

# Money Follows the Person Rebalancing Demonstration

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

### 2023 Survey Results

April 2024

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## **I. Introduction, Methods, and Analysis**

As part of the comprehensive Money Follows the Person program (MFP) quality management strategy, 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 the Department of Social Services (DSS) MFP case management system MyCommunityChoices.com to explore the experiences of various groups of MFP participants, including surveys completed in 2023 and surveys completed for the cohort of consumers who transitioned in 2022.

### **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 found 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 2023

A total of 571 HCBS CAHPS surveys were completed with MFP participants in 2023: 323 1 month and 248 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 2023

This section presents select results from the 312 1 month surveys completed in 2023 with consumers residing in the community. HCBS CAHPS key results and areas of interest from the previous 2022 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 2022

The full set of both 1 month (n=302) and 12 month (n=246) MFP HCBS CAHPS surveys are available for consumers who transitioned in 2022. 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 422 consumers who transitioned in 2022 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 2023 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 2023

A total of 571 HCBS CAHPS surveys were completed with MFP participants in 2023: 323 1 month and 248 12 month surveys (Table 1.1). Setting indicates where the consumer was residing when the survey was completed. Over nine out of ten consumers (93%) were in the community at the time of their survey.

Table 1.1. Surveys Completed in 2023 by Setting

	Community n (%)	Institution n (%)
1 Month	312 (96.6)	11 (3.4)
12 Month	218 (87.9)	30 (12.1)
All 2023 Surveys	530 (92.8)	41 (7.2)

One month surveys were planned to be completed between 30 and 45 days post-transition. On average, 1 month surveys were completed 38 days post-transition, and 12 month surveys were completed an average of 11.3 months post-transition (Table 1.2).

Table 1.2. Time From Transition to Survey Completion in 2023: 1 Month and 12 Month Surveys

	Minimum	Maximum	Mean	Standard Deviation
1 Month Survey (Days)	21	91	38.40	10.891
12 Month Survey (Months)	11	14	11.33	0.937

Table 1.3 shows the home and community-based program of survey respondents by setting and time point. In 2023, 60-64% of community surveys at either 1 or 12 months were completed with consumers from either the Connecticut Home Care Program for Elders using agency-based services (CHCPE-AB) or the Personal Care Assistant waiver using agency-based services (PCA-AB). The largest percentage of institutional surveys at either time point were completed with CHCPE-AB consumers.

Table 1.3. Home and Community-Based Program – Surveys Completed in 2023 by Time Point and Setting\*

	All	1 Month		12 Month	
	Surveys n (%)	Community n (%)	Institution n (%)	Community n (%)	Institution n (%)
ABI waivers	7 (1.2)	2 (<1.0)	0 (0)	5 (2.3)	0 (0)
CHCPE-AB	194 (34.0)	109 (34.9)	4 (36.4)	65 (29.8)	16 (53.3)
CHCPE-SD	16 (2.8)	10 (3.2)	1 (9.1)	5 (2.3)	0 (0)
DDS waivers	18 (3.2)	8 (2.6)	2 (18.2)	6 (2.8)	2 (6.7)
Katie Beckett	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Mental Health waiver	15 (2.6)	9 (2.9)	1 (9.1)	5 (2.3)	0 (0)
MH State Plan	55 (9.6)	37 (11.9)	1 (9.1)	16 (7.3)	1 (3.3)
PCA-AB	161 (28.2)	91 (29.2)	2 (18.2)	66 (30.3)	2 (6.7)
PCA-SD	46 (8.1)	17 (8.2)	0 (0)	23 (10.6)	6 (20.0)
PD State Plan	28 (4.9)	10 (3.2)	0 (0)	17 (7.8)	1 (3.3)
RCH/Other	31 (5.4)	19 (6.1)	0 (0)	10 (4.6)	2 (6.7)

\*See Appendix D for a complete list of acronyms

Table 1.4 shows survey and respondent characteristics for surveys completed in 2023. Use of proxies, or someone else completing the survey on behalf of the consumer, fell again this year. The 2023 overall proxy rate was 17.5%, which is just over the 16.6% overall proxy rate in 2019. Completion of the survey by the MFP consumer alone or with assistance is the first choice for a participant experience survey such as the HCBS CAHPS. However, there are MFP participants who cannot complete the survey even with assistance or who express that they want someone else to answer for them. Having an unpaid person who is close to the participant complete the survey allows for the inclusion of these consumers' experiences.

Table 1.4. Respondent and Survey Characteristics – Completed in 2023 by Time Point and Setting

	1 Month		12 Month	
	Community	Institution	Community	Institution
	N=312 n (%)	N=11 n (%)	N=218 n (%)	N=30 n (%)
Survey Respondent				
By self	232 (74.4)	10 (90.9)	150 (68.8)	22 (73.3)
With assistance	29 (9.3)	1 (9.1)	24 (11.0)	3 (10.0)
By proxy	51 (16.3)	0 (0)	44 (20.2)	5 (16.7)
Assistant Relationship				
Spouse/partner	6 (21.4)	0 (0)	9 (26.1)	0 (0)
Adult child	6 (21.4)	0 (0)	5 (21.7)	0 (0)
Parent	5 (17.9)	0 (0)	4 (17.4)	0 (0)
Attorney or legal representative	0 (0)	0 (0)	1 (4.3)	0 (0)
Paid staff person	2 (7.1)	0 (0)	2 (8.7)	0 (0)
Other	9 (32.1)	1 (100)	5 (21.7)	3 (100)
Proxy Relationship				
Spouse/partner	3 (5.9)	0 (0)	9 (20.5)	1 (20.0)
Adult child	18 (35.3)	0 (0)	18 (40.9)	3 (60.0)
Parent	16 (31.4)	0 (0)	9 (20.5)	0 (0)
Attorney or legal representative	2 (3.9)	0 (0)	2 (4.5)	1 (20.0)
Other	12 (23.5)	0 (0)	6 (13.6)	0 (0)
How Person Assisted*				
Answered some questions	24 (85.7)	0 (0)	21 (91.3)	2 (66.7)
Restated/reminded/prompte for questions	14 (50.0)	1 (100)	14 (60.9)	2 (66.7)
Translated questions	1 (3.6)	0 (0)	0 (0)	0 (0)
Helped with use of assistive or communication equipment	1 (3.6)	0 (0)	0 (0)	0 (0)
Other help provided	0 (0)	0 (0)	0 (0)	0 (0)
Survey mode				
Telephone	306 (98.1)	9 (81.8)	214 (98.2)	20 (66.7)
In-person	6 (1.9)	2 (18.2)	4 (1.8)	10 (33.3)
Survey used				
English	300 (96.2)	11 (100)	212 (97.2)	28 (93.3)
Spanish	12 (3.8)	0 (0)	6 (2.8)	2 (6.7)

\*Could assist in one or more way

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 male (27% at 1 month, 47% at 12 months). Similar to national trends, overall respondents residing in facilities were more likely to be over age 65, White, non-Hispanic, and/or female compared to younger, Black, Hispanic and/or male respondents (Travers et al., 2021) (State of Connecticut, 2023).

Table 1.5. Demographics – Surveys Completed in 2023 by Time Point and Setting

		1 Month		12 Month	
		Community %	Institution %	Community %	Institution %
Age		N=312	N=11	N=218	N=30
	<18	2.2	0	1.4	0
	18-44	11.2	0	15.6	3.3
	45-54	11.9	9.1	15.6	0
	55-64	33.0	27.3	30.7	33.3
	65-74	23.1	36.4	19.7	33.3
	75+	18.6	27.3	17.0	30.0
Language		N=309	N=11	N=216	N=28
	English	79.9	81.8	79.6	85.7
	Spanish	2.9	0	1.4	3.6
	Multilingual/Other	17.2	18.2	19.0	10.7
Race		N=309	N=10	N=214	N=29
	White	58.6	90.0	65.0	82.8
	Black	34.3	10.0	30.8	17.2
	Other	7.1	0	4.2	0
Ethnicity		N=310	N=11	N=215	N=29
	Non-Hispanic	82.3	90.9	81.4	89.7
	Hispanic	17.7	9.1	18.6	10.3
Education Level		N=308	N=11	N=214	N=29
	< 8th Grade	8.1	9.1	4.7	13.8
	Some high school	15.9	0	15.4	6.9
	High school degree	40.6	54.5	42.5	34.5
	Some college	22.7	18.2	25.2	31.0
	4 year college	9.4	9.1	7.9	10.3
	> 4 year degree	3.2	9.1	4.2	3.4
Gender		N=312	N=11	N=218	N=30
	Male	53.5	27.3	48.6	46.7
	Female	46.5	72.7	51.4	53.3



## Section 2. 1 Month Community Surveys Completed in 2023

This section presents select results from the 312 1 month surveys completed in 2023 with consumers residing in the community. Results include areas of interest from the 2022 report for comparison, 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 11 1 month institutional surveys are available for any specific questions.

Consumers reported using a number of program services at 1 month post transition, especially care management (85%) and personal care assistance (PCA) services (71%) (Table 2.1). Reported service use increased for PCA services by 10% this year compared to 2022. Homemaking and care management services also experienced a slight increase of 5%. “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).

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

	Community n (%)
Personal care assistant/attendant services	214 (70.6)
Behavioral health services	1 (<1)
Homemaking services or Homemaker-Companion**	203 (67.0)
Care management services***	266 (85.3)
Job coach or vocational supports	0 (0)
Recovery assistance services (MHW only)	5 (55.6)
Community Service Provider (MHW only)	7 (77.8)
None of these services	12 (3.8)

\* Consumers can use more than one service

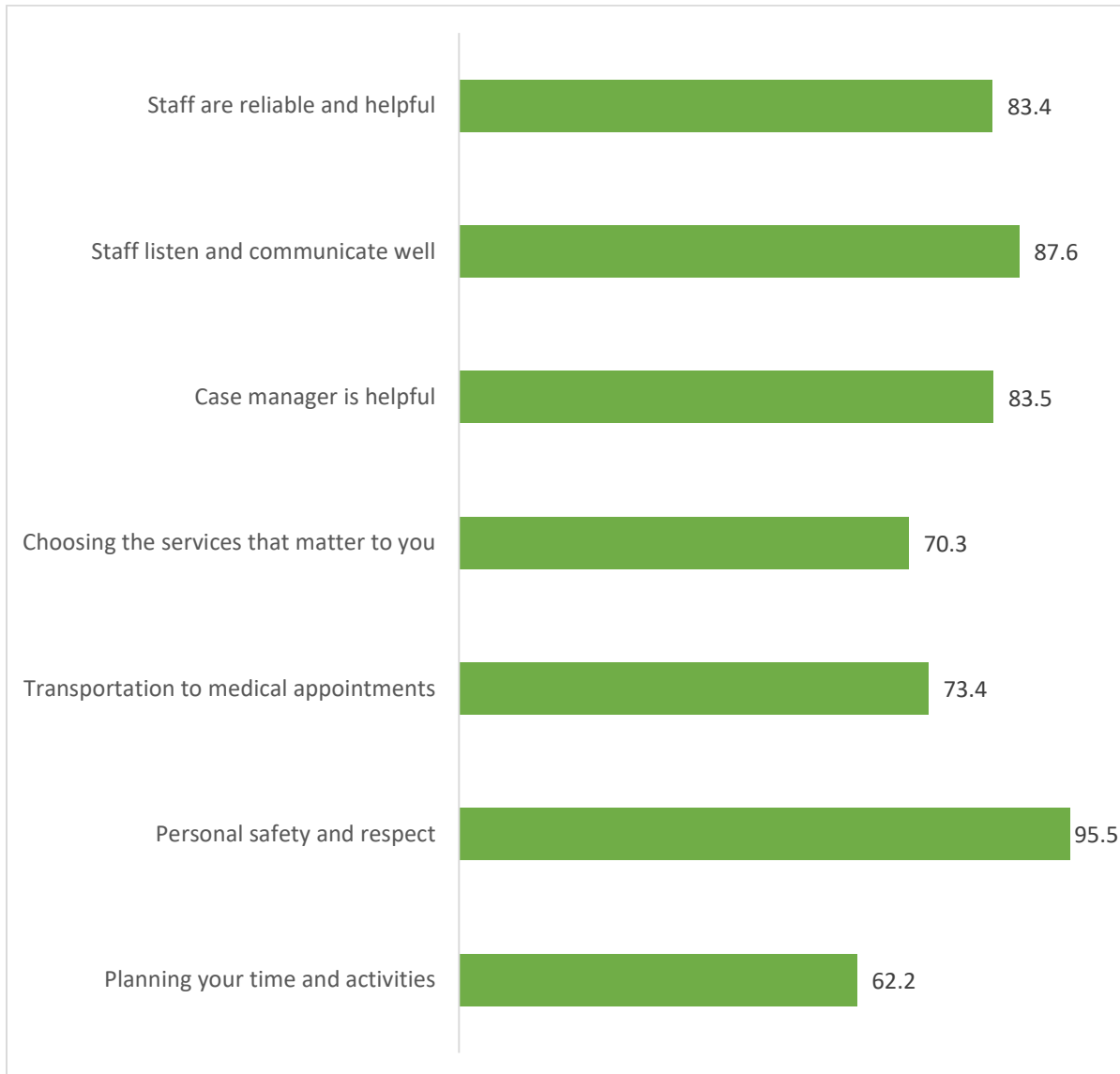
\*\*Homemaking tasks can be provided by PCA or separate homemaking staff

\*\*\*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” once again received a much lower score than the other composites, as just 62% of respondents gave this measure the highest score. Respondents also gave notably lower scores to medical transportation and choosing the services that matter to you. The latter composite includes whether the care plan addresses what the participant views as important and their paid staff’s knowledge of their care plan.

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. Between 71-76% of participants gave their homemaking staff, personal assistant/behavioral health staff, or care manager/TC a 9 or 10. The percentage of participants rating their care manager/TC a 9 or 10 increased over the past year, from 65% in 2022 to 72% in 2023. This trend continues in Figure 2.3, which shows the percentage of consumer who would “definitely” recommend their staff person. The percentage of participants who would “definitely” recommend their care manager/TC increased from 72% in 2022 to 77% in 2023.

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

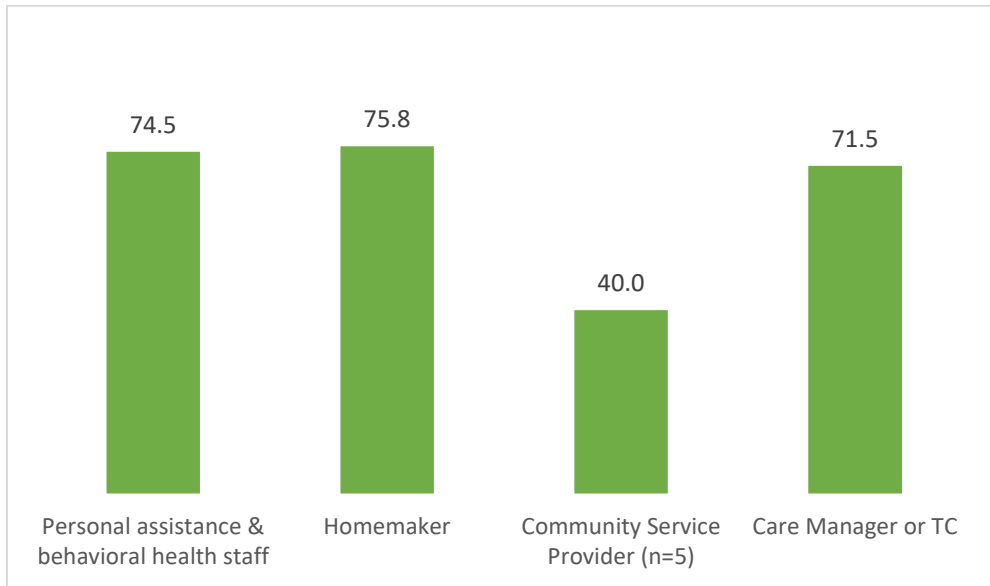
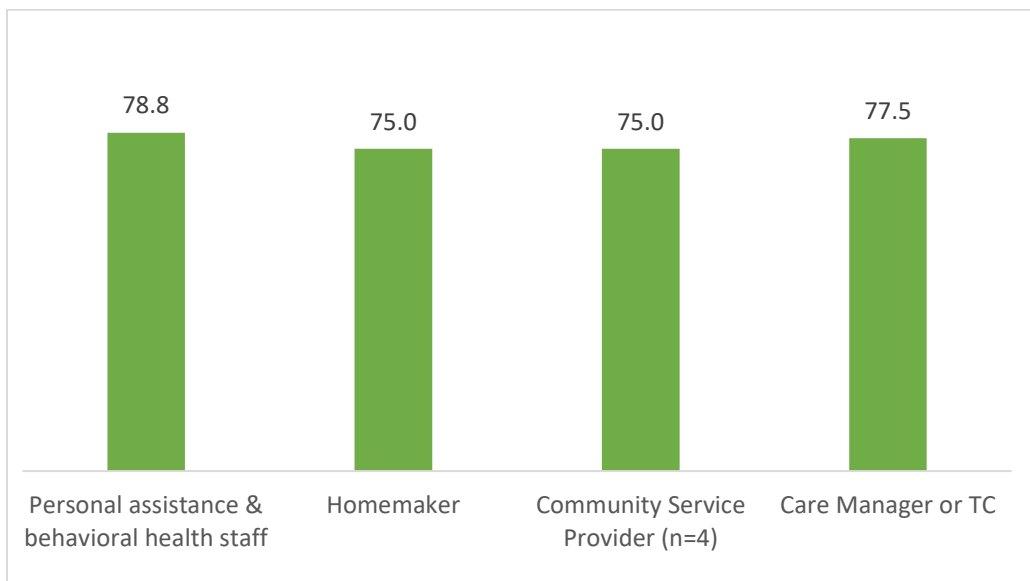


Figure 2.3. Recommendation: Percentage Who “Definitely” Recommend Their Staff



Care manager

When asked about their care manager at 1 month, most participants (90%, up from 82% in 2022) knew who their care manager was, and 89% could contact them when needed (Table 2.2).

Table 2.2. Care Manager Contact

Care Manager	Yes n (%)	No n (%)
Know who care manager is	281 (90.1)	31 (9.9)
Able to contact care manager when need to	241 (88.9)	30 (11.1)

Positive comments about their SCM, TC or transition team included:

*It's a wonderful program, it's a life-giving program and I think they are doing a great job. They saved my life.*

*Both housing coordinator and discharge coordinator [TC] were very helpful.*

*I love it. I love the way they help people and what they do. It takes a lot of work but they do it and make it work.*

*The team was amazing, and they prepared us – they did shopping before he got here.*

*Everything and everyone has [sic] been great. I don't know what we would have done without the SCM [name]. She was so helpful when it came to all the paperwork and back and forth with the nursing home. And the aide has been wonderful.*

Some respondents reported that at one month post-transition they did not have the support they needed from their MFP SCM or TC.

*The care manger never calls me back. So I started calling the TC, and she takes like 2 weeks usually to respond to a phone call, if at all. She was supposed to submit our application for SNAP back in November when we were planning on discharging [consumer], and I had to call a few weeks ago to see what was up with that. Turns out she never submitted the application and had to do it which delayed that process a lot.*

*We had a hard time communicating with care manager. There is not a lot of transparency. We are too busy advocating for ourselves and cannot look into other available options. Only way we could get the entrance ramp was not through DSS but was contacting a State Representative, and once she got involved, we were able to get it.*

*It took two years to find housing to transition out of the nursing home. TC has not been responsive to help with getting needed household items like lamps, broom and mop and it has been almost a month and I still have no EBT (Electronic Benefits Transfer) card.*

Others expressed concerns and issues they encountered once in the community, including not enough paid supports, issues with direct care staff such as lack of training or poor quality of care, lack of transportation, and need for socialization. Consumers found not having enough hours in their care plan and lack of consistent staff to be especially problematic. Some relied on friends or family members to fill in and provide the extra support needed to live in the community.

*We had a replacement aide who was not good. She refused to do tasks and didn't follow instructions with food we bought so we had to throw away expensive food. I told the agency we never wanted her again. I do like the program but that caught me off guard.*

*He needs 24 hour care and he receives 11.*

*There is a slight language barrier. The aides have heavy accents and sometimes it is hard to understand. One we can communicate with better than the other and as of yesterday, the other one who likes to just be attentive to my mom, I had to speak with her about the laundry and not letting it get too piled up. ... I am there in and out but not constantly there watching – I go in to make sure my mom has breakfast and dinner and I run errands for her as well as myself. I am monitoring what is going on but again if [aide] could get better at listening and understanding, we could muddle through. I don't want anyone to lose their job, but she needs to understand she needs to assist and not just watch TV with my mom. There isn't a lot that needs to be done but the dishes, laundry and things like that. There is not a lot to do.*

*I just would like a couple more hours for my caregiver hours. I am here alone from 1 to 6 pm.*

*The aides they send out need to be properly trained. [The agency] knew I am a Hoyer lift yet they sent out two aides that are not Hoyer trained. I have one right now who is, but she is leaving in March and I'm afraid they won't find another person. As it is, I am stuck in bed from 1 to 5 pm because the aides can only come from 9 am to 1 pm and 5 pm to 9 pm. I am grateful for the hours I get but it's not ideal. I have to do a lot of advocating for myself and I'm glad I can. I don't know what other people who are not as vocal or educated as I am would do. Also, the SCM does not always get back to me fast enough. Her voice mail says she replies to calls within one day, but it usually takes her a week.*

*I want in-home paid support as it is too much on [my husband]. I need someone to come in in the morning to change me and wash me up for just a couple of hours.*

*The PCA agencies are a huge problem. I went through two different agencies, and four different PCAs and still have not found someone who has the experience to care for my mom. Even the owner of one of these agencies did not know how to provide the proper care. The issue is that MFP is recommending these agencies, and none of [the agencies] have people with enough experience or training to care for someone who is bed bound and cannot do any basic personal care like for my mother. I feel that changing diapers and bed pads, and making sure my mom is properly, emphasis on properly, cleaned is not asking that much from a PCA. And so far none of them have done it. How is that possible when MFP is recommending them? These agencies need to be vetted prior to partnering with MFP. This program has been around for a while and it just doesn't make sense that there is a still such a huge shortcoming with PCA agencies, a giant part of this program. I feel like I'm not asking for much. I would be over the moon to just find a reliable person that would ... change and clean my mom when she needs it. Nothing else. And I can't find that basic care.*

State plan consumers who are not eligible for services or their family members expressed concerns about lack of paid support in the community. One consumer living in a residential care home (RCH) just really wanted an apartment so he could have his pets again.

*I wish they would got me a place closer to where I can get a bus and not so far and closer to visit family. I haven't received any help yet and they should have had that set up before I came home.*

*I do not want to stay here at the RCH [Residential care Home]. There is no hot water. I want my dogs, cats, and birds back when I move into an apartment.*

Several consumers reported financial concerns one month post-transition. One person expressed needing their social security check as they were two months behind on rent. Said another consumer, "I have not received my SAGA (State-Administered General Assistance) money and I cannot pay my bills."

### Physical and Mental Health

Consumers reported worse physical health in this year – 42% of consumers rated their physical health as fair or poor, compared to 36% in 2022 (Figure 2.4). There were a few comments about need for medications or prescription refills, which was concerning, especially given the poor health of many of these consumers.

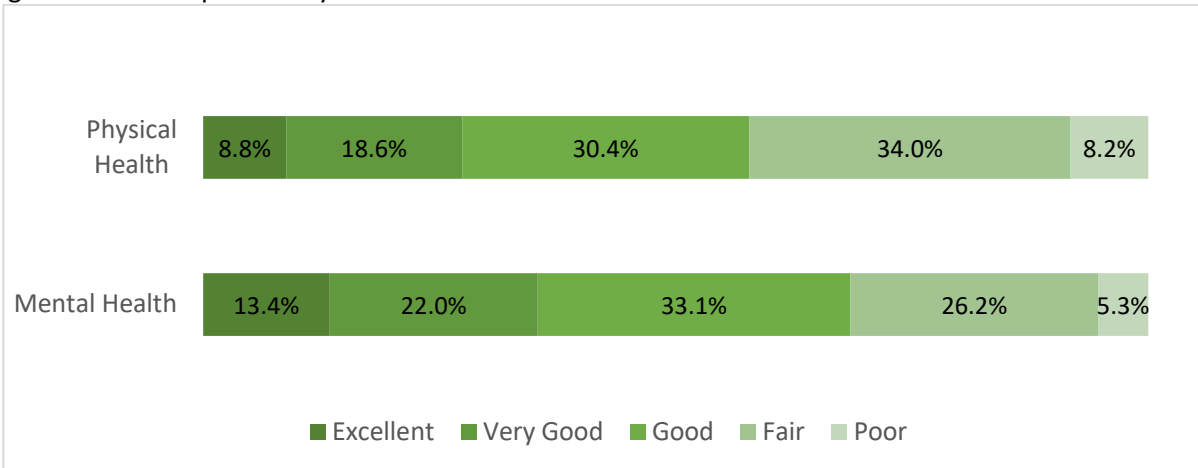
*I've been having problems getting my prescriptions filled and I feel sick because it has been over a week.*

In comparison to 2022, consumers reported better overall mental or emotional health – 69% said their mental health was good or better. Still, one-third of consumers reported having at least one depressive symptom in the last month. Commented a family member respondent:

*He needs grab bars and new hospital bed. Also, he needs mental health counseling. He is so depressed and now he is not communicating, so we do not know what he wants.*

At 1 month post-transition, 15% of community consumers reported falling since transition, a decrease from the 19% in 2022. There was also a decrease this year from 24% to 18% for those who used the emergency room in the month post-transition.

