2021 there were very few comments linking COVID-19 to their experience with their direct support staff. Consistent with last year, family members remarked that they often provided this missing support in order for their loved one member to continue living in the community.

His aides have been sporadic and there seems to be no set schedule with them. We get new people all the time and never know who is going to be coming or when. People are showing up late or not at all.

There is terrible communication between the agencies and the PCAs about what a client needs. They just show up not knowing a thing about me or my needs and often times don't have the skills I need. The main thing I need is rides to appointments and groceries and so many times they have sent me people who can't drive. One time a woman came and had to call her husband to come pick us both up because I couldn't put off grocery shopping any longer. He showed up with their child and we all had to go to the store together to shop which was so scary during COVID, and I am immunocompromised. But I had no choice, I needed food. These situations have caused me so much stress which affects my health and blood pressure. So you asked a question if a PCA has ever hit or hurt me – and I said no because I know you mean physically. But truly they have hurt me because the stress of dealing with them affects my health. Something needs to change here. I know I am not alone in my stories.

I would like some help during the day and at night because my mother gets up all night long. I worked with the case manager supervisor to get her care plan changed so instead we could get more home care, not the nurse or PT.... [At transition the SCM] said they would get the home care agency and that there were lots of agencies in the area. ... I spoke to [the SCM's] supervisor, who said that agencies often did not like coming to my town - So why didn't they tell me that at the beginning instead of saying there were all these agencies in this area? It took 18 days to find an aide just for one night. But with the care plan changed, things should get better.

I would like to get more consistency in my caregivers and better experience. I need people who are able to meet my needs and be reliable. It's been up and down with help after my usual caregiver left after 7 months. The agency is sending some people in the last month who do not know their job.

We had trouble with so many aides. I think I went through 5 before getting the one we have now who is wonderful.

We have had a lot of trouble with staffing. It has been so hard to find a consistent person that meets our needs.

I will say that the aides, the PCAs, need more training with the community of people they are working for. The aides are very inconsistent and very vocal about what they are to do and not do in terms of job description.

The agency told me that my mom had to learn to speak English, even though she's 83 years old and monolingual Spanish. ... [I want] the PCAs ... to interact with my mom. They would be on their phones, and that was not acceptable. So I'd call the agency and let them know to send another person.

The aide that comes in when the live-in takes vacation should be able to do everything the regular live-in can, and that has not been the case. Overall I think the program is great, but there is definitely room for improvement.

Consumers also mentioned needing more support than was in their care plan or not getting the paid services they expected.

He needs more hours. The people who come in to help are wonderful, but there is so much time that he is alone and needs help. He has had multiple strokes, and there have been several hours

that have gone by with him being stuck in the house and barely able to move. I (daughter) can only do so much because of my work. We really need more hours.

I'd like to have more PCA hours. My aide does not have enough time to help me with grocery shopping, taking me to my medical appointments, bathing, and other chores. I really need the assistance. She's even worked for free and that's not right – I don't want her doing that. She's doing that out of kindness of her heart.

The aides have been wonderful – got really lucky with them. The TC has been helpful too. I thought Independent Living Skills coaching was going to be a part of his care plan, but he has not received that at all. I thought it was going to be once a week.

A noticeably smaller percentage of consumers (63-64%) gave their SCM, TC, or care manager the highest rating. Consumers experienced confusion knowing who to turn to for help, lack of consistent follow-up post-transition, issues with getting services, and communication concerns. Some consumers felt like they were promised supports or assistive technology, but found after transition this was not the case. A few consumers spoke of needing to speak to the care manager supervisor in order for things to get done. Consumers expressed mixed experiences with different MFP staff and different members on their transition team:

I'm grateful for what has been done for my husband, I but I have to be honest and say there's a lot I'm not satisfied with. I feel like these MFP people are supposed to make my life easier, but honestly it has felt like I am doing a lot of the work on my own and having to constantly push for updates and for things to get done. I shouldn't have to do that. I have to ask multiple times ... to get one thing done for me. I feel like his discharge from the nursing home was really rushed at the end, and I was nervous that not everything was going to be ready, and that I was going to be left to fend for myself. They assured me that would not happen and now I feel like that's exactly what happened.

I am very happy with [SCM name], she has been very helpful. She's fought to have my son return home.

I've worked as a case manager and understand the MFP program. The only thing I do not like about the program is the housing coordination part of it. I have a housing voucher through the program, I was promised help in searching for an apartment, and that has not happened. It is very difficult to get a hold of the housing coordinator... The transition coordinator is the only one that has been actively engaging with me and making sure that I am okay.

The transition coordinator [name] has been absolutely wonderful – she has come out of her way to help me.

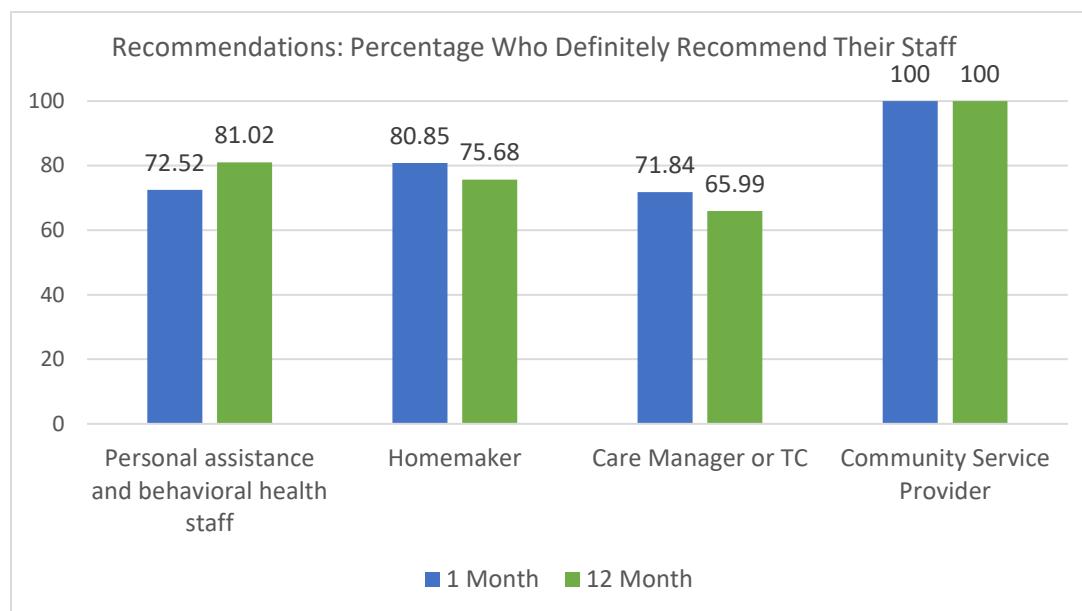
I feel that the program is not doing what they say they will be doing. The program told me that I would be going to the residential care home first to see how I did, and then they will be looking for an apartment for me. They now tell me that they have stopped looking for an apartment. I feel like I got shortchanged.

I want to mention that my care manager is excellent. I'm really nervous to lose her now that I'll be done with MFP soon and transferred to a state care manager. I'm certain that I won't get someone even remotely as good as [SCM name].

Recommendations

The percentage of consumers who would “definitely” recommend their PCAs, homemaking staff, or case managers varied over time (Figure 3.3). Most noticeably, PCA recommendations increased from 73% to 81%, while case manager recommendation fell from 72% at 1 month to 66% at 12 months.

Figure 3.3. Recommendations by Setting: Percentage Who “Definitely” Recommend Their Staff



B. Unmet Need and Physical Safety

Consumers who reported receiving paid assistance with any kind of personal care or behavioral health were asked if they needed help with four everyday activities: personal care (dressing/bathing), meals, medications, and using the toilet (Table 3.3). Those who reported receiving homemaker services were considered to need help with housekeeping tasks such as cleaning or laundry. Over 80% of consumers in both 1 and 12 months reported receiving assistance with personal care, such as dressing or bathing, or making meals/eating.

Table 3.3. Self-reported Assistance with Everyday Activities

Needs assistance with:	1 Month n (%)	12 Month n (%)
Personal care	268 (84.0)	181 (81.9)
Meals or eating	261 (81.8)	189 (85.5)
Taking medications	213 (67.2)	151 (68.6)
Using the toilet	183 (57.9)	126 (57.0)
Housekeeping or laundry	249 (57.6)	177 (56.4)

To determine unmet need in these areas, community consumers who had personal care staff were asked if they did not do the activity since transition (the 1 month survey) or in the past 3 months (the 12 month survey) specifically because of lack of staff to assist them. At 1 month, eleven participants (< 5%) indicated one or more unmet need: 6 for personal care, 1 for taking medications, 4 for using the toilet, 3 for meals or eating, and 2 for household tasks. At 12 months, nine participants indicated one or more

unmet need: 2 for personal care, 2 for taking medications, 2 for using the toilet, and 4 for meals or eating (separate items, consumers can report more than one).

Participants not receiving personal assistance were asked if they always had the assistance they needed for bathing/dressing, meals, medications, and toileting. Twenty-two individuals at 1 month (28.2% of those asked) and eight participants at 12 months (12.1% of those asked) had an unmet need for one or more of these tasks.

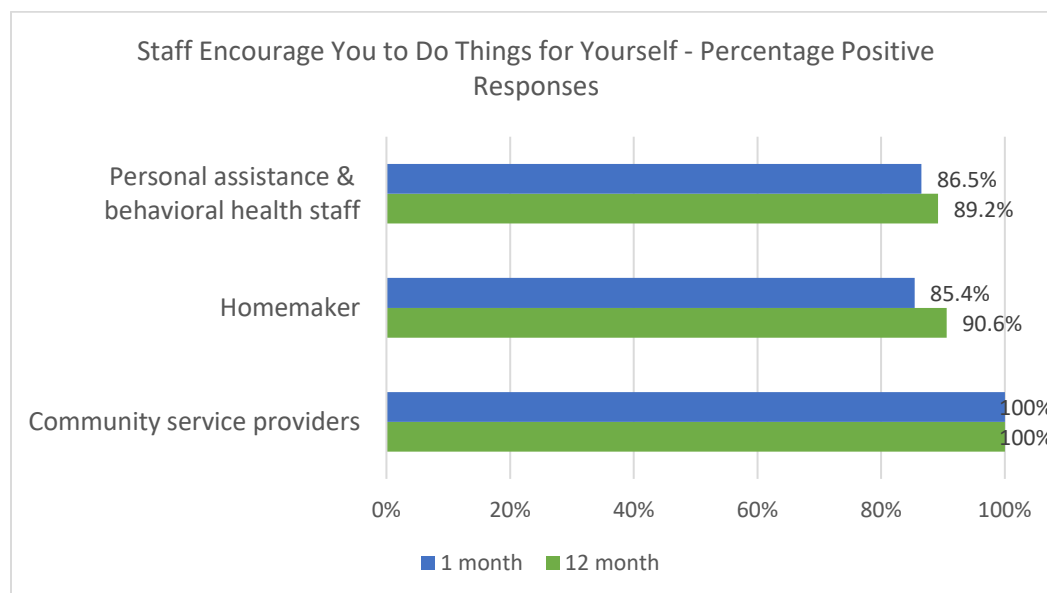
One 1 month and two 12 months participants reported that a staff person had hit them or hurt them; two of these consumers were working with someone to resolve the problem.

C. Additional Staff and Care Manager Measures

Personal Privacy and Encouragement

The majority of participants at both time points said their staff “always” provided them enough privacy for bathing or dressing (93% 1 month, 96% 12 month). A majority of participant also agreed that their staff encouraged them to do things for themselves, with percentages increasing over time especially for homemaking staff (Figure 3.4). All 8 (1 month) and 7 (12 month) MHW who self-reported receiving CSP services, agreed that their CSP staff encouraged them to do things for themselves.

Figure 3.4. Do Staff Encourage You to Do Things for Yourself - Percentage Positive Responses

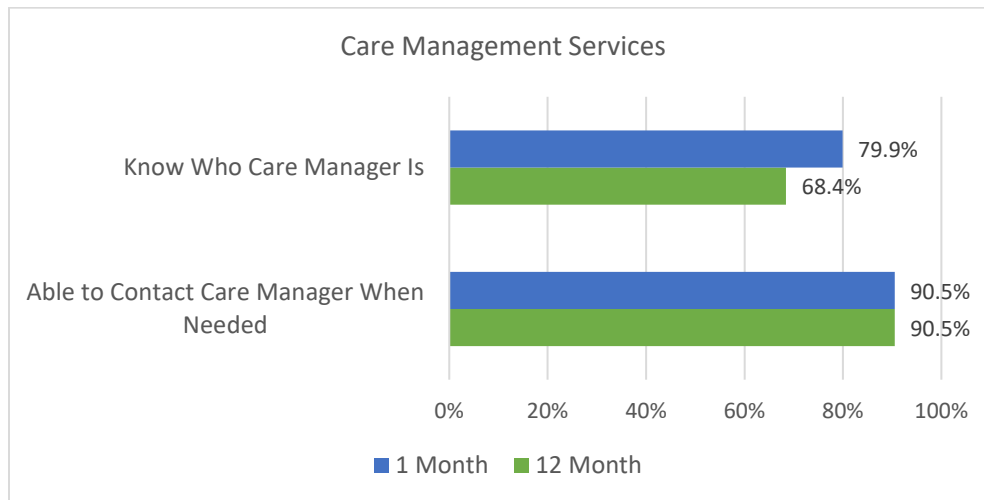


Care Managers and Care Plans

When asked if they knew who their care manager was, 80% of consumers at 1 month and 68% of consumers at 12 months said they did (Figure 3.5). The great majority of these consumers at either time point were able to contact their care manager when they needed to. That 20% of consumer at 1 month did not know who their care manager is, even though they have at least a TC, is concerning. Comments indicated that for some consumers or family members, there was confusion about who to turn to for assistance, even just one month after transition.

Things have been good but I really wish the "pieces" of this program were more clear. I don't feel like the program and what is offered is explained well enough to the participants and their family. For example, I knew who [name] is but I did not know that s/he is my mom's care manager and that I could reach out to them with questions or about things my mom needs. I just wish everything was more clear cut and less confusing.

Figure 3.5. Care Management Services - Percentage Positive Responses



Consumers asking their care managers or TCs for assistance with changing services increased over the year, while requests for mobility or other specialized equipment decreased (Figure 3.6). Figure 3.7 shows that consumers would most likely contact their care manager for changes to their care plan, which increased from 59% to 64% over the year. Another 19-23% would contact friends or family.

Figure 3.6. Asked Care Manager for Assistance with Changing Services or with Equipment – Percentage Positive Responses

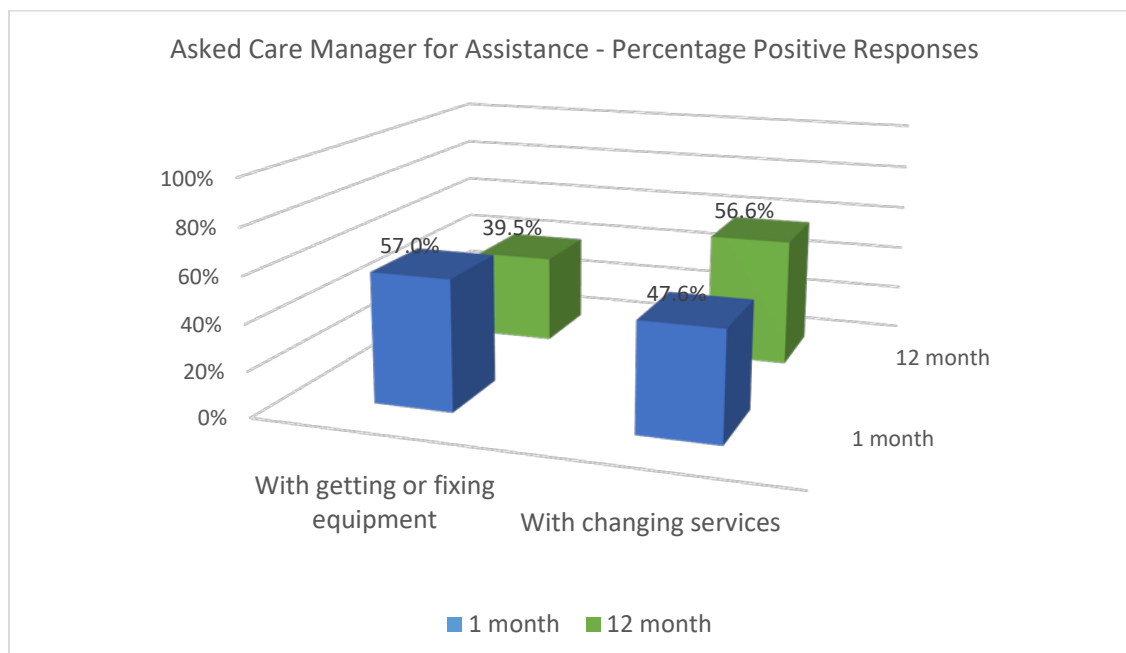
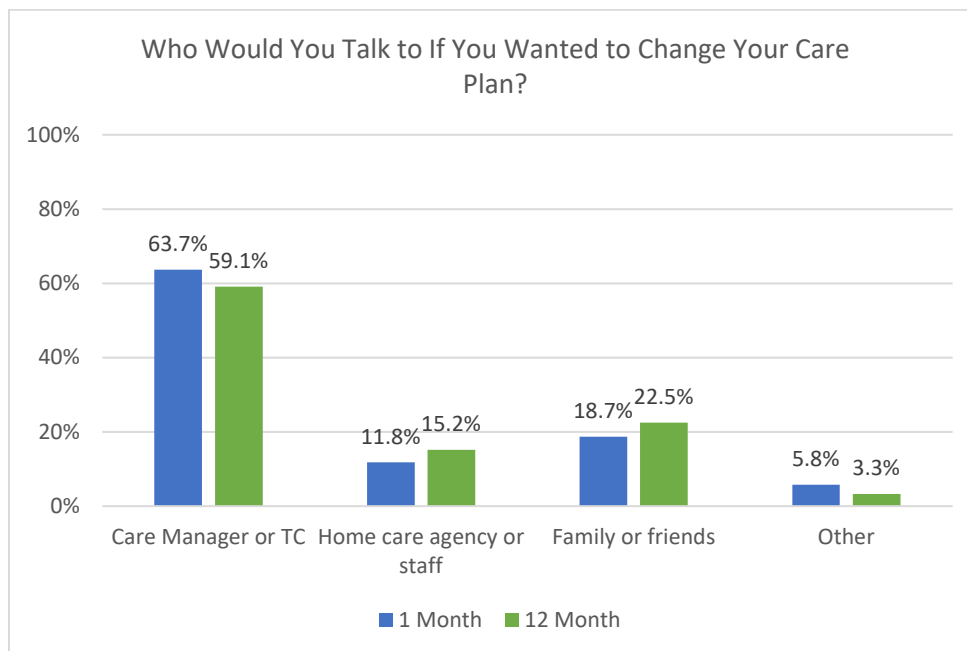


Figure 3.7. Who Would You Talk to if You Wanted to Change Your Care Plan?*

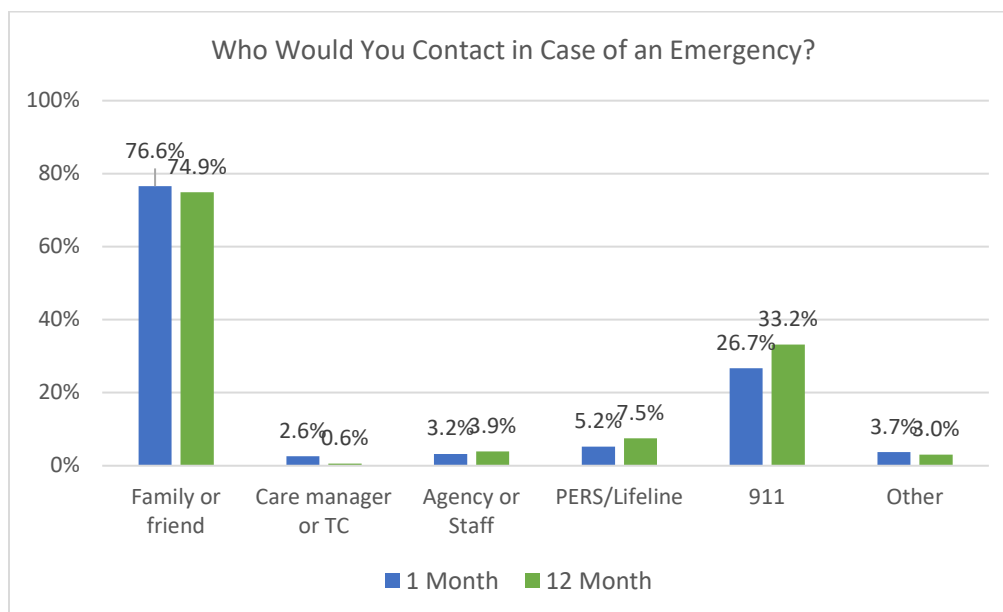


*Can name more than one

Emergency Contact

About three-quarters of consumers in the community at either time point said they would contact their family or friends in case of an emergency (Figure 3.8).

Figure 3.8. Who Would You Contact in Case of an Emergency?*



*Can name more than one

D. Self-Direction

Almost all consumers at either time point reported they used agency-based services (Figure 3.9). Of consumers who hired their own staff, about half at either time point employed family members (Figure 3.10; see Section 4 for a more in depth look at self-directed consumers). When asked if they picked the people who help them, between 26-30% of all participants at either time point said they chose their own staff. One consumer's comment highlighted how hiring family and friends made a real difference in their life:

We are really happy with this program. Before she went into the nursing home we had aides from agencies and they were not trust worthy. We had a lot of problems with that but now that I have been able to hire family and friends, things have been a lot better.

Figure 3.9. How Do You Hire Your Aides?

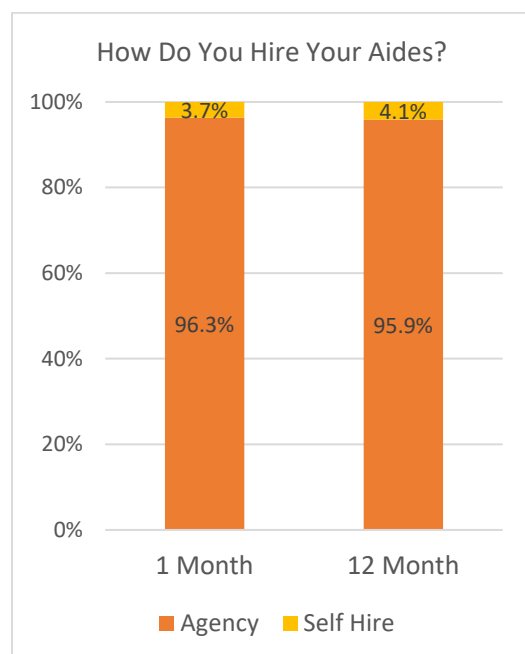
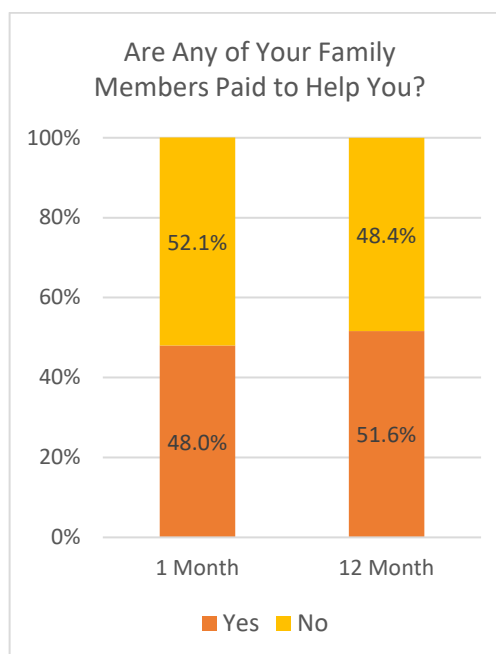


Figure 3.10. Employ Family Members



E. Living Situation and Social Support

Although 58% of consumers at 1 month and 60% at 12 months lived alone or without other adults, about 70% of all consumers had a family member who lived nearby (Table 3.5). The percentage of consumers who could see either their nearby family members or friends when they wanted to increased substantially from 2020. For example, in 2020, only 70% of participants at either time point could see their family members, compared to 91-95% this year, and consumers seeing their nearby friends increased from 49-57% last year to 81-93% this year. The overall decrease in COVID positivity rate, along with people feeling more comfortable seeing people outside their homes, likely contributed to this change. About 60% of consumers at either time point reported receiving assistance around the house from either family or friends, which is also an increase from last year (in 2020 52-55% reported having this support). One consumer's comment highlighted the importance of having nearby family or other social support once in the community.

I don't really have access to the things I need. I really need more help. I have three lung conditions and going out to get something like groceries in this heat is so hard. I don't have much food right now. I have to take the bus to get around and it's just really hard. I don't have informal support either as they put me in an apartment far away from my family. They're over an hour away. I hope I can move as soon as this lease is up.

Some of the 60% of consumers who lived alone expressed struggles with loneliness and lack of social connection. Connecting to one's community does not automatically happen upon transition, and this is one area which MFP might consider providing more support. For example, linking the consumer with community or volunteer groups, such as Friendly Visitors or therapy dogs, upon transition might help alleviate feeling so alone. Expressed one consumer:

I'd like to get a pet, or someone to live with me to keep me company.