Figure 2.4. Self-Reported Physical and Mental Health

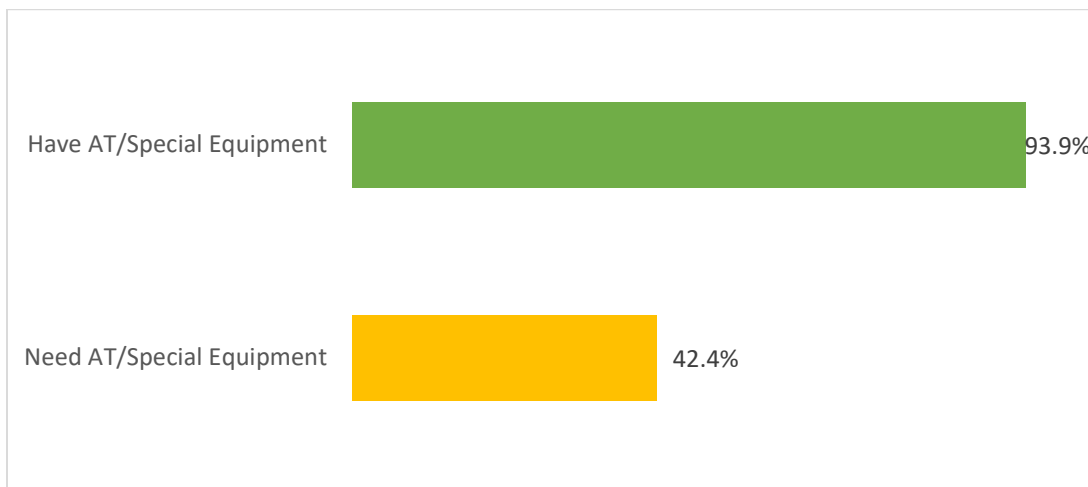


Assistive Technology and Special Equipment

MFP provides consumers with different types of assistive devices, special equipment, and modifications to enhance the consumer’s independence as long as they are needed because of a disability or health condition, are in their home and community-based program services, and fit 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 almost all (94%) consumers reported having at least one type of assistive device or special equipment, two out of five (42%) 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 continues to increase each year – 24% of consumers in 2021, and 34% in 2022, 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 (83%), special medical equipment (69%), or home modifications (62%) (Figure 2.6). When asked what type of equipment or devices they still needed, 10-16% of consumers still needed home modifications, a personal emergency response system (PERS), electronic medical devices, or special medical equipment 1 month post transition. Comments included:

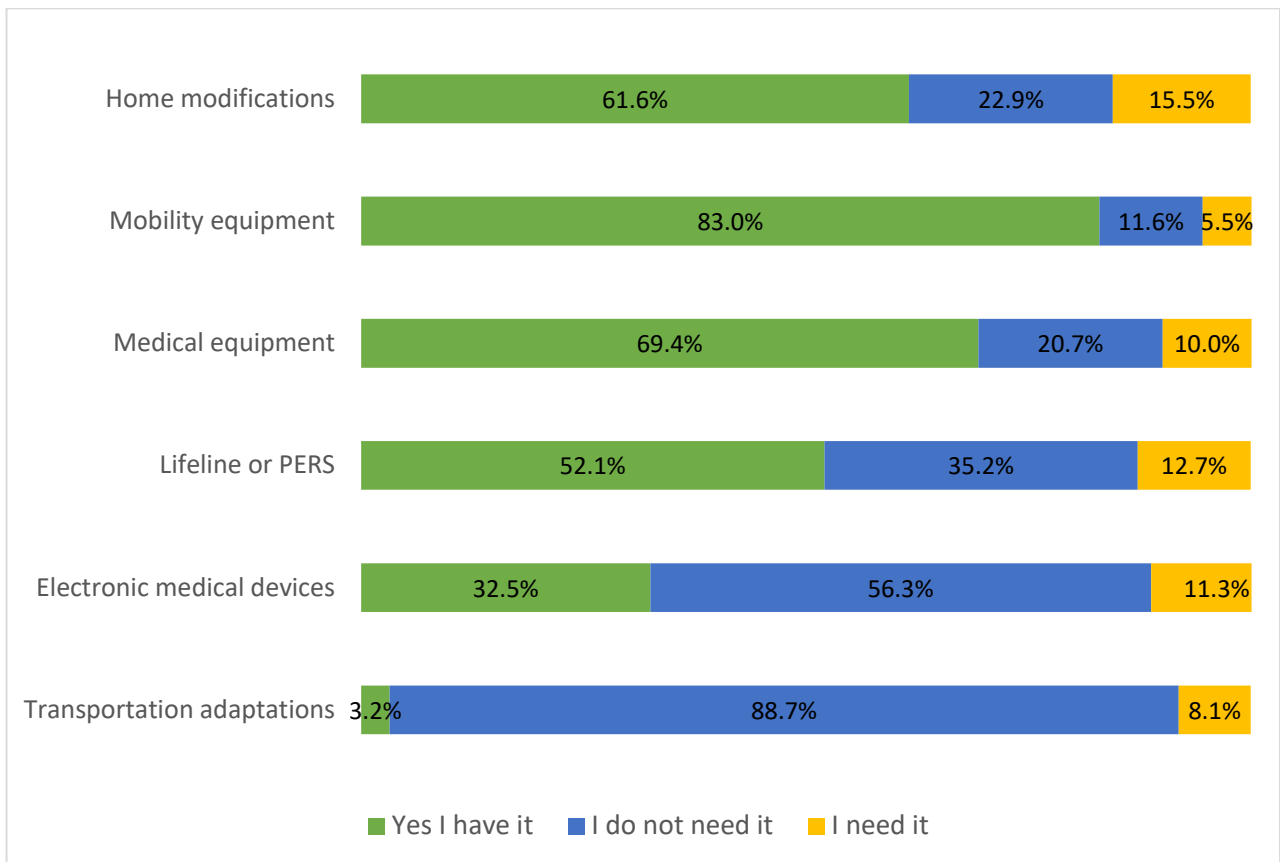
*I need my walker, grab bars and a raised toilet seat.*

*I would like my Lifeline back. I get 9 [PCA] hours a week. I'm afraid I will fall when the aide is not around.*

*She needs a detachable shower head.*

*I put orders in for a new shower chair for [consumer] and wheelchair which has not been taken care of for a whole month. He is not able to bathe and his head is not supported in his chair. Also, the kitchen table has a bar underneath which prevents his wheelchair from sitting close to the table. He is not able to eat at his own kitchen table.*

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 2022

This section reports the experiences of consumers who transitioned in 2022 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 home and community-based services (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 422 consumers transitioned in 2022. Altogether, they completed 548 HCBS CAHPS surveys: 302 1 month and 246 12 month surveys (Table 3.1). The majority (92%) of surveys were completed with consumers residing in the community, an increase of 1% from the previous year. This resulted in 285 1 month and 217 12 month community surveys completed for consumers who transitioned in 2022. Section 3 reports data from the 502 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 2022 Transitions by Time Point and Survey Setting

	Community Surveys n (%)	Institution Surveys n (%)	Settings Combined n (%)
1 Month	285 (94.4)	17 (5.6)	302 (100.0)
12 Month	217 (88.2)	29 (11.8)	246 (100.0)
Both Time Points	502 (91.6)	46 (8.4)	548 (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 MFP 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.

Use of care management services showed a noticeable difference from 1 month to 12 months, decreasing from 79% at 1 month to 54% at 12 months. This is not unexpected as some MFP consumers may not have much care management support at 12 months after transition. After six months, MFP care 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	171 (61.7)	133 (62.7)
Independent Living Skills Trainer (ILST) (ABI waiver only)	3 (1.1)	2 (<1)
Homemaking services or Homemaker-Companion	174 (62.8)	133 (62.7)
Care management services	225 (78.9)	118 (54.4)
Job coach or vocational supports	0 (0)	0 (0)
Recovery assistance services (MHW only)	5 (62.5)	4 (80.0)
Community Service Provider (MHW only)	7 (87.5)	2 (40.0)
None of these services	16 (5.6)	32 (14.7)

\* Consumers can use more than one service

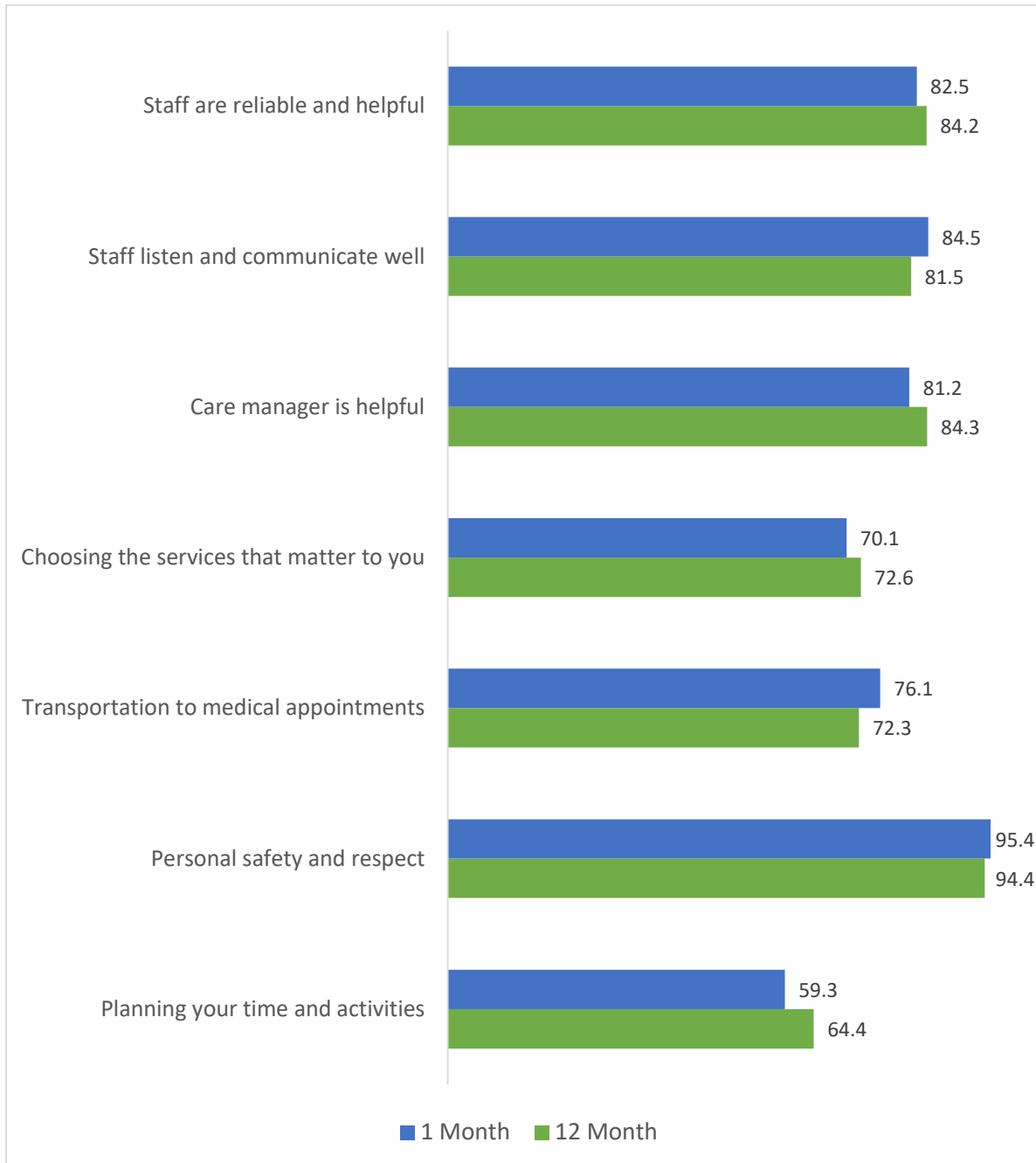
### A. HCBS CAHPS Key Results

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. Similar to previous years, consumers at both timepoints gave the highest scores to personal safety and respect, followed by both staff and case manager composites. Staff listen and communicate decreased slightly, from 85% at 1 month to 81% at 12 months. Medical transportation, already low compared to almost all the composites at 76%, fell to 72% by 12 months. As in previous years, consumers gave the composite planning your time and activities the lowest score. At 1 month, just 59% of consumers gave the highest score for this composite, although this increased to 64% at 12 months.

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



\*“Staff” combines all PCA, ILST, recovery assistant (RA), community service provider (CSP), homemaking, companion, life skills coach, and community mentor staff

### Global Ratings

Although global ratings for PCA/RA/ILST staff and care managers remained stable over time, a greater percentage of consumers at both time points gave their PCAs/RAs/ILST staff the highest rating (74-75%) compared to their care managers (64-65%) (Figure 3.2). Meanwhile, homemaking staff ratings fell from 76% at 1 month to 71% at 12 months. Positive comments about PCAs or other HCBS staff included:

*She is doing well and her PCAs are godsends. They are worth their weight in gold. (12 month)*

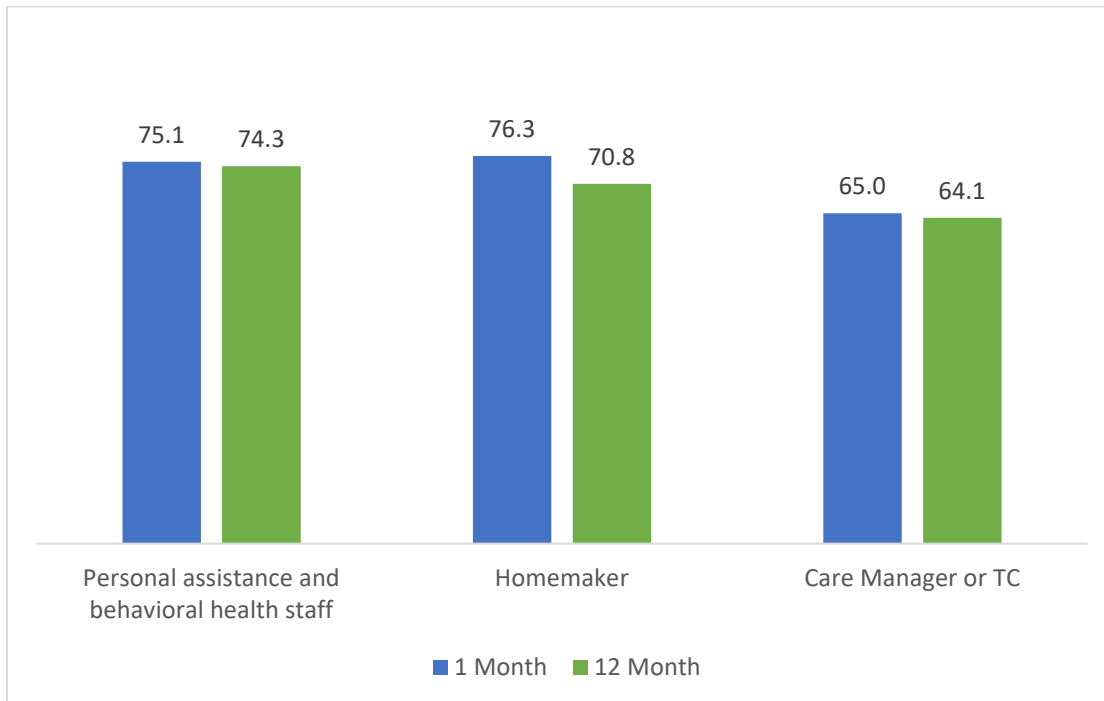
*The agency and staff have been wonderful for the most part. The quality of care has been lower when my main person is not there, but [it is] still acceptable. (12 month)*

*I appreciate my RA [MHW Recovery Assistant], he does a lot for me. He deserves a raise. (12 month)*

*I am really happy and glad I am getting PCA help. I have been healthier than I have ever been. PCAs have kept me going in the same direction. Having them check on me have helped my mental health and to lose weight. (12 month)*

*Hiring someone with the RA title is crucial towards independence and improvement. (1 month)*

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



\*In Figures 3.2, 3.3, 3.4 “Personal assistance & behavioral health staff” combines all PCA, ILST, recovery assistant, life skills coach, and community mentor staff

At the same time, many consumers shared the multiple issues they have experienced with getting assistance, such as staffing turnover, lack of basic training such as using a Hoyer lift, difficulty finding staff, quality of work, lack of agency staff supervision, and language barriers. Another common theme was a disconnect between the consumers/family members and agency PCA/homemaking staff regarding the PCA/homemaker’s role and task expectations. Consumers also commented that they needed more assistance than what could be provided by MFP. A few consumers said they cancelled their services because they were so unhappy with them.

*The aides they send out need to be properly trained. They knew I am a Hoyer lift yet they sent out two aides that are not Hoyer trained. I have one right now who is, but she is leaving in March and I'm afraid they won't find another person. As it is, I am stuck in bed from 1 to 5 pm because the aides can only come from 9 am to 1pm and then from 5 pm to 9 pm. I am grateful for the hours I get but it's not ideal. I have to do a lot of advocating for myself and I'm glad I can. I don't know what other people who are not as vocal or educated as I am would do. Also the SCM does not always get back to me fast enough. Her voice mail says she replies to calls within one day, but it usually takes her a week. (1 month)*

*I wish the aides knew what they were supposed to do. (12 month)*

*The home health agency is sending people that do not speak Spanish to [my brother's] home. He has an aide that's been working with him from the beginning that does speak Spanish but the other aides do not. It has been a struggle for my brother. (12 month)*

*We are greatly concerned with the next aide to take over because it took us 10 aides to find a good one. (12 month)*

*I still do not have help on weekends as promised. My daughter is a CNA/HHA, and I wonder if she can be paid to help. (1 month)*

*Things are better now than they were in the beginning. I was still grateful in the beginning but it was a challenge finding the right PCAs. (12 months)*

*The first aide was very neglectful. [My mother] had fallen several times and the aide did not inform the agency or me. Due to neglect from the aide, [my mother] was severely dehydrated which led to a hospitalization for urinary tract infection. (1 month)*

*The availability and reliability of competent aides ... Another aide could not take verbal direction – now [I'm] concerned for [my] safety. The third aide is traveling an hour and a half [to get here] and has called out three times in two weeks. (1 month)*

*I really don't like it. I had some wonderful aides and they won't send them back to me. I would be happy if I got the aides that were good to me, but I was told they were on another case and so many people switch from me. I get bad aides. (1 month)*

*The only reason my aide isn't a 10 is because of the language barrier. We make it work, and she is very helpful, it's just really hard to communicate. (1 month)*

Self-directing consumers also had difficulty finding staff to hire. As in previous years, in 2023 self-directing consumers also mentioned issues with Allied, such as staff not getting paid on time and difficulty navigating the self-hire process.

*Allied was not very helpful. I felt alone without any help. I cannot image how someone, an elder, would be able to navigate it. The benefits he gets from having PCA services are absolutely great. (1 month)*

*Hiring of aides is a difficult process. I could not find aides on Allied but had to find them myself through the newspaper. The whole process with Allied was confusing. If the family member did not have an advocate, they would not be able to do it. (12 month)*

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

*I need a PCA to help me – I am currently not getting any help at home. (12 month)*

*He really liked his TC [name] and now he does not have a replacement at the moment. He has been waiting for his Independent Living Skills Trainer for a while now. (12 month)*

*There are many things wrong with this program. I feel like I was just left here to die. I only had PCA services for 3 months before my aide said that she is no longer coming. I need aides because I cannot remember things. I need reminders to take medications, I need aides to get to the grocery store and to remember to get to my medical appointments. I also was not receiving my Social Security for 5 months. I lived off peanut butter and jellies for 2 months because there was no money for food. I also need a shower handle because it is difficult to shower and clean without one. I am giving up. (12 month)*

A few participants expressed that they did not want the services they were getting. ABI participants in particular felt the services took away from their independence. A couple of other participants got frustrated with the quality of services and felt they would be better off without them.

*I think MFP should not listen to a doctor's orders, but they should talk to the person themselves and see what the person should need. I have been independent, and I get out of the hospital, and they provided me too many services and overstepped boundaries. (1 month)*

*The State is wasting their money on a PCA for me. I've been trying to get rid of the PCA or at least get the hours reduced since I moved out of the nursing home. It's a scam honestly. They come in, they sleep, they watch TV or order food, sleep more, get something done for me, and then go hang out on the couch. This is the easiest money they've ever made. I don't need anyone to help me yet they keep sending someone. (12 month)*

Some consumers cautioned that unless the staff and overall support issues were resolved, the future of the MFP program and the State's ability to adequately support people in the community were uncertain.

*I am grateful for MFP for all they did do for me, but I was also bullied by paid help/aide who was not caring, honest or wanted to work. The person who came here initially was insulting and the supervisor was appalled. [I] felt [the aides] were not interested in the person and more interested in the paycheck. I finally cancelled the service. The aide traumatized me! I was trained myself as a Home Health Aide, but MFP will only survive if they can find good help and hold onto them. I needed help on Sundays to put out trash cans and a few other things like laundry. (12 month)*

*The state is in a bind and they have very limited resources to care for people properly. I tried to be as objective in my responses as possible. I had some issues early on, but because of that experience I'm reluctant to complain about anything. (12 month)*

*She has been distraught because she felt that since her services have not been put in place that she would have to go back to the nursing home. She wants to be able to stay in the community. She also fears that her needs may become more of an issue as she ages and that she may not be a fit for the program. She mentioned how she may need an operation and how this may change her needs, and she's concerned that she would be kicked off the program. She spoke with the home health agency today and they will be sending a PCA this week. (1 month)*

Once again, respondents mentioned that family or friends filled in the gaps, not only with assistance with personal care and daily activities, but also financial assistance.

*I've been living here for over a month now and my home health aide services are still not set up or started. Right now I am relying on my girlfriend for making sure I have everything. She has also been the one getting what I need – she got me a walker from the senior center. So far MFP hasn't supplied anything. (1 month)*

*My aides did not work out. They were constantly changing and I could not get a consistent aide. A lot of them were lazy and did not want to work and they expected us to provide them with food. The final straw was the last aide that made her own sandwich and grabbed a water bottle and sat on the couch. They just could not follow my directions and I couldn't take it anymore. Luckily my husband is able to provide care for me, and I asked them to stop sending the PCAs. I think that the aides are not paid well and it gives them no reason to want to do a good job. (1 month)*

## Recommendations

Despite issues with paid staff, Figure 3.3 shows that a high percentage of consumers at both 1 and 12 months (82-83%) would “definitely” recommend their PCAs/RAs/ILSTs to family or friends. Meanwhile, at 1 month 73% of consumers recommended their homemakers this highly, which dropped to 67% at 12 months. Care manager ratings increased over time, from 73% to 78%. Compared to 2022, recommendations for PCA/RA/ILST staff and care managers both increased substantially in 2023. Positive comments about SCMs and TCs included:

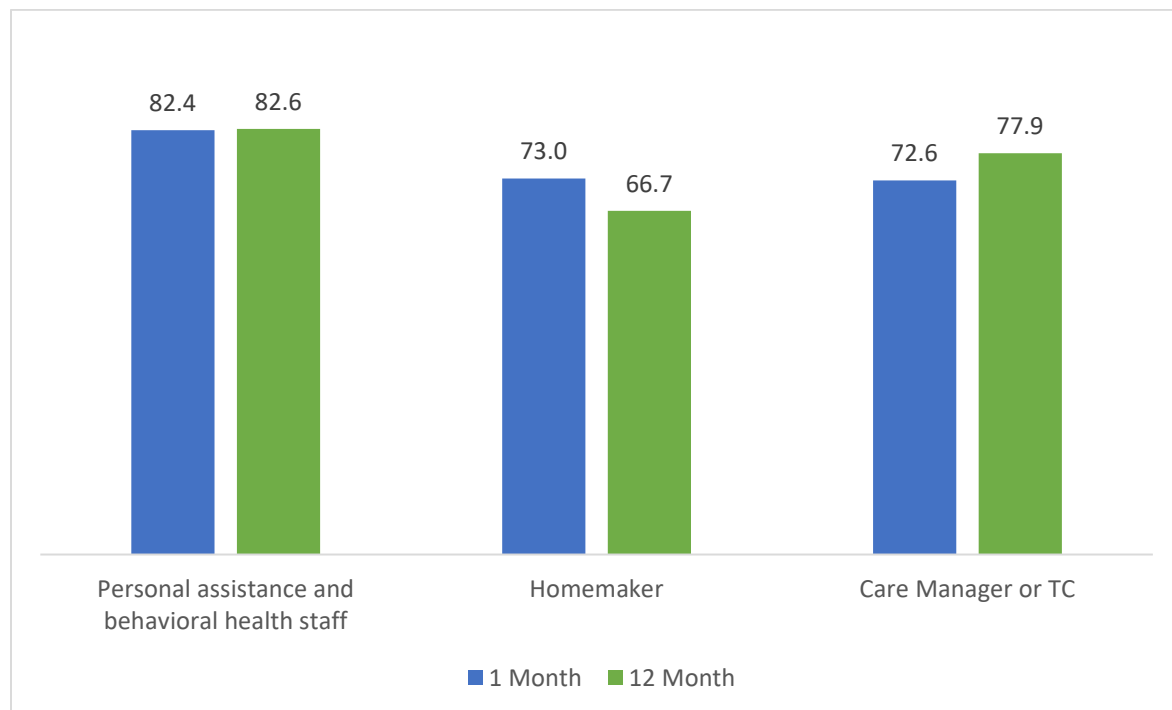
*Everything and everyone has been great. I don't know what we would have done without the SCM [name]. She was so helpful when it came to all the paperwork and back and forth with the nursing home. And the aide has been wonderful. (1 month)*

*My TC [name] was completely awesome. I want to give her a glowing recommendation. (12 month)*

*HC [name] and TC [name] were very knowledgeable and helpful. They are beautiful people. The way they treated me was so kind. (1 month)*

*The transition with the MFP team was excellent. (1 month)*

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



\*In Figures 3.2, 3.3, 3.4 “Personal assistance & behavioral health staff” combines all PCA, ILST, recovery assistant, life skills coach, and community mentor 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 homemaking services were considered to need help with housekeeping tasks such as cleaning or laundry. While 84% of 1 month participants needed assistance with personal care, at 12 months this fell to 75%.

Table 3.3. Self-reported Assistance with Everyday Activities

Needs assistance with:	1 Month	12 Month
	n (%)	n (%)
Personal care	147 (84.0)	101 (74.8)
Meals or eating	134 (77.0)	112 (82.4)
Taking medications	103 (59.2)	84 (61.8)
Using the toilet	98 (56.0)	68 (50.0)
Housekeeping or laundry	174 (63.5)	133 (66.2)

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, 12 participants (6% of those with PCAs or homemakers) indicated one or more unmet need: 2 for personal care, 3 for taking medications, 6 for using the toilet, 1 for meals or eating, and 2 for household tasks. At 12 months, 11 participants (7% of those with PCAs or homemakers) indicated one or more unmet need: 5 for personal care, 2 for taking medications, 3 for using the toilet, 1 for meals or eating, and 1 for household tasks (separate items, consumers can report more than one).

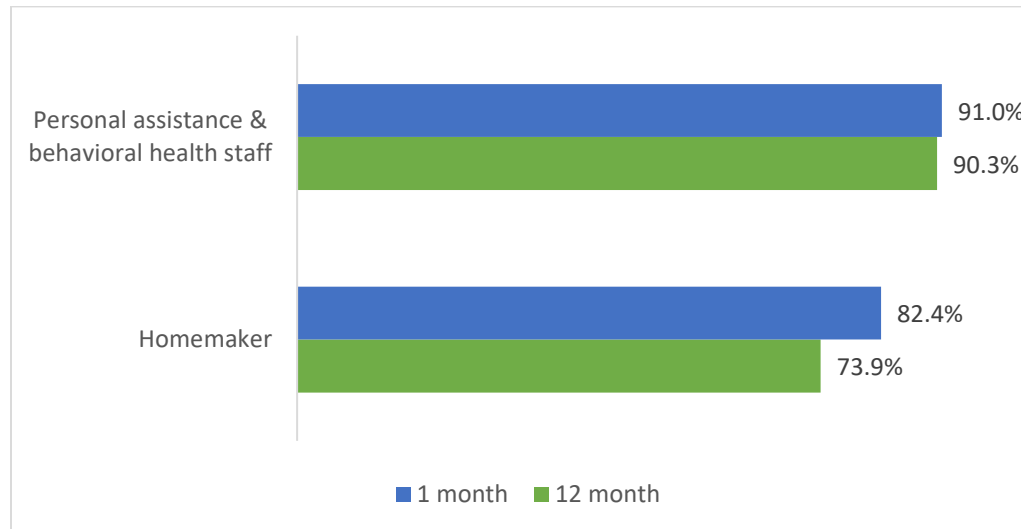
Participants not receiving personal assistance were asked if they always had the assistance they needed for bathing/dressing, meals, medications, and toileting. Thirteen individuals at 1 month (12% of those asked) and seven participants at 12 months (9% of those asked) had an unmet need for one or more of these tasks. Although no participants at 12 months said staff hit or hurt them, two participants at 1 month reported staff had either hit or hurt them. Both participants said there was someone working with them to fix 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 (92% 1 month, 93% 12 month). A majority of participants agreed that their staff encouraged them to do things for themselves. Homemaking staff however, experienced a noticeable drop from 1 month (82%) to 12 months (74%) (Figure 3.4).