Table 3.5. Living Situation and Social Support*

		1 Month %	12 Month %
Number of adults living in household		N=473	N=342
	1	57.9	59.7
	2-3	34.7	33.9
	4+	7.4	6.4
Lives with family member/s		N=199	N=139
	Yes	73.4	72.7
	No	26.6	27.3
Lives with non-family		N=199	N=138
	Yes	30.7	35.5
	No	69.4	64.5
Family member/s live nearby		N=476	N=345
	Yes	69.1	71.6
	No	30.9	28.4
Friend/s live nearby		N=474	N=345
	Yes	46.8	43.5
	No	53.2	56.5
Can see nearby family		N=329	N=247
	Yes	90.6	95.1
	No	9.4	4.9
Can see nearby friends		N=222	N=150
	Yes	81.1	93.3
	No	18.9	6.7

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

Figure 3.11. Assistance from Family or Friends around the House

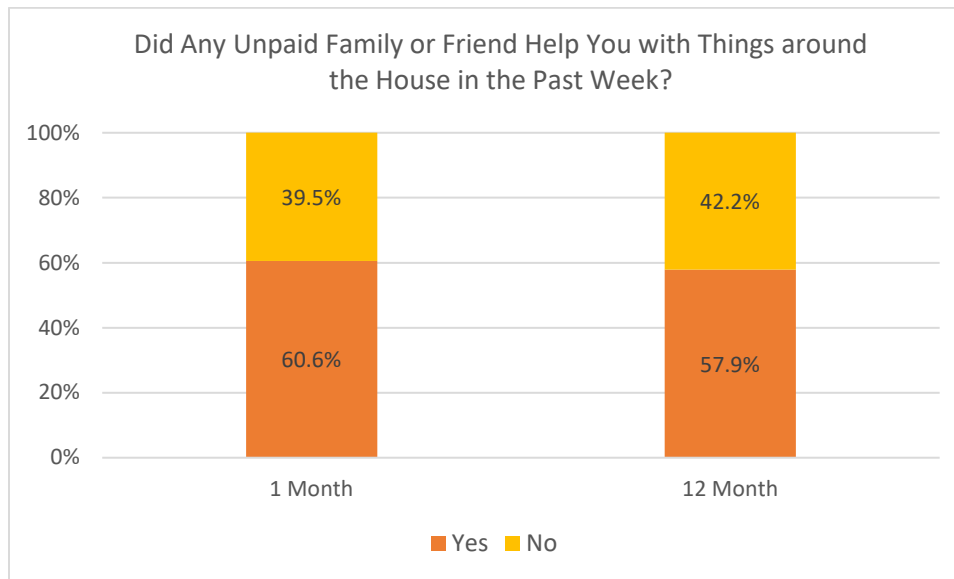
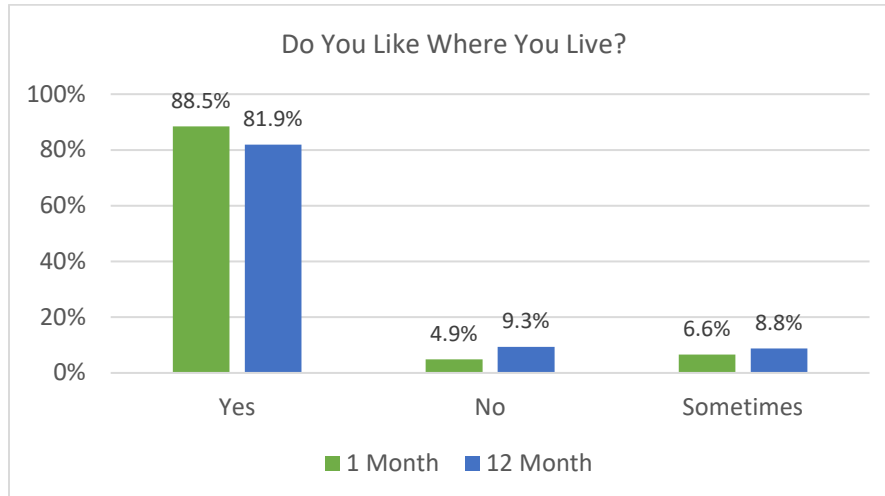


Figure 3.12 shows that the majority of consumers at both time points said they liked where they live, although the number decreased somewhat from 1 to 12 months (89%, 82%). Almost all consumers at both 1 month (96%) and 12 months (90%) felt safe where they live.

Figure 3.12. Do You Like Where You Live?



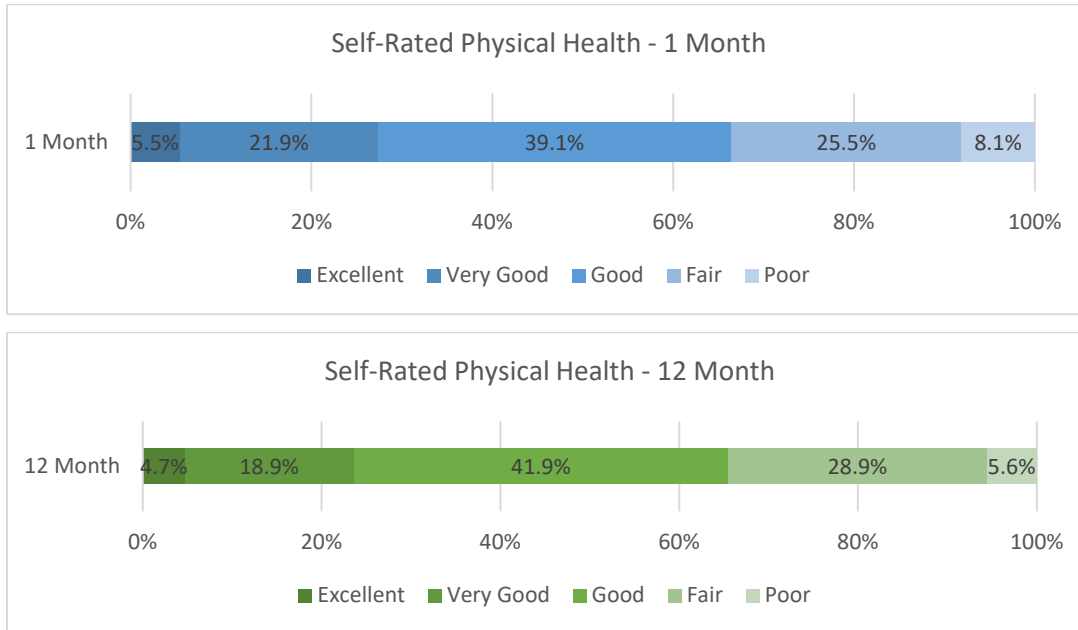
F. Physical Health

Physical Health, Falls

Self-rated physical health declined slightly over time: at 1 month, 28% of consumers rated their physical health as very good or excellent, compared to 24% at 12 months, and at 12 months slightly more consumers rated their health as fair or poor (Figure 3.13). One consumer spoke of the long term effect on their health after having COVID when in the facility.

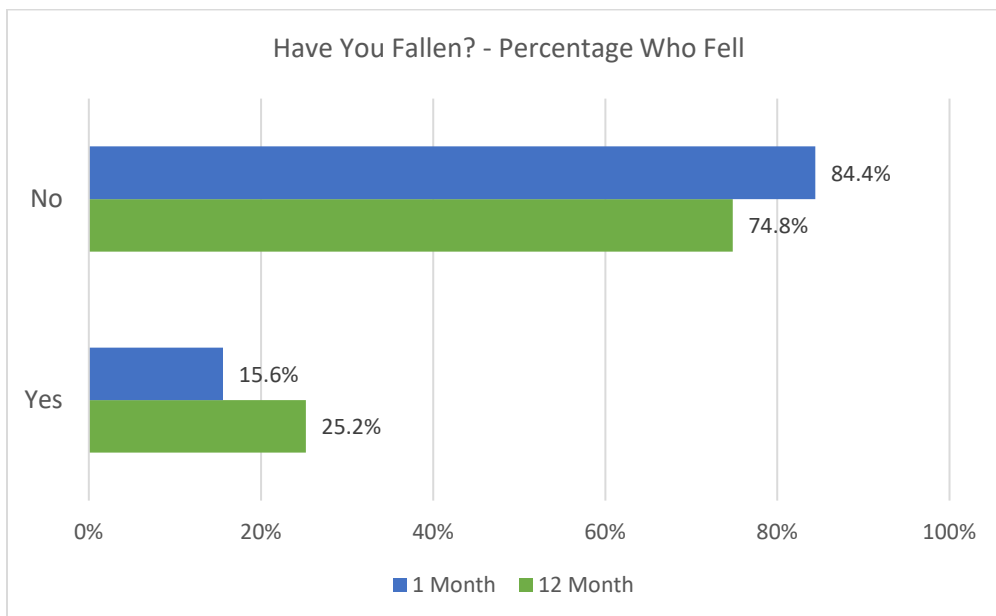
I would have worked if I could but I was being treated for cancer and also got COVID last year [before transition] that I still have not recovered from. It damaged my lungs to the point that I now have COPD and can't walk more than 20 feet without having to stop and catch my breath.

Figure 3.13. Self-Reported Physical Health



Sixteen percent of consumers reported falling between transition and their 1 month survey (Figure 3.14). This percentage increased to 25% by the 12 month survey, which is not surprising due to the longer timeframe (since transition at 1 month, since 1 month survey at 12 months) (Figure 3.14).

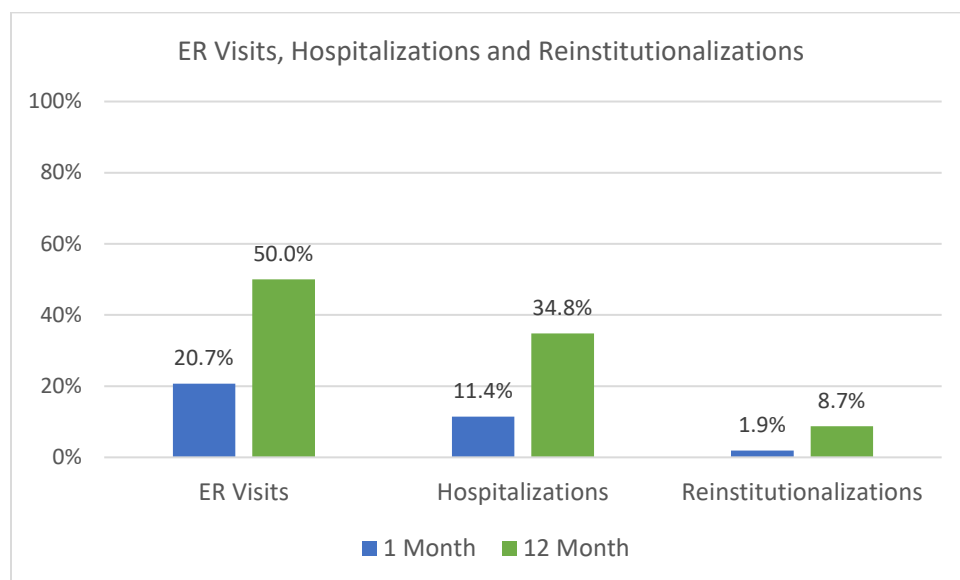
Figure 3.14. Falls



Emergency Room, Hospital and Facility Use

As can be expected, emergency room and hospital use were reported more often at 12 months due to the longer timeframe (Figure 3.15). Fifty percent of participants interviewed at 12 months had been hospitalized and 35% had used an emergency room. One-fifth of consumers residing in the community had been to the emergency room (ER) by their 1 month survey. By 12 months, 9% of consumers had been reinstitutionalized and subsequently discharged home sometime after their 1 month survey.

Figure 3.15. Emergency Room Visits, Hospitalizations, and Reinstitutionalizations



G. Mental Health

Mental Health

Self-rated mental and emotional health declined over time: at 1 month, 34% of consumers rated their mental or emotional health as very good or excellent, compared to 28% at 12 months (Figure 3.16). Unlike last year, this year only a few consumers specifically mentioned the impact of COVID-19 on their mental health:

I am pretty lonely. COVID has made that a lot worse.

Approximately one-third of consumers (29-33%) had depressive symptoms at both time points (Figure 3.17). Although these rates are lower than those surveyed in 2020, they remain higher than in the general population: in 2020, 24.2% of adults in Connecticut reported symptoms of depression (National Center for Health Statistics, (2020-2021)). These data indicate a need for enhanced mental and emotional support post-transition. Some comments highlighted how one's emotional health is connected to the ability to go out, which can be limited if you do not have the transportation or other support.

I would love for nonmedical transportation to get my mother out in the community for improved mental health.

I would like for someone to bring me to the Spanish Mass on Sundays, when they could.

Figure 3.16. Self-Reported Mental Health

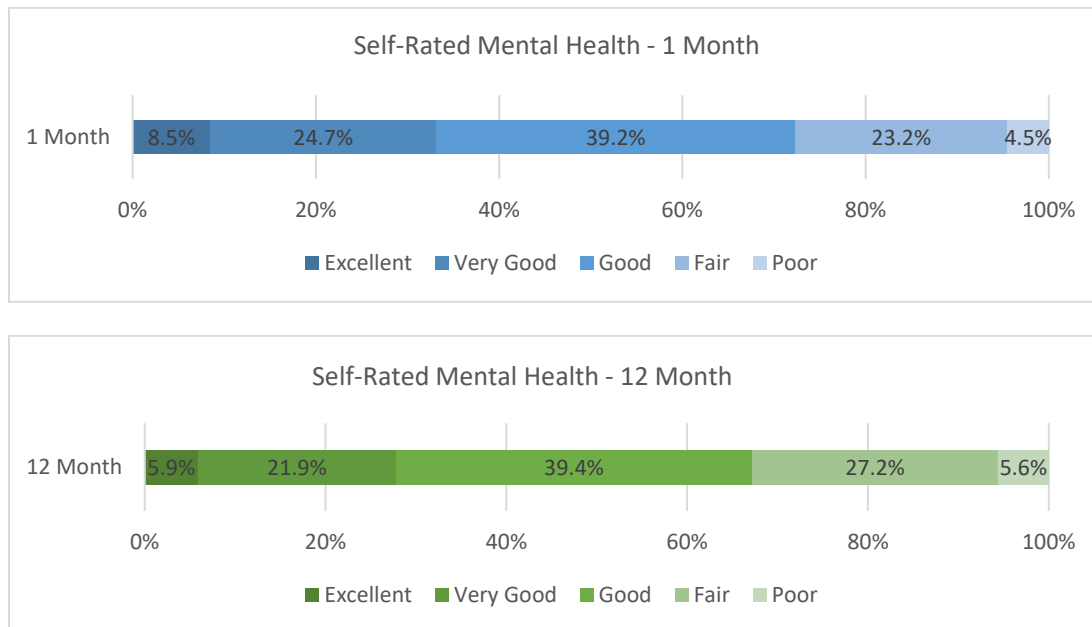
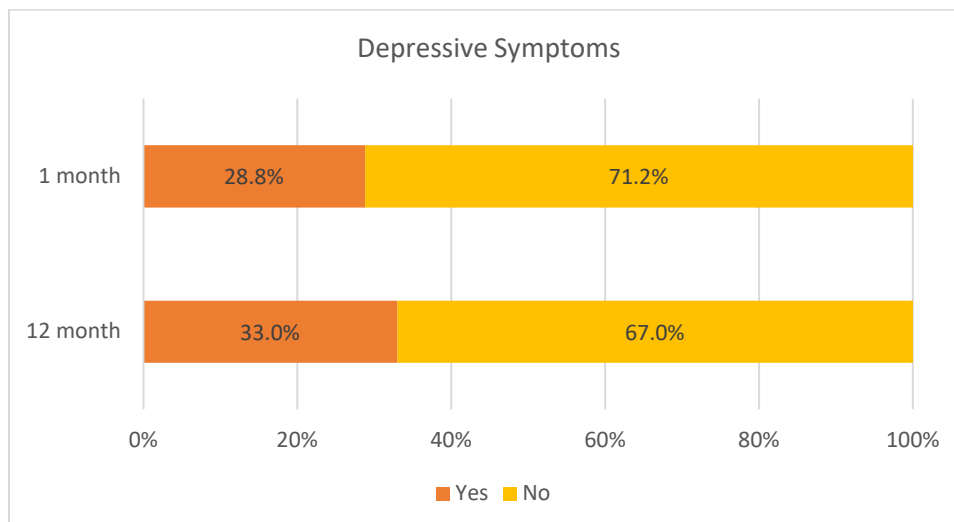


Figure 3.17. Depressive Symptoms*



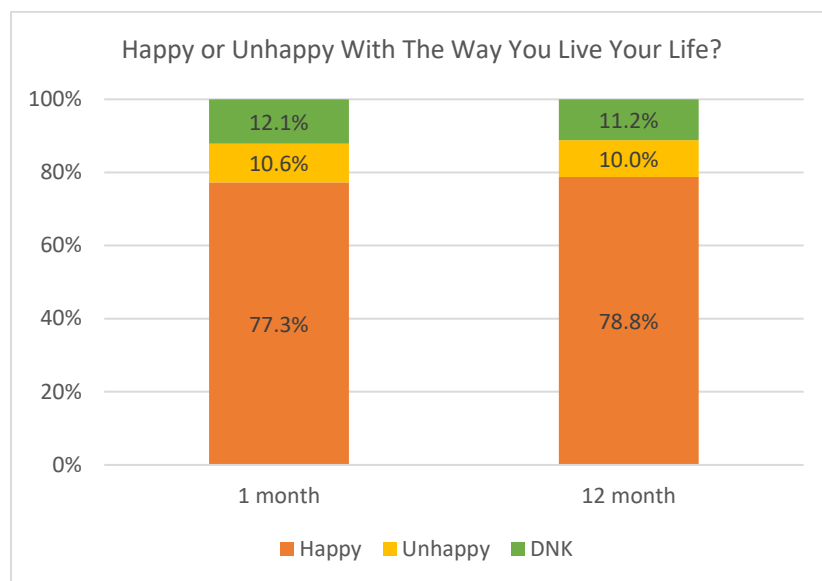
*Depressive symptoms were determined using the Patient Health Questionnaire (PHQ-2) (Whooley et al., 1997).

Overall Quality of Life

Global life satisfaction stayed stable once in the community. Between 77-79% of consumers reported feeling happy with the way they live their life at both 1 and 12 months (Figure 3.18).

I think my mom has a new lease on life since leaving the nursing home and wish everyone knew about this program.

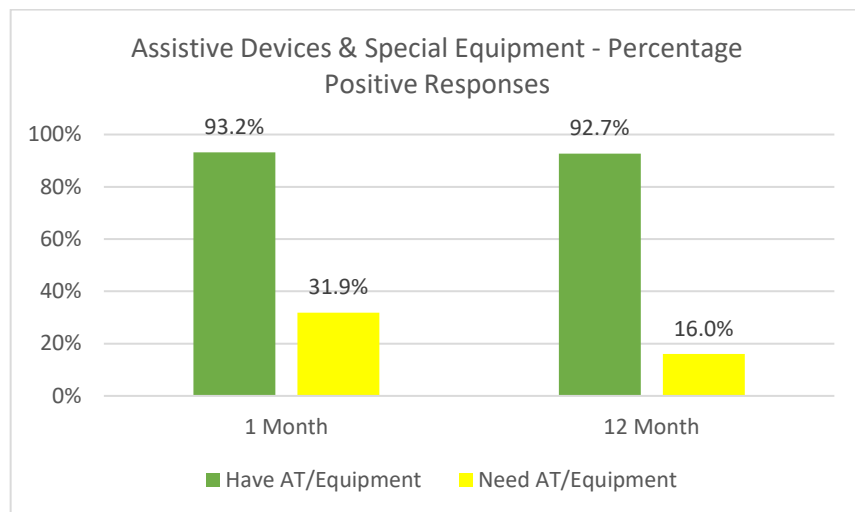
Figure 3.18. Happy or Unhappy with the Way You Live Your Life



H. Assistive Devices, Medical Equipment, Home Modifications

The vast majority (93% at 1 month and 12 months) of community consumers reported having at least one type of assistive device, special equipment, or home modification (Figure 3.19).

Figure 3.19. Have or Need any Type of Assistive Device, Home Modification, or Special Equipment – Percentage Positive Responses



At the same time, data show that at 1 month, 32% of consumers lacked some type of device or modification needed for community living. By 12 months, this number was reduced by half to 16% who still needed at least one assistive device. Comments indicated that multiple factors affected the continued need for necessary equipment or home modifications.

After being out of the nursing home I still had no bed. It is being delivered in a week after a month [in the community].

We are hoping to get a power chair because right now I'm not able to leave my room without it. That of course affects a lot, including my mental health. I really can't do much by myself right now.

I'm not able to take a proper shower because I don't have any grab bars. They said I need a script from the doctor, but I feel like that should have been done and set up before I left the nursing home. I could have got a script from that doctor.

I just really want to hurry up and get a larger bed as I don't feel safe. I also need a Hoyer lift and a wheelchair that fits me.

One of the biggest problems so far that wasn't addressed is medications. It was a nightmare getting all his meds he needed from the nursing home and his diabetes equipment. It was really scary for me because I had no way to check his blood sugar for a few days and that was simply not okay. There needs to be a better system in healthcare for that.

I would love to be able to have a blood pressure cuff and a breathing machine. It would be good to have those at home so I could check it at home. Mine was lost in the move [from the nursing home to the community].

I'm extremely disappointed with MFP. Everything is dangled in front of you in terms of medical equipment, home mods, the speed in which they think you're getting out of the nursing home. I had to buy all of my equipment and the mods they made to my bathroom do not work.

I wish there were more devices or equipment for those who are vision impaired. That's one of my mom's biggest hurdles and it impacts her safety. I wish there were more programs or options for her.

I need a wheelchair that can fit through my hallways and the bathroom. I cannot get to my appointments because the chair is too big for the van. They want to bring me in an ambulance.

I had to buy a raised toilet seat with my own money because the process to get one from the doctor takes too long. I'd rather pay the money myself so my boyfriend can be more comfortable and independent in the bathroom right away without having to wait for a doctor's appointment.

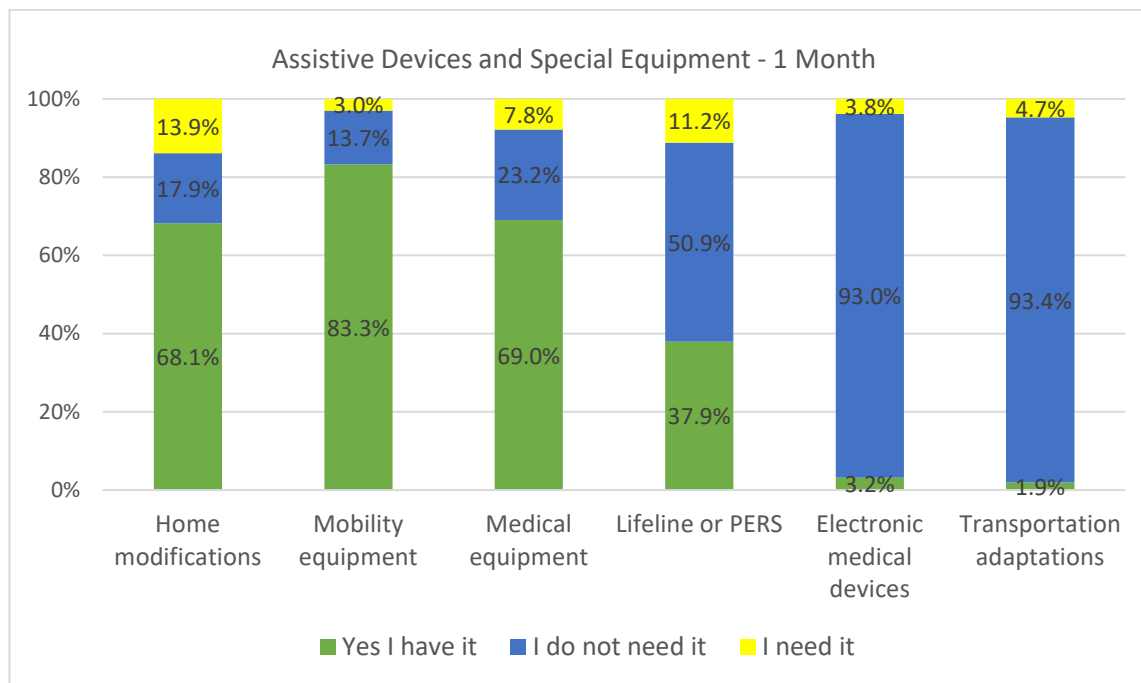
I still do not have a shower chair... I haven't had a normal shower since I left the nursing home. I need more help with things around the house than what they thought. I cannot really get to the buttons on the stove and have use of one arm.

Everything has been good but the bathroom modifications are taking too long. I don't want my son to continue to go without a real shower.

Consumers most often reported having mobility equipment, home modifications, or special medical equipment at both 1 and 12 months post transition (Figures 3.20 and 3.21). Although a personal emergency response system (PERS) is allowed under most budgets, only 38% of consumers at either 1 or 12 months reported having one.

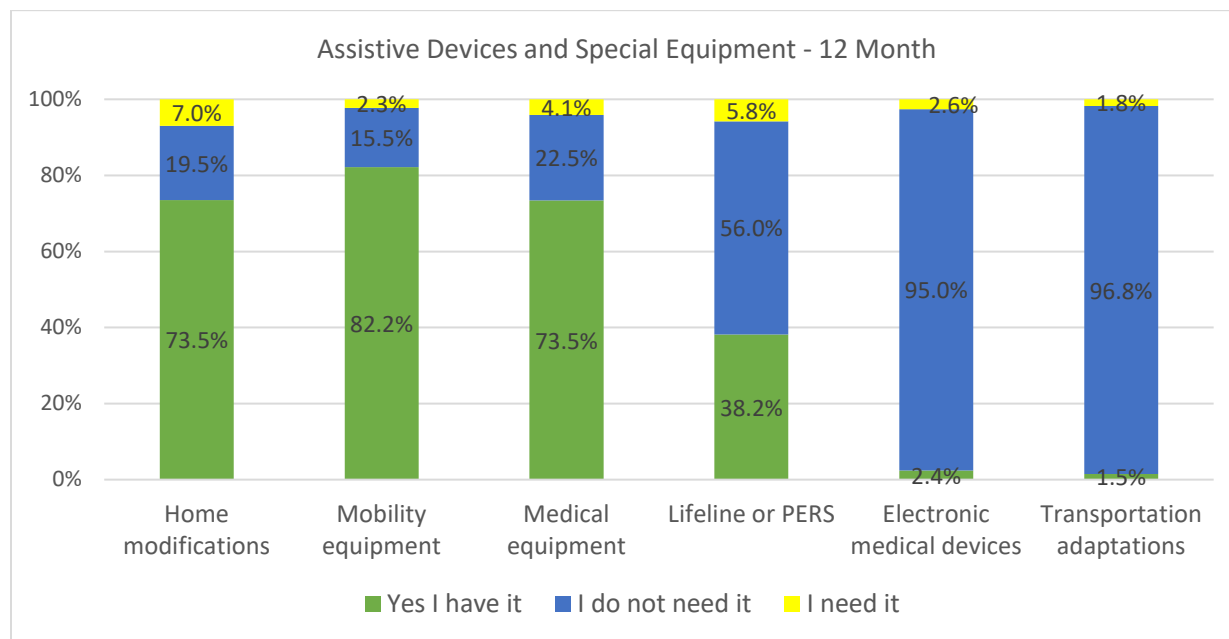
At 1 month post-transition, consumers most commonly still needed home modifications (14%), a PERS (11%), or special medical equipment (8%). The lack of special equipment and/or devices in the community decreased from 1 month to 12 months for all categories. Still, at 12 months post-transition, 7% of consumers reported they still needed home modifications and 6% still needed a PERS. Not having necessary home modifications or equipment can jeopardize one's ability to live successfully in the community, and providing these before or soon after transition should continue to be a program goal.

Figure 3.20. Assistive Devices, Home Modifications, and Special Equipment Items – 1 Month*



*Examples of all categories are found in the MFP HCBS CAHPS survey in Appendix A.

Figure 3.21. Assistive Devices, Home Modifications, and Special Equipment Items – 12 Month



More than 70% of participants reported having internet access at their home, and 61% of consumers at both 1 month and 12 months owned a computer, tablet, or smart phone. Overall, less than 5% of consumers at 1 month or 12 months said they needed some type of internet capable device, and at 1 year post-transition, the just 4% of consumers still needed internet access (Figures 3.22 and 3.23).

Figure 3.22. Internet Devices

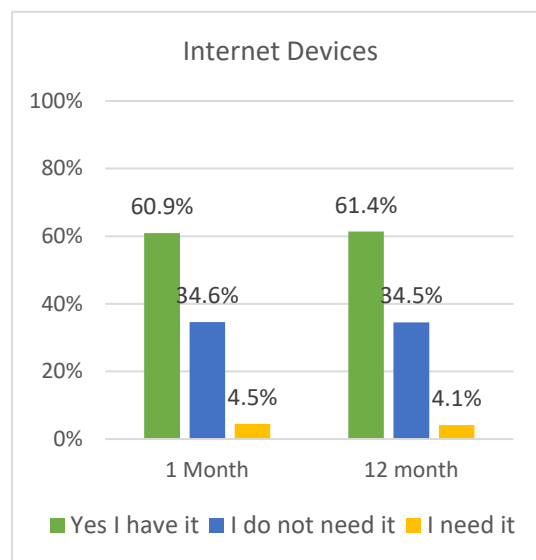
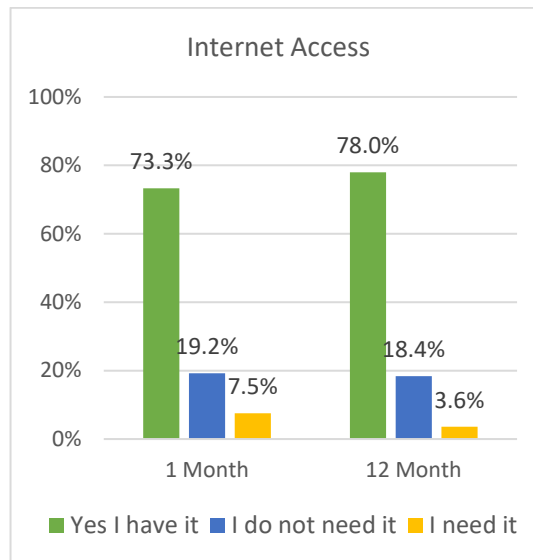


Figure 3.23. Internet Access



I. Other Services

A small number of participants at either 1 month (n=37) or 12 months (n=27) received a home delivered meal service, and very few reported using a day program (Tables 3.5 and 3.6).

Table 3.6. Home Delivered Meal Service Rating

Scale:	1 Month	12 Month
	n (%)	n (%)
Excellent	8 (21.6)	4 (14.8)
Very Good	8 (21.6)	7 (25.9)
Good	11 (29.7)	5 (18.5)
Fair	4 (10.8)	10 (37.0)
Poor	6 (16.2)	1 (3.7)

Table 3.7. Day Program Rating

Scale:	1 Month	12 Month
	n (%)	n (%)
Excellent	2 (33.3)	1 (50.0)
Very good	0 (0.0)	0 (0.0)
Good	3 (0.5)	0 (0.0)
Fair	1 (16.7)	1 (50.0)
Poor	0 (0.0)	0 (0.0)

Only 38% of participants at 1 month, and 47% at 12 months, reported using a van or transportation service for medical and/or nonmedical services. Although 78% of participants gave the medical transportation composite the highest scores at 12 months (Figure 3.1), comments indicated that increased access to nonmedical transportation would clearly make a difference in many consumers' lives. Consumers depended on nonmedical transportation not only for community engagement, but also for basic necessities such as getting food.

I also need rides to the grocery store, I'm having a hard time getting food. The battery in my electric wheelchair is shot so I'd have enough to get down there but not enough to get back. And either way I wouldn't have enough room on the chair to bring the groceries back. I'm working on getting a PCA for a few days a week, and I'm hoping that person will be able to drive me places. Other than figuring that out, things have been great. I really like my place and I'm so happy to be out of the nursing home.

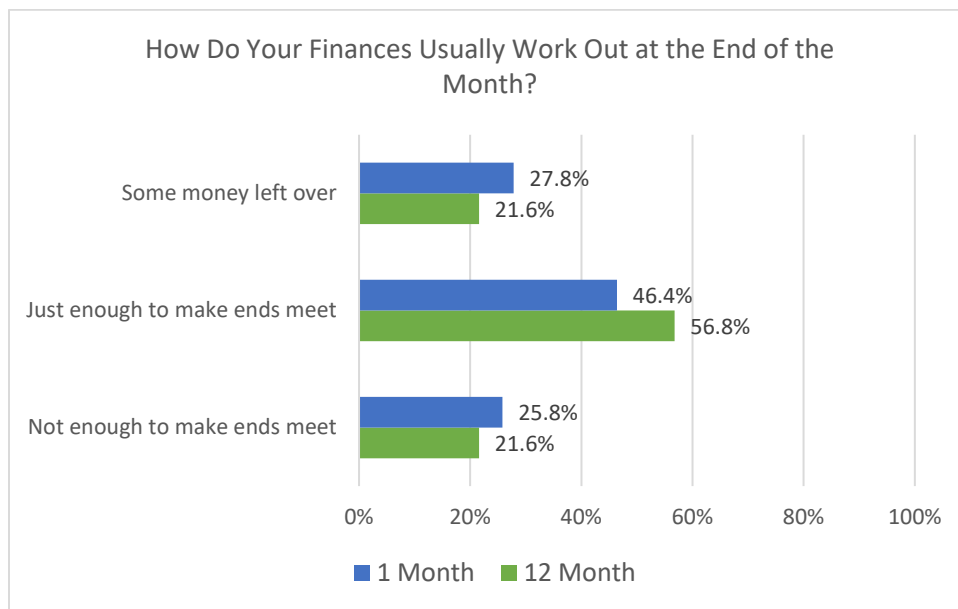
J. Finances, Employment, and Volunteering

Over one quarter of consumers did not have enough money to make ends meet at 1 month after transition, as did 22% at 12 months (Figure 2.24). Food insecurity was mentioned by several participants, whether caused by lack of or inadequate food stamps, transportation, or paid/unpaid support

I thought everything would be all set for me when I got to the apartment – I’m still missing my lifeline, and my food stamps have not come in. I was supposed to have meals-on-wheels and that has not happened. I currently waiting for a call from my TC regarding those things.

It's been very hard getting to food bank to get to food. I lost my food stamp card and won't get another until after Christmas. I will reach out again to the food banks today to see if anyone answers.

Figure 3.24. How Do Your Finances Usually Work Out at the End of the Month?

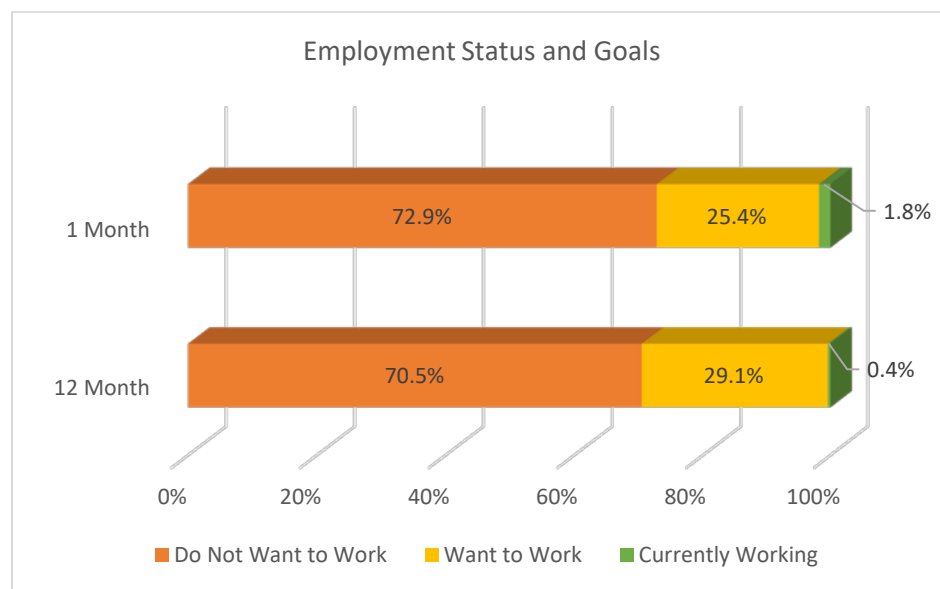


Employment and Volunteering

All community residing consumers age 18 and older were asked questions regarding work status and employment goals (Figure 3.25). Similar to 2020, although very few consumers were working, 30% of unemployed participants at 1 month and 25% at 12 months wanted to work. Given having a job often increases independence and community involvement, providing employment supports for consumers who want to work living would be an area to explore. One person spoke enthusiastically about his employment plans:

I'm going to be going back to school for manufacturing field. I am looking for places to volunteer at to get more experience.

Figure 3.25. Employment Status and Goals



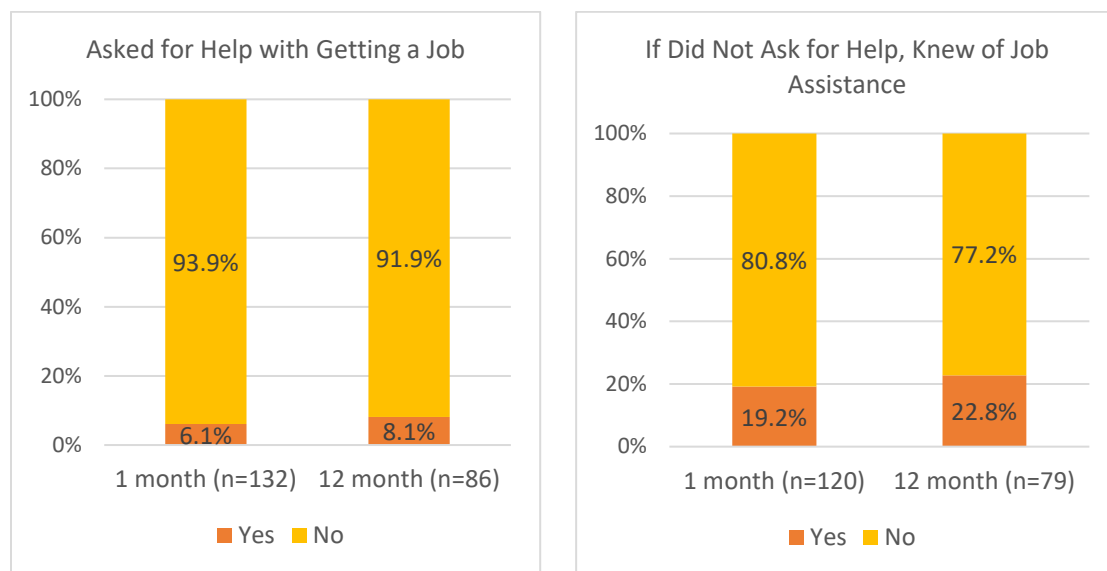
Not surprisingly, when asked what was holding them back from working, health and disability related concerns were the most frequently reported reason for not working, especially for participants who wanted to work (Table 3.7). Few to no participants who wanted to work reported that training/education, looking but can't find work, potential loss of benefits, or employment resources were challenges to employment. Compared to unemployed participants who wanted to work, participants who did not want a job were much more likely to give retirement or "nothing is holding me back" as the reason for not working. COVID-19 was mentioned as a challenge to working by a few consumers who wanted to work.

Table 3.7. Most Common Reasons for Not Working

Most Common Reasons for Not Working	1 Month Would like to work N= 133 n (%)	12 Month Would like to work N= 86 n (%)	1 Month Does not want to work N= 322 n (%)	12 Month Does not want to work N= 247 n (%)
Health Concerns	113 (85.0)	79 (91.9)	177 (55.8)	124 (53.7)
Transportation	9 (6.8)	6 (7.0)	1 (<1.0)	4 (1.6)
Retired	1 (<1.0)	0 (0)	43 (13.4)	41 (16.6)
Nothing/Do not want to work	6 (4.5)	1 (1.2)	137 (77.4)	93 (37.7)

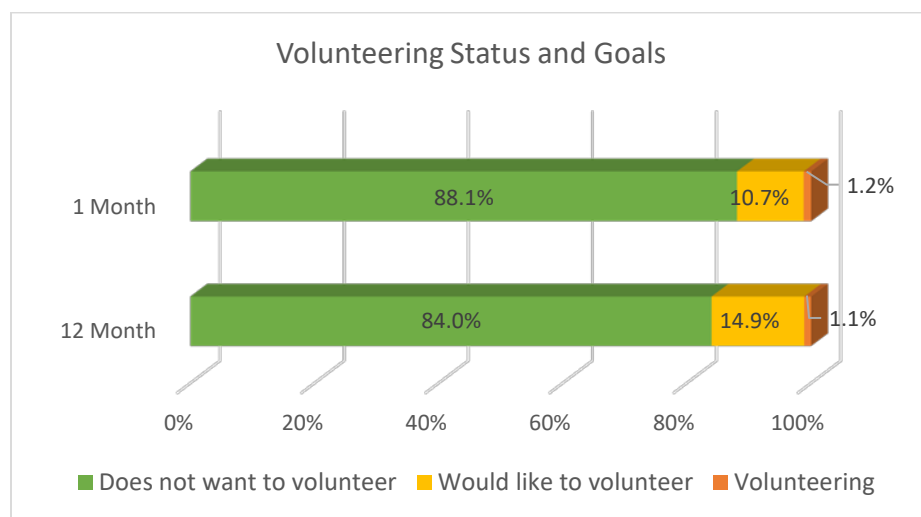
Only 6-8% of unemployed participants at either time point had asked for assistance with finding a job (Figure 3.26). Of those who did not ask for help, only about one-fifth at either 1 month (19%) or 12 months (23%) knew there was assistance to help them find a job (Figure 3.27). Providing outreach to increase awareness of job assistance and encouragement to use these resources might help people who want to work become employed.

Figure 3.26. Sought Out Employment Assistance



The percentage of consumers at 1 month and 12 months who want to volunteer dropped significantly from 2020 to 2021. In 2021 only 15% of consumers at 1 month, and 11% at 12 months, were interested in volunteering, compared to 26% of 1 month and 21% of 12 month consumers last year (Figure 3.28). Even though fewer consumers expressed this interest this year, connecting these participants with volunteering opportunities would likely increase their community engagement and support overall well-being.

Figure 3.28. Volunteering Status and Goals



Section 4. Experiences of Waiver and Non-waiver Consumers from 1 Month to 12 Months Post-transition

The cohort of community living consumers who transitioned in 2020 were separated into those who met the requirements for a waiver at transition (waiver consumers) and those who were not eligible for a waiver. Consumers accepted to a waiver were eligible for waiver HCBS at transition. Waiver consumers comprised 71% of the 1 month and 75% of the 12 month samples (Table 4.1). Consumers not accepted

to a waiver transitioned using state plan or other community Medicaid services. Referred to here as state plan consumers, they comprised the remaining 25-29% of the community surveys. This section examines differences between these two groups of consumers. Data is shown by waiver/state plan and by survey time point. Only select data is shown to focus on any pronounced differences.

Table 4.1. Waiver or State Plan Status by Survey Time Point

	1 Month n (%)	12 Month n (%)
Waiver	340 (71.4)	258 (74.6)
State Plan	136 (28.6)	88 (25.4)
All programs	476 (100.0)	346 (100.0)

Services and Select Demographics

At transition, waiver consumers are eligible for various waiver services to assist them with daily living tasks. Meanwhile, most state plan consumers need no ongoing assistance with these tasks and receive limited or no HCBS. Table 4.2 highlights differences in self-reported service use between the two groups. For example, at 1 month, 83% of waiver consumers report using some type of personal care assistance, compared to only 18% of state plan consumers. State plan use of both PCA and homemaking services, low to begin with, also decreases over time.

Use of case management services is also quite different, even soon after transition. Waiver case managers are not assigned to waiver consumers until 3 to 12 months post-transition. However, MFP TCs provide case management services to waiver and state plan consumers for at least the first 1 to 3 months post-transition. Still, state plan consumers were 33% less likely to report using case management services at just 1 month post transition – 76% of waiver consumers reported using case management at 1 month post transition, compared to 50% of state plan consumers. It is not clear why TCs are apparently less involved with non-waiver consumers just a few weeks after transition. It may also be that state plan consumers do not consider TCs to be case managers.

Table 4.2. Self-reported Home and Community-Based Services Use*

	1 Month		12 Month	
	Waiver n (%)	State Plan n (%)	Waiver n (%)	State Plan n (%)
Personal care assistant/attendant services	283 (83.2)	24 (17.6)	199 (81.6)	13 (14.4)
Behavioral health services	6 (1.8)	2 (1.5)	4 (1.6)	1 (1.1)
Homemaking services or Homemaker-Companion	222 (65.3)	27 (22.4)	163 (66.8)	14 (15.9)
Care management services	258 (75.9)	68 (50.0)	184 (71.3)	20 (22.7)
Recovery assistance services (MHW)	12 (85.7)	0 (0)	11 (78.6)	0 (0)
Community Service Provider (MHW)	8 (57.1)	0 (0)	7 (50.0)	0 (0)
Job coach or vocational supports	0 (0)	0 (0)	0 (0)	0 (0)
None of these services	6 (1.8)	51 (37.5)	7 (2.7)	58 (65.9)

* Consumers can use more than one service

Overall, waiver consumers are more likely to be older –78% of these consumers are 55 or older, while 76% of state plan consumers are between the ages of 45-64. State plan consumers are also more likely to be male (Table 4.3).

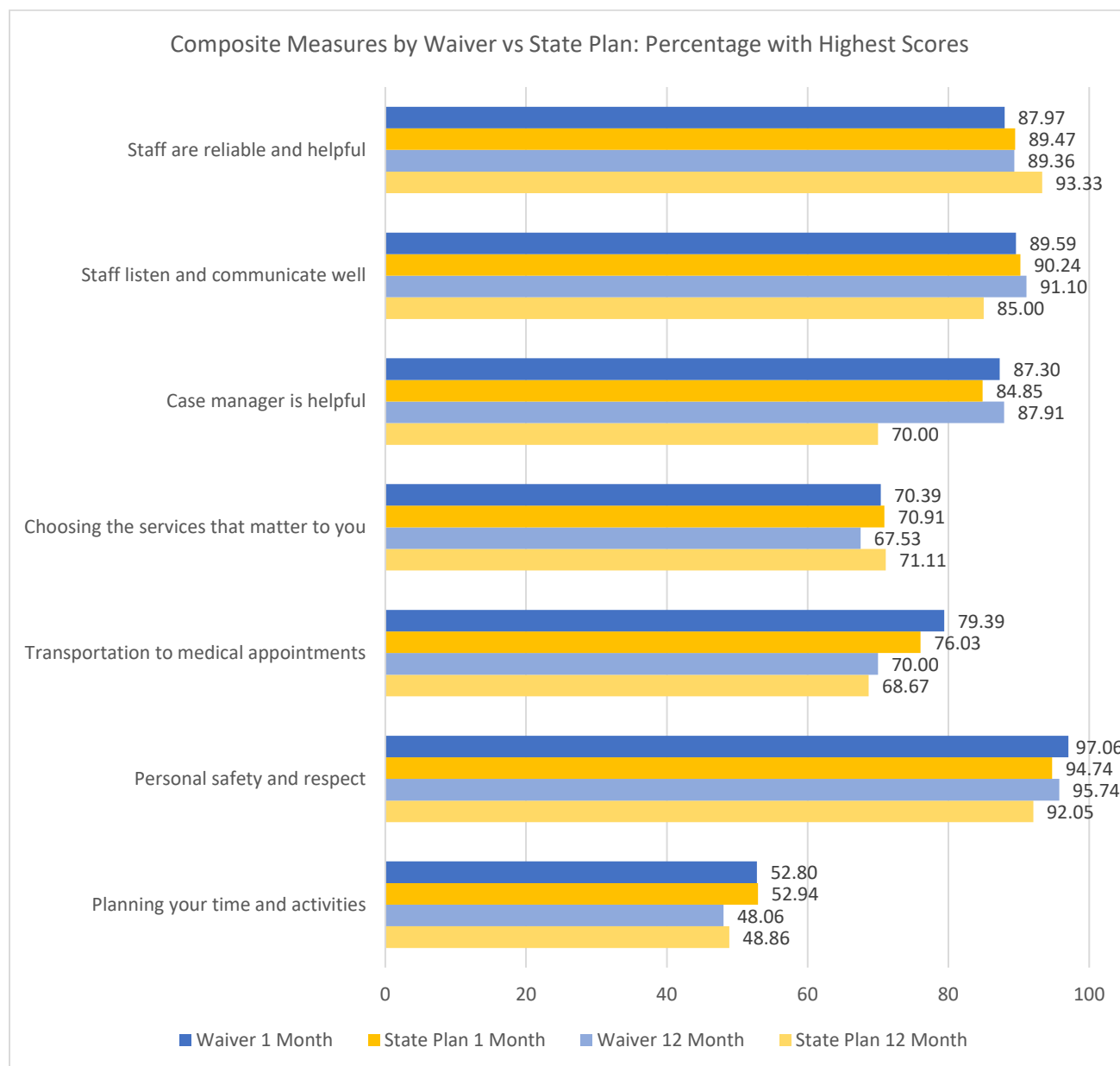
Table 4.3. Demographics – Waiver/State Plan by Time Point

		1 Month		12 Month	
		Waiver %	State Plan %	Waiver %	State Plan %
Age		N=340	N=136	N=258	N=88
	<18	<1.0	<1.0	1.2	1.1
	18-24	1.8	0.0	1.9	0.0
	25-34	5.3	4.4	7.0	3.4
	35-44	3.8	7.4	3.5	5.7
	45-54	10.3	26.5	9.7	27.3
	55-64	27.1	49.3	26.7	48.9
	65-74	24.4	8.8	26.0	9.1
	75+	26.5	2.9	24.0	4.5
Gender		N=340	N=136	N=258	N=88
	Male	47.1	61.8	48.4	65.9
	Female	52.9	38.2	51.6	34.1

HCBS CAHPS Key Results: Composites, Global Ratings, and Recommendations

Most of the composite measures did not show any striking differences or noticeable trends between the two groups at either time point, with the exception of case manager is helpful and staff listen and communicate well at 12 months (Figure 4.1). At 12 months, 88% of waiver consumers gave the highest score for the care manager composite, compared to only 70% of state plan consumers. At 12 months state plan consumers were also less likely to give the highest score for staff listen and communicate well compared to waiver consumers (91% waiver, 85% state plan).

Figure 4.1. Composite Measures by Waiver vs. State Plan: Percentage with Highest Scores



When PCA/behavioral health/RA staff and homemaking staff were analyzed separately, as in the ratings and recommendations, different trends emerged. Unexpectedly, at 12 months, a much greater percentage of state plan consumers gave their PCAs the highest rating. This same trend is seen for care manager ratings at 1 month (Figure 4.2). State plan consumers were also more likely to definitely recommend their care manager staff at both 1 and 12 months (Figure 4.3). Meanwhile, at 12 months, waiver consumers were much more likely to highly rate or definitely recommend their homemaking staff.

It may be that comparing percentage differences between these populations has some limitations, given the small number of state plan consumers who reported using these services. For example, at 12

months, only 14 state plan consumers had PCA/behavioral health staff, 14 used homemaking services, and 20 reported having a case manager (Table 4.2).

Figure 4.2. Global Ratings by Waiver vs. State Plan: Percentage Who Rate Their Staff a 9 or 10

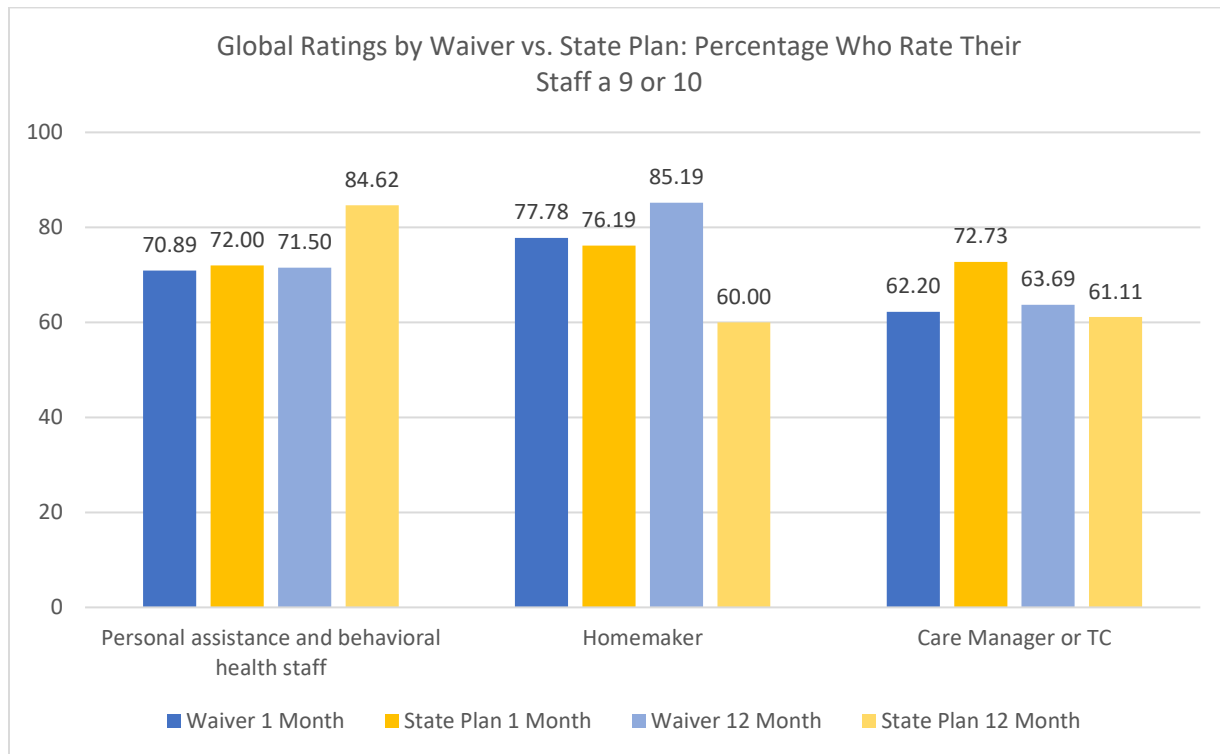
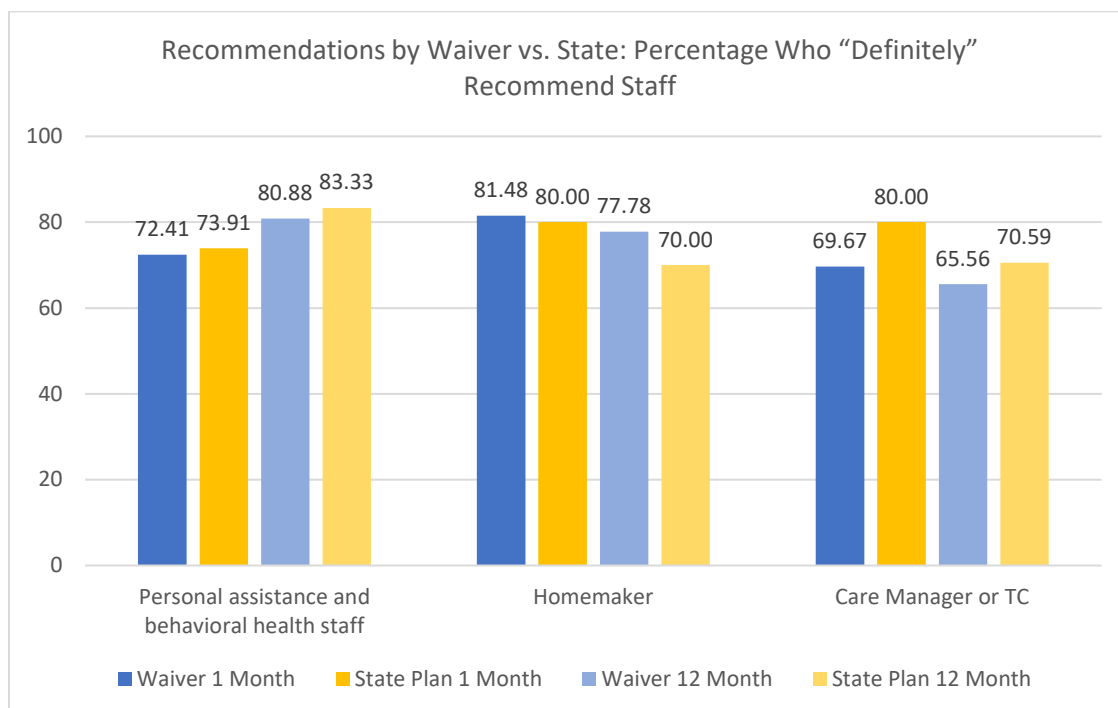


Figure 4.3. Recommendations by Waiver vs. State Plan: Percentage Who “Definitely” Recommend Staff



Case Manager Items

Not surprisingly, by one year post transition, a noticeably lower percentage of state plan consumers reported having a case manager or service coordinator. State plan consumers were also less likely to be able to reach this person when they needed to (Figures 4.4 and 4.5).