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



\*In Figures 3.2, 3.3, 3.4 “Personal assistance & behavioral health staff” combines all PCA, ILST, recovery assistant, life skills coach, and community mentor staff.

**Care Managers and Care Plans**

When asked if they knew who their care manager was, 82% of consumers at 1 month and 71% of consumers at 12 months said they did (Figure 3.5). This significant drop is reflective of the structure of the MFP program. After 6 months, consumers do not have any SCM services, and TC services are reduced to one telephone call a month. Most of these consumers at either time point were able to contact their care manager when they needed to. However, that 18% of consumers at 1 month did not know who their care manager is, even though they have at least a TC, is concerning.

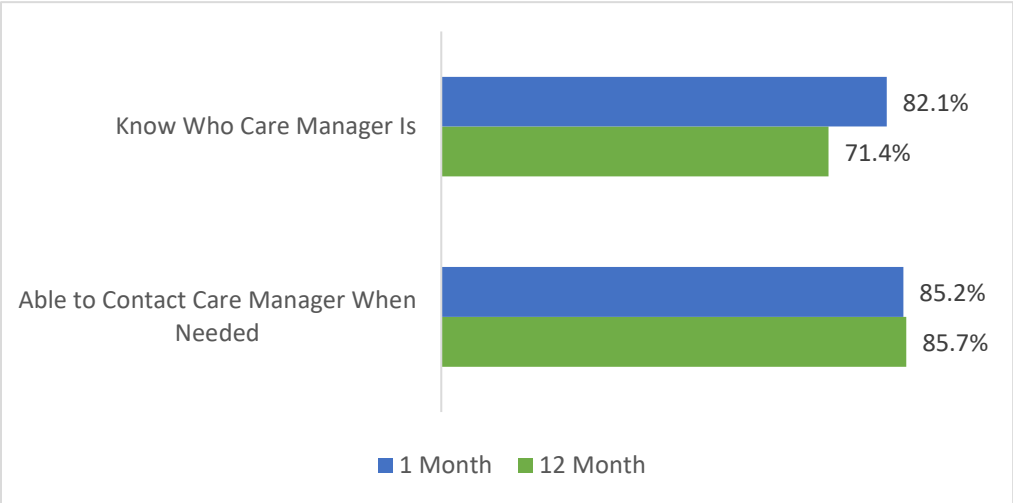
Comments indicated that for some consumers or family members, communication with their care managers or TCs was difficult, which was likely worsened by MFP staff turnover. In addition to confusion about whom to turn to for assistance, some consumers expressed frustration that their concerns were not addressed or even heard. Comments indicated that more proactive and responsive care manager support is needed post-transition. In some cases, it appeared that the case manager was not fully informed about providers or services available.

*We don't currently have a care coordinator, and since January they have changed. I have never spoken with a care coordinator, so I always talk to [TC]. I was told whoever's desk my file ends up on is who I work with, and I feel like [consumer] has been left behind with that. I never understood what a care coordinator could do for us since I always reach out to TC. We also reached out to [TC] last month about hours for PCA, but we were over budget. We would have to reach out in December for this, and I don't know who to reach out for that. We have also never had a home visit in the year she has been home. (12 month)*

*I couldn't get an answer from [SCM name]. I've had to call the manager in order for her to return any of my calls. I asked about adult day programs – they said MFP doesn't do that and I was told to go to senior center. I asked about a respite program, and I was told that MFP does not provide that and that there aren't any respite hours available. (1 month)*

*The case manager wasn't very responsive. It was very difficult to replace aides that were neglecting mom. [Case manager] made it seem like if you complain too much, the [home care] agency will dump you. She made me fear I wouldn't get the care for [my mother]. She made it feel like you get what you get. And the OTs and PTs were telling me there were plenty of [home care] agencies. The emergency MFP worker was extremely helpful. (12 month)*

Figure 3.5. Care Management Services - Percentage Positive Responses





Asking care managers for assistance with getting or fixing specialized equipment decreased substantially over the year post transition (61% 1 month, 42% 12 month), while the percentage of consumers asking for help with changing services increased by 5% (Figure 3.6).

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

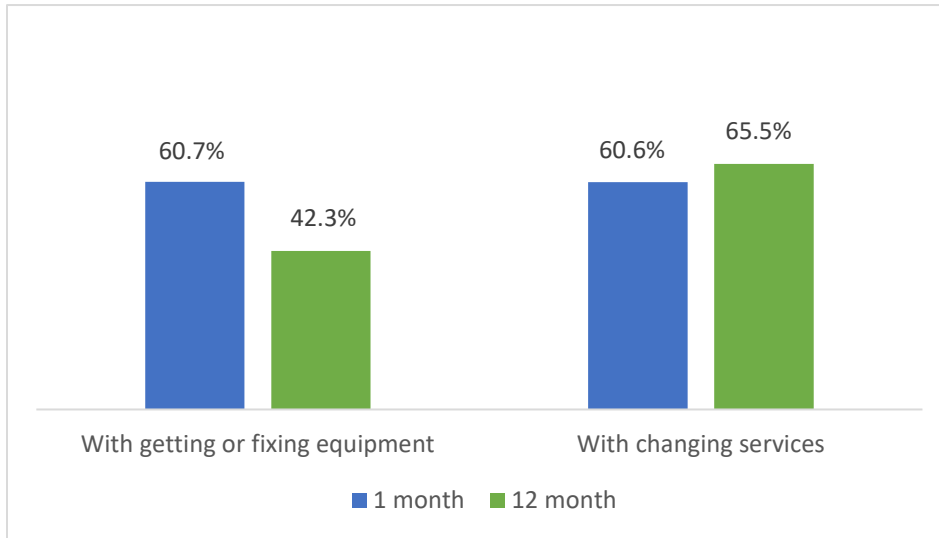
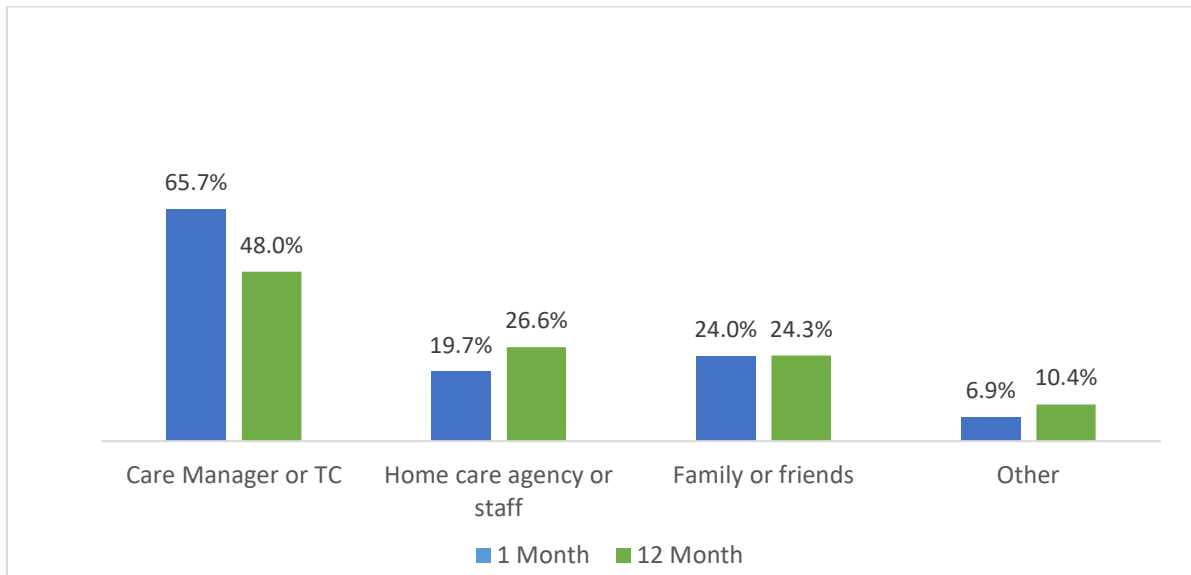


Figure 3.7 shows that at both 1 and 12 months, consumers would most likely contact their care manager for changes to their care plan, followed by contacting family or friends at 1 month.

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

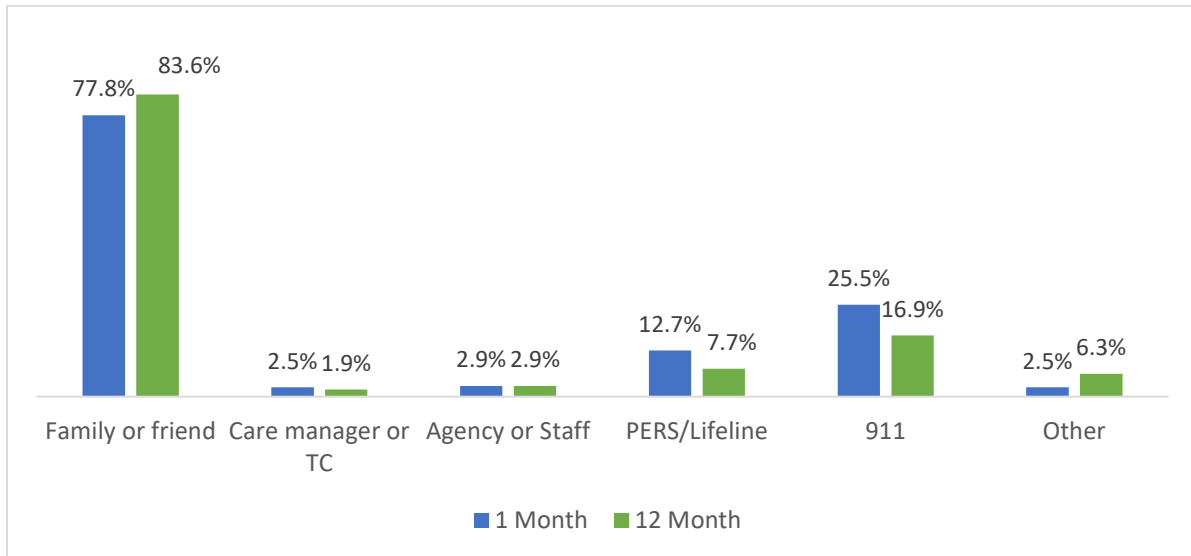


\*Can name more than one

### **Emergency Contact**

Most consumers reported that they were more likely to contact family or friends in case of an emergency at 1 month (78%) and 12 months (84%). At 12 months consumers were less likely to contact 911 (26% at 1 month, 17% at 12 months) (Figure 3.8).

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



\*Can name more than one

#### D. Self-Direction

About 90% of consumers at 1 month (92%) and 12 months (89%) reported they used agency-based services to hire their aides (Figure 3.9). The percentage who hired their own family members as staff decreased from 39% at 1 month to 29% at 12 months (Figure 3.10; see Section 4 for a more in depth look at self-directed consumers). At 1 month, 18% of consumers reported they picked the people who are paid to help them, while at 12 months that increased to 32% (Table 3.4).

Figure 3.9. How Do You Hire Your Aides?

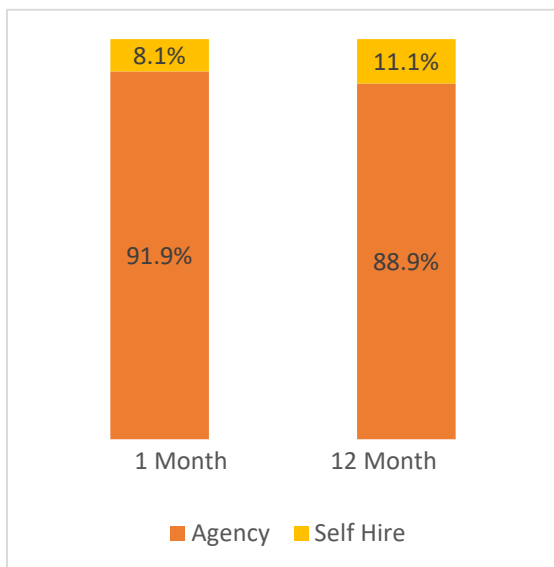


Figure 3.10. Employ Family Members

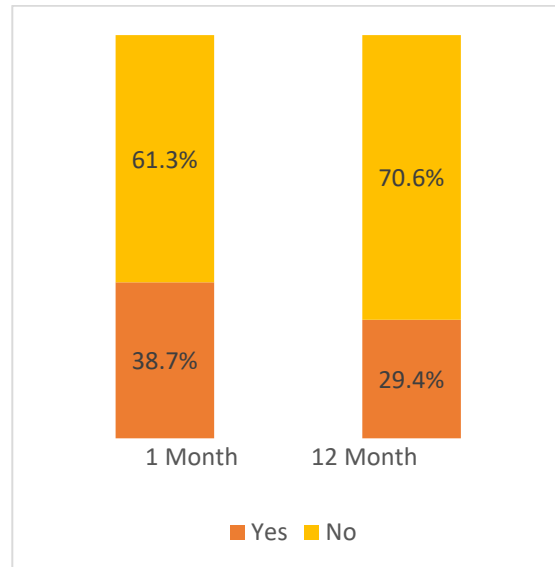


Table 3.4. Do You Pick the People Who Are Paid to Help You?

	1 Month n (%)	12 Month n (%)
Yes	39 (17.8)	54 (32.1)
No	180 (82.2)	114 (67.9)

### E. Living Situation and Social Support

As shown in Table 3.5, living situation and family/friends living nearby did not differ much between timepoints. Although just under 60% of consumers at either timepoint lived alone or without other adults, about 70% of all consumers at either timepoint had a family member who lived nearby. Most consumers who had nearby family members or friends could see them when they wanted to. In addition, between 70-74% of consumers who did not live alone resided with family member(s) at either time point. Unfortunately, about one-fifth of consumers living alone did not have nearby informal support – 20% of consumers living alone at 1 month and 17% of consumers living alone at 12 months did not have any nearby family or friends. When asked if they got unpaid help from family or friends with things around the house, 65% of consumers reported this assistance at 1 month, which decreased to 58% at 12 months (Figure 3.11).

Some consumers 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.

*I would like to get an emotional support pet especially after the aide has gone [home] to have someone beside me. (12 month)*

For another consumer, moving to an assisted living with onsite resident activities provided additional social support.

*We're both very happy and satisfied that she's there and her needs are being met. She has plenty of activities to participate and we visit whenever she can. (12 month)*

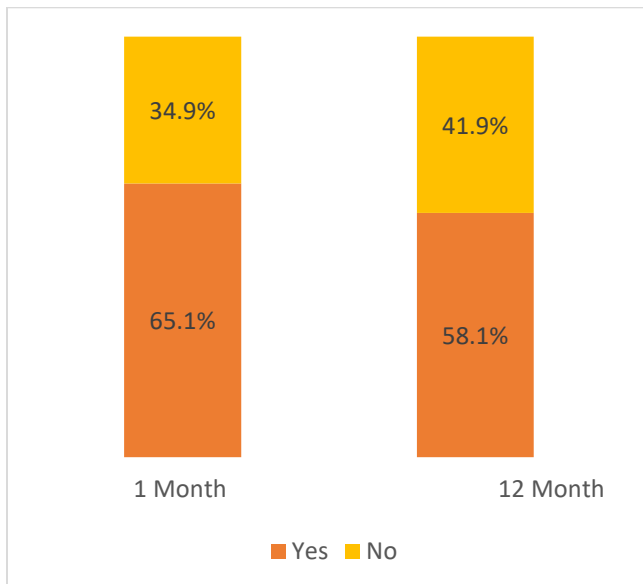
Table 3.5. Living Situation and Social Support\*

		1 Month %	12 Month %
Number of adults living in household		N=282	N=216
	1	57.5	58.8
	2-3	36.9	37.5
	4+	5.7	3.7
Lives with family member/s		N=121	N=89
	Yes	70.3	74.2
	No	29.8	25.8
Lives with non-family		N=121	N=89
	Yes	32.2	29.2
	No	67.8	70.8
Family member/s live nearby		N=284	N=216
	Yes	68.7	71.8
	No	31.3	28.2
Friend/s live nearby		N=284	N=214
	Yes	50.0	50.9
	No	50.0	49.1
Can see nearby family		N=193	N=155
	Yes	93.8	92.9
	No	6.2	7.1
Can see nearby friends		N=141	N=109
	Yes	93.6	93.6
	No	6.4	6.4

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

When asked if they got unpaid help from family or friends with things around the house in the past week, 65% of consumers reported this assistance at 1 month, which decreased to 58% at 12 months (Figure 3.11).

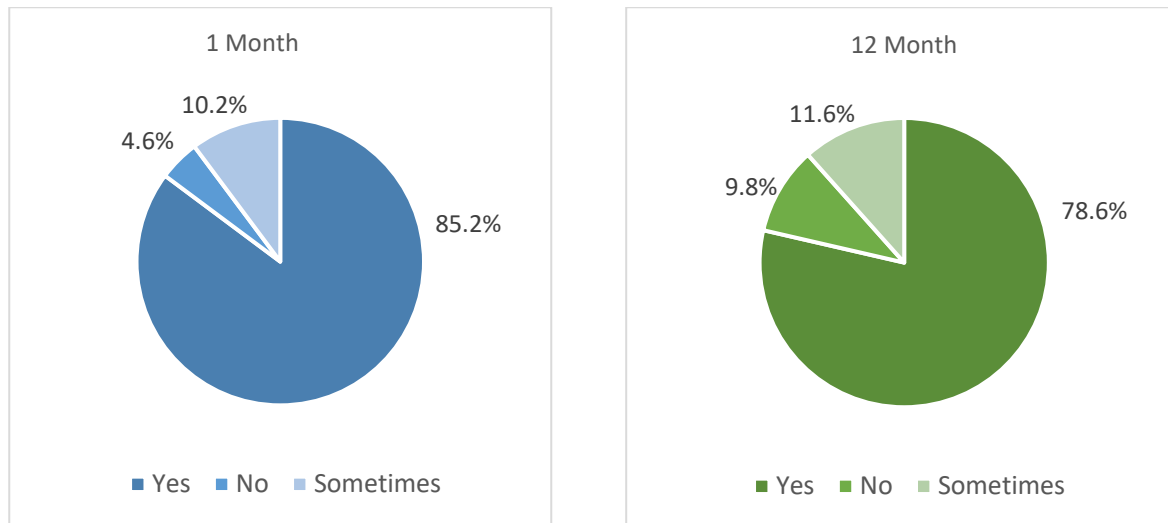
Figure 3.11. Assistance from Family or Friends Around the House



Although the majority of consumers at either timepoint said they liked where they live, this percentage decreased over the year (85% 1 month; 79% 12 months). These percentages are also both lower than in 2022, when 90% at 1 month and 87% at 12 months said they liked where they live. On the more positive side, almost all consumers at both 1 month (94%) and 12 months (91%) felt safe where they live. One consumer was especially happy with her new apartment because she got to live with her dog again:

*I am so lucky that I was accepted into this program. I feel so lucky that they took the time to find me a place where I could also have my dog again. There's always ups and downs, but I'm happy to have my own place. (1 month)*

Figure 3.12. Do You Like Where You Live?



One theme seen in 2023 consumer comments was dissatisfaction with housing, both with their living situation and experiences with MFP housing staff. Housing is one of the top challenges for consumers when planning to transition back into the community from a facility (UConn Health, Center on Aging, 2023). It is difficult to find affordable, accessible housing, especially given the high housing and rental costs. If a consumer has a residence to move back into, sometimes even with available modifications they find that their previous living situation no longer really fits their needs or that they can only use part of their residence, such as the consumer who expressed, “I would like an apartment that everything is on the first floor. I live in a duplex with two stories [but am] living in the downstairs.”

While some people were very happy with their community living situation, others were not:

*His day program is great - he loves it and has a good friend there. The staff are very good. But- at the group home where he lives, there, I don't know what is happening there. I am not welcome there - they also would not let his sister come visit him. He is with me [mother] every weekend. When I take him back, he does not want to get out of the car. He gets acne and they said they would shave him every day, but they only do it once a week. If he did not come home with me on the weekends, he would just be sitting there all day. He just got a new [waiver] case worker, and they are opening up a space for him in another group home run by the same people who do his day program, so it should get better. The new case worker has already talked to me, [consumer's] father, and gone to see [consumer]. (12 month)*

*I am disappointed with my housing and the people who live in the neighborhood. (12 month)*

*I would like to move closer to my family so I have more support. My family live in Hartford area and I'm all the way in Waterbury. (12 month)*

*I want more help trying to get my own apartment rather than living in the RCH. I was still sick when I was trying to figure out MFP and I was confused and didn't realize I was going to lose my apartment to be able to stay here instead. I had an apartment when I was living in the nursing home. And now I owe money to the nursing home, too. I don't really get it. I wish I had more clarity because I did not make the right decision. (1 month)*

Dissatisfaction with the housing process, MFP housing support, and/or housing coordinator (HC) staff was expressed several times. Consumers also mentioned difficulties with landlords and getting home modifications done after transition.

*They took a long time to find an apartment, which put a burden on us – my niece and myself. The housing coordinator did not do anything for us and we had to find our own Section 8 apartment in a very short time or we would lose it. (12 month)*

*I felt thrown out/abandoned with no support from MFP after my amputation, about two months after transition. I was told by the housing coordinator to call her two months before the end of the year lease to discuss finding accessible housing options. The landlord refused to install home modifications like handrails. I do not feel safe especially if there was a fire here. There was supposed to be a meeting when I was in the hospital to discuss a care plan, and that never happened. (12 month)*

*He has been asking for help in getting a wider ramp that fits his wheelchair, but he has not been able to get this modification. (12 month)*

## **F. Physical Health**

### ***Physical Health, Falls***

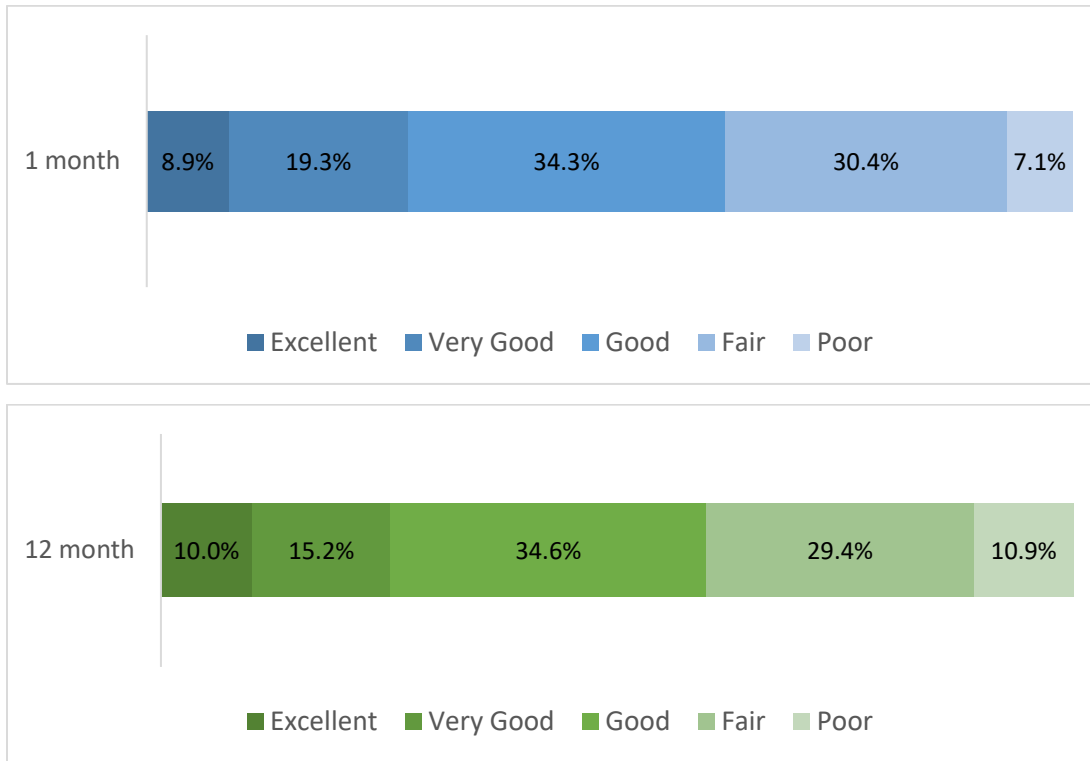
Just above a quarter of consumers rated their physical health as very good or excellent at 1 month (28%), with a slight decline of 3% for consumers rating their physical health at 12 months (Figure 3.13). Between 38-40% of consumers at either timepoint rated their health as fair or poor. Given this population is nursing home eligible, that such a large portion report such poor health is expected. For some, however, going home with family members gave them a real boost in both physical and mental health.

*Coming home has been for the better and gives him the routine that he needs. There has been a dramatic change physically and emotionally for the better for both of us. (12 month)*

Some still face challenges to their health, even while actively working to make improvements. This has proven to be burdensome for consumers working on recovery while in a nursing home.

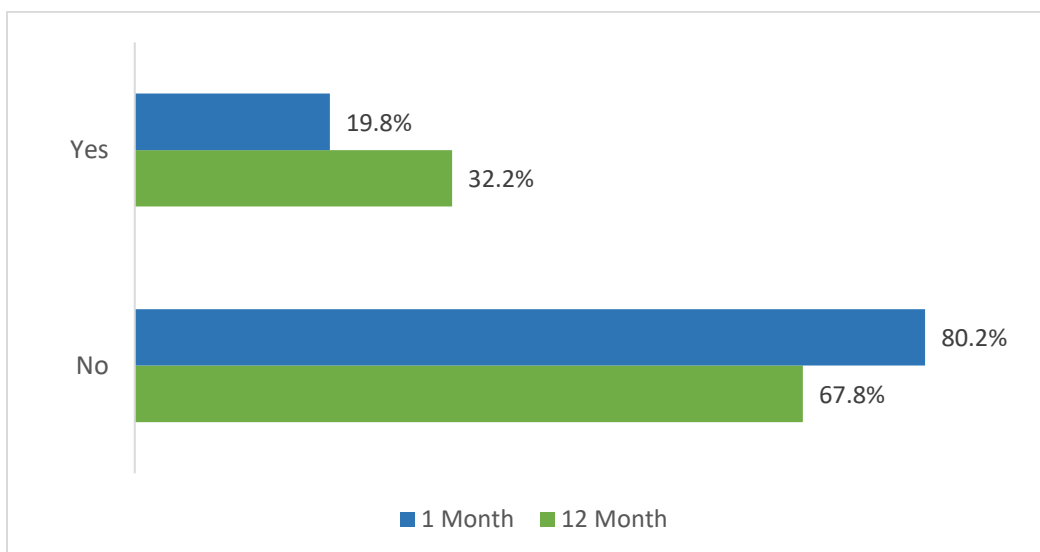
*I am concerned about how long it is taking me to walk better. I lost my strength [at nursing home]. This bothers me a lot. I am doing PT and OT, and nurse is checking my medications and blood pressure. (12 month)*

Figure 3.13. Self-Reported Physical Health



Twenty percent of consumers reported falling between transition and their 1 month survey (Figure 3.14). This percentage increased to 32% by the 12 month survey, which is not surprising due to the longer timeframe (since transition to 1 month, since 1 month survey to 12 months) (Figure 3.14).

Figure 3.14. Falls

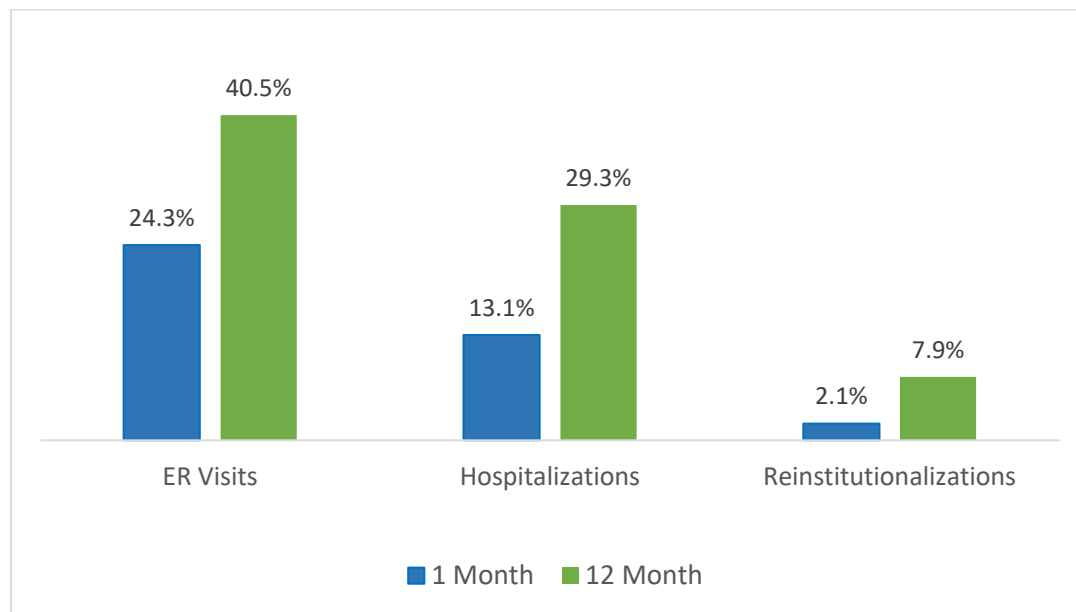


**Emergency Room, Hospital and Facility Use**

As can be expected, emergency room (ER) and hospital use were also reported more often at 12 months due to the longer timeframe (Figure 3.15). Forty-one percent of participants interviewed at 12 months had used an emergency room, and 29% had been hospitalized. By 12 months, 8% of consumers were

reinstitutionalized, either short or long term. With the exception of reinstitutionalizations at 1 month, reductions were seen in all three metrics from the previous year.

Figure 3.15. Emergency Room Visits, Hospitalizations, and Reinstitutionalizations



## G. Mental Health

### *Mental Health*

Self-rated mental and emotional health declined only slightly over time: at 1 month, 34% of consumers rated their mental or emotional health as very good or excellent, compared to 32% at 12 months (Figure 3.16). This represents a notable decrease in self-reported mental health at 12 months compared to last year when 37% of community consumers reported very good or excellent mental health at 12 months. Between 30-33% of consumers reported poor to fair mental or emotional health at either timepoint.

Symptoms of depression were essentially stable over time – 35 to 36% of consumers reported depressive symptoms at either 1 or 12 months (Figure 3.17). These rates are 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, including actively connecting participants with the resources and supports they need. Expressed one consumer at 1 month post-transition, “I wish I knew how to get a referral for psychiatric help.” Consumers sometimes find they have a limited circle of support or wish they could engage more often with others in the community. Others rely on their paid staff for social support. A few consumers commented on fear or anxiety about their future ability to remain in the community as they grow older.

*I would like to find programs or activities for her as I do worry that she doesn't not get enough social time now that she is not in a facility. I also would like her to be more active and start doing PT. (1 month)*

*I could use more help on the weekends. I don't have anyone for those days and it's really hard to do things on my own. Not to mention it's lonely not having anyone to talk to. I have a lot of anxiety about how things are going to go in the future. (1 month)*



Lack of non-medical transportation and not enough community activities contributed to some consumers feeling isolated or depressed.

*Living in a suburb there is not much to do and I can't drive. (12 month)*

*There's nothing for me to do and that makes me depressed. I don't have good transportation so I can't go to places I want to go. I just watch TV a lot. (1 month)*

Figure 3.16. Self-Reported Mental Health

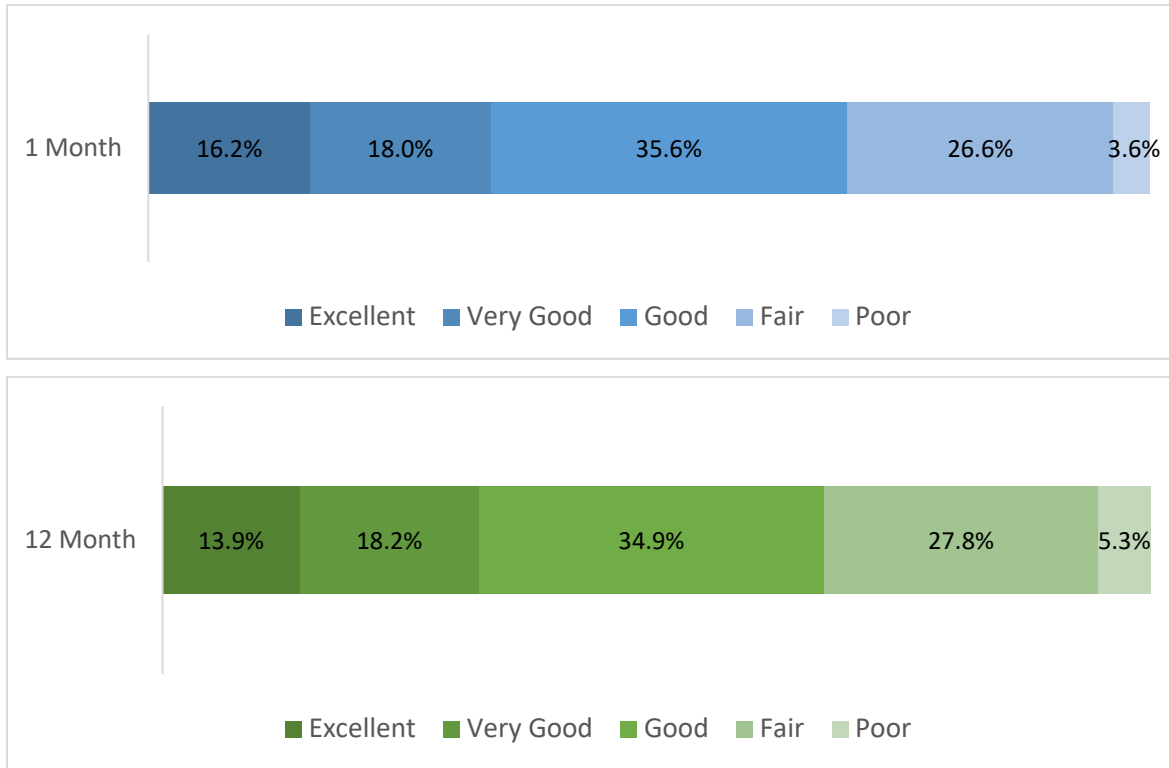
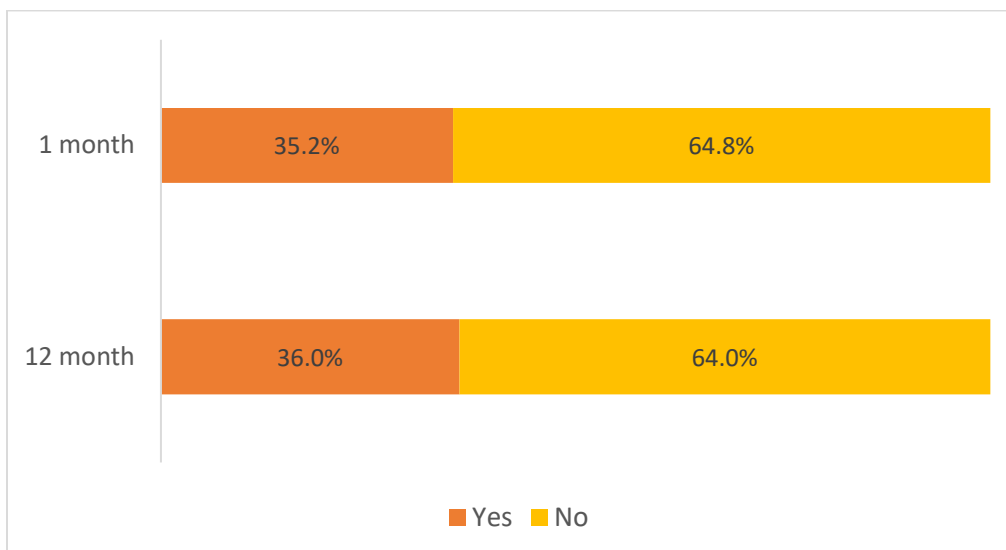


Figure 3.17. Depressive Symptoms\*

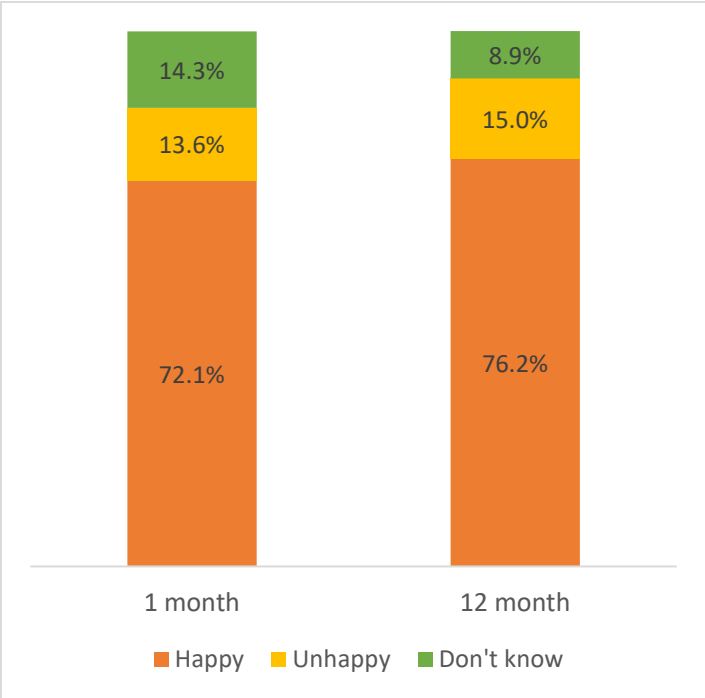


\*Depressive symptoms were determined using the Patient Health Questionnaire (PHQ-2) (Whooley et al., 1997).

**Overall Quality of Life**

Global life satisfaction increased over the year, with most consumers being happy with the way they live their life at both time points. At 1 month 72% of community residing consumers said they were happy with their lives; this increased to 76% at 12 months (Figure 3.18).

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



**H. Assistive Devices, Medical Equipment, Home Modifications**

The majority (92% at 1 month and 94% at 12 months) of community consumers reported having at least one type of assistive device, special equipment, or home modification (Figure 3.19). Although, at 1 month (34%) and at 12 months (37%), data showed that consumers lacked some type of device or modification needed for community living. This need has increased by approximately 10% from the previous year’s data.

Some consumers expressed a need for really simple, inexpensive, and easy to get assistive technology or devices, such as a reacher-grabber, walker, or shower chair. These can make such a difference in a person’s life and independence. It is difficult to understand why MFP consumers who need them are missing these devices. Necessary home modifications, such as ramps for safety, should be in place prior to transition.

- She needs a new walker and wheelchair. (1 month)*
- I need a reacher if possible because my hands don’t work well, and when nobody is here I have to wait to pick up something I dropped. (1 month)*
- I’m afraid I might fall because I don’t have any grab bars installed. (1 month)*
- I need a shower chair and a raised toilet seat because I can’t sit on the toilet. They haven’t gotten me a shower chair yet and I am upset about that. I haven’t taken a shower since I’ve been here. (1 month)*
- Any support with a hospital bed or shower chair would be appreciated. (1 month)*

*I'm waiting on a ramp to be installed. It's hard to leave my house right now without it. I don't know what the hold-up is. (1 month)*

*The program is vital, I just wish I could find a way for people to feel more comfortable with it and trust it. I do need PT and OT. I also need a joystick replaced for a motorized chair I was prescribed. I have been left 8 weeks without it as they cannot get the part, so I will need a new chair from my doctor's prescription. (12 month)*

*He is very happy with the services from his PCA. The one thing he wish he had was an entrance ramp so that he can get in and out of his apartment independently when his PCA is not there. (12 month)*

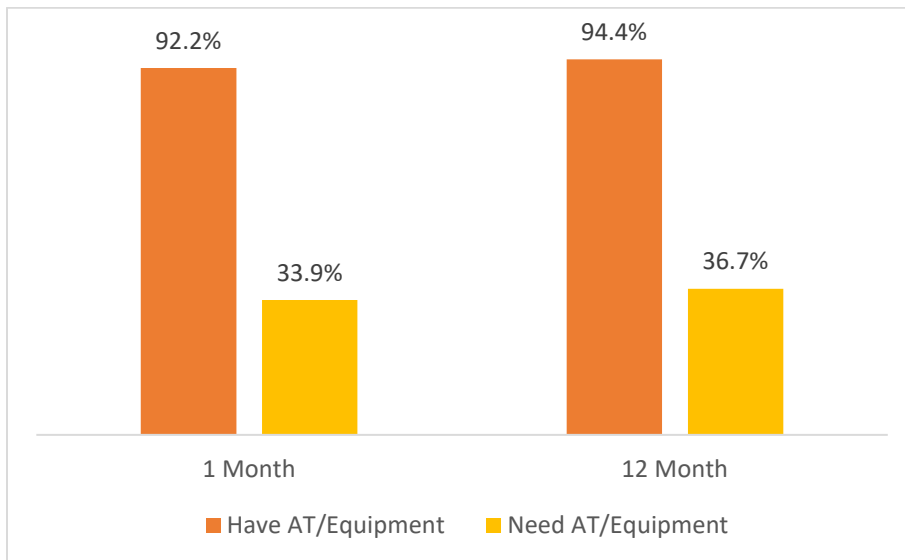
*I would like to get an air mattress for discomfort. (12 month)*

*[Consumer] needs a new bariatric bed. He is too tall. He is getting wounds on his feet because he is too big for his bed. His bariatric bed request has not been approved because he does not weigh enough. He needs more incontinent supplies like briefs. [Consumer] also has mobility issues. He tried to get motorized scooter and or wheelchair and neither have come in. (12 month)*

Sometimes medical insurance or budget limitations made it difficult to get the proper equipment to keep a person out in the community, such as the parent who was finding the manual lift to be physically challenging within just 1 month of transition:

*I wish we could get more hours and certain equipment such as the blood pressure cuff, roll-in shower and the Sera lift to make it easier to transfer my son. The manual crank lift is difficult. (1 month)*

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

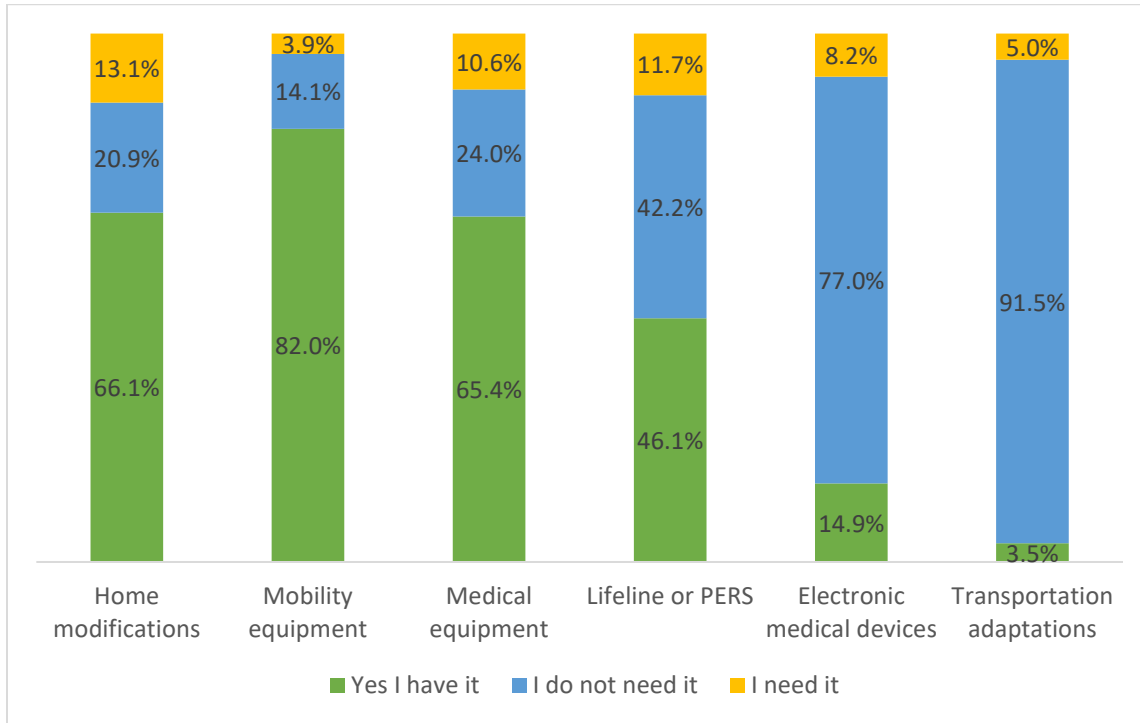


Consumers most often reported having mobility equipment, home modifications, or special medical equipment at both 1 and 12 months post transition (Figures 3.20 and 3.21). Although a personal emergency response system (PERS) is allowed under most budgets, only 46-51% of consumers at either 1 or 12 months reported having one.

At 1 month post-transition, consumers most commonly needed home modifications (13%), a PERS (12%), or special medical equipment (11%). At 12 months, 15 percent of consumers reported they still needed home modifications. Compared to 1 month after transition, there was a 3% increase in the

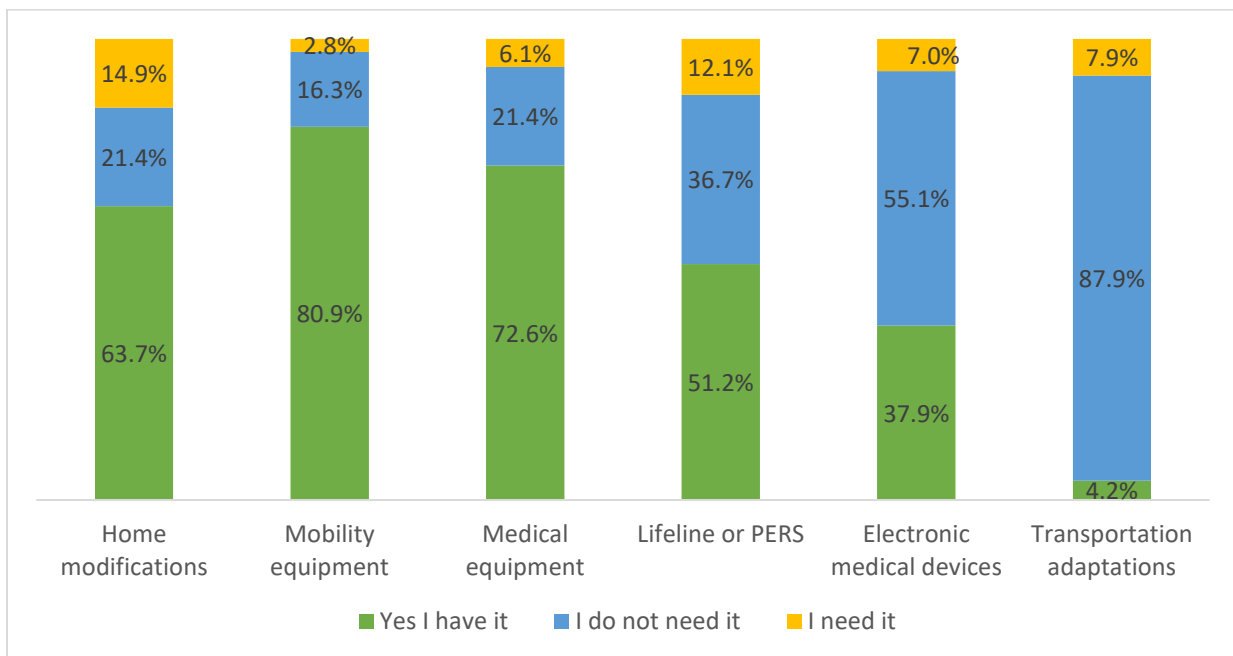
number of consumers who reported needing transportation aides at 12 months. There was a slight decrease in the number of consumers who still needed mobility equipment or electronic medical devices.

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



At both 1 and 12 months post-transition, more than 80% of participants reported having internet access at their home, and approximately 75% of consumers owned a computer, tablet, or smart phone. Overall,

less than 9% of consumers at 1 month or 12 months said they needed some type of internet capable device, and at 1 year post-transition, just 6% of consumers still needed internet access (Figures 3.22 and 3.23).

Figure 3.22. Internet Devices

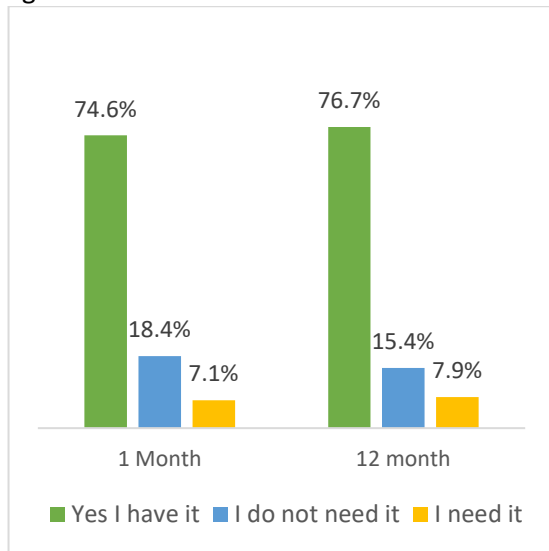
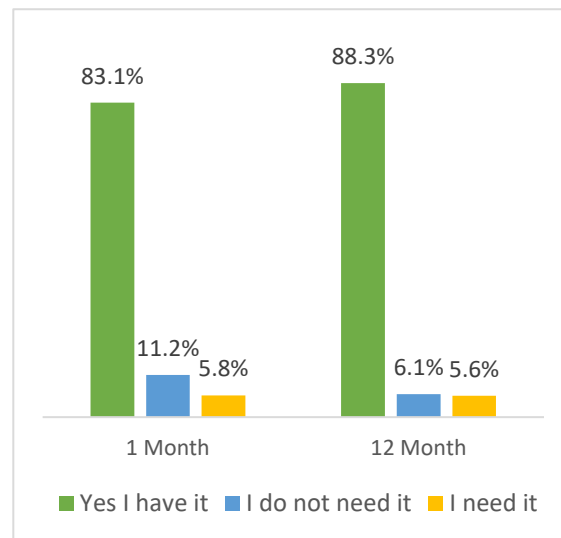


Figure 3.23. Internet Access



## I. Other Services

Nearly half of all participants at either time point reported using a van or transportation service for medical and/or nonmedical services. A small number of participants at either time point used a home delivered meal service, and very few reported using a day program (Tables 3.6 and 3.7).

Table 3.6. Home Delivered Meal Service Rating

	1 Month N=19 n (%)	12 Month N=20 n (%)
Excellent	6 (31.6)	6 (30.0)
Very Good	5 (26.3)	6 (30.0)
Good	7 (36.8)	4 (20.0)
Fair	1 (5.3)	2 (10.0)
Poor	0 (0)	2 (10.0)

Table 3.7. Day Program Rating

	1 Month N=4 n (%)	12 Month N=6 n (%)
Excellent	2 (50.0)	2 (33.3)
Very Good	1 (25.0)	2 (33.3)
Good	1 (25.0)	1 (16.7)
Fair	0 (0)	1 (16.7)
Poor	0 (0)	0 (0)

## Finances, Employment, and Volunteering

Thirty-one percent of consumers did not have enough money to make ends meet at both 1 and 12 months (Figure 3.24). Food insecurity (not having enough food, trouble getting SNAP or food stamps) was mentioned by several participants, whether caused by lack of or inadequate food stamps, transportation, or paid/unpaid support. Family members also expressed financial anxiety, indicating that the MFP consumer was not given enough money to live on, and so they had to supplement or step in.