Figure 4.4. Knows Who Case Manager Is, Waiver vs. State Plan

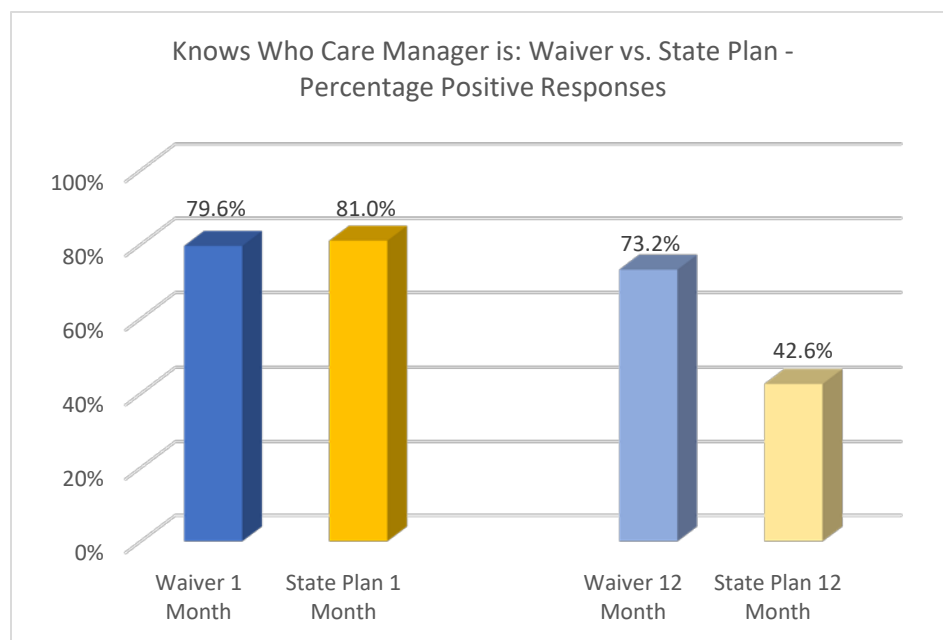
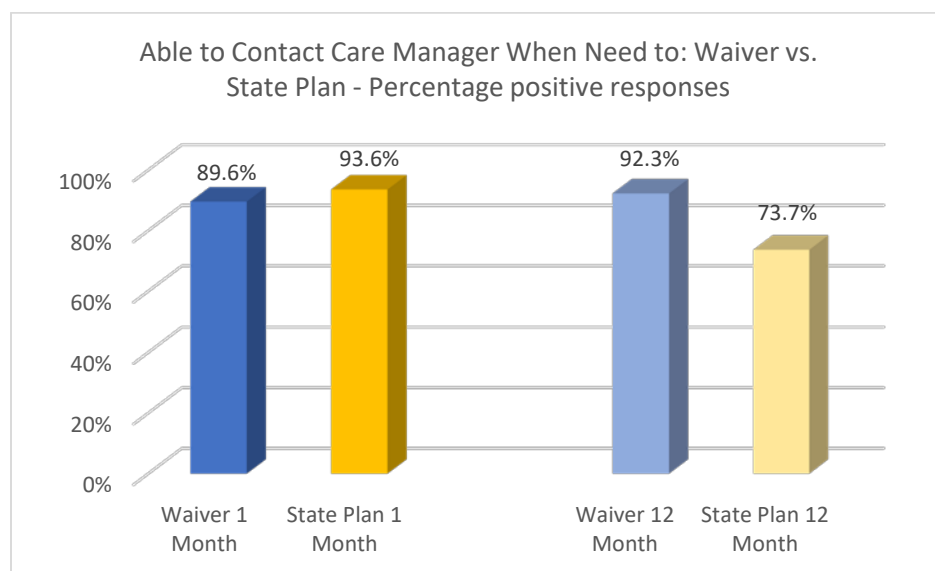
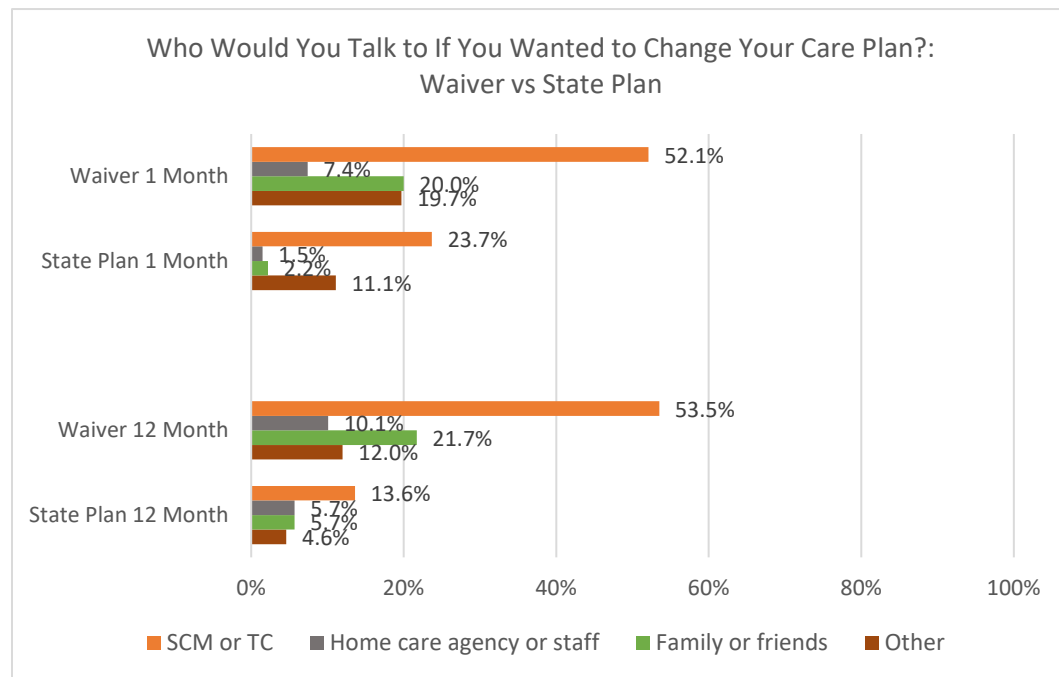


Figure 4.5. Able to Contact Case Manager, Waiver vs. State Plan



Although at 1 month both waiver and state plan consumers received TC services and waiver services have not started, waiver consumers were more likely to talk to their TC or SCM if they wanted to change their care plan at both 1 and 12 months post transition (Figure 4.6). Overall, waiver consumers reported having more resources to use if they wanted changes to their services.

Figure 4.6. Who Would You Talk to if You Wanted to Change Your Care Plan? – Waiver vs. State Plan



Living Situation and Social Support

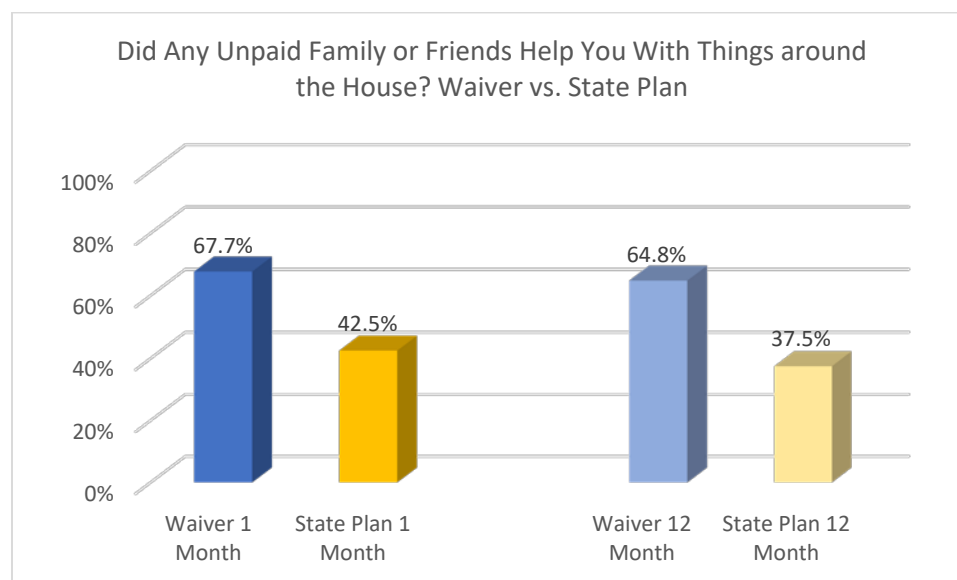
Consumers with state plan services reported less social support overall than consumers who receive services through a waiver. Consumers with state plan services are much more likely to live alone –three-quarters of consumers with state plan services lived alone at either time point, compared to half of waiver consumers (Table 4.4). State plan consumers were also less likely to either live with family or have family member who lived nearby.

Table 4.4. Living Situation and Social Support: Waiver vs. State Plan

		1 Month Waiver %	1 Month State Plan %	12 Month Waiver %	12 Month State Plan %
Number of adults living in household		N=339	N=134	N=234	N=88
	1	50.4	76.9	53.9	76.1
	2-3	43.1	13.4	40.9	13.6
	4+	6.5	9.7	5.1	10.2
Lives with family member/s		N=168	N=31	N=118	N=21
	Yes	77.4	51.6	77.1	47.6
	No	22.6	48.4	22.9	52.4
Lives with non-family		N=168	N=31	N=117	N=21
	Yes	27.4	48.4	32.5	52.4
	No	72.6	51.6	67.5	47.6
Family member/s live nearby		N=340	N=136	N=257	N=88
	Yes	74.1	56.6	76.3	58.0
	No	25.9	43.4	23.7	42.1
Friend/s live nearby		N=338	N=136	N=257	N=88
	Yes	53.6	47.8	41.6	48.9
	No	46.4	52.2	58.4	51.1

Waiver recipients also report getting more assistance from family or friends around the house, which is not surprising given waiver consumers are more likely to live with or near family members (Figure 4.7).

Figure 4.7. Family or Friends Help You around the House – Waiver vs. State Plan (Percentage Yes)



Compared to state plan consumers, waiver consumers were more likely to like where they live and feel safe living there (Figures 4.8 and 4.9). Most strikingly, at 12 months only 67% of state plan consumers liked where they live, compared to 87% of waiver consumers. Note that all of these consumers were living in the community at the time of these interviews; this analysis excludes those in institutional settings.

Figure 4.8. Do You Like Where You Live? Waiver vs. State Plan

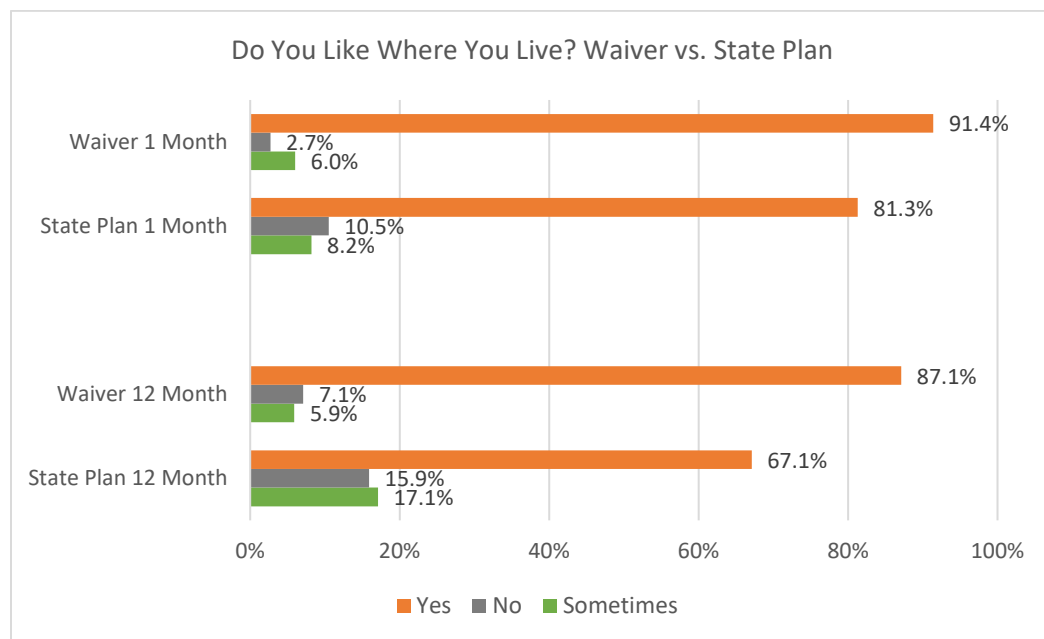
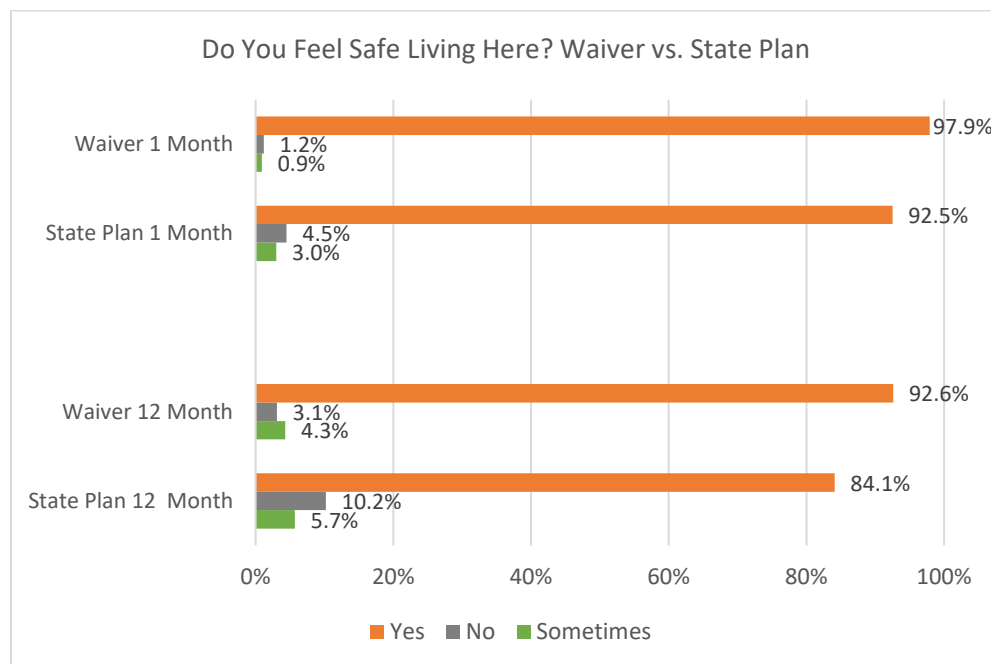


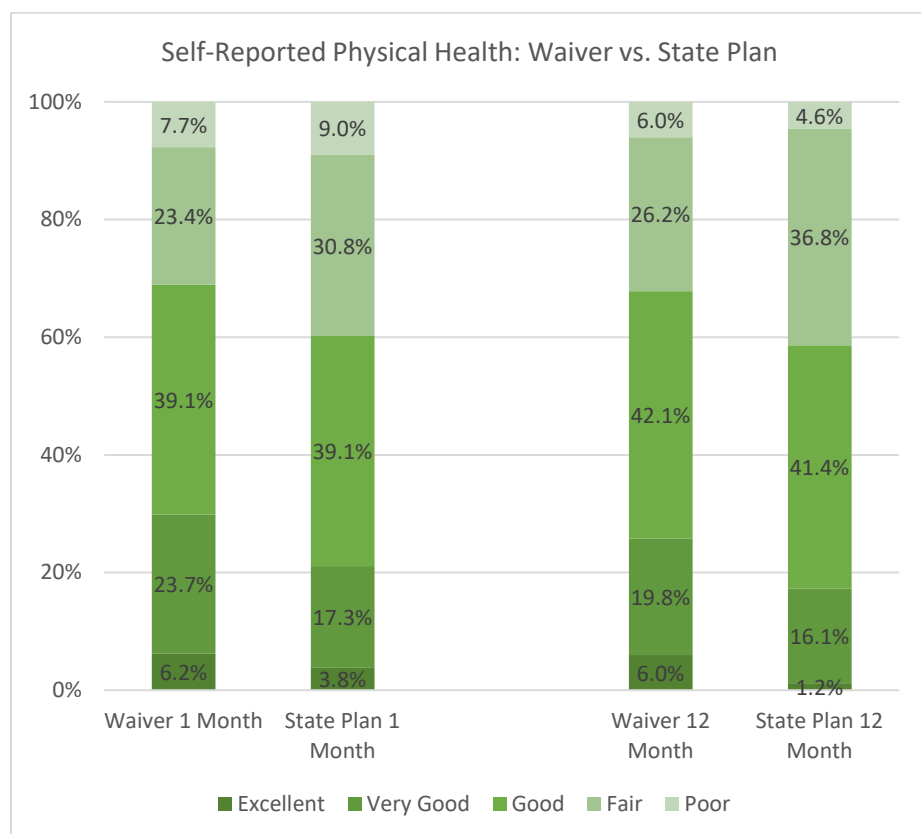
Figure 4.9. Do You Feel Safe Living Here? Waiver vs. State Plan



Physical Health

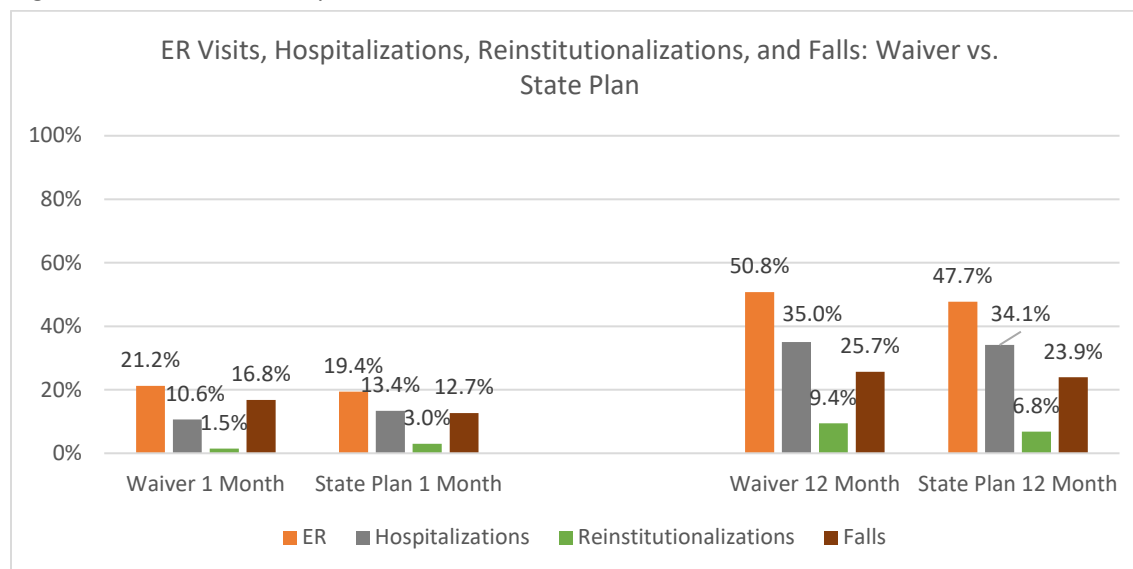
While substantial percentages of either group gave low ratings for their physical health, this was especially true for state plan consumers (Figure 4.10). At 1 month, 40% of state plan and 31% of waiver consumers said their physical health was fair or poor, and these between group differences stayed fairly constant over the year.

Figure 4.10. Self-reported Physical Health: Waiver vs. State Plan



Rates of ER visits, hospitalizations, nursing home readmissions, and falls did not show sizeable differences or trends between the two groups of consumers (Figure 4.11). At both time points, waiver consumers were slightly more likely to experience a fall or go to the emergency room. At 12 months post transition, 9% of waiver consumers were reinstitutionalized, as were 7% of state plan consumers. The age and functional status differences between the two groups may account for these findings.

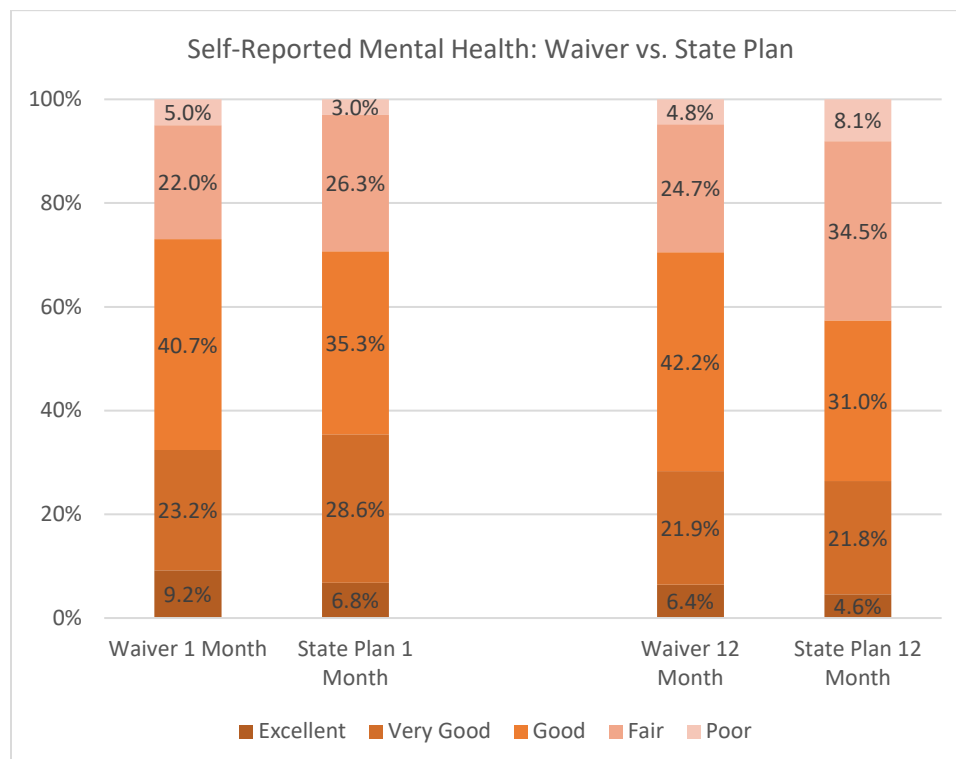
Figure 4.11. ER Visits, Hospitalizations, Reinstitutionalizations, and Falls: Waiver vs. State Plan



Mental Health

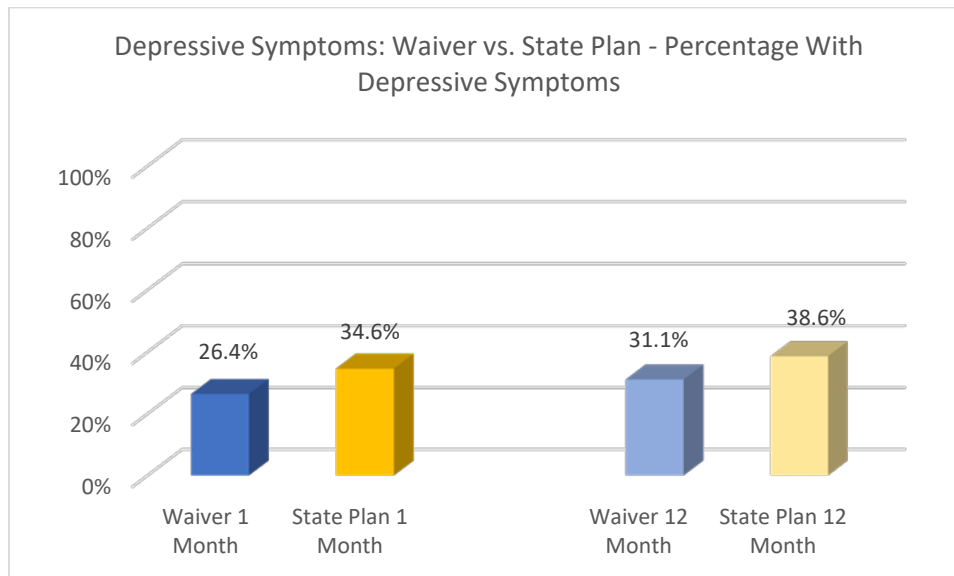
In general, waiver consumers reported better mental or emotional health (Figure 4.12). At 1 month these differences were small – 73% of waiver and 71% of state plan consumers reported their mental health was at least good. At 12 months, state plan consumers reported much poorer mental health. Forty-three percent of state plan consumers reported their mental health as fair or poor, compared to 30% of waiver consumers. The reason for the worsening of state plan consumers’ mental health or the between group differences is not clear.

Figure 4.12. Self-Reported Mental Health: Waiver vs. State Plan



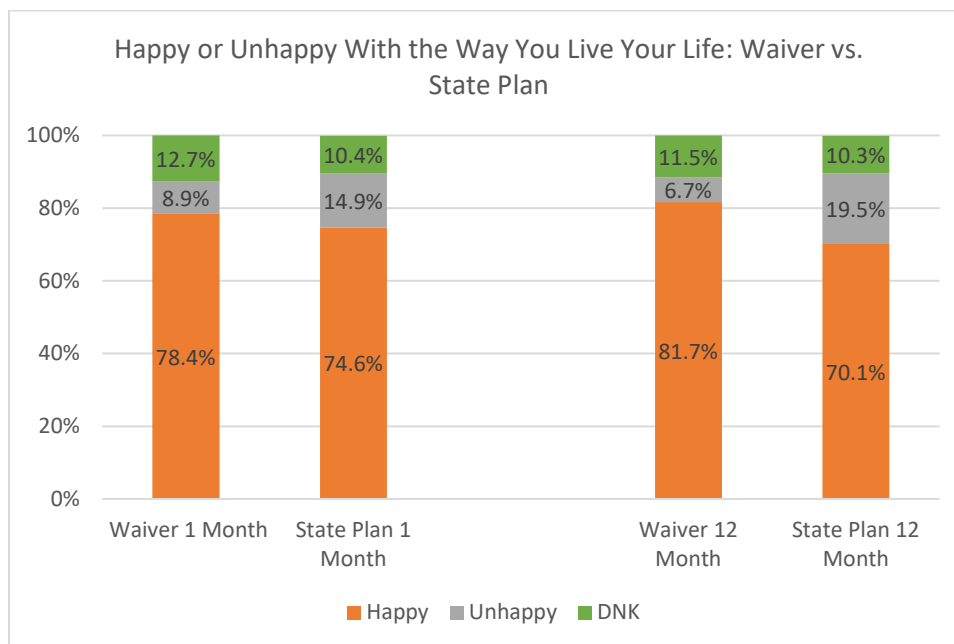
State plan consumers reported much higher rates of depressive symptoms (Figure 4.13). At 1 month, 35% of state plan consumers reported depressive symptoms, which increased to 39% at 12 months.