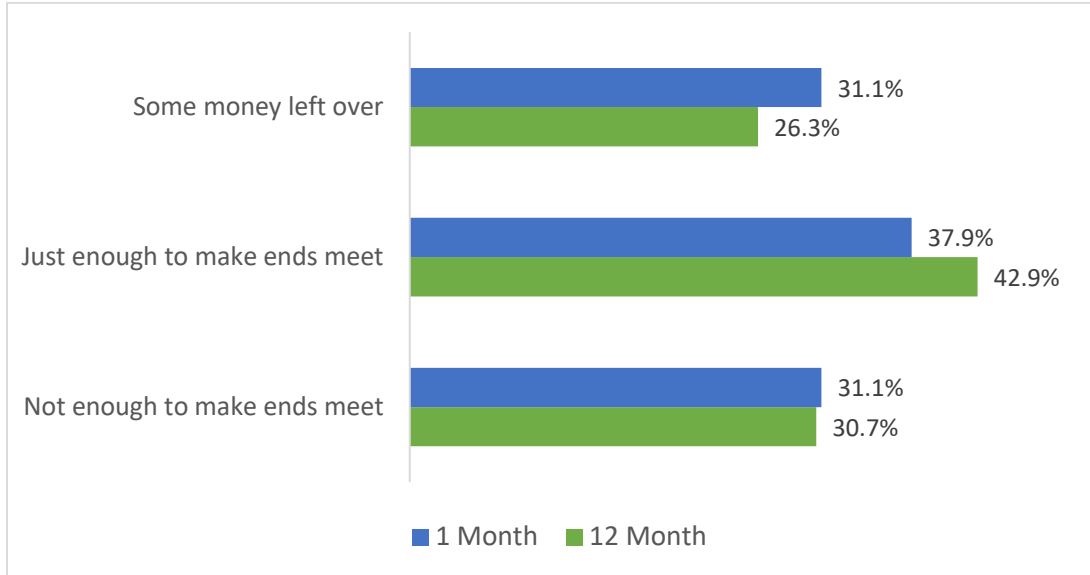
*I need help with moving [my mother's] furniture from old apartment to my apartment but we cannot afford movers. I had to cut my work hours to care for [my mother] who does not speak English. I am applying for Adult Family Living so I can be paid as caregiver. We are so stressed financially and there is no Social Security and we are not getting food stamps. I also would like my mother to socialize more and will look into senior center. (1 month)*

*What [my mother] receives from the state is not enough. I cover her expenses. (1 month)*

*I have not received my money. It is a nightmare, it is no one's fault – nobody can do anything. I need bras and things since I have gained weight. (1 month)*

*I need more assistance with food stamps. They used to give me \$30-40 but not anymore. (12 month)*

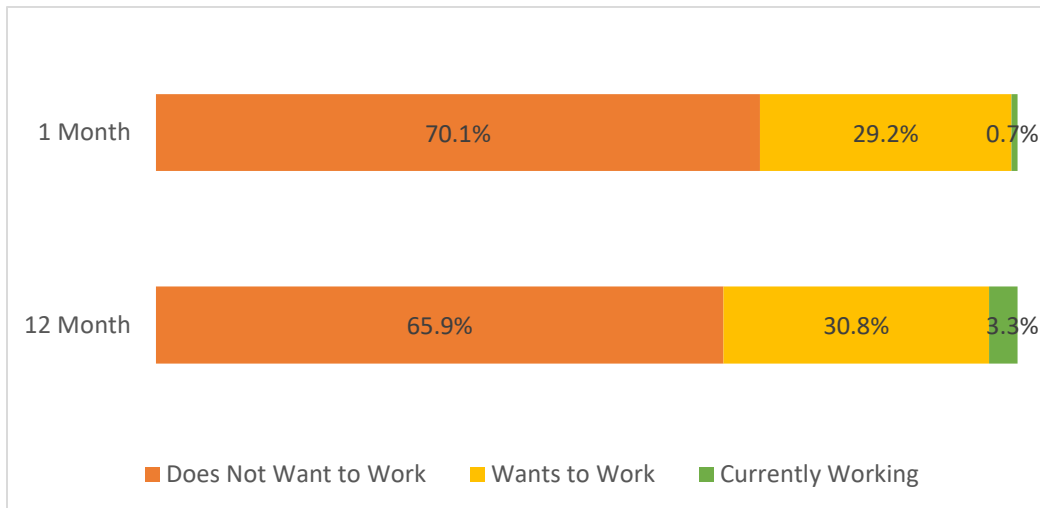
Figure 3.24. How Do Your Finances Usually Work Out at the End of the Month?



### Employment and Volunteering

All community residing consumers aged 18 and older were asked questions regarding work status and employment goals (Figure 3.25). Although very few consumers were working, about 30% of unemployed participants at both 1 month and 12 months wanted to work. These rates are higher than in 2022, when 23% of 1 and 12 month consumers wanted to work. Having a job often increases independence and community involvement. Connecting consumers who want to work with existing state and town employment supports is an area to focus on.

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, especially for participants who wanted to work (Table 3.8). 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 say retirement or "nothing is holding me back" as the reason for not working.

Table 3.8. Most Common Reasons for Not Working

Most Common Reasons for Not Working	Would like to work		Does not want to work	
	1 Month N= 82 n (%)	12 Month N= 65 n (%)	1 Month N= 197 n (%)	12 Month N= 139 n (%)
Health Concerns	69 (84.2)	55 (84.6)	104 (52.8)	85 (61.2)
Transportation	6 (7.3)	2 (3.1)	1 (<1)	4 (2.9)
Retired	0 (0)	0 (0)	21 (10.7)	11 (7.9)
Nothing/Do not want to work	4 (4.9)	2 (3.1)	75 (38.1)	40 (28.8)

Less than 10% of unemployed participants at either time point asked for assistance with finding a job (Figure 3.26). Of those who did not ask for help, only 25% at 1 month and 41% at 12 months 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

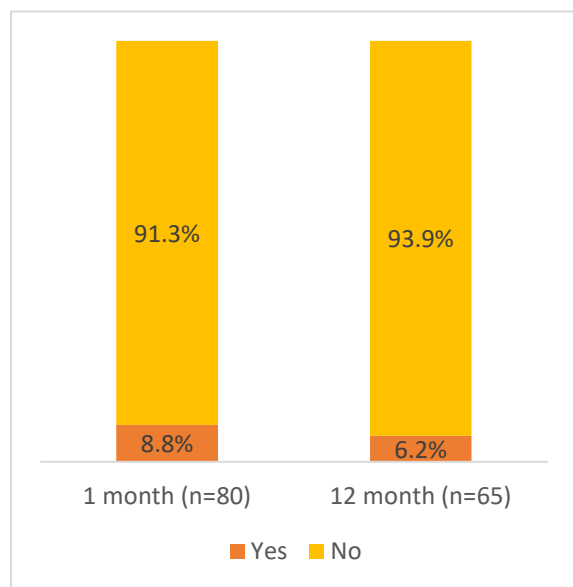
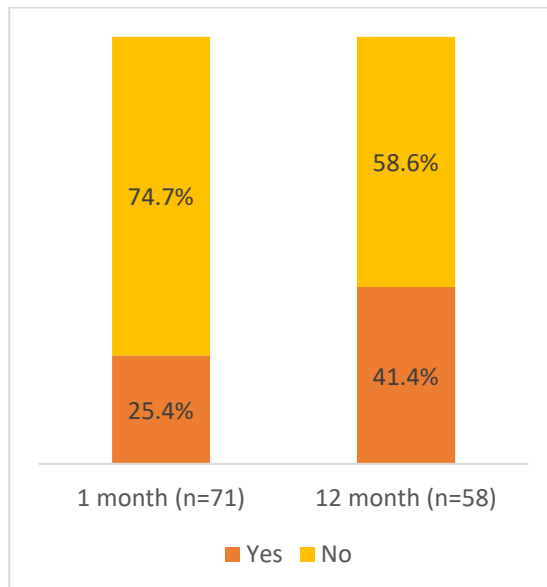


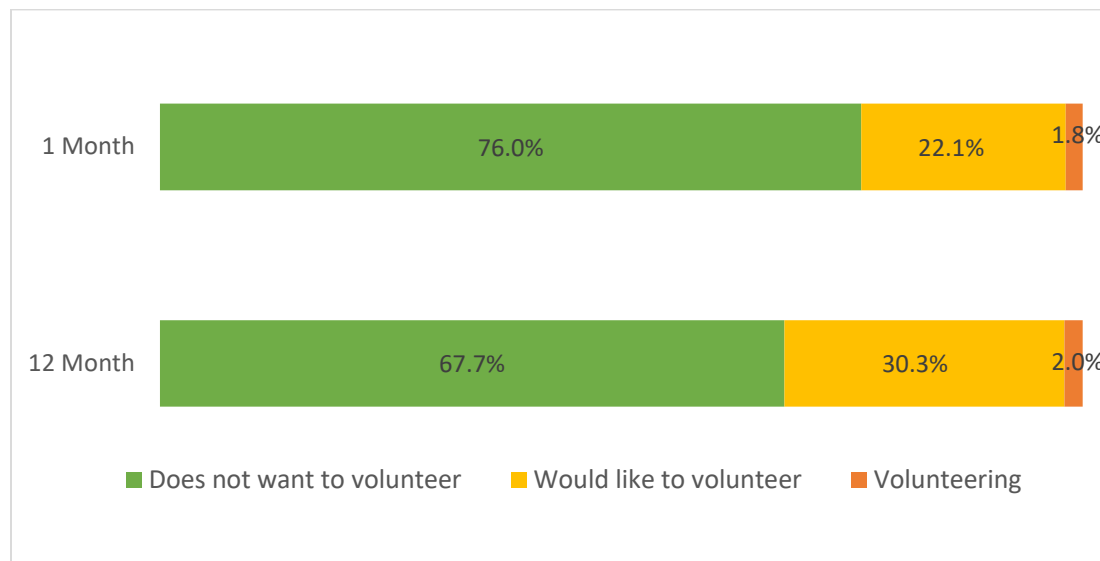
Figure 3.27. Aware of Employment Assistance



The percentage of consumers interested in volunteer work rose from 1 month to 12 months. Only 22% of consumers wanted to volunteer at 1 month, while 30% were interested at 12 months. The increase is not only indicated between 1 and 12 months, but also from what was reported in the previous year, where just 20% of consumers wanted to volunteer at 12 months. Consumers having more stability with their services and care needs may have contributed to the spike in interest by 12 months (Figure 3.28).

Connecting these participants with volunteering opportunities would likely increase their community engagement and support overall well-being.

Figure 3.28. Volunteering Status and Goals



## J. MFP program experiences

Although the HCBS CAHPS survey focused on services and experiences post-transition, other comments touched on the respondents’ experience with the MFP program or transition process. Some of this feedback was very positive, and overall people were so happy to be out of the facility. At the same time, respondents expressed confusion over what to expect from the program and who to go to for assistance. They wanted more information about what community services were available. They also wondered why they had not heard about MFP sooner.

*If it wasn't about the first nursing home [I was in], I would not know about MFP. A lot of people at nursing homes do not know about MFP. The second nursing home discouraged me. The MFP Housing and Transition coordinators found the accessible housing and made sure everything was all set. I was lucky enough to have a social worker to help me find out about housing and put me on waiting lists. The nursing home does not give nursing facility clients choice. The administer prejudices clients, and it [MFP program] was not posted widely in the nursing home. I called the Ombudsman and [they] introduced me to MFP. If I hadn't called the Ombudsman, none of this would have happened. Everything started to happen – forms, etc. I've had more help here than I ever did in the nursing home. The cost is way lower. My world has turned around. I am enjoying my life here! (1 month)*

*I wish they would provide us with more information on programs or other types of help that are available to him. (1 month)*

*I would like a number I can call if I have any questions. (1 month)*

Other feedback indicated need for better communication, both from the MFP staff to the consumer and family members, and between MFP and other HCBS programs. MFP staff turnover was mentioned a few times, as was the need for consistent follow-up.

*Lots of turnover with case manager – we haven't known who ours is for the past six months. We've also been waiting on Meals on Wheels for over six months. The communication at transition was horrendous because the 'consumer' was already on a home care plan so we didn't*



*even need MFP, but we were [told] that if he discharged without MFP, there wouldn't be any services received. (12 month)*

*I will say that it's been pretty confusing trying to figure out who is who and what is what with this program. I had a girl show up out of nowhere at my apartment and apparently she's working on my case but she never called or introduced herself previously. Don't get me wrong, everyone has been really nice and helpful, but it's just a lot all at once and it's confusing. (1 month)*

Appropriate housing which is affordable can be difficult to locate especially given the increase in rental costs. Consumers' comments expressing dissatisfaction with the housing process reflected this challenge. Consumers also mentioned difficulties with landlords and getting home modifications done after transition. Unfortunately, some consumers found that the community housing they transitioned to was not a good fit for them after all, such as the consumer who at 1 month commented, "I need a first floor apartment because I can't do these 23 stairs to my second floor."

Program structural guidelines could also be frustrating to consumers, and limitations regarding the transition budget were mentioned on a few occasions. One consumer could not understand why he was not allowed to buy a couch over the cost limit even if family members paid the difference. Another expressed frustration that he could not use transition budget funds to buy the items that he really needed, even though there was money left over because he already owned some of the items the funds could be used for.

## 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 2022 were separated into those who met the requirements for a waiver at transition and those who were not eligible for a waiver. Consumers accepted to a waiver (waiver consumers) were eligible for waiver HCBS at transition. Waiver consumers composed 80% of both the 1 month and 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 composed the remaining 20% 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	227 (79.6)	174 (80.2)
State Plan	58 (20.4)	43 (19.8)
All programs	285 (100.0)	217 (100.0)

### Services and Select Demographics

At transition, waiver consumers meet nursing facility level of care and are eligible for various waiver services to assist them with daily living tasks. State plan consumers do not meet facility level of care and do not need extensive assistance with activities of daily living (ADLs). Because of this, they receive limited or no HCBS. Table 4.2 highlights differences in self-reported service use between the two groups. For example, at 12 months, 76% of waiver consumers reported using some type of personal care assistance, compared to only 9% of state plan consumers.

Use of case management services is also quite different, especially 12 months post 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. In 2023, state plan consumers were slightly less likely to report using case management services 1 month post transition – 80% of waiver consumers reported using case management at 1 month post transition, compared to 74% of state plan consumers. The gap widens significantly at 12 months, with 60% of waiver consumers reporting the use of case management services, compared to 33% of state plan consumers.

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	164 (74.9)	7 (12.1)	129 (76.3)	4 (9.3)
Behavioral health services	3 (1.4)	0 (0)	2 (1.2)	0 (0)
Homemaking or Homemaker-Companion	164 (74.9)	10 (17.2)	126 (74.6)	7 (16.3)
Care management services	182 (80.2)	43 (74.1)	104 (59.8)	14 (32.6)
Recovery assistance services (MHW)	5 (62.5)	0 (0)	4 (80.0)	0 (0)
Community Service Provider (MHW)	7 (87.5)	0 (0)	2 (40.0)	0 (0)
Job coach or vocational supports	0 (0)	0 (0)	0 (0)	0 (0)
None of these services	4 (1.8)	12 (20.7)	8 (4.6)	22 (51.2)

\* Consumers can use more than one service

Unlike previous years, waiver and state plan consumers were the same age on average (60 years old). State plan consumers were more likely to be male (Table 4.3).

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

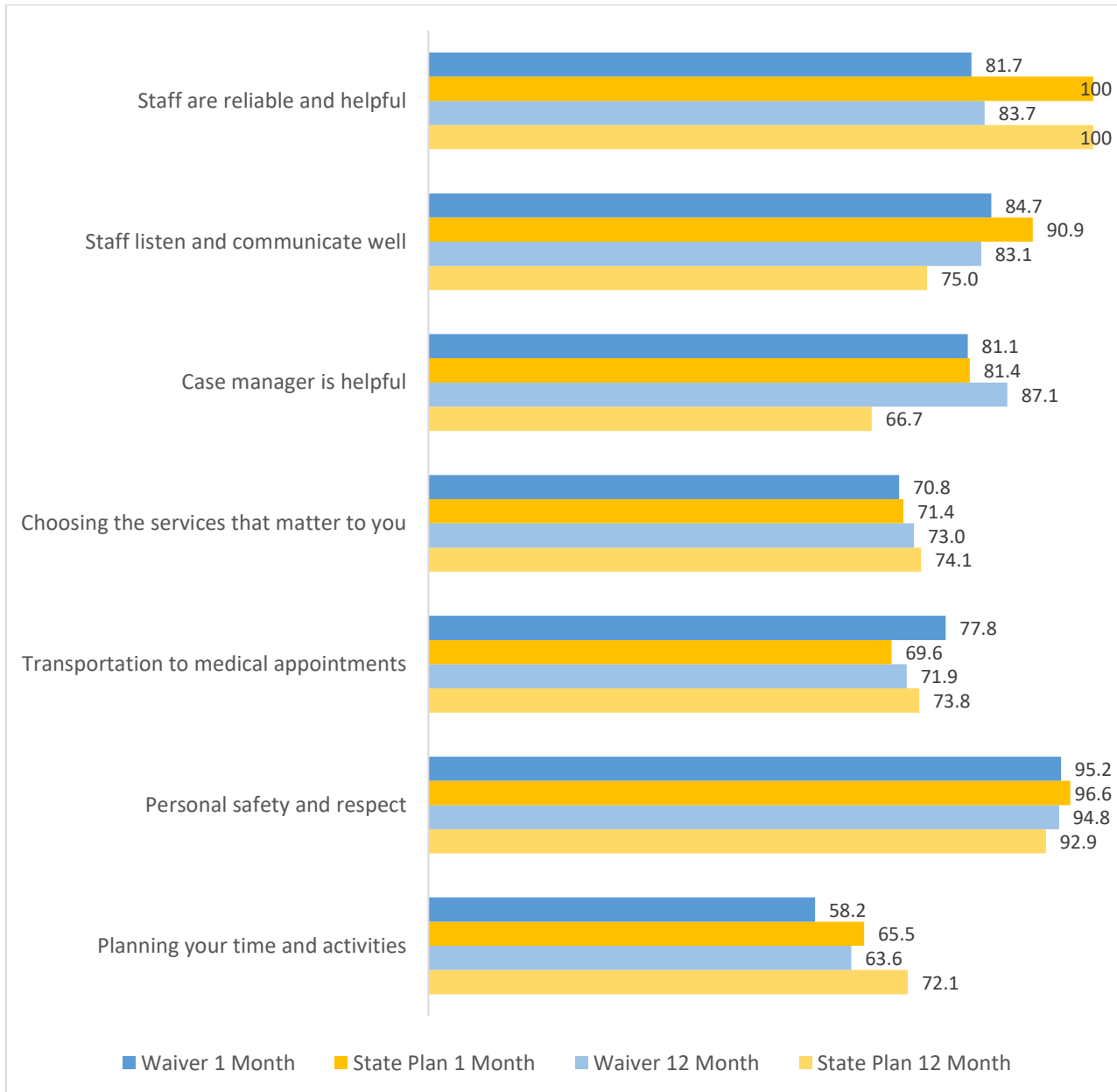
		1 Month		12 Month	
		Waiver %	State Plan %	Waiver %	State Plan %
Age		N=227	N=58	N=174	N=43
	<18	<1.0	1.7	1.1	2.3
	18-24	2.6	0.0	1.7	0.0
	25-34	4.8	6.9	5.7	2.3
	35-44	7.9	10.3	10.3	7.0
	45-54	11.9	20.7	13.2	23.3
	55-64	26.4	44.8	27.6	46.5
	65-74	25.1	12.1	21.3	11.6
	75+	20.3	3.4	19.0	7.0
Gender		N=227	N=58	N=176	N=43
	Male	47.1	58.6	46.6	58.1
	Female	52.9	41.4	53.4	41.9

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

Several of the composite measures showed noticeable differences between the two groups (Figure 4.1). For example, at both 1 and 12 months, 100% of state plan consumers gave the highest scores for the composite staff are reliable and helpful, compared to 82-84% of waiver consumers. On the

other hand, at 12 months, 87% of waiver consumers gave the highest score for the care manager composite, compared to only 67% of state plan consumers.

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



Both groups gave very similar global ratings for PCAs and case managers at 1 month and at 12 months (Figure 4.2). The percentage of consumers who would “definitely recommend” their PCAs or case managers varied between the groups and time points with no discernable trends (Figure 4.3). State plan consumers were much less likely to recommend their homemaking staff at both time points.

Comparing percentage differences for staff global ratings and recommendations between these populations has some limitations, given the small number of state plan consumers who reported using PCA and homemaking services in particular. For example, at 1 month, only 4 state plan consumers had PCA staff and 7 used homemaking services.

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

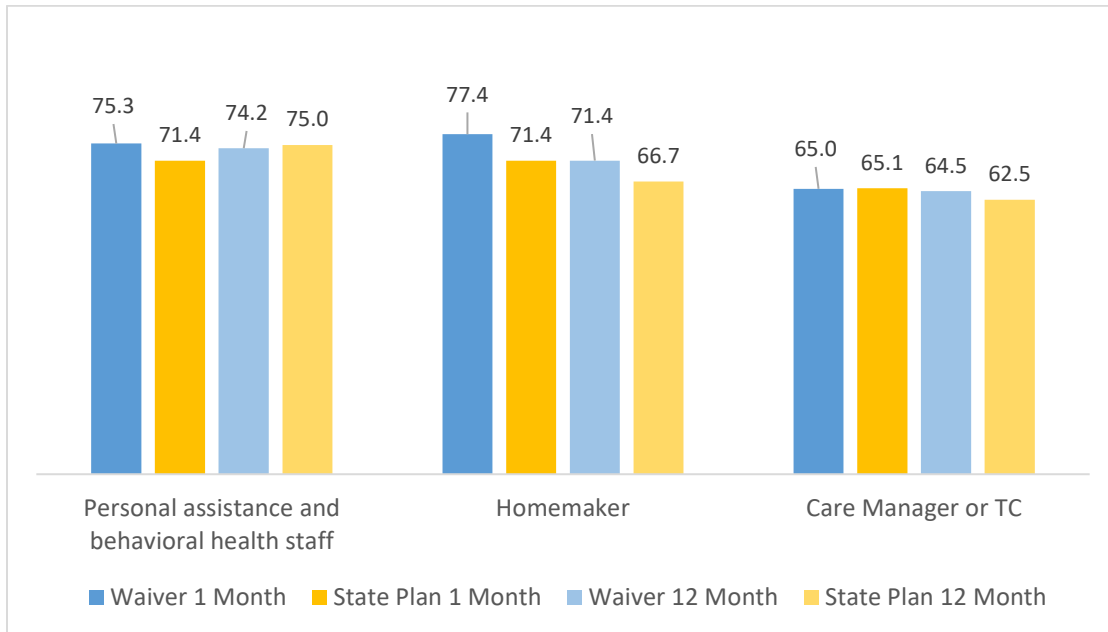
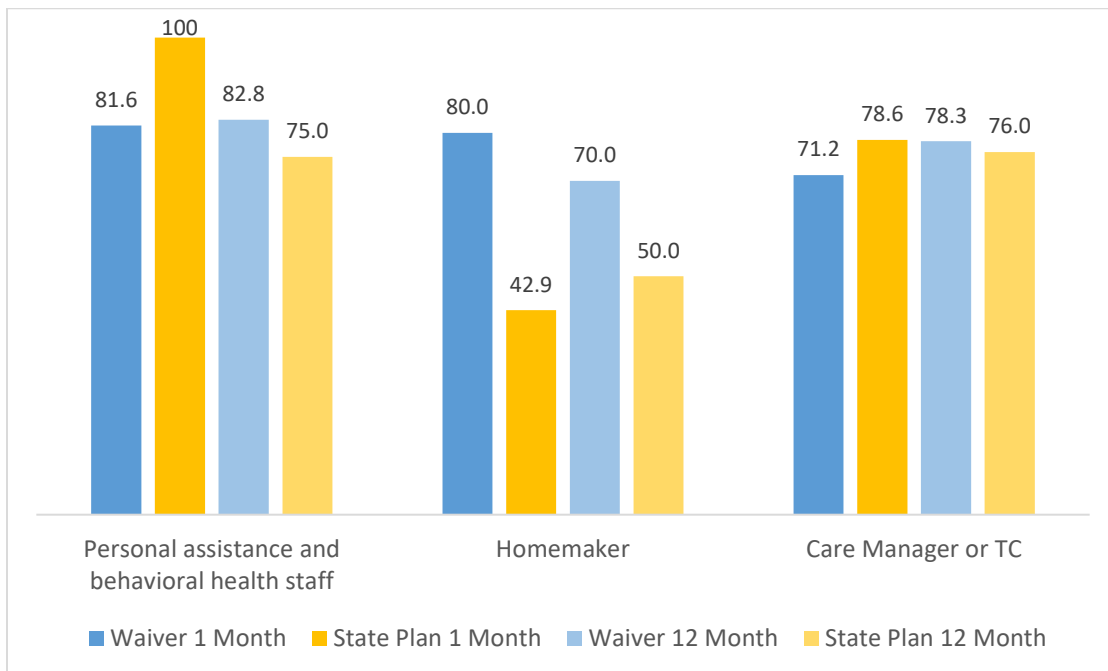


Figure 4.3. Recommendations by Waiver vs. State Plan: Percentage Who “Definitely” Recommend Staff



### Case Manager Items

By one year post transition, a noticeably lower percentage of both state plan and waiver consumers reported knowing their case manager or service coordinator. However, the percentage of state plan consumers who reported knowing their case manager at 12 months increased over the past year, from 49% in 2022 to 68% in 2023 (Figure 4.4). By 12 months, state plan consumers were much less likely to be able to contact their case managers (Figure 4.5).

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

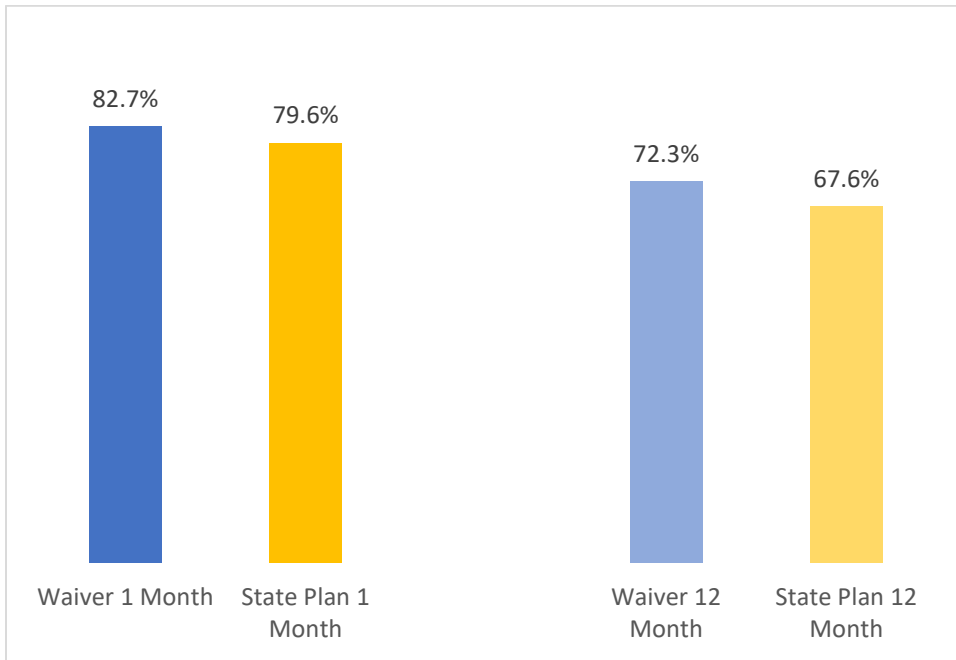
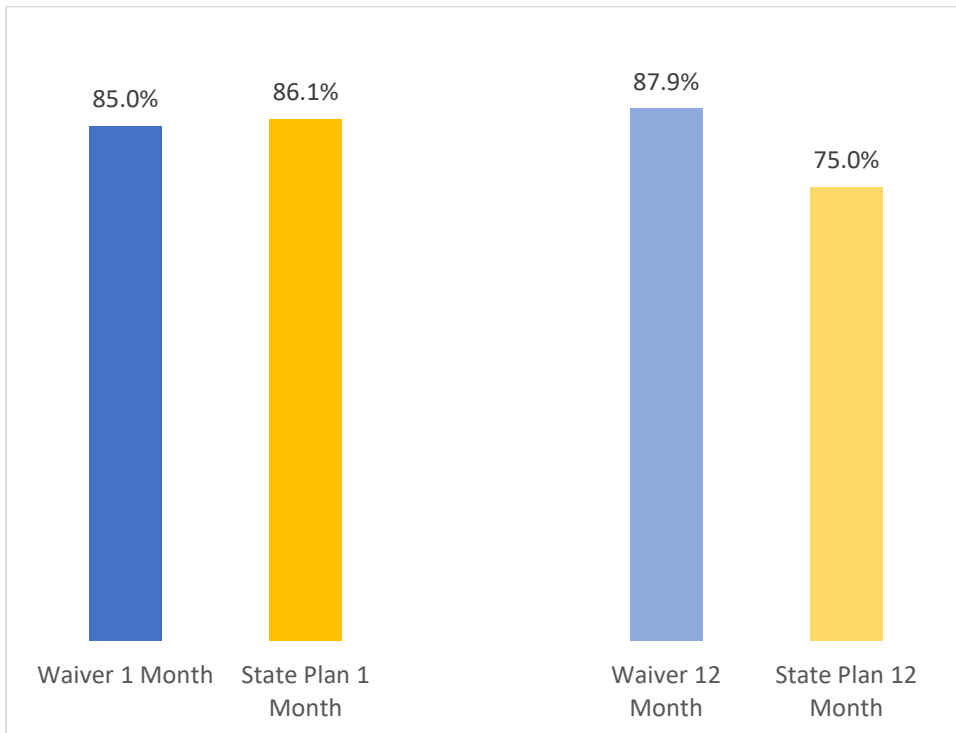
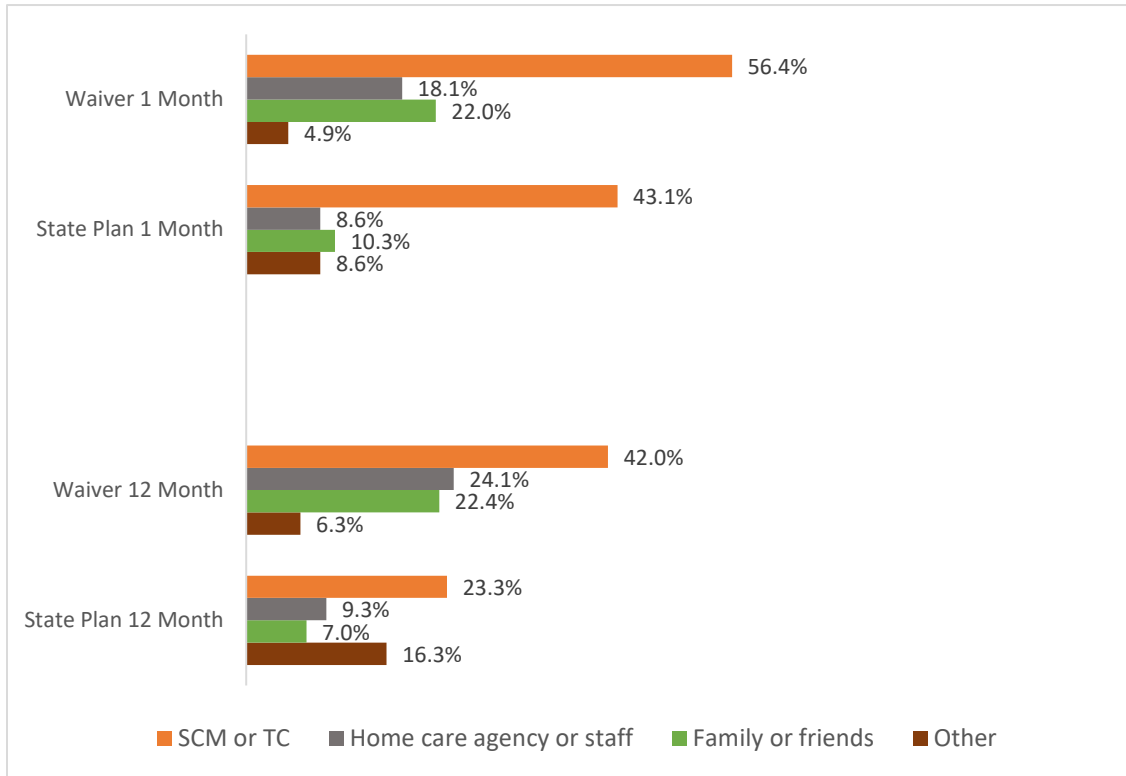


Figure 4.5. Able to Contact Case Manager, Waiver vs. State Plan



Although at 1 month both groups of consumers received TC services and waiver services had not started, waiver consumers were still more likely to talk to their TC or SCM if they wanted to change their care plan, especially at 12 months post transition (Figure 4.6). Overall, waiver consumers reported having more resources to turn to 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*

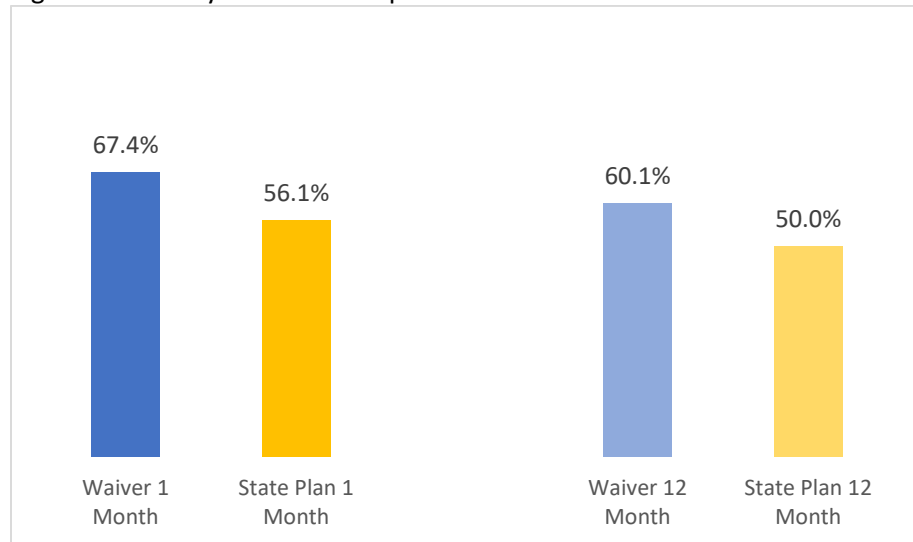
Overall, consumers with state plan services reported less social support than consumers who received services through a waiver, especially at 1 month. Consumers with state plan services were much more likely to live alone at both time periods – 81% of consumers with state plan services lived alone at 12 months, compared to 54% of waiver consumers (Table 4.4). At 1 month, state plan consumers were less likely to live with family or have family members 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=224	N=58	N=174	N=42
1	55.4	65.5	53.5	81.0
2-3	42.0	17.2	42.5	16.7
4+	2.7	17.2	4.0	2.4
Lives with family members	N=101	N=20	N=81	N=8
Yes	75.3	45.0	74.1	75.0
No	24.8	55.0	25.9	25.0
Lives with non-family	N=101	N=20	N=81	N=8
Yes	26.7	60.0	29.6	25.0
No	73.3	40.0	70.4	75.0
Family members live nearby	N=226	N=58	N=173	N=43
Yes	71.7	56.9	72.3	69.8
No	28.3	43.1	27.8	30.2
Friends live nearby	N=226	N=58	N=172	N=42
Yes	49.1	53.5	52.3	45.2
No	50.9	46.6	47.7	54.8

Waiver consumers were more likely to report getting unpaid assistance around the house from family or friends at both 1 and 12 months. However, state plan consumers reported a large increase in informal support around the house compared to last year – in 2022 at 12 months 29% of state plan consumers reported this help, compared to 50% in 2023 (Figure 4.7).

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



Waiver consumers were consistently more likely to like where they live and to feel safe living there than state plan consumers (Figures 4.8, 4.9). By 12 months after transition, only 69% of state plan consumers liked where they lived.

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

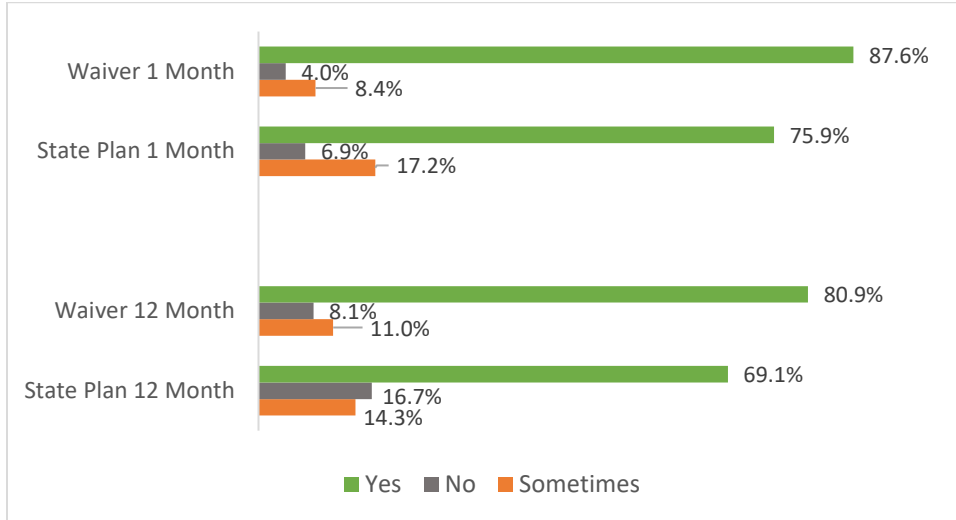
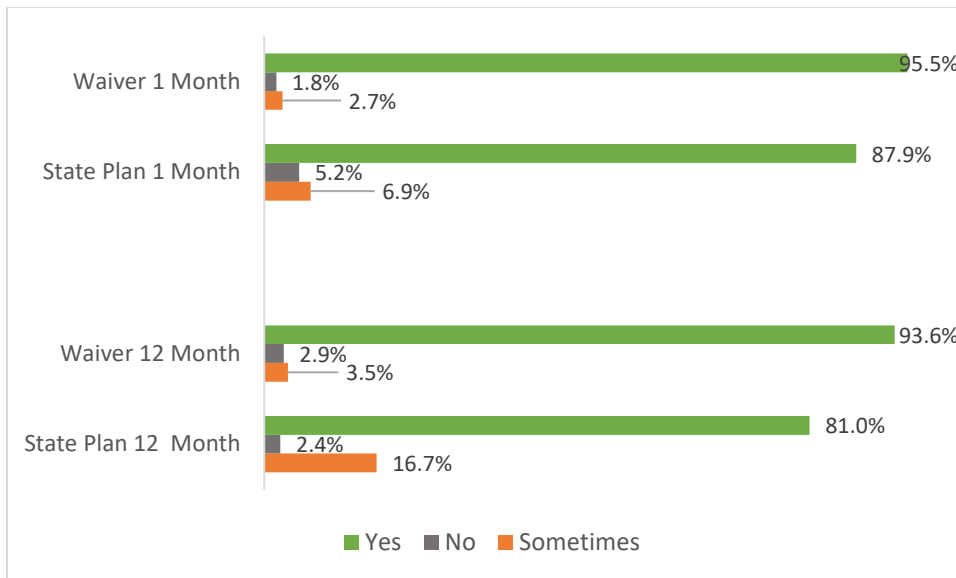


Figure 4.9. Do You Feel Safe Living Here? Waiver vs. State Plan

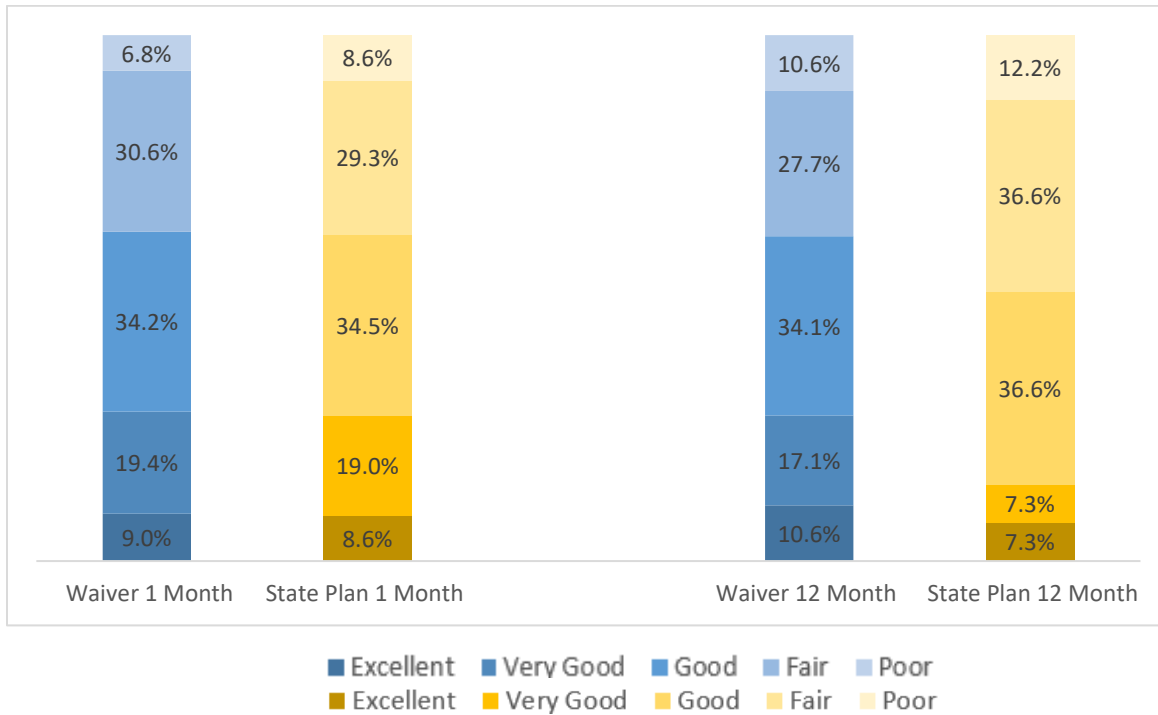


### Physical Health

When asked to rate their physical health, 37-38% of both waiver and state plan consumers reported fair or poor health (Figure 4.10). However, by 12 months, state plan consumers indicated that their overall physical health had worsened relative to waiver consumers. Nearly half (49%) of state plan consumers reported fair or poor health at 12 months, while the percentage of waiver consumers in fair or poor health remained stable at 37-38%.

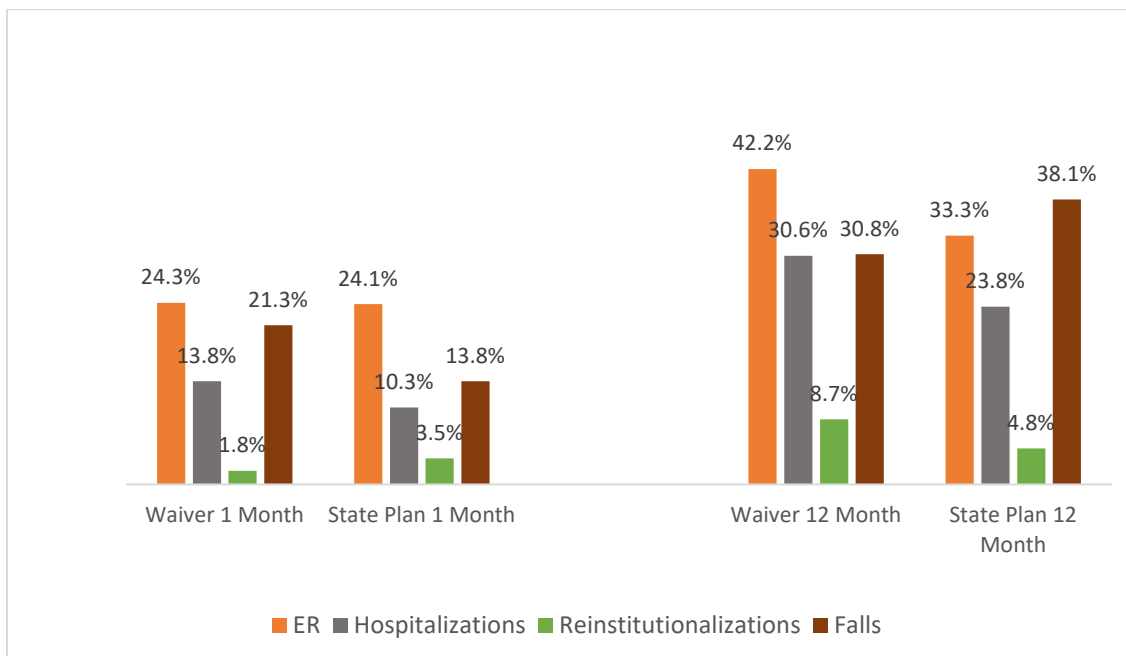


Figure 4.10. Self-reported Physical Health: Waiver vs. State Plan



Rates of emergency room visits, hospitalizations, nursing home readmissions, and falls showed some between group differences with few identifiable trends (Figure 4.11). At 12 months, waiver consumers experienced more emergency room visits than state plan consumers (42% to 33% respectively), which may contribute to the higher rate of hospitalizations among the waiver group.

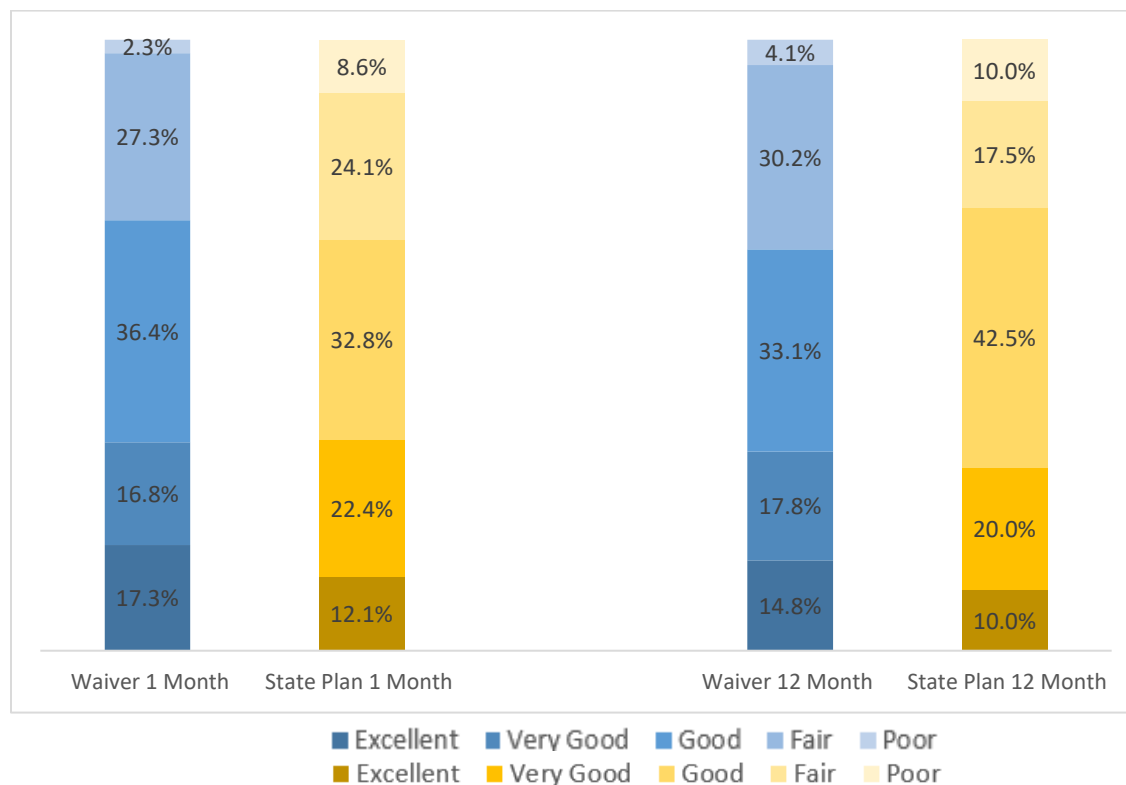
Figure 4.11. ER Visits, Hospitalizations, Reinstitutionalizations, and Falls: Waiver vs. State Plan



## Mental Health

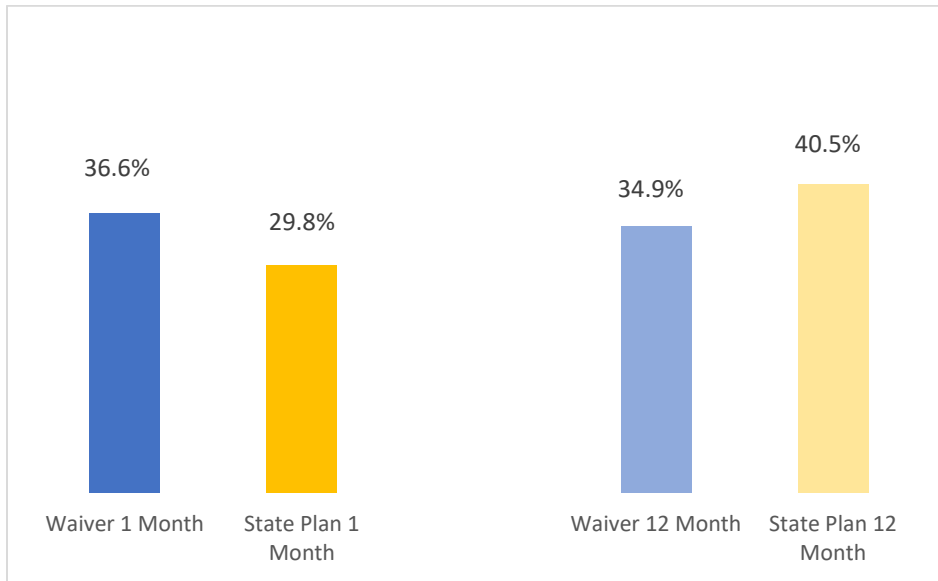
There were some differences between the two groups when comparing reported mental or emotional health status (Figure 4.12). At 12 months, state plan consumers reported slightly better mental health than waiver consumers – 73% of state plan consumers reported their mental health good, very good or excellent, compared to 66% of waiver consumers. This differs from 2022 when both state plan and waiver consumers rated their mental health better at 12 months.

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



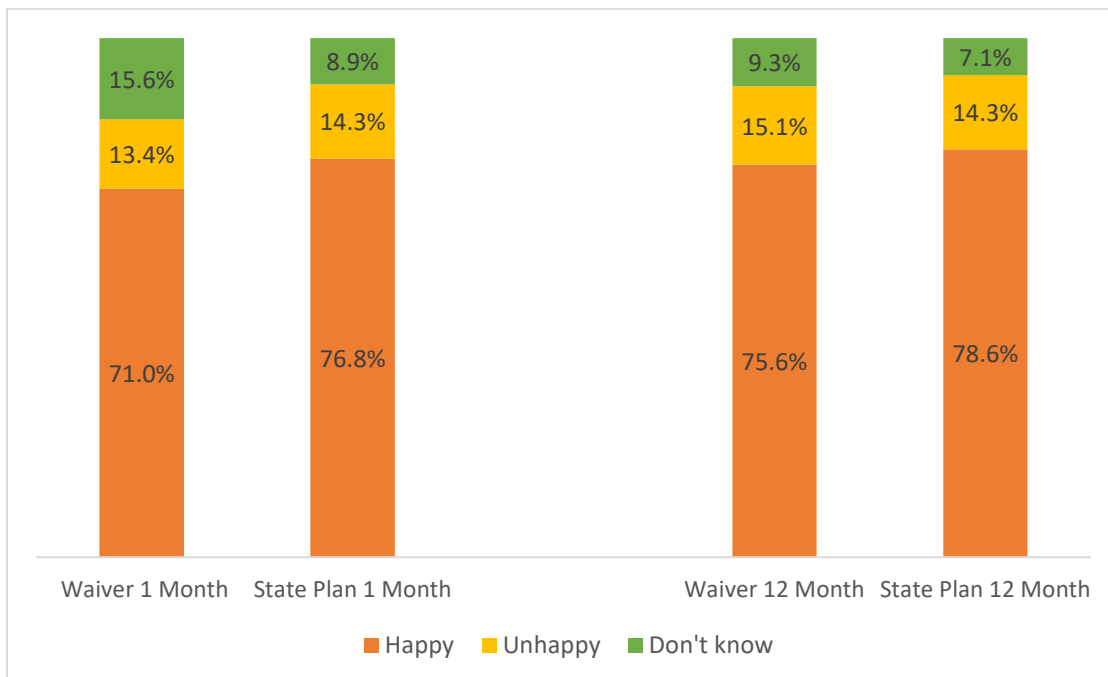
Consumers were asked whether they experienced depressive symptoms, characterized by a lack of interest in doing things and/or or feeling down, depressed or hopeless. Unlike last year, there were some notable differences in depressive symptoms between the two groups. At 1 month, waiver consumers were more likely to report depressive symptoms, but by 12 months post transition, state plan consumers reported more depressive symptoms (Figure 4.13). It is interesting that at 12 months state plan consumers reported better mental health compared to waiver consumers, but still reported more depressive symptoms.

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



As shown in Figure 4.14, the majority of both waiver and state plan consumers reported being happy with the way they live their life at either time point, with little difference between both groups. The percentage of state plan consumers reporting being happy increased over last year – in 2022 67% reported being happy with the way they live their life, compared to 79% this year.

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 home modifications, mobility or medical equipment, or a PERS unit at both 1 and 12 months. This may be an effect of the greater physical needs of waiver consumers. It could also be that waiver consumers have greater access to some of these items, given that state plan consumers reported

greater unmet need for a PERS unit and medical equipment at 12 months.

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=226	N=57	N=173	N=42
	I have it	72.1	42.1	69.4	40.5
	I do not need it	14.2	47.4	15.6	45.2
	I need it	13.7	10.5	15.0	14.3
Mobility equipment		N=226	N=57	N=173	N=42
	I have it	88.1	57.9	86.1	59.5
	I do not need it	8.4	36.8	11.0	38.1
	I need it	3.5	5.3	2.9	2.4
Medical equipment		N=226	N=57	N=173	N=42
	I have it	74.8	28.1	82.7	31.0
	I do not need it	15.0	59.7	13.3	54.8
	I need it	10.2	12.3	4.1	14.3
Lifeline or PERS		N=225	N=57	N=173	N=42
	I have it	55.1	10.5	60.1	14.3
	I do not need it	33.3	77.2	30.6	61.9
	I need it	11.6	12.3	9.3	23.8
Internet capable devices		N=226	N=57	N=173	N=42
	I have it	73.9	77.2	78.0	71.4
	I do not need it	18.6	17.5	14.5	19.1
	I need it	7.5	5.3	7.5	9.5
Internet access		N=223	N=55	N=172	N=41
	I have it	85.2	74.6	89.0	85.4
	I do not need it	10.8	12.7	5.8	7.3
	I need it	4.0	12.7	5.2	7.3

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

Community living consumers who transitioned in 2022 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 respondent’s answer determined the service type 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, at 1 month 86% of consumers used agency-based services, while just 14% self-directed their services. By 12 months, use of self-directed services increased to 21%. With the addition of agency-based services to the PCA waiver, use of agency-based services at 1 month post-transition has grown substantially over the past 4 years, from 69% in 2020 to 86% in 2023.