Figure 4.13. Depressive Symptoms: Waiver vs. State Plan – Percentage with Depressive Symptoms



Although the majority of waiver and state plan consumers reported being happy with the way they live their life, state plan consumers were more likely to report feeling unhappy, especially at 12 months (Figure 4.14). While 82% of waiver consumers were happy with the way they live their lives at 12 months, only 70% of state plan consumers felt that way.

Figure 4.14. Happy or Unhappy With the Way You Live Your Life: Waiver vs. State Plan



Assistive Device, Special Medical Equipment, Home Modifications

As shown in Table 4.5, compared to state plan consumers, noticeably more waiver consumers reported having mobility equipment, medical equipment, or a PERS unit at both 1 and 12 months. This again may be an effect of the greater physical needs of waiver consumers. However, state plan consumers often reported a greater unmet need for these devices than did waiver consumers. This is especially true for a PERS unit – 18% of state plan consumers lacked a needed PERS unit at 1 month, and 10% still did so at 12 months, compared to 9% of 1 month and 4% of 12 month waiver consumers. State plan consumers also reported a notably higher unmet need for medical equipment at both 1 and 12 months. At 1 month, 11% of state plan consumers needed medical equipment to continue to live in the community, compared to 7% of waiver consumers.

Table 4.5. Special Equipment and Assistive Devices: Waiver vs. State Plan

		1 Month Waiver %	1 Month State Plan %	12 Month Waiver %	12 Month State Plan %
Home modifications		N=340	N=134	N=255	N=88
	I have it	73.5	54.5	81.2	51.1
	I do not need it	12.4	32.1	11.8	42.1
	I need it	14.1	13.4	7.1	6.8
Mobility equipment		N=340	N=134	N=255	N=88
	I have it	89.1	68.7	87.8	65.9
	I do not need it	8.5	26.9	9.8	31.8
	I need it	2.4	4.5	2.4	2.3
Medical equipment		N=340	N=134	N=255	N=88
	I have it	78.2	45.4	84.3	42.1
	I do not need it	15.0	44.0	9.8	53.4
	I need it	6.8	10.5	2.4	4.6
Lifeline or PERS		N=338	N=134	N=255	N=88
	I have it	50.0	7.5	48.6	8.0
	I do not need it	41.4	74.6	47.1	81.8
	I need it	8.6	17.9	4.3	10.2
Internet capable devices		N=335	N=131	N=254	N=88
	I have it	57.3	70.2	58.7	69.3
	I do not need it	38.5	24.4	37.4	26.1
	I need it	4.2	5.3	3.9	4.6
Internet access		N=336	N=132	N=249	N=88
	I have it	73.5	72.7	79.1	75.0
	I do not need it	19.6	18.2	18.5	18.2
	I need it	6.9	9.1	2.4	6.8

Section 5. Community Experiences by Service Type: Agency-based vs. Self-directed Services over Time

Community living consumers who transitioned in 2020 were next stratified by service type into those who used agency-based services and those who used self-directed services. This section examines differences between these two groups of consumers; data is shown by service type and by time point. To measure consumer self-direction, consumers living in the community 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 caregivers or aides?” The consumer’s answer determined the category – agency-based consumers or self-directed consumers. Only participants who answered this question are included in this section. As shown in Table 5.1, consumers using agency-based services comprised 79% of the 1 month and 75% of the 12 month sample. *This is a marked increase from 2020, when 69% at 1 month and 68% at 12 month used agency-based services.*

Services and Select Demographics

Table 5.1. Service Type: Agency vs. Self-direct

	1 Month n (%)	12 Month n (%)
Agency-based	275 (79.0)	188 (74.6)
Self-directed	73 (21.0)	64 (25.4)
Total	348 (100.0)	252 (100.0)

Similar to 2020, compared to agency-based consumers, self-directed consumers reported greater use of personal care, homemaking, and care management services at both 1 and 12 months post transition (Table 5.2). Use of homemaking services at both 1 and 12 months show the greatest difference between the two groups. It might be that self-directing consumers are more aware of all the different tasks that their staff are hired to do and, therefore, differentiate homemaking services from personal care. It is not clear why self-directed consumers are more likely to report using case management services, especially since at 1 month post-transition all consumers have TC services. It is possible that TCs and SCMs are more involved with their self-directed consumers, while agency-based consumers are expected to contact the home care agency for problems such as staffing.

Table 5.2. Self-reported Home and Community-Based Services Use: Agency vs. Self-direct*

	1 Month		12 Month	
	Agency n (%)	Self-direct n (%)	Agency n (%)	Self-direct n (%)
Personal care assistant/attendant services	228 (86.7)	69 (95.8)	149 (85.1)	58 (90.6)
Behavioral health services	8 (2.9)	0 (0)	4 (2.1)	0 (0)
Homemaking services or Homemaker-Companion services	170 (64.6)	62 (87.3)	113 (64.6)	54 (87.1)
Care management services	205 (74.5)	61 (83.6)	131 (69.7)	47 (73.4)
Recovery assistance services (MHW only)	11 (91.7)	1 (100.0)	11 (84.6)	0 (0)
Community Service Provider (MHW only)	7 (63.6)	0 (0)	7 (58.3)	0 (0)
Job coach or vocational supports	0 (0)	0 (0)	1 (<1.0)	0 (0)
None of these services	0 (0)	0 (0)	0 (1.0)	0 (0)

* Consumers can use more than one service

Agency-based consumers were more than two times as likely as self-directed consumers to be 65 years and older (Table 5.3). Agency-based consumers were more likely to be female than self-directed consumers at 1 month, but the opposite was true at 12 months.

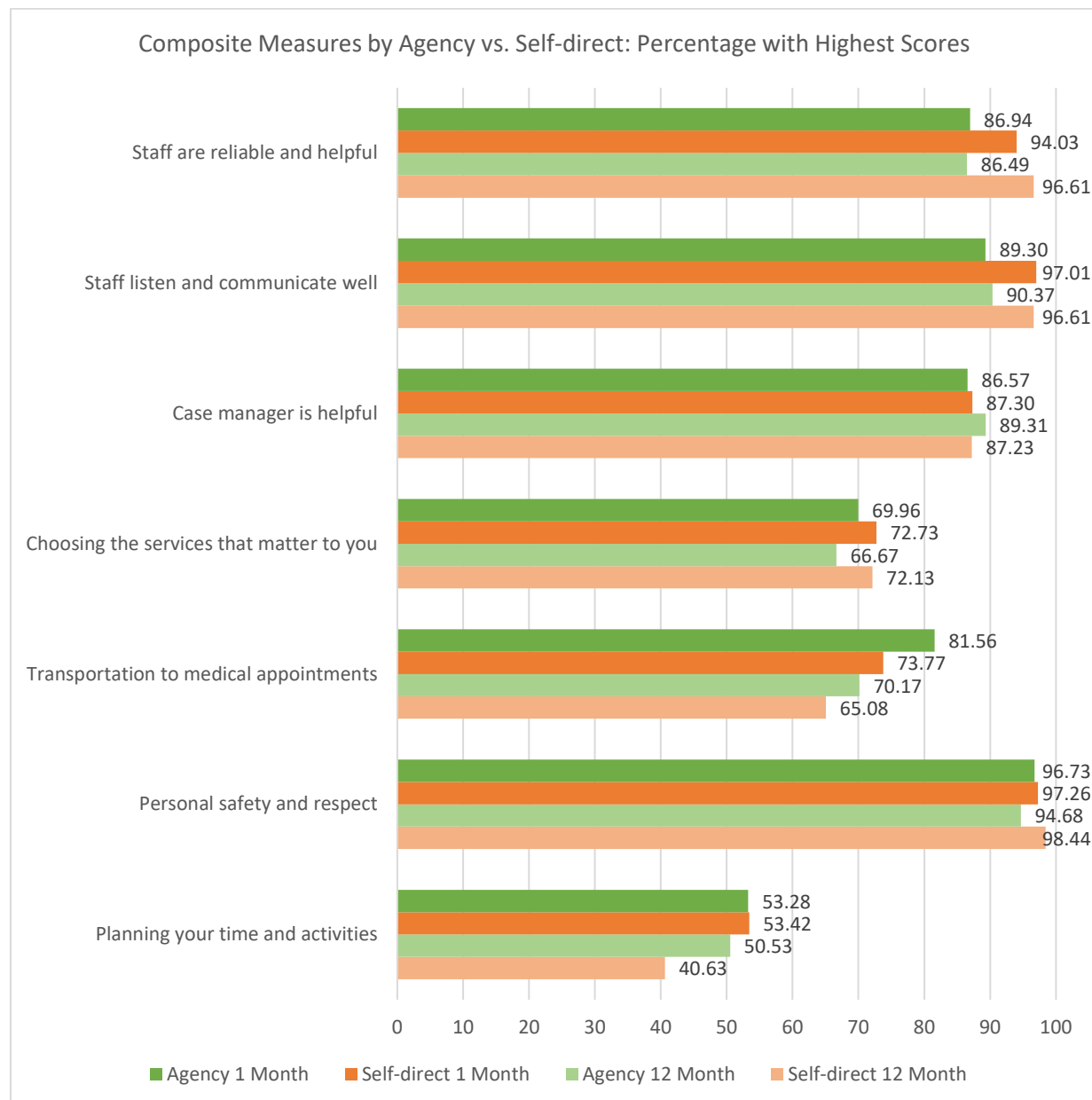
Table 5.3. Demographics: Agency vs. Self-direct

		1 Month		12 Month	
		Agency %	Self-direct %	Agency %	Self-direct %
Age		N=275	N=73	N=188	N=64
	<18	1.1	1.4	1.1	3.1
	18-24	1.5	2.7	2.7	0.0
	25-34	4.4	6.8	5.3	9.4
	35-44	3.3	9.6	1.1	7.8
	45-54	7.6	21.9	7.4	17.2
	55-64	28.4	37.0	26.1	35.9
	65-74	26.5	8.2	27.7	18.8
	75+	27.3	12.3	28.7	7.8
Gender		N=275	N=73	N=188	N=64
	Male	46.5	53.4	49.5	46.9
	Female	53.5	46.6	50.5	53.1

HCBS CAHPS Key Results: Composites, Global Ratings, and Recommendations

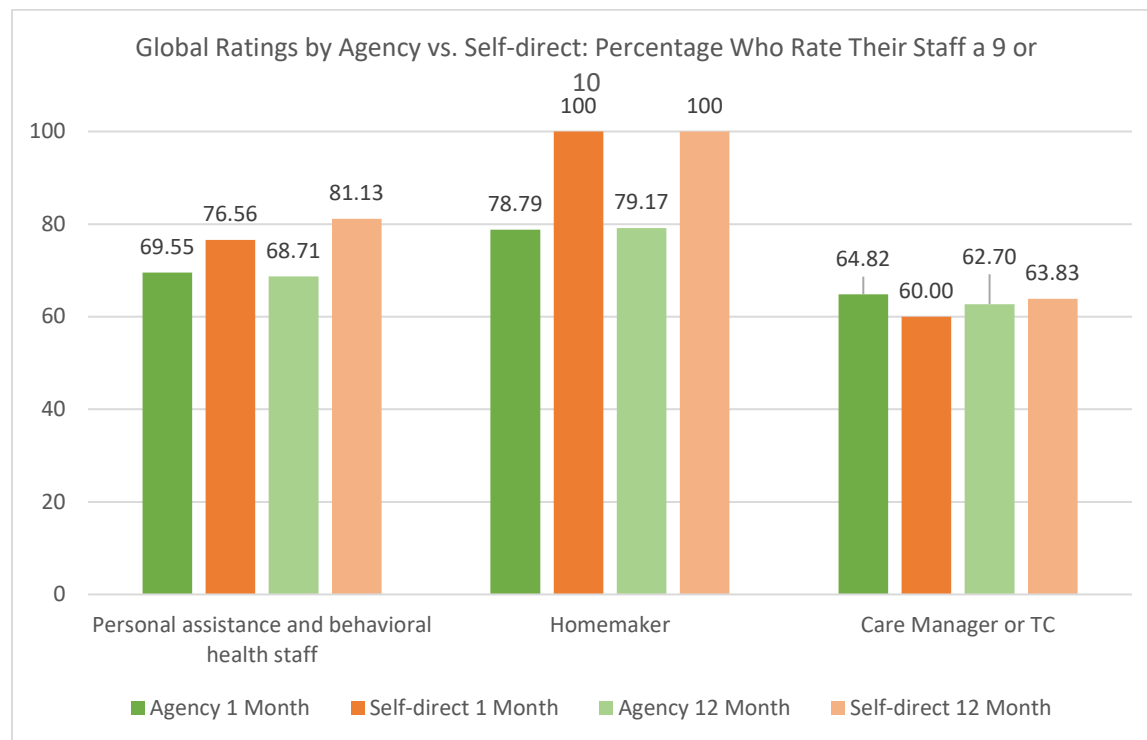
Several differences in the composite measures existed between agency-based and self-directed consumers (Figure 5.1). Self-directed consumers were much more likely than agency-based consumers to report that their staff were reliable and helpful, their staff listened and communicated well, and that they could choose their services at both 1 and 12 months. The most notable difference was for planning your time and activities at 12 months. While similar percentages of both agency-based and self-directed consumers gave the highest score to being able to plan their time and activities at 1 month, self-directed consumers had a significant decrease in this at 12 months (51% agency vs. 41% self-direct). While more agency-based consumers reported having more consistent and accessible transportation to medical appointments, both groups experienced a sharp drop in this composite at 12 months. It is not clear why self-directed consumers' medical transportation experience is less satisfactory than agency-based consumers, given access to medical transportation is not dependent on how one's staff are hired.

Figure 5.1. Composite Measures by Agency vs. Self-direct: Percentage with Highest Scores



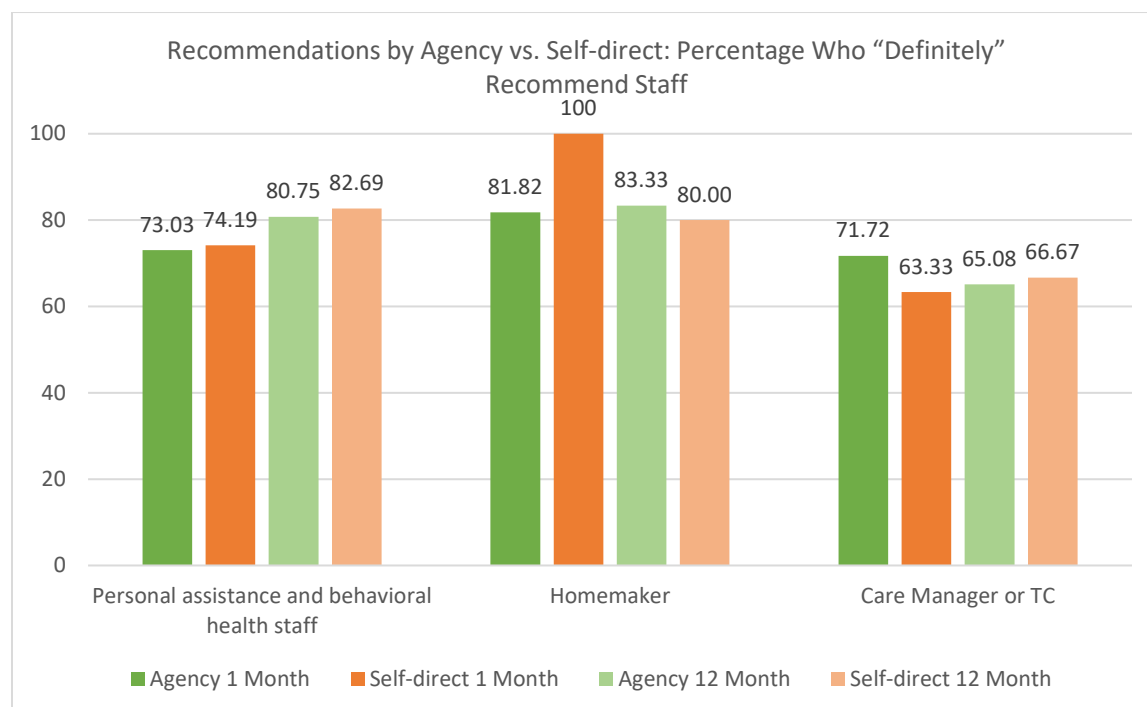
Staff ratings and recommendations also showed some marked differences between the two groups of consumers (Figure 5.2). In particular, at 1 and 12 months after transition, self-directed consumers rated their personal care and homemaking staff noticeably higher than agency-based consumers. More specifically, self-directed consumers all rated their homemaking staff a 9 or 10 at both 1 month and 12 month post-transition. Because most self-directed consumers used their PCAs for homemaking tasks as well as personal care, the homemaking only staff sample size for self-directed consumers was very small (n=5 1 month, n=5 12 month). This limits the comparison of homemaking services scores between agency-based and self-directed consumers. Although agency-based consumers gave their care managers higher ratings at 1 month (65% agency-based, 60% self-directed), this difference is not seen at 12 months.

Figure 5.2. Global Ratings by Agency vs. Self-direct: Percentage Who Rate Their Staff a 9 or 10



Similar to global ratings at 1 month, agency-based consumers were more likely to “definitely” recommend their case managers, while a greater percentage of self-directed consumers would definitely recommend their homemaking staff at 1 month (Figure 5.3).

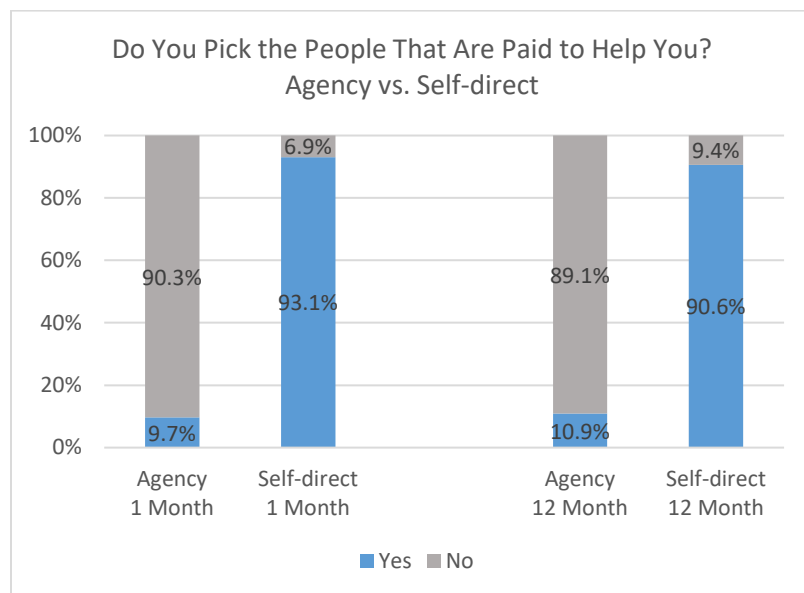
Figure 5.3. Recommendations by Agency vs. Self-direct: Percentage Who “Definitely” Recommend Staff



Choice of Paid Assistants

Figure 5.4 shows the dramatic differences between the groups when asked, “Do you pick the people who are paid to help you?” Not surprisingly, over 90% of self-directed consumers chose their paid assistants at either time point, compared to 10-11% of agency-based consumers. At 1 month 48% of self-directed consumers employed family members as paid assistants, which increased to 52% by 12 months.

Figure 5.4. Do You Pick the People That Are Paid to Help You? Agency vs. Self-direct



Assistance with Everyday Activities

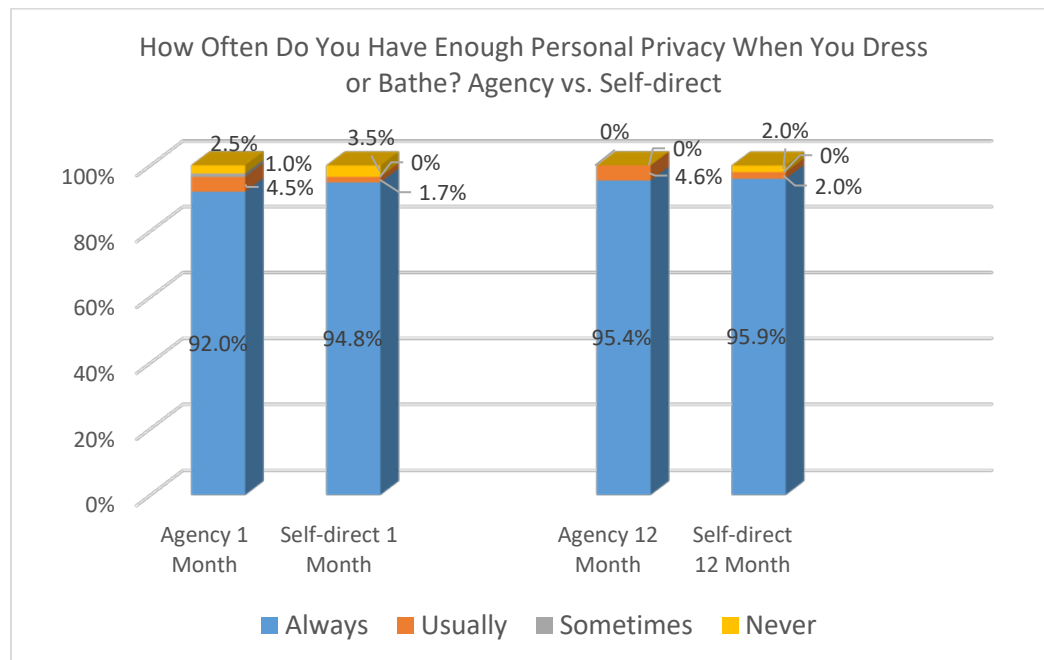
Consumers who received personal care assistance were asked what tasks they needed assistance with. As seen in Table 5.4, greater percentages of self-directed consumers reported needing assistance with each activity at both 1 and 12 months.

Table 5.4. Self-reported Assistance with Everyday Activities: Agency vs. Self-direct

Needs assistance with:	1 Month Agency Based n (%)	1 Month Self-direct n (%)	12 Month Agency Based n (%)	12 Month Self-direct n (%)
Personal care	203 (83.2)	59 (90.8)	131 (80.4)	49 (90.7)
Meals or eating	191 (78.3)	61 (93.9)	133 (81.6)	52 (96.3)
Taking medications	149 (61.6)	55 (84.6)	109 (67.3)	38 (70.4)
Using the toilet	137 (56.6)	43 (67.2)	85 (52.2)	41 (75.9)
Housekeeping or laundry	170 (65.1)	62 (87.3)	113 (64.9)	54 (87.1)

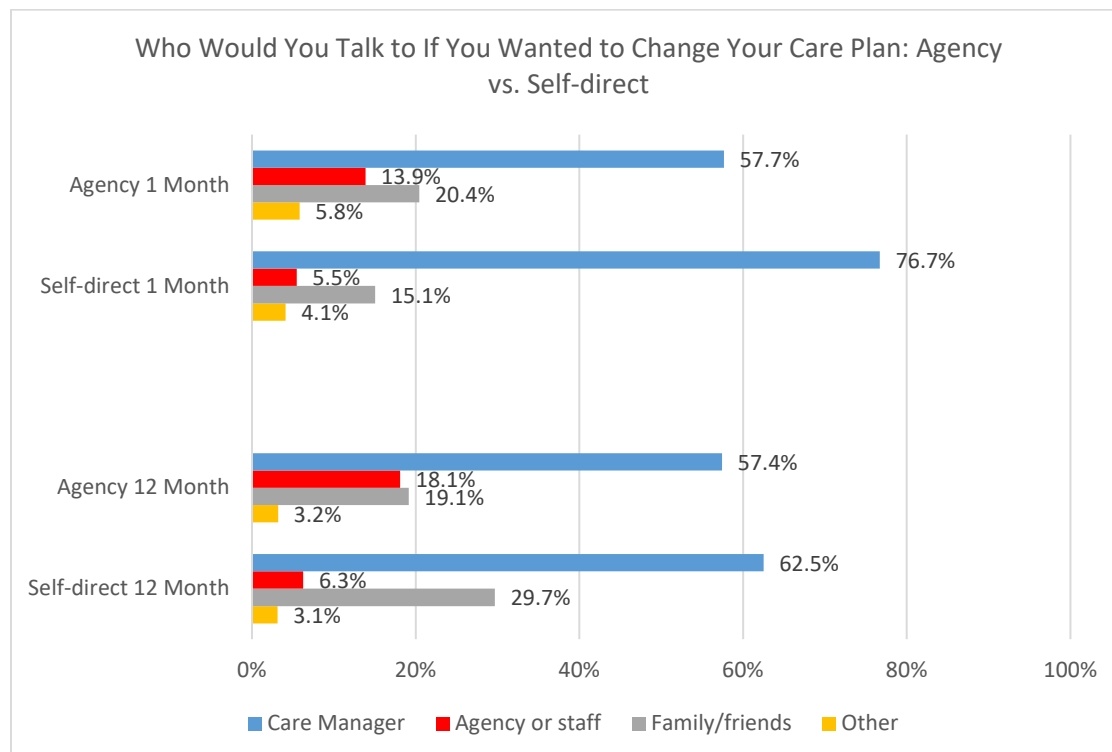
When asked how often they had enough personal privacy when bathing or dressing, slightly fewer agency-based consumers said they always had enough privacy at 1 month compared to self-directed consumers (Figure 5.5). Both agency-based consumers and self-directed consumers reported having privacy over 95% of the time at 12 months.

Figure 5.5. How Often Do You Have Enough Personal Privacy When You Dress or Bathe? Agency vs. Self-direct



Self-directed consumers were most likely to call their care manager to change their care plan at either time point (Figure 5.6). At both time points, more agency-based consumers would contact either the home care agency or a staff member to change their care plan, while at 12 months more self-directed consumers would turn to family or friends.