## Services and Select Demographics

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

	1 Month n (%)	12 Month n (%)
Agency-based	181 (85.8)	126 (78.8)
Self-directed	30 (14.2)	34 (21.3)
Total	211 (100.0)	160 (100.0)

Compared to agency-based consumers, self-directed consumers reported greater use of personal care and homemaking services at 1 month (Table 5.2). Use of case management varied by timepoint. At 1 month self-directed consumers reported greater use of this service, while at 12 months, agency-based consumers were more likely to report using case management.

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	139 (79.9)	27 (90.0)	102 (83.6)	29 (85.3)
Behavioral health services	2 (1.1)	0 (0)	1 (<1.0)	1 (2.9)
Homemaking services or Homemaker-Companion services	138 (79.3)	27 (90.0)	102 (83.6)	24 (70.6)
Care management services	147 (81.2)	27 (90.0)	81 (64.3)	18 (52.9)
Recovery assistance services (MHW only)	5 (71.4)	0 (0)	3 (75.0)	0 (0)
Community Service Provider (MHW only)	6 (85.7)	0 (0)	2 (50.0)	0 (0)
Job coach or vocational supports	0 (0)	0 (0)	0 (0)	0 (0)
None of these services	0 (0.0)	0 (0)	1 (<1.0)	0 (0)

\* Consumers can use more than one service

At both 1 and 12 months, agency-based consumers were more likely than self-directed consumers to be 65 years or older (Table 5.3). Self-directed consumers were more likely to be female at 1 month.

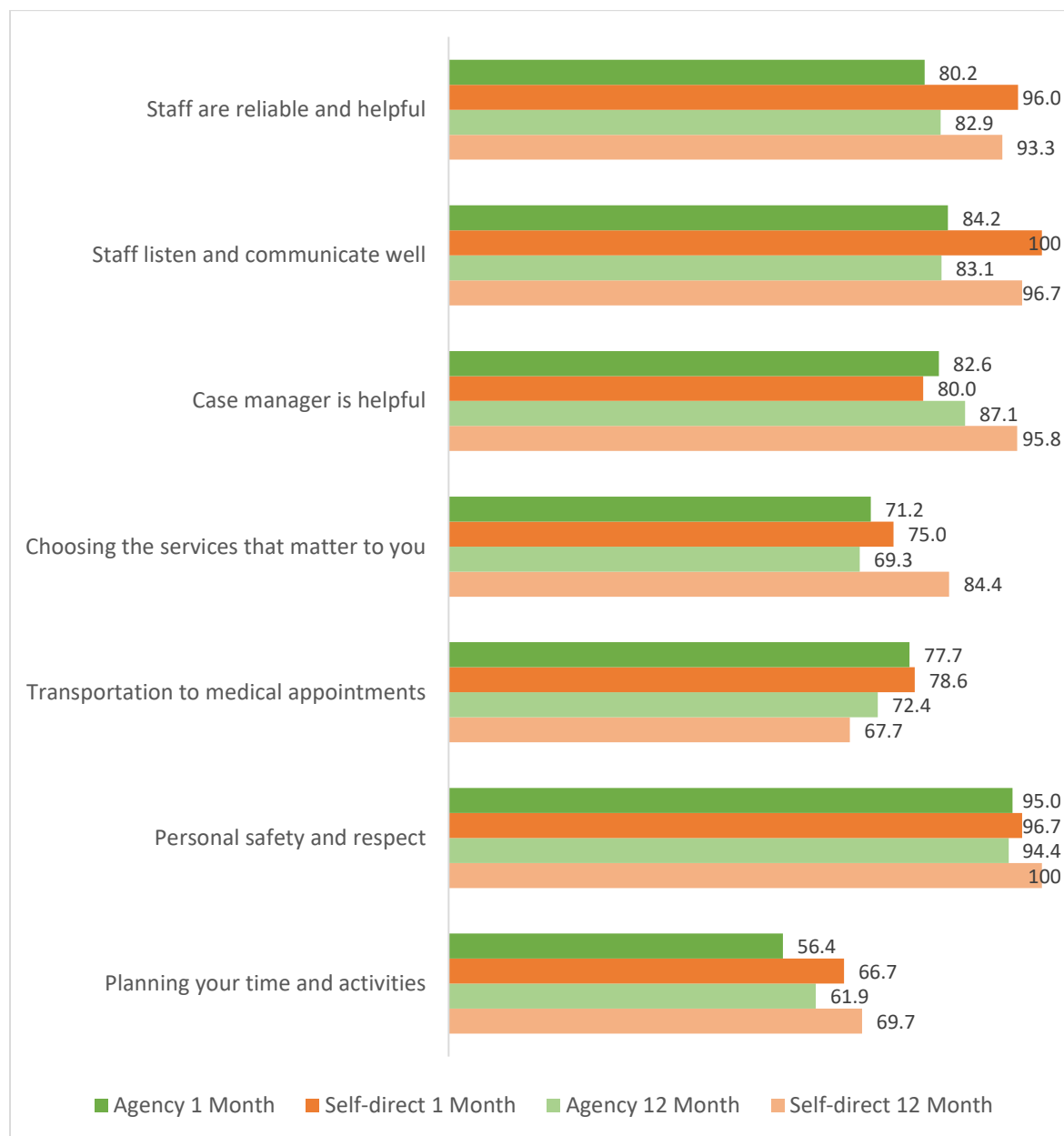
Table 5.3. Demographics: Agency vs. Self-direct

	1 Month		12 Month	
	Agency %	Self-direct %	Agency %	Self-direct %
Age	N=181	N=30	N=126	N=34
<18	<1.0	3.3	<1.0	2.9
18-24	1.7	10.0	0	8.8
25-34	3.9	10.0	3.2	11.8
35-44	6.6	6.7	10.3	8.8
45-54	10.5	13.3	12.7	14.7
55-64	29.8	23.3	27.0	32.4
65-74	24.9	20.0	24.6	11.8
75+	22.1	13.3	21.4	8.8
Gender	N=181	N=30	N=126	N=34
Male	45.9	40.0	42.9	44.1
Female	54.1	60.0	57.1	55.9

## 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 and listened and communicated well. Overall, self-directed consumers reported higher ratings for all the composite measures, including choosing the services that matter to you at 12 months. While similar percentages of both groups gave the highest score to this composite at 1 month, self-directed consumers had a significant increase by 12 months (69% agency vs. 84% self-direct).

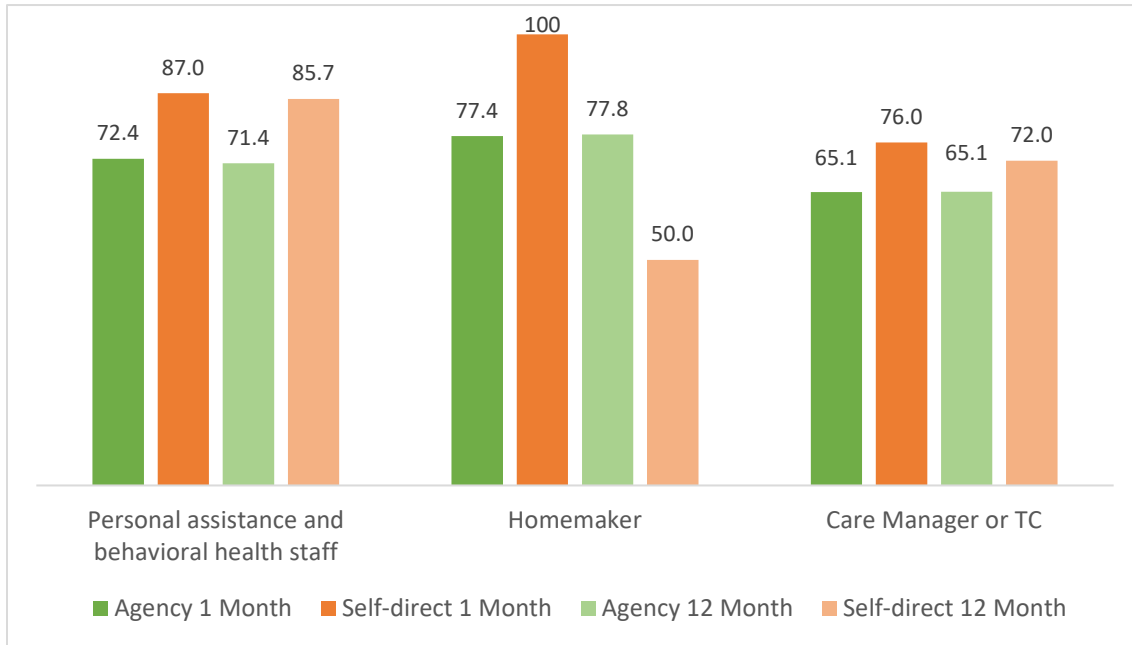
Figure 5.1. Composite Measures by Agency vs. Self-direct: Percentage with Highest Scores



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 staff notably higher than agency-based consumers. Because most self-directed

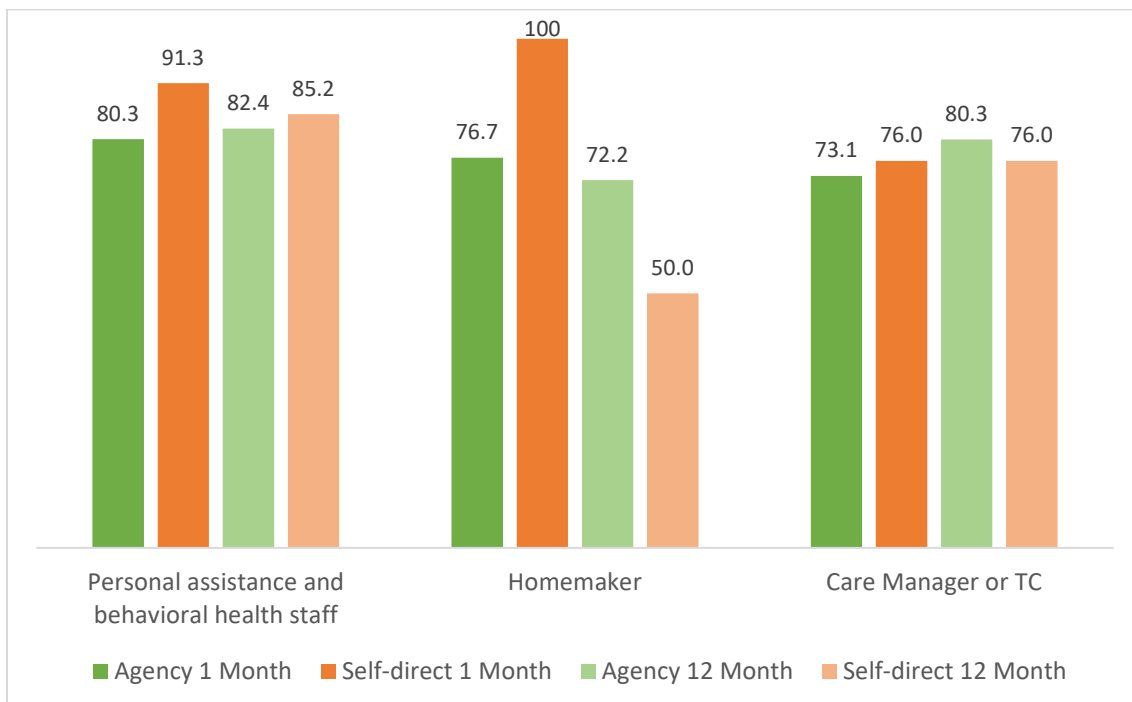
consumers used their PCAs for homemaking tasks as well as personal care, the homemaking only staff sample size for self-directed consumers was very small (n=1 1 month, n=2 12 month), which limits group comparisons for this particular service. Self-directed consumers were more likely to rate their care managers a 9 or 10 at both time points.

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



Similar to global ratings, self-directed consumers were more likely to “definitely” recommend their PCAs, especially at 1 month (Figure 5.3).

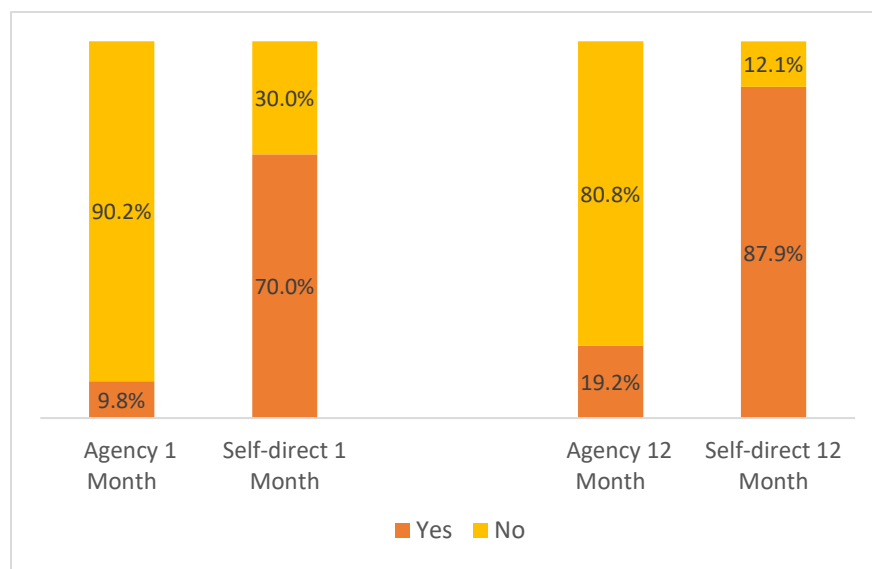
Figure 5.3. Recommendations by Agency vs. Self-direct: Percentage Who “Definitely” Recommend Staff



### 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?” As can be expected, self-directed consumers were much more likely to report choosing their paid assistants at both time points.

Figure 5.1. 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 almost all activities.

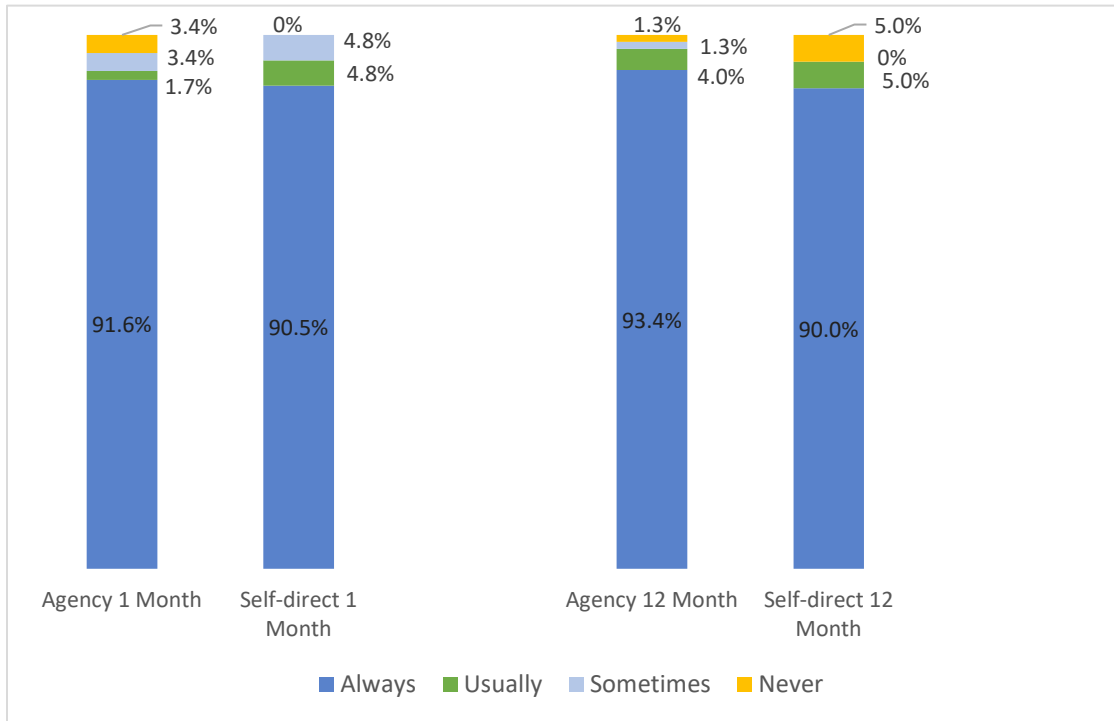
Table 5.4. Self-reported Assistance with Everyday Activities: Agency vs. Self-direct

Needs assistance with:	1 Month	1 Month	12 Month	12 Month
	Agency Based n (%)	Self-direct n (%)	Agency Based n (%)	Self-direct n (%)
Personal care	122 (83.6)	22 (91.7)	77 (73.3)	23 (82.1)
Meals or eating	112 (77.2)	19 (79.2)	86 (81.9)	24 (85.7)
Taking medications	83 (57.2)	16 (66.7)	63 (60.0)	19 (67.9)
Using the toilet	83 (56.9)	14 (58.3)	48 (45.7)	20 (71.4)
Housekeeping or laundry	138 (79.3)	27 (90.0)	102 (85.0)	24 (72.7)

The overwhelming majority ( $\geq 90\%$ ) of both agency-based and self-directed consumers reported always having enough personal privacy when receiving help with bathing or dressing (Figure 5.5).

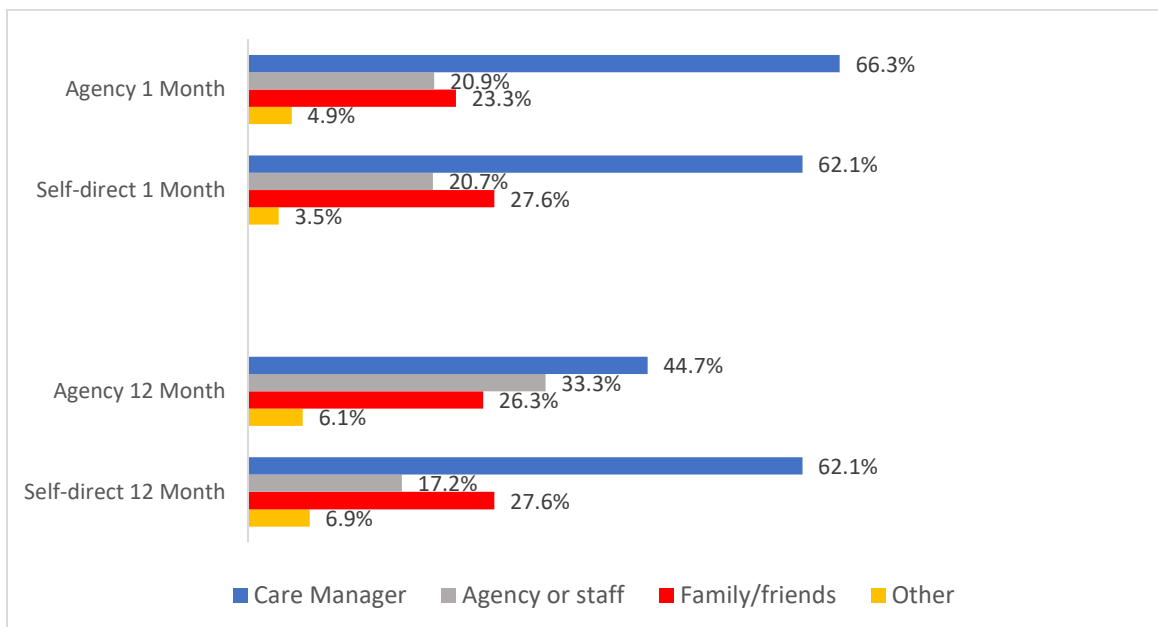


Figure 5.5. How Often Do You Have Enough Personal Privacy When You Dress or Bathe? Agency vs. Self-direct



At both 1 and 12 months, both agency-based and self-directed consumers were most likely to contact their case managers, SCMs, or TCs to change their care plan, next usually turning to family or friends (Figure 5.6). Agency-based consumers showed an interesting shift over time. By 12 months, the percentage of agency-based consumers who would contact their case manager to change their care plan dropped, while the percentage of these consumers who would contact an agency or staff increased.

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

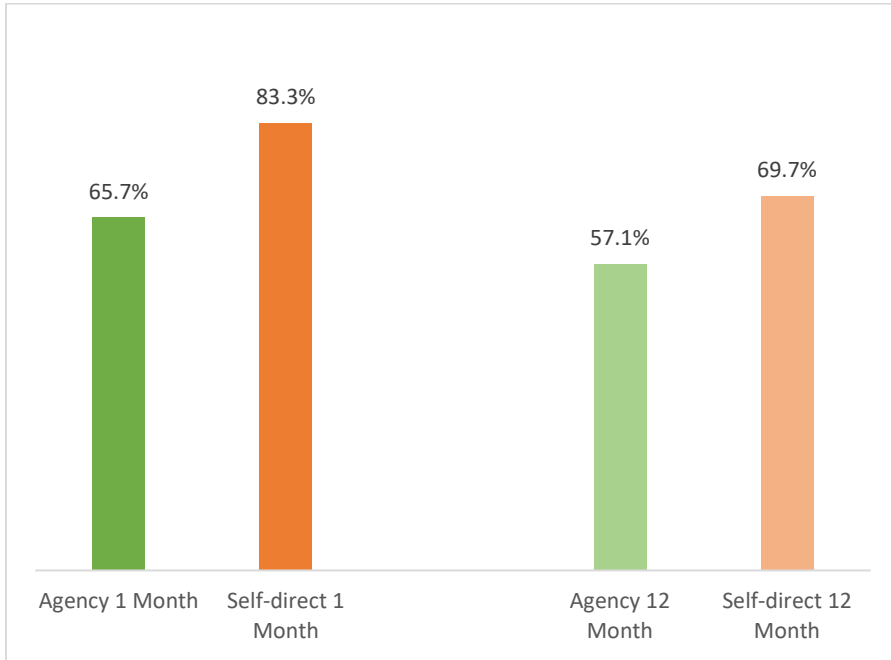
Household composition showed strong differences between the two groups of consumers (Table 5.5). The percentage of each group who live alone is most striking – at both time points, agency-based consumers were much more likely to live alone. Of the consumers who lived with someone, at both time points agency-based consumers were less likely to live with family, but much more likely to live with someone they were not related to, such as a live-in PCA. At 1 month, a greater percentage of agency-based consumers had family members who lived nearby, although by 12 months self-directed consumers were just as likely to live near family members.

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=179	N=30	N=126	N=34
1	58.1	36.7	59.5	26.5
2-3	39.1	56.7	36.5	70.6
4+	2.8	6.7	4.0	2.9
Lives with family member/s	N=75	N=19	N=51	N=25
Yes	69.3	89.5	64.7	92.0
No	30.7	10.5	35.3	8.0
Lives with non-family	N=75	N=19	N=51	N=25
Yes	33.3	10.5	39.2	8.0
No	66.7	89.5	60.8	92.0
Family member/s live nearby	N=180	N=30	N=126	N=33
Yes	73.3	60.0	73.0	72.7
No	26.7	40.0	27.0	27.3
Friend/s live nearby	N=180	N=30	N=126	N=32
Yes	50.0	43.3	52.4	56.3
No	50.0	56.7	47.6	43.8

Figure 5.7 shows that at 1 and 12 months post-transition, self-directed consumers reported receiving much more informal support from family and friends for household tasks, especially at 1 month post-transition. This is consistent with the higher rate at which family members live with self-directed consumers.

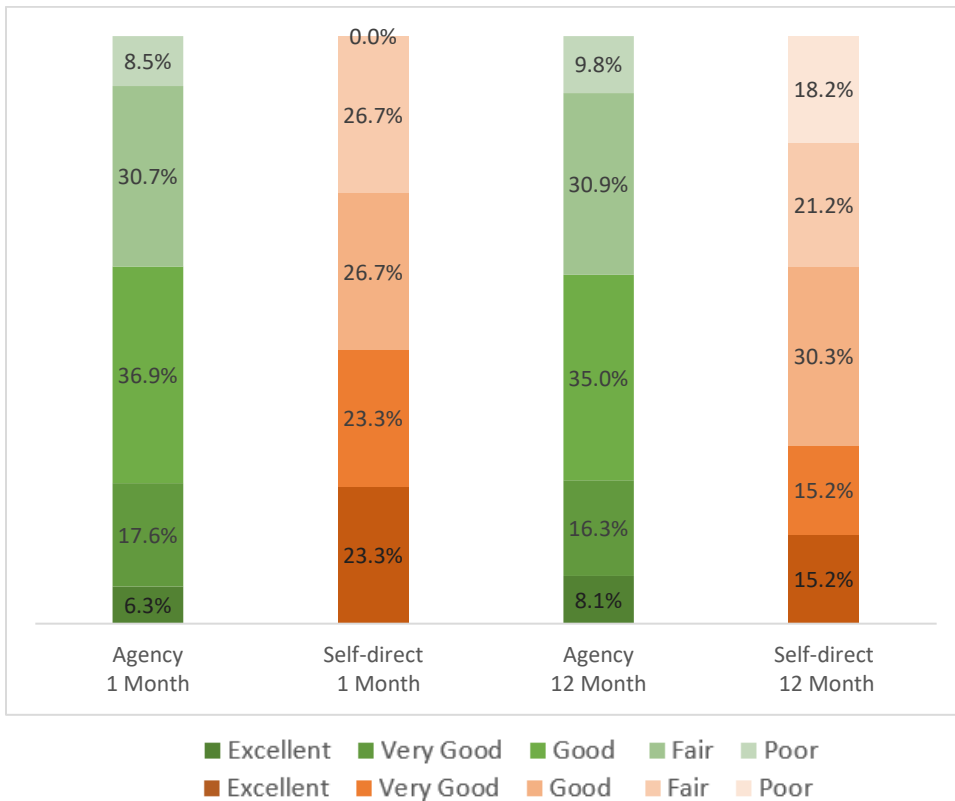
Figure 5.7. Assistance from Unpaid Family or Friends with Things Around the House: Agency vs. Self-direct (Percentage Yes)



### Physical Health

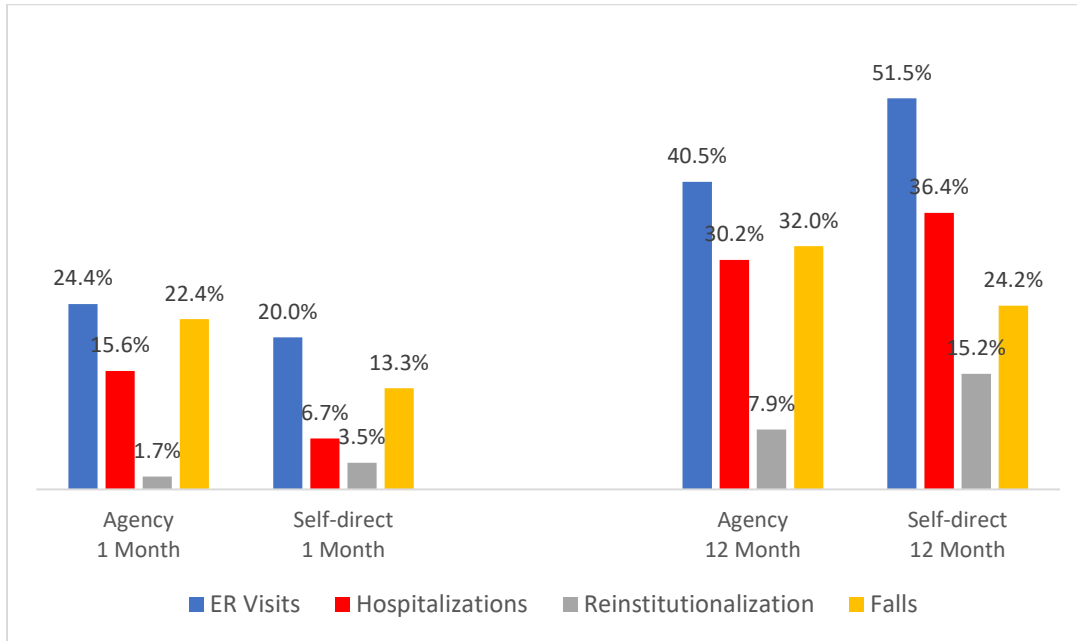
Self-directed consumers were more likely to report very good or excellent physical health, especially at 1 month post transition (Figure 5.8).