Figure 5.6. Who Would You Talk to If You Wanted to Change Your Care Plan? Agency vs. Self-direct



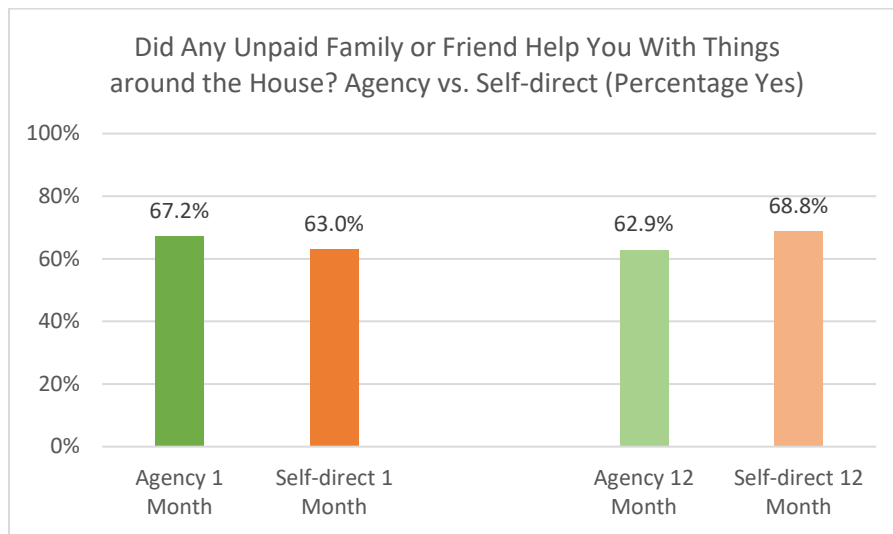
Living Situation and Social Support

Household composition showed strong differences between the two groups of consumers (Table 5.5). The percentage of each group who live alone is most striking – at both time points, agency-based consumers were much more likely to live alone. At 1 month, 56% of agency-based consumers lived alone, compared to 37% of self-directed consumers. For those consumers who lived with someone, self-directed consumers were more likely to live with family, while agency-based consumers more often lived with non-family. With respect to other social support, a greater percentage of self-directed consumers lived near family at 12 months, and self-directed consumers were more likely to have nearby friends at both time points. At 1 month, agency-based consumers reported receiving more informal support from family and friends for household tasks, although by 12 months a greater percentage of self-directed consumers reported receiving this type of support (Figure 5.7).

Table 5.5. Living Situation and Social Support: Agency vs. Self-direct

		1 Month Agency %	1 Month Self-Direct %	12 Month Agency %	12 Month Self-Direct %
Number of adults living in household		N=273	N=73	N=185	N=64
	1	55.7	37.0	60.0	43.8
	2-3	37.4	57.5	34.6	51.6
	4+	7.0	5.5	5.4	4.7
Lives with family member/s		N=121	N=46	N=74	N=36
	Yes	75.2	78.3	73.0	83.3
	No	24.8	21.7	27.0	16.7
Lives with non-family		N=121	N=46	N=74	N=36
	Yes	31.4	21.7	39.2	22.2
	No	68.6	78.3	60.8	77.8
Family member/s live nearby		N=275	N=73	N=188	N=64
	Yes	73.1	72.6	73.9	81.3
	No	26.9	27.4	26.1	18.8
Friend/s live nearby		N=274	N=73	N=187	N=64
	Yes	43.4	58.9	40.1	51.6
	No	56.6	41.1	59.9	48.4

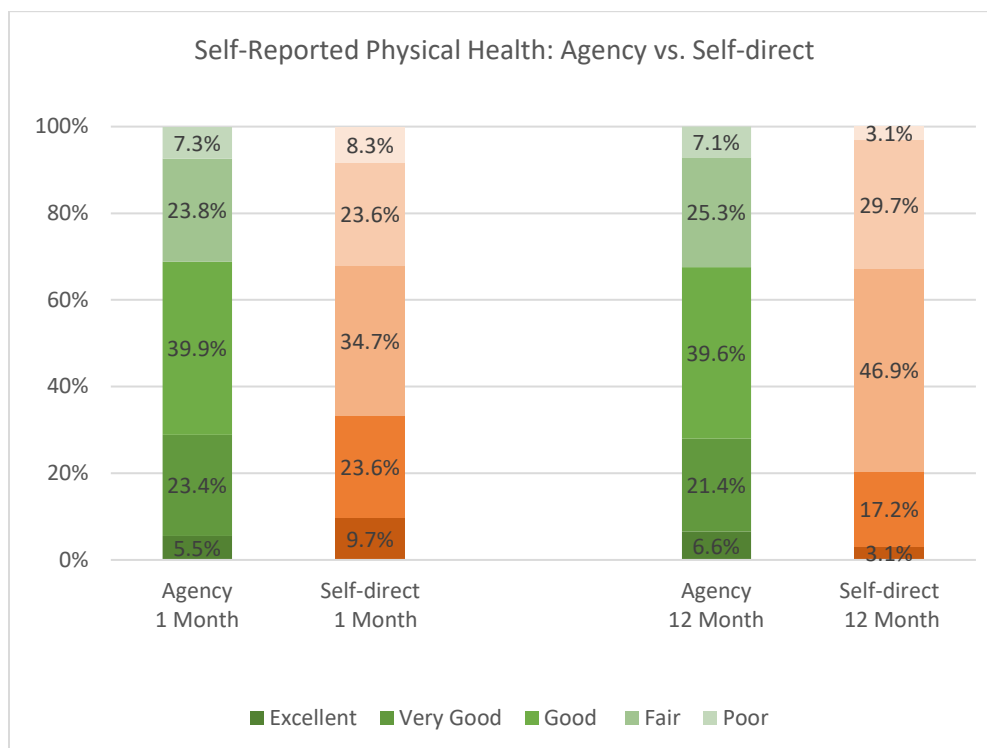
Figure 5.7. Assistance from Unpaid Family or Friends with Things around the House: Agency vs. Self-direct (Percentage Yes)



Physical Health

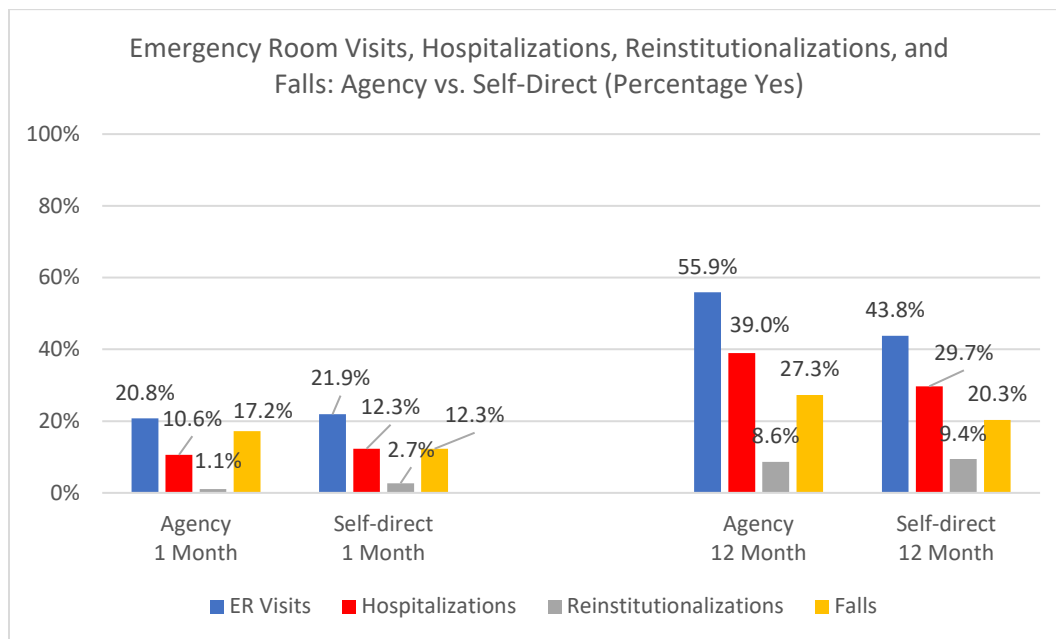
Self-reported physical health showed some differences but no identifiable trends between the two groups (Figure 5.8). At 1 month, more self-directed consumers rated their health as very good or excellent, while at 12 months, more agency-based consumers reported having very good or excellent health.

Figure 5.8. Self-Reported Physical Health: Agency vs. Self-direct



There were some differences in falls, ER visits, hospitalizations, and reinstitutionalizations between agency-based and self-directed consumers, especially at one year post transition (Figure 5.9). Most notably, at 12 months, agency-based consumers used the ER and were hospitalized more often than self-directed consumers. At both time points, agency-based consumers were also more likely to have fallen.

Figure 5.9. Emergency Room Visits, Hospitalizations, Reinstitutionalizations, and Falls: Agency vs. Self-direct (Percentage Yes)



Mental Health

While at 1 month, both groups of consumers reported similar rates of very good or excellent mental or emotional health, at 12 months more self-directed consumers reported their health as very good to excellent mental health (Figure 5.10). Accordingly, 33% of agency-based consumers reported fair or poor mental health at 12 months compared to only 24% of self-directed consumers. When asked if they were happy or unhappy with the way they lived their life, more self-directed consumers said they were happy at both time points compared to agency-based consumers (approximately 85% self-directed, 77% agency-based) (Figure 5.11).

Figure 5.10. Self-Reported Mental Health: Agency vs. Self-direct

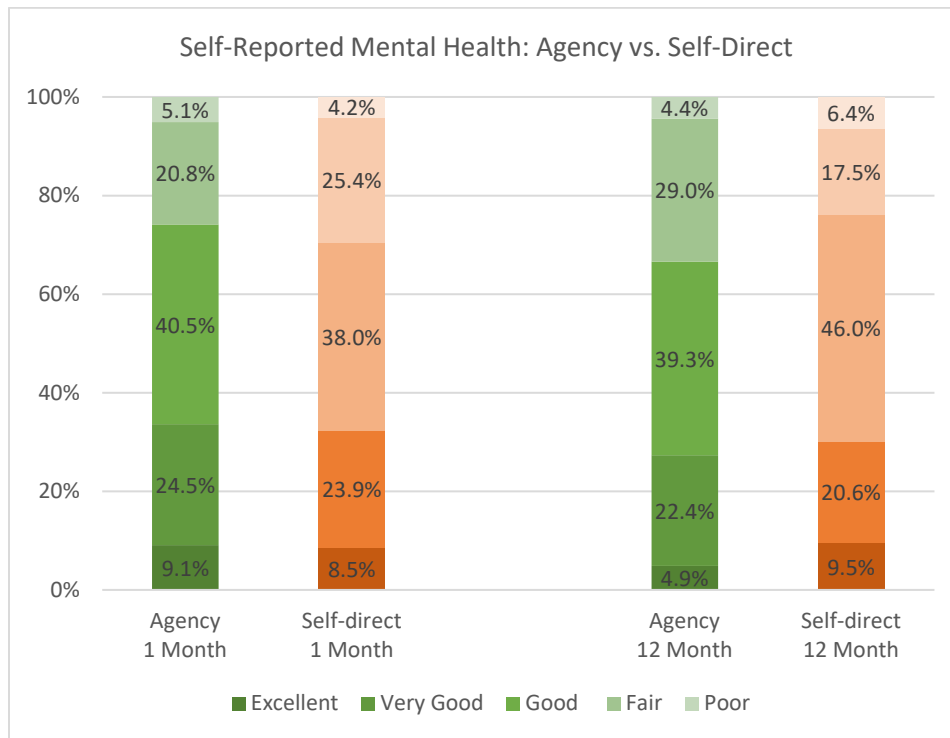
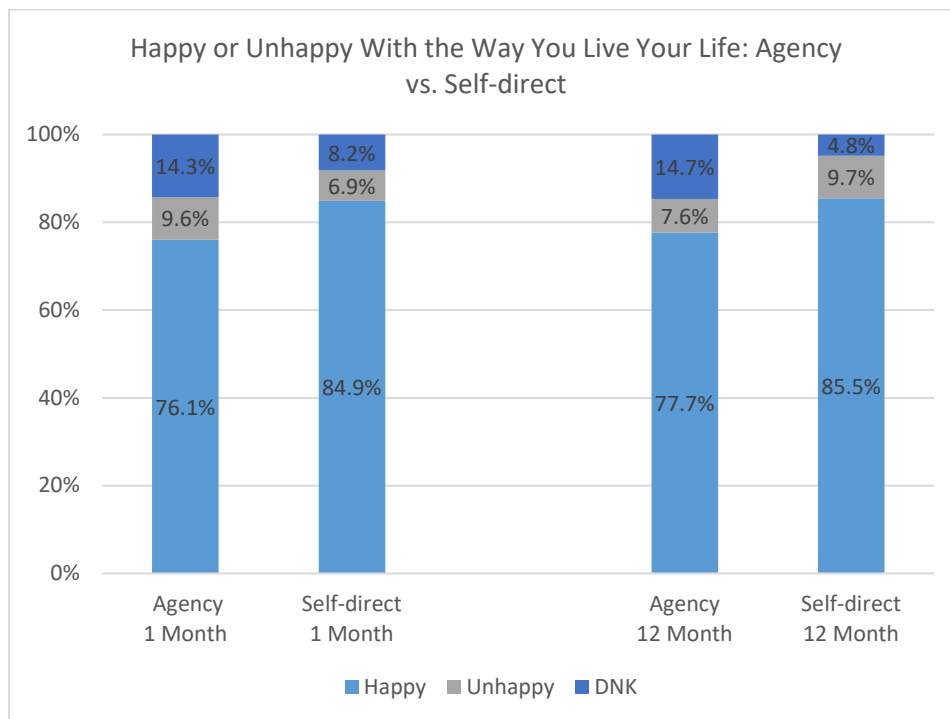


Figure 5.11. Happy or Unhappy With the Way You Live Your Life: Agency vs. Self-direct



Assistive Device, Special Medical Equipment, Home Modifications

As shown in Table 5.6, with the exception of a PERS unit, overall self-directed consumers were more likely to have any assistive devices, home modifications, special medical equipment, or internet devices/access than agency-based consumers, although sometimes the difference was minimal. The difference was greatest for internet devices and internet access. At 1 month, 75% of self-directed consumers reported having internet capable devices, compared to 56% of agency-based consumers. Both agency-based and self-directed consumers reported a need for various types of these items. However, other than agency-based consumers' greater need for home modifications at 12 months, the differences were slight, with no noticeable trend.

Table 5.6. Special Equipment and Assistive Devices: Agency vs. Self-direct

		1 Month Agency %	1 Month Self-direct %	12 Month Agency %	12 Month Self-direct %
Home modifications		N=274	N=73	N=185	N=64
	I have it	73.36	78.08	81.08	81.25
	I do not need it	12.77	10.96	11.35	15.63
	I need it	13.87	10.96	7.57	3.13
Mobility equipment		N=274	N=73	N=185	N=64
	I have it	89.78	91.78	86.49	95.31
	I do not need it	8.39	2.74	10.81	4.69
	I need it	1.82	5.48	2.70	0.00
Medical equipment		N=274	N=73	N=185	N=64
	I have it	77.74	80.82	83.24	87.50
	I do not need it	15.33	10.96	12.97	7.81
	I need it	6.93	8.22	3.78	4.69
Lifeline or PERS		N=272	N=73	N=185	N=64
	I have it	49.63	42.47	47.57	45.31
	I do not need it	40.81	49.32	48.11	50.00
	I need it	9.56	8.22	4.32	4.69
Internet capable devices		N=271	N=72	N=185	N=64
	I have it	56.09	75.00	54.59	73.44
	I do not need it	39.48	22.22	41.08	23.44
	I need it	4.43	2.78	4.32	3.13
Internet access		N=271	N=72	N=181	N=64
	I have it	71.22	90.28	74.59	92.19
	I do not need it	21.77	4.17	23.76	3.13
	I need it	7.01	5.56	1.66	4.69

Section 6. The Reinstitutionalization Effect

This section explores the history and effect of readmission to a facility by following consumers from transition through their 1 or 12 month survey. The 2020 MFP HCBS CAHPS report clearly showed that overall people do better in the community – they are happier, less depressed, are more likely to like where they live, are less likely to experience a fall or hospitalization, have increased choice and control, and are more active in the community (Porter et al., 2021). Even short-term reinstitutionalization can negatively affect the consumer and their family emotionally and physically, causing stress and interrupting the adjustment to community living. Paid caregivers are also affected as they unexpectedly find themselves without work. Long-term reinstitutionalization in particular incurs higher program and personal costs.

A. Reinstitutionalization Pattern in the Year Post Transition

The cohort of the 610 consumers who transitioned in 2020 was analyzed to report history and patterns of reinstitutionalization up to one year post-transition. Data came from the MFP HCBS CAHPS surveys and the Connecticut Department of Social Services (DSS) MyCommunityChoices website.

Table 6.1 shows the participant setting at the each survey time point, as well as any reinstitutionalization in between those time points. The columns “1 Month Setting” and “12 Month Setting” indicate the participant’s location at that time point – either in the community or facility. The columns “Transition to 1 Month” and “1 Month to 12 Month” indicate any reinstitutionalization between the survey time points. If the participant was reinstitutionalized for any amount of time between transition and 1 month, or between 1 to 12 months, then “facility” is listed. “Community” indicates the participant was always in the community during that time and did not go back to a facility even temporarily.

Table 6.1. Participant Setting and Facility Use from Transition to 12 Months

	Transition N=610 n (%)	Transition to 1 Month N=594 n (%)	1 Month Setting N=594 n (%)	1 Month to 12 Month N=519 n (%)	12 Month Setting N=516 n (%)
Community	610 (100)	539 (90.7)	553 (93.1)	390 (75.1)	440 (85.3)
Facility	0 (0)	55 (9.3)	41 (6.9)	129 (24.9)	76 (14.7)

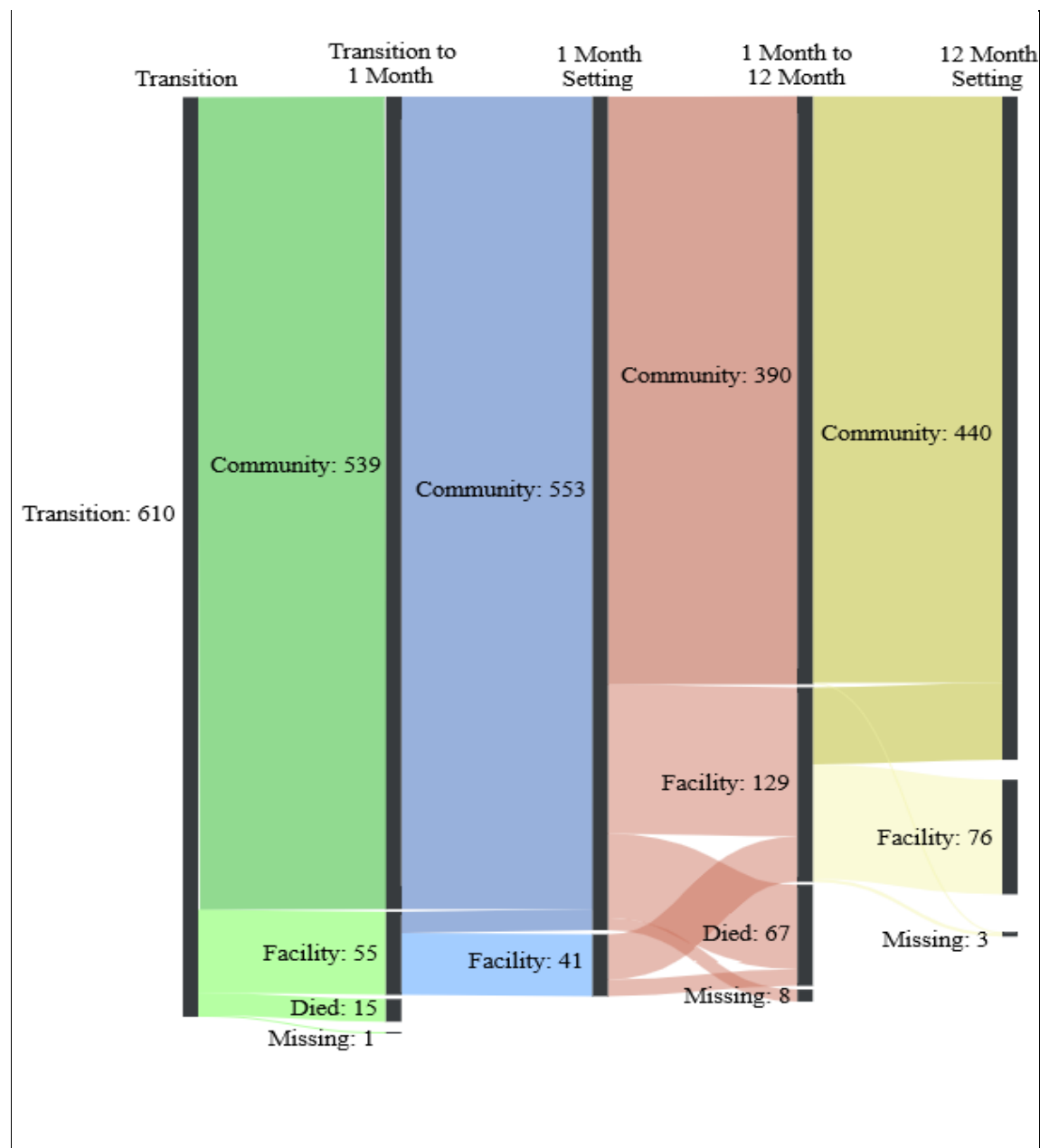
Sankey diagrams illustrate the flow and quantity of cases from one point to the next, or from one point through several different points of time. The proportion of cases determines the size of each flow relative to the total sample. In health policy research, Sankey diagrams often provide a visual aid in tracking a person’s health outcomes over a given period.

The Sankey diagram in Figure 6.1 provides a visual representation of the reinstitutionalization pattern for participants who transitioned in 2020 at five points in time: transition, transition to 1 month, 1 month setting, 1 month to 12 month, and 12 month setting. Four main categories summarize the participant outcomes at each time point: community, facility, died, or missing.

After excluding the cases of participants who were either missing or deceased, 9% of participants had returned to a facility for either a short-term or long-term stay within a month after their transition. At 1 month post-transition, slightly fewer consumers were still in a facility (7%). Not surprisingly, given the longer length of time between the 1 month and 12 month survey, considerably more consumers (25%) had been in a facility either temporarily or long-term. However, at 12 months post-transition, the percentage of participants who were still reinstitutionalized dropped to 15%.

Overall, the setting, reinstitutionalization, and death rates are very similar to those in the 2020 report, with a couple of exceptions. This year there was a small increase in consumers who experienced reinstitutionalization from 1 month to 12 months (23% 2020, 25% 2021). There was a similar increase in the percentage of consumers residing in a facility at 12 months (13% 2020, 15% 2021). Slightly more consumers died by 1 month post-transition (1% 2020, 3% 2021); the percentage of consumers who died between 1 to 12 months showed a minimal decrease (12% 2020, 11% 2021).

Figure 6.1. Diagram of Participant Setting and Facility Use from Transition to 12 Months

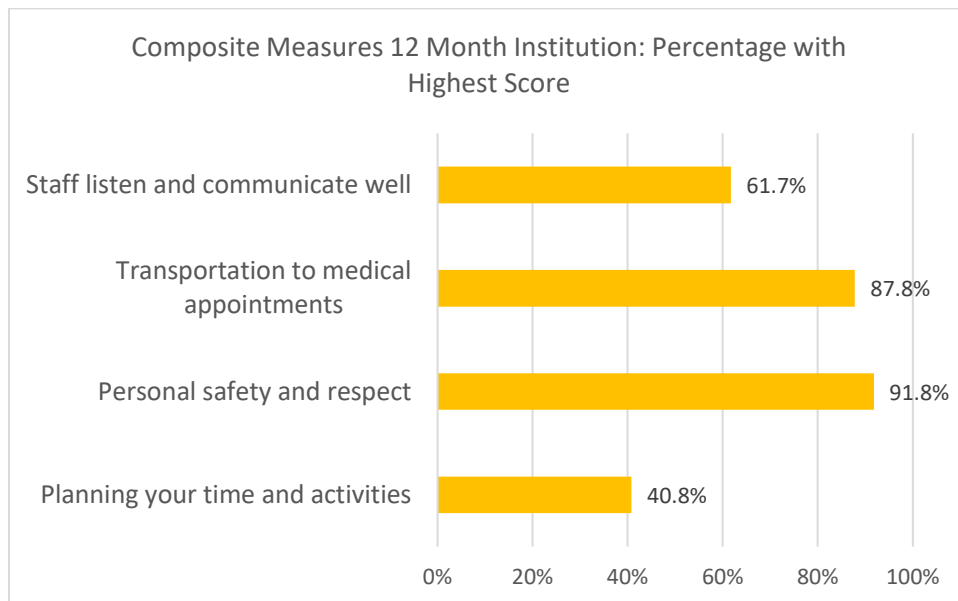


SankeyMATIC: A Sankey Diagram Builder for Everyone. <http://sankeymatic.com>

2020 12 Month Institution: Select Results

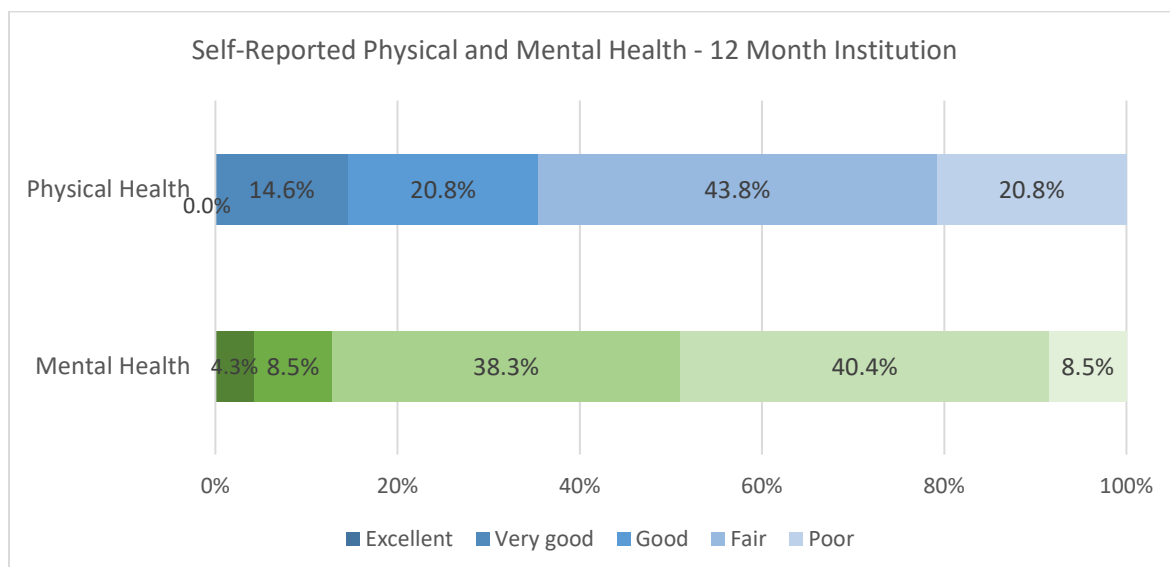
The following figures present 2021 survey data for the 48 consumers who transitioned in 2020 and were in a facility at 12 months. See Section 3 for comparative results for consumers in the community at 12 months. As shown in Figure 6.2, at 12 months, more institutionalized consumers gave the highest scores to both the personal safety and respect (92%) and medical transportation (88%) composites. The percentage of highest scores fell from 2020 for both staff listen and communicate well (2021 62%, 2020 73%) and planning your time and activities (2021 41%, 2020 50%).

Figure 6.2. Composite Measures 12 Month Institution – Percentage with Highest Score



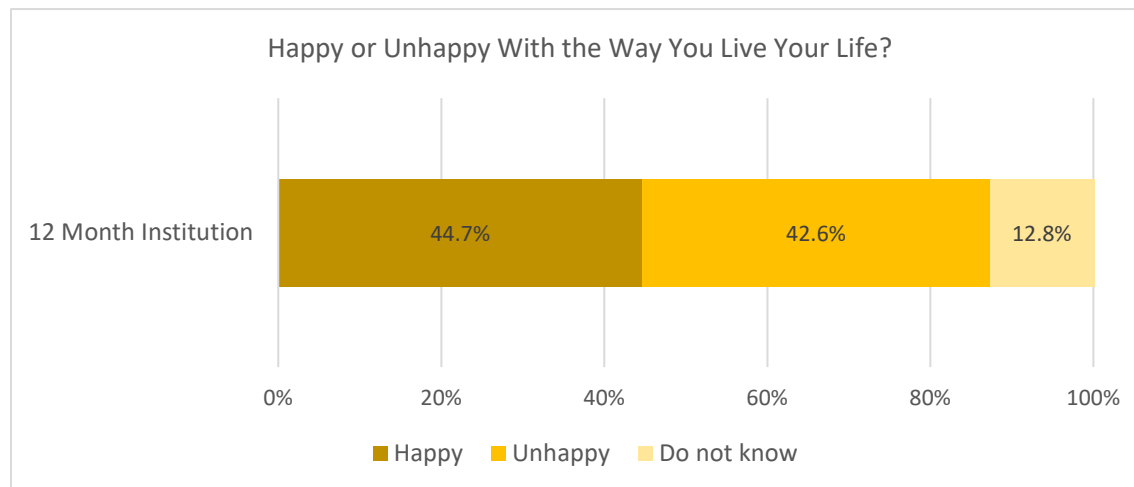
As expected, consumers in an institution at 12 months were much more likely to report fair or poor physical health than those in the community (65% institution, 34% community) (Figure 6.3). Institutionalized consumers were also more likely to report fair or poor mental health (49% institution, 33% community).

Figure 6.3. Self-Reported Physical and Mental Health - 12 Month Institution



Over half (54%) of consumers institutionalized at 12 months reported depressive symptoms, as did 33% of community consumers. In addition, less than half (45%) of reinstitutionalized consumers said they were happy with the way they live their life, compared to 79% of community residing consumers (Figure 6.4).

Figure 6.4. Happy or Unhappy With the Way You Live Your Life – 12 Month Institution



B. Experiences Leading to Reinstitutionalization by the One Month Survey – Consumers Who Transitioned in 2021

This section provides an overview of the experience of reinstitutionalization at one month post-transition for consumers who transitioned in 2021. First, select results contrast consumers who were never reinstitutionalized (always community) with those who were reinstitutionalized even temporarily before their 1 month survey (ever reinstitutionalized). Next, the pre and post-transition community experiences of consumers ever reinstitutionalized by 1 month are examined to look at the circumstances leading up to their readmission to a facility.

A total of 460 consumers transitioned in 2021. Of these, 304 consumers completed a 1 month survey before the end of the year. Almost all consumers (93.8%, n=285) who completed a 1 month survey were living in a community setting at the time of their interview. Three of these consumers had been reinstitutionalized temporarily after transition, resulting in an overall readmission rate of 7.2% (n=22) by the 1 month survey (Table 6.2).

Table 6.2. Transitioned in 2021 – Experienced Reinstitutionalization by 1 Month Survey

	n (%)
Total 1 month surveys	304 (100.0)
Experienced readmission by one month survey	
No – Always in the community	282 (92.8)
Yes – Reinstitutionalized either short or long-term	22 (7.2)

Consumer Characteristics

Consumers who experienced reinstitutionalization by 1 month were more likely to be getting state plan services (Table 6.3). Waiver clients generally receive more support in the community after transition

compared to those with state plan services only, which likely helps them avoid returning to an institution.

Table 6.3. Waiver or State Plan Status by Reinstitutionalization

Service Type	Always Community n (%)	Ever Reinstitutionalized n (%)
Waiver	223 (79.1)	17 (77.3)
State plan	59 (20.9)	5 (22.7)

This population was also more likely to be older, male, less educated, and White compared to those who were never reinstitutionalized.

Table 6.4. Demographics: Always Community vs. Ever Reinstitutionalized

		Always Community n (%)	Ever Reinstitutionalized n (%)
Age	< 55	16 (5.7)	0 (0)
	55-64	9 (3.2)	3 (13.6)
	65-74	210 (74.5)	14 (63.6)
	75+	47 (16.7)	5 (22.7)
Race	White	185 (66.5)	16 (72.7)
	Black	77 (27.7)	5 (22.7)
	Other	16 (5.8)	1 (4.5)
Gender	Male	144 (51.2)	15 (68.2)
	Female	137 (48.8)	7 (31.8)
Education	< High School	61 (22.2)	6 (27.3)
	High school degree	113 (41.1)	9 (40.9)
	> High school	101 (36.7)	7 (31.8)

Physical and Mental Health at One Month

No matter where they were residing at the time of their 1 month survey, consumers who had experienced reinstitutionalization reported being in much poorer physical and mental health (Figures 6.5 and 6.6). Compared to consumers who had never been back to a facility, consumers who had been reinstitutionalized either short or long-term by their 1 month survey reported significantly more depressive symptoms (Table 6.5) and were less happy with the way they live their life (Figure 6.7).

Figure 6.5. Self-Reported Physical Health

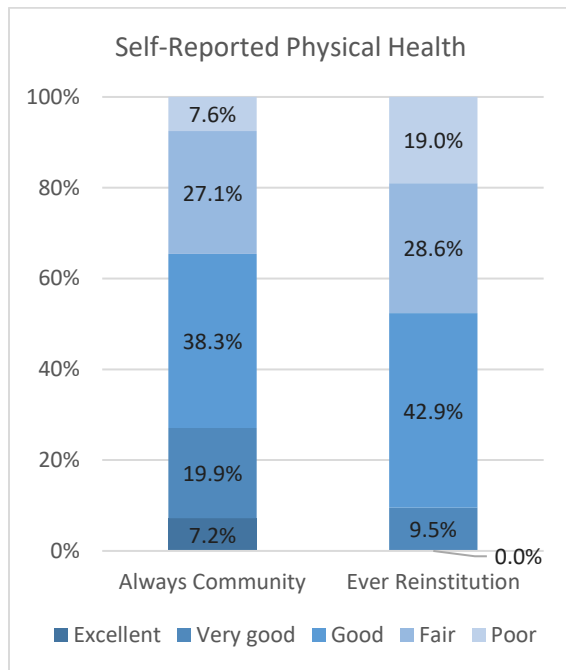


Figure 6.6. Self-Reported Mental Health

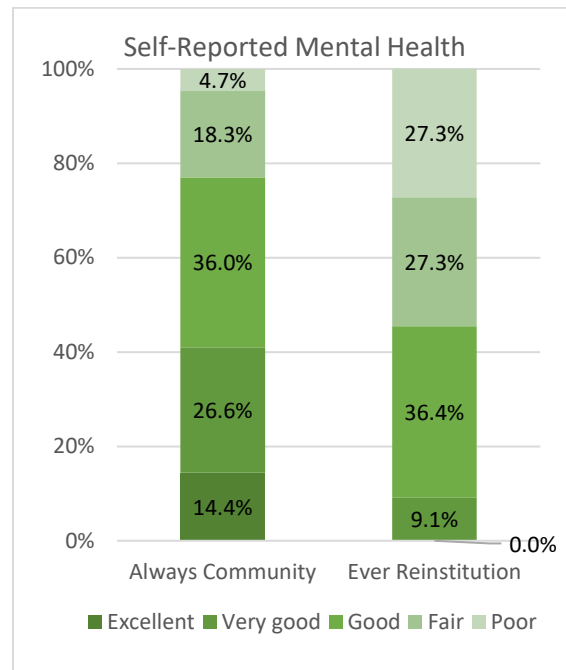
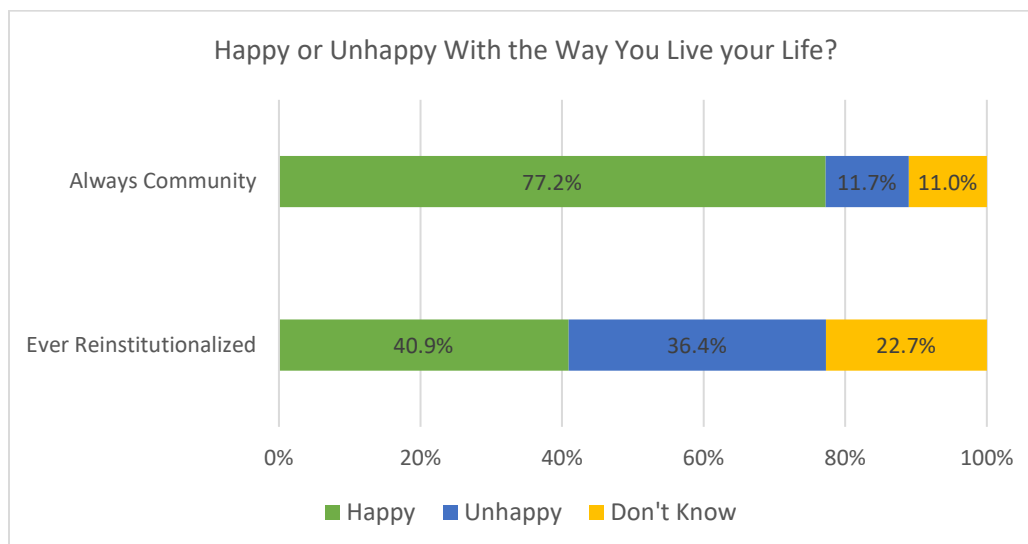


Table 6.5. Depressive Symptoms: Always Community vs. Ever Reinstitutionalized

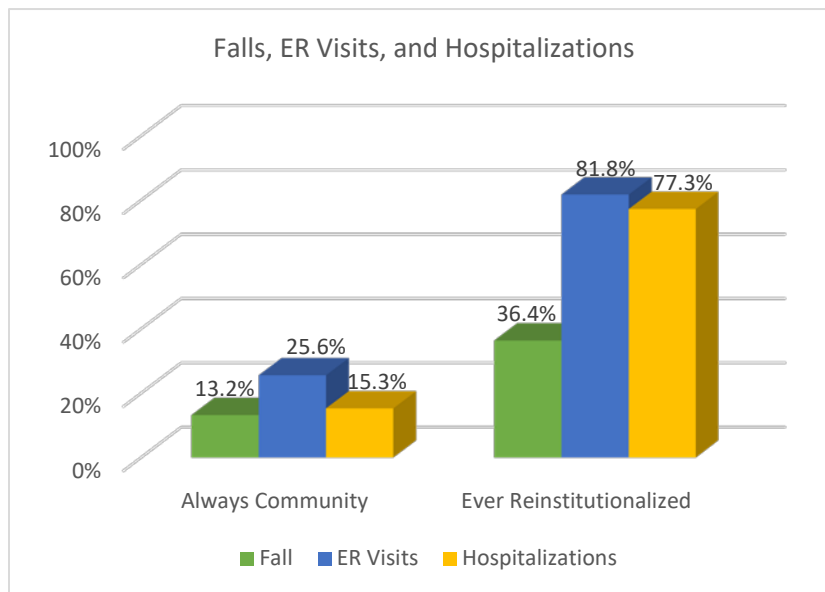
Depressive Symptoms	Always Community n (%)	Ever Reinstitutionalized n (%)
Yes	79 (28.8)	12 (60.0)
No	195 (71.2)	8 (40.0)

Figure 6.7. Happy or Unhappy With the Way You Live Your Life: Always Community vs. Ever Reinstitutionalized



Those who had been reinstitutionalized by the time of their 1 month survey reported falling at almost three times the rate of those who were always in a community. They also had very high rates of emergency room and hospital use, which likely led to their subsequent returns to a nursing facility (Figure 6.8).

Figure 6.8. Falls, ER Visits, and Hospitalizations



The Consumer Experience

Case histories for each of these 22 consumers who experienced reinstitutionalization within 30 to 45 days after transition were created using data from the HCBS CAHPS surveys and the DSS MyCommunityChoices website, including case notes, HCBS program, demographics, living situation, critical incidents, and MFP participation data. These data sources provided a fairly complete picture of a consumer's life pre and post-transition – describing a participant's experiences in the community and providing details regarding the circumstances leading up to their reinstitutionalization. Qualitative analysis was used to identify any issues associated with the reinstitutionalization for each consumer. Using the constant comparative method (Strauss & Corbin, 1990), these elements were assembled under distinct themes until no new themes emerged.

Eleven main themes emerged from this analysis. These themes did not occur in isolation of each other – all consumers had multiple factors which led to their reinstitutionalization. Composite vignettes provide more insight into the consumer's and family member's experiences, as well as the often-overlapping issues contributing to reinstitutionalization.

Consumer physical health decline post-transition

As in 2020, physical health decline post transition was a leading cause of reinstitutionalization within four to six weeks post-transition. Some consumers experienced acute medical incidents, while for others, health conditions which were stable in the facility became worse once in the community. For example, some consumers who could walk independently with or without an assistive device at the facility began to need more and more assistance to do so in the community. Likewise, consumers who could transfer with a lift and just one person in the facility, needed assistance at home from 2 people, sometimes within just one week of transition. Many of these consumers whose physical health declined

already had existing serious conditions such as congestive heart failure or diabetes which require regular monitoring. Other factors in health decline included lack of professional medical care, relying on family members to provide complex care, falls with injury, consumer mental health challenges, and cognitive impairment. Missing paid PCA services also sometimes played a role. In other cases, it was not known why a consumer's physical health declined so rapidly after transition. Unlike in 2020, COVID-19 was not a factor in the rapid return to a facility for any of these consumers.

Insufficient approved home and community-based services

In other cases, the HCBS approved in the care plan did not provide enough support for the consumer once in the community. For example, the consumer might be ineligible for services because they did not meet level of care, as is often the case for consumers who transition with state plan services. For others, the needed services were not provided by the waiver or could not fit within their allowed budget. Then once home, the consumer ended up needing more supports than in their approved care plan. Some examples of this which lead to reinstitutionalization included no overnight care and/or no live-in PCA or not enough PCA hours, such as the consumers who were not able to transfer independently even to use the toilet but had PCA hours for just 4 transfers a day (morning and evening). The lack of enough services was especially difficult for consumers without readily available family members or friends to fill in the gaps. For example, one consumer needed daytime assistance and overnight supervision due in part to her cognitive impairment. The CHCPE waiver does not provide this level of assistance, and family members could not provide the needed overnight supervision. The consumer ended up falling when she tried to get up in the middle of the night and was readmitted to the nursing home.

Lack of PCA or other nonmedical homecare services

Another reoccurring theme was difficulty staffing the approved hours for PCA, homemaker, recovery assistants, personal care, or non-medical homecare services. For example, sometimes PCAs did not show up, did not come on time, or did not do their assigned tasks once there. Other times agencies agreed to staff the case, but later said they did not serve that area or did not have enough PCAs to staff the case. Miscommunication compounded the issue in some cases; for example, the agency or PCA did not understand the extent of assistance needed or the date of transition was changed at the last minute. Personality differences or poor quality care also contributed to staff turnover. In some cases, consumers found themselves without assistance until their next scheduled PCA arrived or for a more extended time if the agency did not have enough staff. Unfortunately, this lack of paid assistance could not always be attenuated by family or friends' attempts to provide the missing care. This was the case with one consumer who transitioned with the PCA waiver and agency-based services. She used a wheelchair with a slide board for transfers. Once home, the client did not have consistent care – no PCAs came for any morning shifts, and the evening PCAs did not always come. Ten days post transition she fell while her family was helping her up and broke her ankle. She went back to the facility for short-term rehabilitation, which then became long-term care. Not having her hospital bed at transition to facilitate her transfers may have played a role in this incident as well.

This lack of available PCAs and other homecare workers affected self-directed consumers as well, making it even more difficult to find and hire reliable PCAs or emergency back-up PCAs. Although COVID-19 was not often mentioned in comments, the pandemic exacerbated an existing homecare workforce shortage (Reinhard et al., 2021). Increasing numbers of people are choosing to receive services in the community, while fewer caregivers are available. This can prove to be too much for consumers, informal supports, and paid caregivers alike, making living in the community too difficult or stressful.

Consumer mental or behavioral health issues

A worsening or exacerbation of mental or behavioral health issues lead to the reinstitutionalization of other consumers. Some consumers whose behavioral issues were not debilitating in the facility suddenly found they could not manage their lives in the community. In addition to poor adjustment to community living, other behavioral health issues which contributed to reinstitutionalization included extreme anxiety, non-compliance with medical or self-care, and not accepting the supports and services needed for stability in the community. Refusing to take medications or accept medical care was a factor in several of these situations. This issue also led to other challenges to community living, such as a decline in an otherwise stable physical condition or inability of family or friends to continue to provide informal assistance.

Lack of family or informal support

Family or other informal supports can play a critical role in the consumer's community supports, providing various assistance such as personal or medical care, medication management, supervision, or household tasks. For example, consumers sometimes transition with ongoing health conditions which require more medical care than can be provided by paid supports, and the family members agree to provide this care so their loved one can come home. Unfortunately, sometimes the family member subsequently finds that they cannot keep up this level of support or becomes overwhelmed. Informal support is especially important for consumers who live alone with no or limited paid supports. Friends or family just checking in can identify unanticipated issues and help resolve them before they become too difficult for the consumer to manage. In addition, family are often the identified back-up help in the care plan. Providing this back up assistance very infrequently can work, but if situations repeatedly arise, family may find they cannot continually fill this role.

Although family or friends sometimes tried to provide the unmet assistance, doing so long-term turned out to be too hard for some people. One consumer's sister, who at first tried to assist her brother who had a recent stroke and was unable to stand or walk, stated his care had become too much for her to physically handle. At transition, the facility physical therapist said the consumer was a 1 person assist for transfers, although he still required maximal assistance for most other activities of daily living. Once home, his health declined somewhat, and one PCA could not transfer him on their own. The sister was already providing back-up assistance for her mother, a CHCPE waiver client with a live-in PCA. She felt overwhelmed and could no longer provide the additional assistance her brother needed. With no one else who could provide this extra care, the consumer could not stay in the community and was readmitted to a nursing home.

Falls with injury

Falls with injury also led to readmissions soon after transition. Most often falling did not happen in isolation of other issues, but resulted from a combination of factors such as functional decline, not enough assistance, or missing durable medical or other equipment. Consumers who needed assistance with transferring were especially at risk of experiencing a fall which led to a readmission. For example, one consumer with hemiplegia from a stroke needed hands-on assistance with bathing, dressing, transferring and toileting. He fell during his first night in the community trying to transfer from the sofa to his wheelchair. He lived alone and the PCA was not there at the time. After being hospitalized following the fall, he decided to go back to the nursing home rather than live alone in the community with hourly PCA assistance. He had no family or friends who could be his back-up, so a live-in PCA was not an option.

Medically complex, multiple-morbidities

Having multiple health diagnoses, especially those which require daily care, also played a role in some facility readmissions. According to a review by Ploeg et al. (2020, page 2), multiple chronic conditions, defined as two or more chronic conditions, “is associated with poorer quality of life, higher rates of healthcare use and costs compared to individuals with no or fewer conditions. These individuals are at high risk for adverse events such as hospitalization and mortality.” For some consumers, their chronic conditions include mental or behavioral health, or substance use disorders. These consumers often need a combination of medical or behavioral supports, PCA, and informal care. Living in the community requires that everything go according to plan – an issue with one support or condition can cause others to fail, leading to reinstitutionalization. With comorbidity, the worsening of one medical condition can have a negative effect on another.

For example, one PCA waiver client’s medical conditions included sliding scale insulin dependent diabetes, neuropathy, limited use of some fingers, anxiety, herniated discs, pain, a history of alcohol abuse, and diabetes related wounds. He needed hands on assistance with most activities of daily living and was in constant pain due to an accident many years ago. Prior to transition, his pain was controlled with oxycodone, which was carefully dispensed at the nursing home. However, within the first month of being in the community, he misused his pain medications and ran out of them before more could be prescribed. The consumer started to use alcohol excessively to alleviate his pain. His diabetes related wounds subsequently got much worse due to lack of self-care. After several hospitalizations for wound care, he subsequently returned to the nursing home for short-term rehabilitation.

Unstable transitions

MFP supports person-centered decision-making and having choice about one’s services, living situation, and other matters. The program is committed to providing everyone who prefers community living a chance to move out of a facility and live in the community, and provides an array of supports to help make this transition work. Consumers who have transitioned report a better quality of life across numerous metrics (Robison et al. 2015). Nonetheless, one theme identified this year was that of consumers leaving the nursing home under what might be considered unstable or unsafe circumstances. Different factors played a role in these situations. For example, one consumer was approved for and offered waiver services, but decided to go out on his own with no services. Other consumers decided to leave without approved durable medical equipment or completed home modifications. Living alone, without any informal supports or emergency back-up, was a factor in other sudden reinstitutionalizations. For others, their unstable or active mental health issues proved to be too challenging once in the community.

One example is a consumer who, in addition to physical impairments, had a diagnosed mental illness and a history of substance use. He lived alone and had limited informal supports. Challenges noted by the SCM upon assessment included fall risk, nonpayment of bills, forgetting to take medications, under or overdose on medications, and isolation. Although the consumer was eager to return home, the process took a very long time due in part to his fluctuating mental health status and other behaviors exhibited during the transition process. For instance, he was not always cooperative with things like signing papers necessary for transition, although other times he would readily work with his transition team. It was also noted that at times while in the nursing home, he refused to take his medications or even eat. His conservator had concerns about his leaving the facility, due in part to the consumer’s previous unsuccessful experiences living in the community. The consumer transitioned with agency-based services and mental health supports. Unfortunately, these were not enough. Once in the community, he quickly deteriorated, and did not take his medications, care for himself, or eat/drink

enough. He was sent to the emergency department by the visiting nurse who stated the consumer could not care for himself in the community, and was subsequently readmitted to a nursing home.

Lack of physical health medical care

Lack of post-transition medical care, such as nursing, wound care, doctor visits, or medications played a role in some readmissions. In two cases, the consumer was discharged without medications due to the facility negligence. Circumstances contributing to poor wound care included inadequate self-care, lack of nursing care, and lack of family to provide this medical care. One consumer missed his doctor appointments – sometimes he apparently refused to go while one time Veyo did not show up to transport him. This in turn caused him to not get the skilled homecare services he needed, as these had to be prescribed by his doctor.

Lack of necessary special equipment, home modifications, or assistive devices

Lack of special medical equipment, such as a hospital bed or assistive devices, was another reoccurring issue leading to facility readmission. Often this occurred within the context of other circumstances, such as the unanticipated need for equipment due to consumer physical functional decline post transition or insufficient support once in the community.

In one case, a consumer who used a wheelchair and could not transfer without assistance transitioned without a Hoyer lift. In addition, he did not have a hospital bed to facilitate transfers in and out of his wheelchair. Once home, it was determined that his wheelchair could not fit into the bathroom. Without the ability to transfer, the consumer was bedbound for almost 2 weeks post-transition. Additional complicating factors included miscommunication with the nursing home regarding his transfer status, difficulties acquiring the medical equipment once in the community due to provider and insurance issues, insufficient approved PCA hours, and informal support who could not provide such physically challenging hands on care.

Consumer cognitive impairment

Cognitive impairment due to dementia with formal diagnosis or altered mental status also led to some reinstitutionalizations. Poor consumer judgment and related behaviors can mean the consumer cannot be safely left alone or needs someone to be ready to assist throughout the night. Once home, this can mean the need for a higher level of care than originally planned for, or for 24-hour supervision, which often is not possible to provide in the community. Spouses or family members still have to sleep, go to their own doctor's appointments, run errands, or work at their paid jobs, and it is not always possible to cover this time with either paid or other informal supports. One example illustrates the various challenges to living in the community associated with some dementia conditions. For one woman, these included issues with staffing, multiple non-medical emergency room visits, and loss of ongoing back up support. Once home, the consumer displayed combative behavior to her live-in PCA, refusing medications and assistance. Different PCAs were tried, but soon no PCA or agency would take the consumer as a client. The consumer required personal assistance and could not be safely left alone. This proved to be too difficult for her son and daughter, who found they could not provide such frequent back-up assistance. Ultimately, this situation led to the consumer going back to the facility for long-term care.

Overall, consumers who had experienced reinstitutionalization by the time of their 1 month survey reported worse physical and mental health. For example, at 1 month, almost half (48%) rated their health as fair or poor, compared to 35% of consumers who remained in the community since transition. Thirty-six percent had fallen at least once, almost triple the rate of consumers who had not been back to an institution since transition. Qualitative themes most commonly associated with either a short or long-term reinstitutionalization for these consumers included physical health decline post-transition,

insufficient approved HCBS in the care plan, lack of PCA and other nonmedical HCBS, consumer mental or behavioral health issues, and lack of or limited family or informal support.

III. Conclusions and Recommendations

Surveys completed in 2021

A total of 754 HCBS CAHPS surveys were completed with MFP participants in 2021: 364 1 month and 390 12 month surveys. Although the ongoing COVID-19 pandemic still limited the number of in-person surveys completed, the number of in-person surveys increased from 2% in 2020 to 9% in 2021. As in 2020, completing fewer surveys in-person increased the number of surveys completed by proxy.

1 Month Community Surveys Completed in 2021

This section examined data from the 341 1 month surveys completed in 2021 with community residing consumers. The percentage of consumers who gave high scores to the composite planning your time and activities, which includes community involvement, was even lower than the previous year, falling from 58% in 2020 to 53% in 2021. The composite choosing the services which matter to you also decreased in 2021 – falling from 71% in 2020 to 65% in 2021. Although 77% of consumers gave the medical transportation composite the highest score, there were still multiple comments about poor transportation service to both medical and nonmedical appointments. In addition, more consumers reported fair or poor physical health this year (37% 2021, 32% 2020). Another notable finding was the unmet need for assistive devices, equipment and home modifications. At 1 month post-transition, one-quarter (24%) of consumers said they still needed at least one or more of these. The first month post transition can be especially difficult as consumers and their family members learn to navigate the HCBS system. Not having the necessary home modifications or equipment can limit one's independence and ability to fully live in the community, and ensuring these are in place before or soon after transition should continue to be a program goal. Unlike 2020, consumers did not comment much on the ongoing pandemic and its effect on their lives or HCB services. This might be indicative of people adjusting to a "new normal," where COVID-19 and its effects on our lives is expected or seen as a normal part of living.

1 and 12 Month Community Surveys Completed with Consumers Who Transitioned in 2020

A total of 610 consumers transitioned in 2020. Altogether, they completed 894 HCBS CAHPS surveys: 499 1 month and 395 12 month surveys. This section reported on the 1 or 12 month surveys completed with consumers residing in the community at the time of their survey (n=822), looking in particular for notable differences by survey time point. Consumers at the 1 month survey reflected on their experiences since transition; at the 12 month survey, consumers considered their experiences in the last 3 months.

When asked about service use, self-reported use of PCA or homemaking services did not show significant changes from 1 to 12 months, while use of case management services decreased over time. This is not unexpected, as by 12 months, any MFP "case management" is reduced to monthly TC calls, and case management for waiver consumers may not have begun.

Similar to 2020, community residing participants gave three composites comparatively low scores at both 1 and 12 months: choosing your services, medical transportation, and most notably, planning your time and activities. The percentage who gave planning your time and activities the highest score was just 54% at 1 month, falling to 48% at 12 months. These percentages are much lower than in 2020, when 64% at 1 month and 59% at 12 months gave the highest score for planning your time and activities.

Choosing the services which matter to you also fell from 2020 to 2021: in 2020 73% gave this composite the highest score, compared to 69% in 2021. These three composites represent participant choice, control, health self-efficacy, and community involvement. These qualities help one to live a fulfilling life and represent areas that the program could continue to work to improve. Although in 2021 only a few comments referenced COVID-19, it is still likely that the ongoing pandemic negatively affected participation in the community. Other comments indicated more support, such as community transportation, is needed to increase their community involvement. In addition, some consumers expressed struggles with loneliness and lack of social connection, especially those living alone. Connecting to one's community does not automatically happen upon transition, and this is one area where MFP might consider providing more support. For example, linking the consumer with community or volunteer groups upon transition might promote social and emotional connection with others. Perhaps the MFP program could partner with local community resources to increase social engagement for program participants post-transition.

While 71 to 72% of community participants rated their current PCAs/RAs/ILSTs a nine or ten, consumers at both 1 and 12 months post-transition commented on the difficulties they had finding reliable and well-trained staff. Staff turnover and lack of consistency was most often mentioned in 2021. The different PCAs often did not know what assistance the consumer needed or how to best provide that support, which sometimes meant consumers and family members had to continually train new staff. Consumers also remarked on communication difficulties with the home care agencies. While historically Connecticut has faced challenges recruiting and retaining people to work as PCAs or in other home care positions, the pandemic exacerbated this workforce shortage. There is a critical need in Connecticut for high quality, consistent HCBS staff. Without an influx of workers, consumers who rely on paid staff for their independence will likely find it increasingly difficult to stay in the community.

Family or friends often play a large role in keeping their loved ones in the community, providing hands on care, social and financial support, or other assistance such as transportation. With the HCBS workforce shortage, these informal caregivers often found themselves helping out more often than expected, causing some to be too overwhelmed to maintain this level of assistance. Informal caregivers are an essential part of the HCBS system, and increased support for them to continue in this role is needed.

Unlike in 2020, the percentage of consumers able to see their nearby friends increased over time – by 12 months 93% of consumers reported they can see their nearby friends as often as they would like to, compared to 81% at 1 month. In addition, the percentage of self-directing consumer who hired family members stayed relatively stable over time. These trends are directly opposite of what was seen in 2020, when the ability to see people not living with you decreased significantly, while employing family members noticeably increased over time. These changes indicate that in 2021 people are more comfortable seeing and hiring people they do not live with or who are not related to them.

Although self-reported physical health remained fairly stable over the year, consumers reported worsening mental health over the year post-transition. At 1 month, 28% of community consumers rated their mental or emotional health as fair or poor, which increased to 33% at 12 months. Similarly, the percentage of consumers reporting depressive symptoms increased over time, from 29% at 1 month to 33% at 12 months. While 77 to 79% of consumers said they were happy with the way they live their life, approximately one-fifth at either time point said they were either unhappy or could not say if they were happy or not. Comments also indicated that becoming part of one's new community does not happen automatically upon transition. Socialization and connection to others are essential to one's mental and emotional health, and connecting consumers with community resources should continue to be a priority of the MFP program.

Assistive devices, special equipment, and home modifications are common among MFP consumers – 93% at either time point reported having at least one of these. Still, at 1 month post-transition, 32% of consumers lacked some type of device or modification they needed to help them live in the community, as did 16% at 12 months. At either time points, some type of home modification or a PERS were most commonly indicated as missing. Many participants do not have the financial resources to purchase these items on their own, and comments indicated that sometimes friends or family paid for items that were essential instead of waiting for doctor’s prescription, Medicaid approval, or for home modifications to be complete. Obtaining needed home modifications and special medical equipment by transition or within a week of being home should continue to be a priority. Better communication and more careful tracking of what participants still need may help meet this goal.

Similar to 2020, when asked about finances, about one quarter of participants said they did not have enough money to make ends meet (26% 1 month, 22% 12 months). Comments indicated that food insecurity in particular was of great concern in 2021.

Experiences of Waiver and Non-waiver Consumers from 1 Month to 12 Months Post-transition

This same cohort of community living consumers who transitioned in 2020 were separated into those who met the requirements for a waiver at transition (waiver consumers) and those who were not eligible for a waiver (state plan consumers). Not unlike last year, waiver consumers comprised 71 to 75% of either the 1 month or the 12 month sample, while 25 to 29% of consumers received state plan services only.

Waiver consumers must meet facility level of care and are eligible for waiver HCBS at transition, while state plan consumers are not eligible for ongoing HCBS personal care or homemaking services. HCBS service use shows this contrast, as 82 to 83% of waiver consumers used personal care assistance at either time point, compared to 14 to 18% of state plan consumers. By 12 months post-transition, approximately two-thirds (66%) of state plan consumers reported using no services, compared to just 3% of waiver consumers.

The difference in use and experience of case management services between the two groups is striking. When the 1 month surveys are completed, all consumers have access to the same MFP case management services, as everyone has a TC and many still have an SCM 1 month post-transition. Consumers often identify their TC or SCM as their case manager at 1 month post-transition. However, even at just 1 month post-transition, state plan consumers are much less likely to report having case management services – 76% of waiver consumers said they had case management services at 1 month post-transition, compared to just 50% of state plan consumers. It may be that state plan consumers just do not see their TCs as case managers, given they get fewer services overall. Helping consumers better understand the different roles and responsibilities of their MFP team may clarify for all consumers whom the consumer should turn to after transition.

Even state plan consumers who said they had case management services gave lower scores than waiver consumers for the composite care manager is helpful, especially by 12 months post-transition. However, case manager ratings and recommendations did not follow this trend. For example, at 1 month post-transition, substantially more state plan consumers rated their case managers a 9 or 10 (62% waiver, 73% state plan). State plan consumers also gave their case managers higher recommendations at both 1 and 12 months post-transition.

Although state plan consumers were a younger cohort, they reported less social support overall. Consumers with state plan services were much more likely to live alone, were less likely to have family living nearby, and were much less likely to get unpaid help from family or friends. State plan consumers

were also less satisfied with their living arrangements and less likely to feel safe where they live. In addition, state plan consumers reported worse mental or emotional health, were less happy overall, and were more likely to have depressive symptoms. While mental health supports are a priority for all consumers, consumers without waiver services seem to have a greater need for mental health resources and services in the community.

Despite not having as high activities of daily living needs as waiver consumers, a greater percentage of state plan consumers reported fair or poor physical health at both 1 and 12 months. In addition, at 1 year post-transition, state plan consumers reported greater unmet need for a PERS or special medical equipment. Fewer state plan consumer had internet access 1 year after transition.

Community Experiences by Service Type: Agency-based vs. Self-directed Services over Time

Community living consumers who transitioned in 2020 were separated into those using agency-based versus self-directed services. Approximately three-quarters of consumers (75-79%) self-identified as using agency-based services, while the remaining 21 to 25% said they hired their own staff. Use of agency-based services showed a marked increase from 2020, when 68 to 69% of consumers used agency-based services. Similar to the previous year, self-directed consumers used noticeably more personal care services, as well as more homemaking and case management services.

Self-directed consumers rated their personal care staff higher than agency-based consumers on almost all staff metrics at both time points. A greater percentage of self-directed consumers rated their PCAs a 9 or 10 and reported the highest scores for the two staff composites covering staff reliability, helpfulness, and communication. It is likely that being the employer, with increased opportunity to choose, train, and manage one's PCAs, allows for a better match and greater consumer satisfaction. Agency-based consumers gave their care managers higher global rating and recommendation scores at 1 month after transition, although other differences were small.

Consumers using self-direction must be able to manage their own services, or have a family member or friend do it for them. A greater sense of autonomy and ability to choose their staff might also be a factor in why self-directed consumers reported greater choice over their services at both 1 and 12 months. This cannot be said for the composite planning your time and activities, when self-directed consumers gave noticeably lower scores for this composite at one year after transition.

There were notable differences in living situation as well. Self-directed consumers were more likely to live with family members at 12 months and were more likely to have friends living nearby. Meanwhile, a greater percentage of agency-based consumers lived alone or with non-family. Differences in mental or emotional health between the two groups were also evident, especially 12 months after transition. One year after transition, agency-based consumers were more likely to report fair or poor mental health (33% agency-based, 24% self-directed). At both time points, agency-based consumers were also less likely to say they were happy compared to self-directed consumers. Although self-reported physical health showed no identifiable trends, at 12 months, agency-based consumers reported more falls, hospitalizations, and ER visits. Agency-based consumers were also more likely to need home modifications at 1 and 12 months post-transition, while self-directed consumers were more likely to still need mobility equipment 1 month after transition.

The Reinstitutionalization Effect

Consumers who transitioned in 2020

This section examined the history and effect of readmission to a facility by following consumers from transition through their 1 or 12 month survey. First, consumers who transitioned in 2020 were followed

from transition through 1 year post-transition to determine reinstitutionalization at four time points after transition. Within 1 month after transition, 9% of participants had returned to a facility for either a short-term or long-term stay. At the time of their 1 month survey, fewer consumers were still in a facility (7%). Unsurprisingly given the longer length of time, nearly one quarter (25%) of consumers had been in a facility between the 1 month and 12 month survey. However, at 12 months post-transition, 15% of participants remained reinstitutionalized.

Select results showed that consumers reinstitutionalized at 12 months rated staff communication and planning your time and activities lower than consumers in the community at 12 months. However, consumers residing in an institution at 12 months were more likely to report having medical transportation compared to those in the community. Consumers reinstitutionalized at 12 months reported worse physical and mental health than community consumers.

Consumers who transitioned in 2021

Next, reinstitutionalization for consumers who transitioned in 2021 and who had completed a 1 month survey (n=304) were considered. Seven percent (n=22) of these consumers were either in a facility at the time of their 1 month survey or were in the community at 1 month but had been in and out of a facility since transition. Compared to consumers who were never readmitted to a facility by 1 month, consumers reinstitutionalized even temporarily reported worse physical and mental health. They also reported a high rate of falls and emergency room and hospital use.

Consumers who had transitioned in 2021 and had experienced reinstitutionalization by their 1 month survey were looked at in more detail. Qualitative analysis identified common circumstances or issues associated with facility readmission. Eleven main themes emerged from this analysis. These themes did not occur in isolation of each other – all consumers had multiple factors which lead to their reinstitutionalization. Qualitative themes most commonly associated with either a short or long-term reinstitutionalization for these consumers included physical health decline post-transition, insufficient approved HCBS in the care plan, lack of PCA or nonmedical HCBS, mental or behavioral health issues, lack of or limited family or informal support, falls with injury, multiple serious comorbidities, unstable transitions, lack of post-transition medical care, lack of special equipment or devices, and consumer cognitive impairment.

Final Thoughts

Despite facing challenges post-transition, the majority of consumers were happy to be out of a facility. Multiple participants expressed their gratitude and appreciation for the program and the support they received which allowed them to leave the institution and return to the community:

As far as the Money Follows the Person, they have helped me so much and have made a beautiful difference in my life.

I'm so happy that I have this [apartment], and I'm so grateful that there's places, like the agency I worked with, that are helping people in this way.

So far so good! I'm grateful there is a program like this out there. When COVID hit, I couldn't see or talk to my mom at all because of her condition. Before that I visited her every day to make sure her care was sufficient. I'm so glad she can be with me all the time now.

We are really appreciative of the program, which has allowed our son to make progress at home which he did not in the inpatient setting.

I'm just very thankful to the Money Follows the Person program for getting me back to being a normal person instead of a patient. I left the nursing home and it was a world of a difference... I am now more alert, and I've received therapy to get me walking. The people who helped me from the MFP program were honest, nice, and very good. I received furniture, groceries, and everything I needed. This program has really helped me a lot. I was tired of being in rehab and wanted to be home. I love the PCAs I have. I'm so glad to be home.

I'm grateful for this opportunity. This has helped me get back on my feet, in my own home, and get my independence back.

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V. Appendices

Appendix A. HCBS CAHPS® Survey – Connecticut Money Follows the Person Community Survey (2019)

Appendix B. Description of the Connecticut Money Follows the Person HCBS CAHPS® Institutional Survey (2019)

Appendix C. MFP HCBS CAHPS® Composite Measures Items

Appendix D. Acronyms

Appendix A. HCBS CAHPS® Survey – Connecticut Money Follows the Person Community Survey (2019)

HCBS CAHPS® survey

MFP Community survey

English

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:
 - i. Agency name(s)
 - ii. Titles of staff who provide care
 - iii. Names of staff who provide care
 - iv. Activities that each staff member provides (this will help with identifying appropriate skip logic)
 - v. Hours of staff who come to the home

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 → GO TO [Interviewer - Screening Failed]

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

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

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

2. How do they help you?

[EXAMPLES OF CORRECT RESPONSES INCLUDE]

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

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

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

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

3. What do you call them?

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

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

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

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

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

[Interviewer - Screening Failed]

¹ ☐ Continue anyhow

² ☐ End Survey

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 OR NOT APPLICABLE → 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 {*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

ITEM AND RESPONSE—FOLLOW ALL ROWS THAT APPLY	ACTION
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 HOMEMAKERS

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

DMHAS ONLY: The next several questions are about the [CSPs, case managers], the staff who are paid to help you manage things and stay organized — such as complete paperwork, make a budget, and find resources in the community.

37. In the last 3 months, how often did {*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 *homemakers* 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 *homemakers* 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 {homemakers} 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 {homemakers} 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

[Interviewer: Do not ask questions 39 or 40 for DMHAS waiver interviews.]

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

- ¹ ☐ YES → GO TO Q41
- ² ☐ NO
- ⁻¹ ☐ DON'T KNOW → GO TO Q41
- ⁻² ☐ REFUSED → GO TO Q41
- ⁻³ ☐ UNCLEAR RESPONSE OR ON DMHAS WAIVER → GO TO Q41

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

- ¹ ☐ YES
- ² ☐ NO
- ⁻¹ ☐ DON'T KNOW
- ⁻² ☐ REFUSED
- ⁻³ ☐ UNCLEAR RESPONSE OR ON DMHAS WAIVER

HOW WELL HOME MAKERS COMMUNICATE WITH AND TREAT YOU

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

- ¹ ☐ Excellent,
- ² ☐ Very good,
- ³ ☐ Good,

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

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

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

YOUR CASE MANAGER

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

48. Do you know who your {case manager} at {AGENCY NAME} is?

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

49. In the last 3 months, could you contact this {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 HOME-DELIVERED MEAL 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 57a
- 2 ☐ REFUSED → GO TO Q57a
- 3 ☐ UNCLEAR RESPONSE → GO TO Q57a
- 4 ☐ NOT APPLICABLE → 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
- 4 ☐ NOT APPLICABLE

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

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

How do you hire and pay your aides or caregivers?

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

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

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

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

58. In the last 3 months, who would you have talked to if you wanted to change your [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
- ⁻⁴ ☐ NOT APPLICABLE

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 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
- 4 ☐ NOT APPLICABLE → 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
- ⁻⁴ ☐ NOT APPLICABLE → 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
- ⁻⁴ ☐ NOT APPLICABLE → 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

EMPLOYMENT MODULE

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

¹ ☐ YES → GO TO EM9

² ☐ NO

⁻¹ ☐ DON'T KNOW → GO TO THE 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

MFP QOL MODULE

QOL_1. INTERVIEWER FILL IN: Where is this person currently residing?

In the community:

- ☐ Home or condominium
☐ Apartment, Not assisted living
☐ Group home of 4 or less individuals
☐ Residential care home
☐ Assisted living
☐ Other community residence (describe): _____

Community to community moves

QOL_2. Since [date], did you move to a different apartment, residence, or community living arrangement?

- ☐ Yes → Go to Question 2a
☐ No → Go to Question 3
☐ Don't know → Go to Question 3
☐ Refused → Go to Question 3

QOL_2a. If Yes: What were the reasons that you moved? (Open-ended)

Satisfaction with where you live

QOL_3. Do you like where you live?

- ☐ Yes
- ☐ No
- ☐ Sometimes
- ☐ Don't know
- ☐ Refused

QOL_4. Do you feel safe living here?

- ☐ Yes
- ☐ No
- ☐ Sometimes
- ☐ Don't know
- ☐ Refused

Falls

QOL_5. A fall is a sudden, accidental change in position causing one to land on a lower level. This does not include near falls, incidents due to an overwhelming external force (such as being hit by a car), or loss of consciousness. Did you fall since [date]?

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

Either to be used as an alternative at interviewer discretion:

A fall is when your body goes to the ground or floor by accident. This does not include if you almost fall, if you lose consciousness, or if someone pushes or runs into you. Did you fall since [date]?

A fall is when your body goes to the ground without being pushed. Did you fall since [date]?

ER visits, hospitalizations, re-institutionalizations

QOL_6. Since [date], did you use an emergency room at a hospital?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

QOL_7. Since [date], were you hospitalized overnight or longer?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

QOL_8. Since [date], were you admitted to a nursing home or other facility overnight or longer?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

Depression symptoms

QOL_9. During the past month, have you often been bothered by feeling down, depressed, or hopeless?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

QOL_10. During the past month, have you often been bothered by little interest or pleasure in doing things?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

Informal assistance

QOL_11. During the last week, did any unpaid family member or friends help you with things around the house?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

Global life satisfaction

QOL_12. Taking everything into consideration, during the past week have you been happy or unhappy with the way you live your life?

- ☐ Happy
- ☐ Unhappy
- ☐ Don't know
- ☐ Refused

Choice of providers

QOL_13. Do you pick the people who are paid to help you?

- ☐ Yes
- ☐ No
- ☐ I do not receive any paid assistance
- ☐ Don't know

☐ Refused

Financial adequacy

QOL_14. In general, how do your finances usually work out at the end of the month? Do you find that you usually end up with ...

- ☐ Some money left over
- ☐ Just enough to make ends meet
- ☐ Not enough to make ends meet
- ☐ Don't know
- ☐ Refused

Volunteering

QOL_15. Are you doing volunteer work or working without getting paid? Probe: Are you doing work but not getting any money for it?

- ☐ Yes → Go to Question 16
- ☐ No
- ☐ Don't know → Go to Question 16
- ☐ Refused → Go to Question 16

QOL_15a. Would you like to do volunteer work or work without getting paid? Probe: Would you like to do work without getting paid for it?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Refused

Assistive technology, Devices, Special equipment

QOL_16. I would like to talk with you about any devices or special equipment you might use or need. Special equipment includes any item, piece of equipment, or technology that helps people live more easily in their homes or do things for themselves.

For each one, please tell me if you currently have it or not. Do you currently have a [READ DESCRIPTION]?

If No: Do you need this to live life as independently as you would like?

	Yes, I have it	No, I do <u>not</u> have it		Do not know	Refuse
		I <u>do</u> need it	I do <u>not</u> need it		
16a. Building or home modifications , such as entrance ramps, wide doorways, roll-in shower, grab bars, stair glide, etc.					

16b. Mobility equipment , such as walker, cane, manual or electric wheelchair, scooter, etc.					
16c. Special medical equipment , such as a hospital bed, Hoyer or transfer lift system, shower chair, raised toilet seat, commode, etc.					
16d. Lifeline, PERS, or a 24 hour life alert system.					
16e. Electronic devices to monitor your health or share health information electronically , such as equipment that reports your blood pressure, weight, etc.; a medication box which notifies someone if you don't take your medications; or a telehealth system that calls to remind you to take medications.					
16f. Transportation aids , such as a lift van, adaptive driving controls, etc.					
16g. Internet capable devices , like a computer, a smart phone, or a tablet.					
16h. Internet access where you are residing now.					

Unmet need for personal care, meals, medications, and toileting

QOL_17. Since [date], did you **always** have the assistance you needed to get dressed, take a shower, or bathe when you needed to?

- ☐ Yes
- ☐ No
- ☐ I do not need any assistance with dressing or bathing.
- ☐ Don't know
- ☐ Refused
- ☐ Not Applicable – Already completed the PCA/Behavioral Health staff questions.

QOL_18. Since [date], did you **always** have the assistance you needed with your meals, such as help making or cooking meals or help eating?

- ☐ Yes
- ☐ No
- ☐ I do not need any assistance with my meals or eating.
- ☐ Don't know

- ☐ Refused
- ☐ Not Applicable – Already answered the PCA/Behavioral Health staff questions.

QOL_19. Since [date], did you **always** have the assistance you needed to take your medicines, such as reminders to take them, help pouring them, or help setting up your pills?

- ☐ Yes
- ☐ No
- ☐ I do not need any assistance with medications.
- ☐ Don't know
- ☐ Refused
- ☐ Not Applicable – Already answered the PCA/Behavioral Health staff questions.

QOL_20. Since [date], did you **always** have the assistance you needed with toileting, including getting help getting on or off the toilet or help changing disposable briefs or pads?

- ☐ Yes
- ☐ No
- ☐ I do not need any assistance with toileting.
- ☐ Don't know
- ☐ Refused
- ☐ Not Applicable – Already answered the PCA/Behavioral Health staff questions.

DMHAS QUESTIONS

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

DMHAS_1. As a result of the services I have received from the Mental Health Waiver, I deal more effectively with my daily problems. Would you say you...

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know
- ☐ Refused
- ☐ Unclear response OR not DMHAS waiver

DMHAS_2. As a result of the services I have received from the Mental Health Waiver, I am better in control of my life. Would you say you...

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

- ☐ Don't know
- ☐ Refused
- ☐ Unclear response OR not DMHAS waiver

DMHAS_3. As a result of the services I have received from the Mental Health Waiver, I do better in social situations. Would you say you...

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know
- ☐ Refused
- ☐ Unclear response OR not DMHAS waiver

DMHAS_4. As a result of the services I have received from the Mental Health Waiver, I can have the life I want in recovery. Would you say you...

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know
- ☐ Refused
- ☐ Unclear response OR not DMHAS waiver

DMHAS_5. As a result of the services I have received from the Mental Health Waiver, I feel that these services help me stay in the community. Would you say you...

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know
- ☐ Refused
- ☐ Unclear response OR not DMHAS waiver

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?

Question 98 is not in MFP Follow-Up 2:

98. We are doing a separate survey for family members of people who transition out of facilities. The survey asks family members questions about their caregiving, living arrangements, health, and well being. The survey is voluntary. It will not affect your participation in the Money Follows the Person program or any benefits or services you receive. Is there a family member we can send the survey to?*

**If the person says they have no family member, ask if they have a close friend we can send survey to.*

- ☐ No, I do not want you to contact my family member.
- ☐ Yes, you can contact my family member.
- ☐ I have no family member to contact, but you can contact my close friend.
- ☐ I have no family members or close friends that you can contact.
- ☐ Ineligible (Consumer in a Facility or Nursing Home, or Caregiver does not speak English or Spanish)

Name, address, and phone of person to contact:

First and last name: _____

Relationship to consumer: _____

Street: _____

Apt. _____

City: _____ State: _____ Zip: _____

Telephone: _____

Email address: _____

Best way to contact: _____

Contact notes: _____

END OF QUESTIONS

Thank you for completing this interview with me.

MFP Follow-Up 1 Only: We will be calling you again in 11 months to find out how you are doing. In case we have trouble reaching you, what is the name, address, and phone number of a close relative or friend who is not living with you and is likely to know your location in the future? For example, a mother, father, brother, sister, aunt, uncle, or close friend.

Alternative contact information:

Name: _____

Relationship: _____

Street Address: _____

Apt. or Unit: _____

City: _____

State: _____ ZIP: _____

Contact Phone: _____

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

AASCC: 203-752-3040

CCCI Eastern region: 860-885-2960

CCCI North Central region: 860-257-1503

CCCI Northwest region: 203-596-4800

SWCAA: 203-333-9288

WCAAA: 203-465-1000

Autism waiver: 860-424-5865

Katie Beckett waiver: 860-424-5582

DMHAS: 866-548-0265

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

INTERVIEWER QUESTIONS

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

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

☐ Participant by his/herself

Participant telephone numbers: _____ → Go to F1

- ☐ Participant with assistance from another person.

If Assisted

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

First name: _____

Last name: _____

Telephone numbers: _____ → Go to F1

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

If Proxy:

Proxy Contact Information:

Proxy First name: _____

Proxy Last name: _____

Proxy Telephone numbers: _____ → Go to P1

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

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

P2. Is the proxy also a legal representative?

- ☐ Yes
☐ No

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

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

F1. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

- ¹ ☐ YES
² ☐ NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

- ¹ ☐ YES
² ☐ NO → GO TO END OF SURVEY

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

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

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

- ¹ ☐ YES
² ☐ NO → GO TO END OF SURVEY

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

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

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

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

F7. Relationship to participant:

- ☐ Spouse/partner
- ☐ Adult child
- ☐ Parent
- ☐ Attorney or legal representative
- ☐ 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

Interview done by:

- ☐ Telephone
- ☐ In-person
- ☐ Other: _____

Participant Information:

First name: _____
 Middle name: _____
 Last name: _____

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

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

- ☐ Yes
- ☐ No
- ☐ Do not know

Program:

- ☐ MFP

Community First Choice?

- ☐ Yes
- ☐ No
- ☐ Do not know

Name of interviewer: _____

Date Interview Complete: _____

Appendix B. HCBS CAHPS Institutional Survey Description

HCBS CAHPS Institutional Survey – UConn

2-13-2019

Overall changes from the HCBS CAHPS Community survey:

- The Cognitive screen is not used in the HCBS CAHPS Institutional survey
 - The Identification section is not used. “Facility staff” is programmed into the survey questions.
 - The HCBS CAHPS Institution survey contains a subset of the Community survey questions.
 - The Employment Module is not asked.
 - The DMHAS Questions are not be asked.
 - The QOL Module is asked.
-

Appendix C. CT MFP HCBS CAHPS® 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 D. Acronyms

ABI	Acquired Brain Injury waiver
AT	Assistive devices or technology
CAHPS®	Consumer Assessment of Healthcare Providers and Systems
CHCPE	Connecticut Home Care Program for Elders waiver
CHCPE-AB	Connecticut Home Care Program for Elders waiver – Agency-based
CHCPE-SD	Connecticut Home Care Program for Elders waiver – Self-directed
COVID-19	Coronavirus disease 2019
CSP	Community service provider
DDS	Department of Development Services
DSS	Department of Social Services
ER	Emergency room
HCBS	Home and community-based services
HCBS CAHPS® survey	Consumer Assessment of Healthcare Providers and Systems Home and Community-Based survey
ILST	Independent Living Skills Trainer
MFP	Money Follows the Person program
MHW	Mental Health waiver
PCA	Personal care assistant or attendant
PCA-AB	Personal Care Assistance waiver – Agency-based
PCA-SD	Personal Care Assistance waiver – Self-directed
PERS	Personal emergency response system
RCH	Residential care home
RA	Recovery assistant
SCM	MFP Specialized Care Manager
TC	MFP Transition Coordinator