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



Rates of emergency room visits, hospitalizations, reinstitutionalizations, and falls varied between the two groups over time (Figure 5.9). Most notably, at 1 month, agency-based consumers were twice as likely to be hospitalized. However, at 12 months, self-directed consumers had higher utilization rates of all three types of health services, with a notably higher likelihood of emergency room visits. By 12 months post-transition, self-directed consumers were also almost twice as likely to have experienced a short or long term reinstitutionalization. On the other hand, agency-based consumers were more likely to fall than self-directed consumers at both time points.

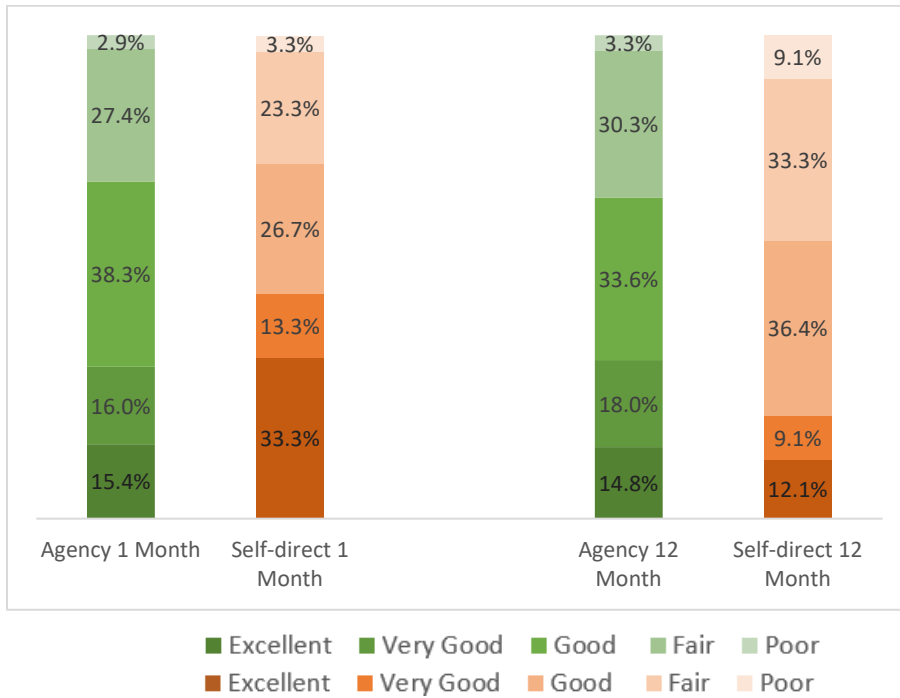
Figure 5.9. Emergency Room Visits, Hospitalizations, Reinstitutionalizations, and Falls: Agency vs. Self-direct (Percentage Yes)



### Mental Health

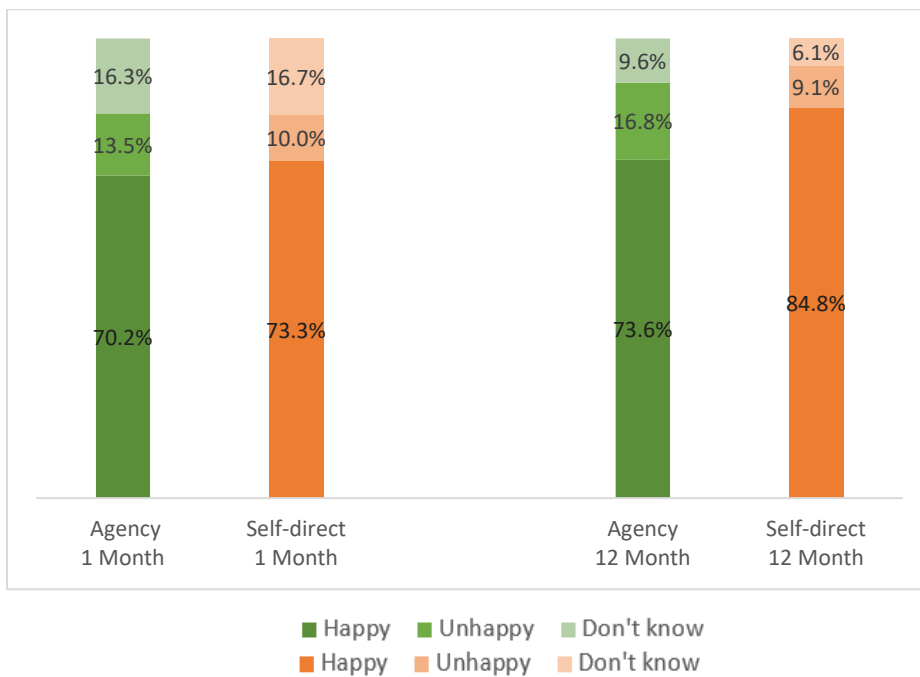
Although at 1 month, self-directed consumers reported a considerably higher rate of very good to excellent mental health, by 12 months this was no longer the case (Figure 5.10). By one year post-transition, 33% of agency-based consumers reported very good to excellent mental health, compared to 21% of self-directed consumers.

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



Although both groups expressed feeling happy with the way they live their life at similar rates 1 month post transition, self-directed consumers were much more likely to report this at 12 months (85% self-directed, 74% agency-based) (Figure 5.11). Agency-based consumers were more likely to report symptoms of depression at both 1 and 12 months post transition (data not shown).

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



### ***Assistive Device, Special Medical Equipment, Home Modifications***

Both agency-based and self-directed consumers reported having or needing various assistive devices, special equipment, and home modifications (Table 5.6). The differences between these groups in use was greatest for home modifications, medical equipment, and internet devices. Both groups also reported an unmet need for various types of these items, although differences were slight with no notable trends.

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=180	N=30	N=126	N=33
I have it	73.9	66.7	67.5	84.9
I do not need it	12.2	16.7	16.6	3.0
I need it	13.9	16.7	15.9	12.1
Mobility equipment	N=180	N=30	N=126	N=33
I have it	90.0	90.0	86.5	93.9
I do not need it	6.7	3.3	11.1	0
I need it	3.3	6.7	2.4	6.1
Medical equipment	N=180	N=30	N=126	N=33
I have it	77.8	66.7	83.3	93.9
I do not need it	10.6	23.3	11.9	3.0
I need it	11.7	10.0	4.8	3.0
Lifeline or PERS	N=179	N=30	N=126	N=33
I have it	55.9	53.3	60.3	60.6
I do not need it	33.0	36.7	29.4	30.3
I need it	11.2	10.0	10.3	9.1
Internet capable devices	N=180	N=30	N=126	N=33
I have it	75.0	56.7	74.6	90.9
I do not need it	18.3	26.7	14.3	9.1
I need it	6.7	16.7	11.1	0.0
Internet access	N=177	N=30	N=126	N=33
I have it	84.8	80.0	88.9	97.0
I do not need it	10.7	13.3	4.8	3.0
I need it	4.5	6.7	6.4	0

## **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 to 12 month surveys. The 2022 MFP HCBS CAHPS report clearly showed that overall people do better in the community – they are happier, less depressed, more likely to like where they live, less likely to be hospitalized, and have increased choice and control (Porter et al.,

2023). 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 Medicaid and personal costs.

### A. Reinstitutionalization Pattern in the Year After Transition

The cohort of the 422 consumers who transitioned in 2022 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 DSS MyCommunityChoices website.

Table 6.1 shows the participant setting at 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. Participants who died or could not be found are excluded from Table 6.1 but are shown in Figure 6.1 below.

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

	Transition N=422 n (%)	Transition to 1 Month N=414 n (%)	1 Month Setting N=414 n (%)	1 Month to 12 Month N=364 n (%)	12 Month Setting N=364 n (%)
Community	422 (100)	380 (91.8)	386 (93.2)	272 (74.7)	309 (84.9)
Facility	0 (0)	34 (8.2)	28 (6.8)	92 (25.3)	55 (15.1)

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.

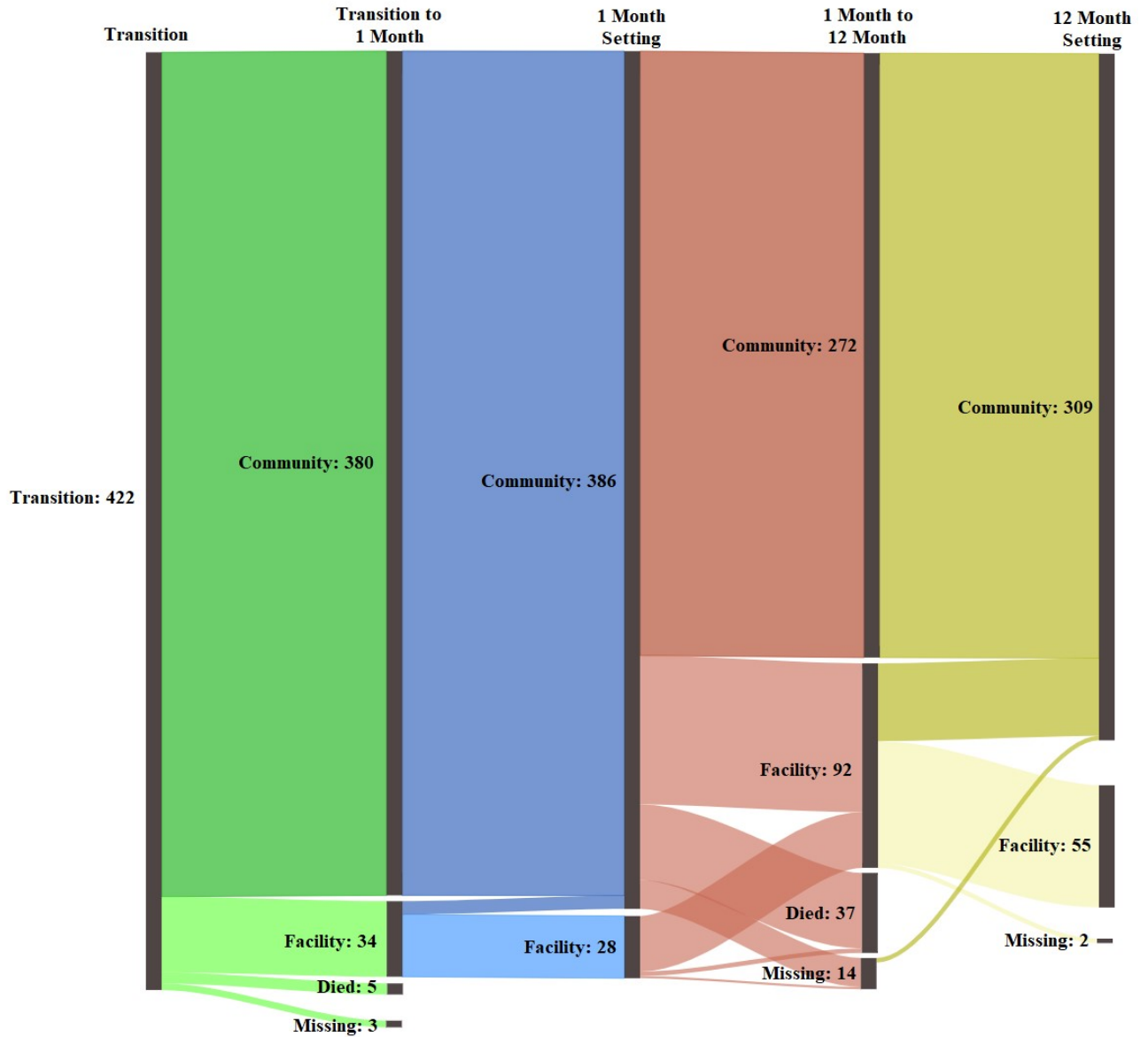
The Sankey diagram in Figure 6.1 provides a visual representation of the reinstitutionalization pattern for participants who transitioned in 2022 at five points in time: transition, transition to 1 month, 1 month setting, 1 month to 12 months, and 12 month setting. Four main categories summarize the participant outcomes at each time point: community, facility, died, or missing.

After excluding the cases of participants who were either missing or deceased, 8% of participants returned to a facility for either a short or long-term stay within a month after their transition. With only a small number of (n=6) discharges by 1 month post-transition, 7% of consumers remained in a facility at 1 month post-transition. As expected, given the longer length of time between the 1 month and 12 month surveys, 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 2022 report, with a few exceptions. This year there was a noticeable decrease in consumers who experienced a reinstitutionalization from 1 month to 12 months (32% 2022, 25% 2023). There was also a decrease in the percentage of consumers residing in a facility at 12 months (20% 2022, 15% 2023). The percentage of consumers who died over the span of their transition to 12 month time point decreased by one

percentage point at both the 1 month post-transition (2% 2022, 1% 2023), and the 1 to 12 month time point (10% 2022, 9% 2023).

Figure 6.1. Diagram of Participant Setting and Facility Use from Transition to 12 Months for 2022 Transitions



Made at SankeyMATIC.com

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



**2022 12 Month Institution: Select Results**

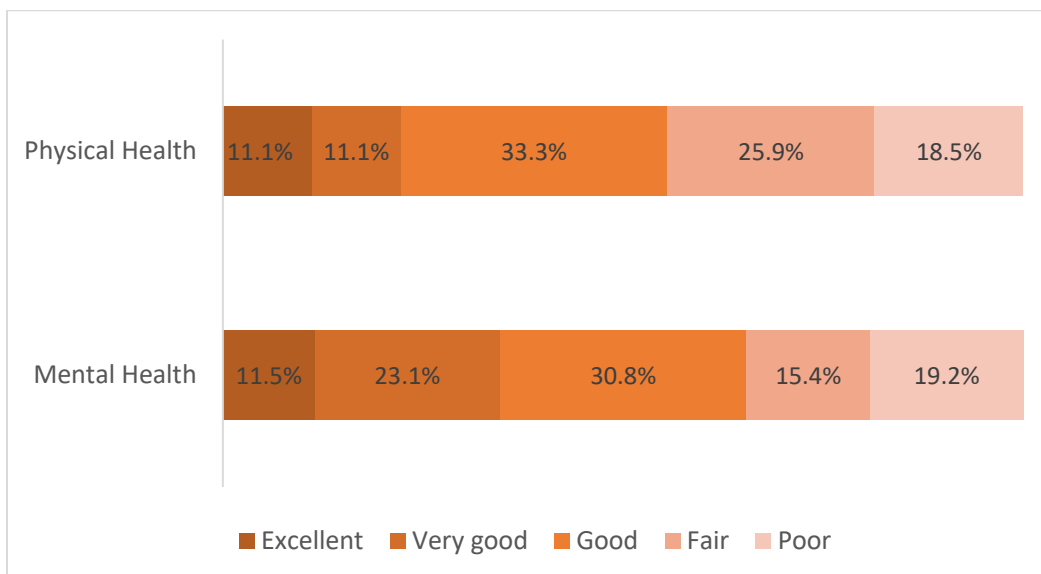
The following figures present 2023 survey data for the 29 consumers who transitioned in 2022 and were in a facility at 12 months. See Section 3 for comparative results for consumers in the community at 12 months. The percentage of consumers in a facility at 12 months who gave the highest score for medical transportation increased this year (63% 2022, 71% 2023), making it comparable to the medical transportation score given by community consumers (72%) at 12 months.

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



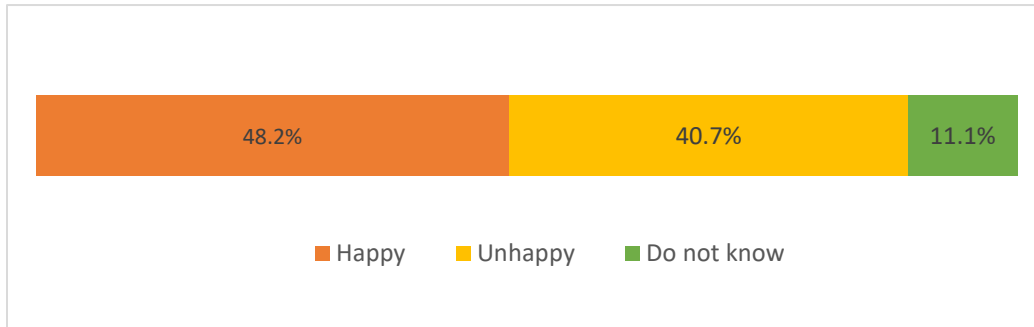
Unlike previous years, self-reported physical and mental health were very similar between the two groups (Figure 6.3). This year 25% of community and 22% of reinstitutionalized consumers reported very good or excellent physical health at 12 months. This represents a large increase in the percentage of reinstitutionalized consumers with very good or excellent health at 12 months, as only 13% reported this in 2022. Meanwhile, 35% of reinstitutionalized consumers reported very good or excellent mental health at 12 months, as did 32% of community consumers.

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



Still, reinstitutionalized consumers reported higher rates of depressive symptoms than community consumers. Two-thirds (67%) of consumers institutionalized at 12 months reported depressive symptoms, a 17% increase from 2022. In addition, 41% of reinstitutionalized consumers said they were unhappy with the way they live their life, compared to 27% the previous year (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 2023

This section provides an overview of the experience of reinstitutionalization at one month post-transition for consumers who transitioned in 2023. 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 480 consumers transitioned in 2023. Of these, 285 consumers completed a 1 month survey before the end of the year. Almost all consumers (96.8%, n=276) who completed a 1 month survey were residing in the community at the time of their interview. None of these community residing consumers had been reinstitutionalized even temporarily by 1 month. The remaining 9 (3.2%) consumers who were in an institution represent the total 1 month readmission rate (Table 6.2). This re-institutionalization rate for 2023 transitions is less than half the rate for 2022 transitions, when 7.2% of consumers who completed a 1 month surveys were reinstitutionalized either short or long term by that time.

Table 6.2. Transitioned in 2023 – Experienced Reinstitutionalization by 1 Month Survey

	n (%)
Total 1 month surveys	285 (100)
Experienced readmission by one month survey	
No – Always in the community	276 (96.8)
Yes – Reinstitutionalized either short or long-term	9 (3.2)

### Consumer Characteristics

Waiver consumers composed 78% of the entire sample and 100% of the reinstitutionalized consumers (Table 6.3).

Table 6.3. Waiver or State Plan Status by Reinstitutionalization by 1 month survey

Service Type	Always Community N=276 n (%)	Ever Reinstitutionalized N=9 n (%)
	Waiver	216 (78.3)
State Plan	60 (21.7)	0 (0)

Reinstitutionalized consumers were also more likely to be older, female, 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	66 (23.9)	1 (11.1)
	55-64	93 (33.7)	2 (22.2)
	65-74	66 (23.9)	3 (33.3)
	75+	51 (18.5)	3 (33.3)
Race	White	162 (59.1)	8 (100)
	Black	93 (33.9)	0 (0)
	Other	19 (6.9)	0 (0)
Gender	Male	145 (52.7)	2 (22.2)
	Female	130 (47.3)	7 (77.8)
Education	< High school	63 (23.1)	1 (11.1)
	High school degree	115 (42.1)	5 (55.6)
	> High school	95 (34.8)	3 (33.3)

### Physical and Mental Health at One Month

Surprisingly, consumers who always resided in the community at 1 month post-transition were more likely to be in fair or poor health (Figure 6.5). However, consumers who were reinstitutionalized by 1 month reported worse mental health (Figure 6.6). Compared to consumers who had never been back to a facility, consumers who had been reinstitutionalized by their 1 month survey also reported more depressive symptoms (Table 6.5) and were much less happy with the way they lived their life (Figure 6.7).

Figure 6.5. Self-Reported Physical Health

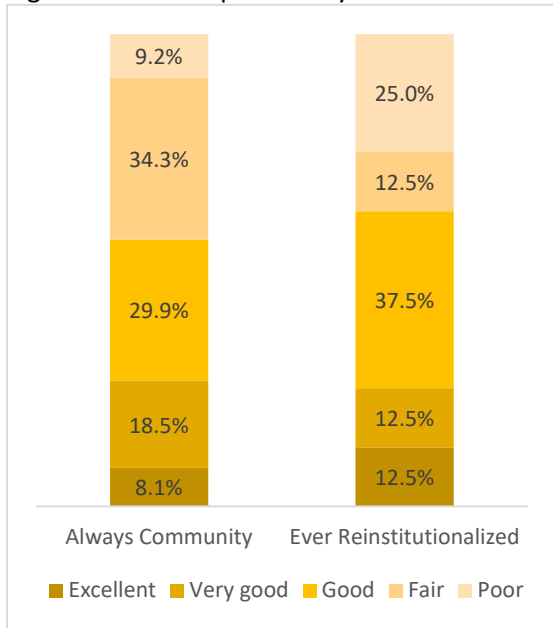


Figure 6.6. Self-Reported Mental Health

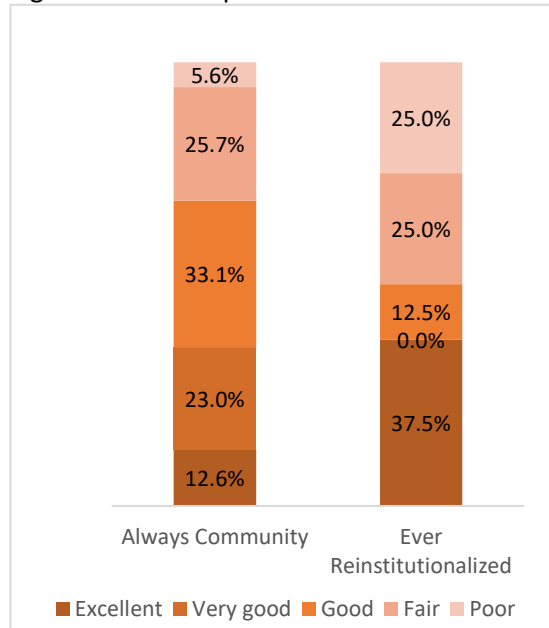
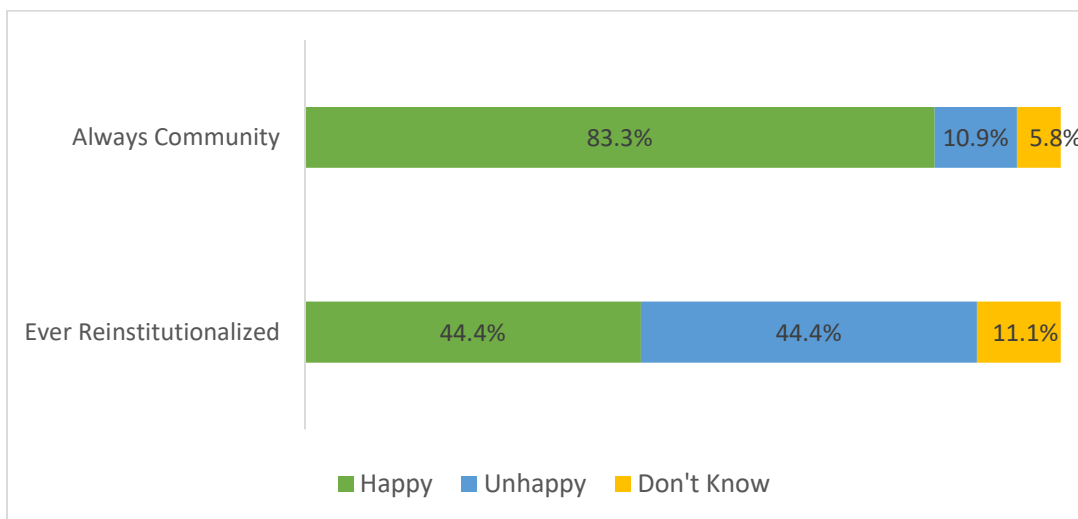


Table 6.5. Depressive Symptoms: Always Community vs. Ever Reinstitutionalized

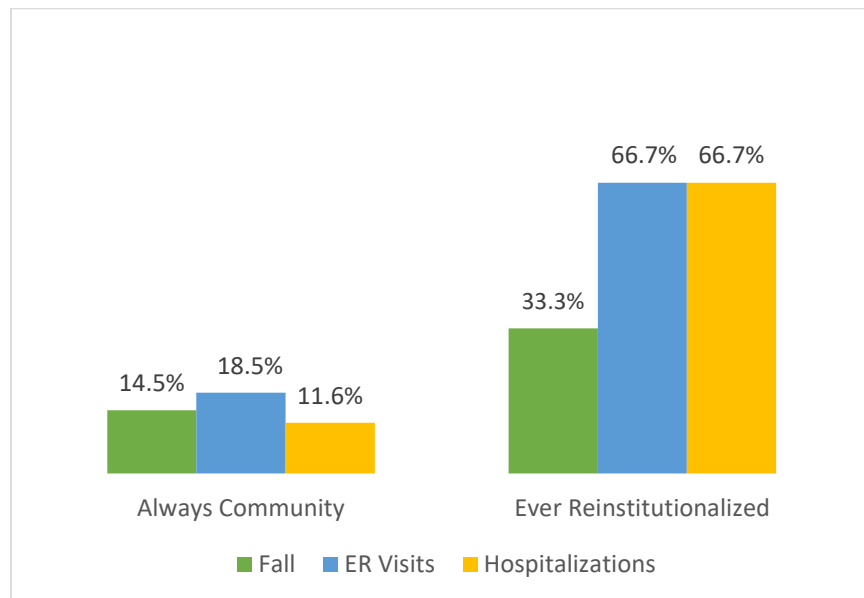
Depressive Symptoms	Always Community n (%)	Ever Reinstitutionalized n (%)
Yes	90 (32.7)	4 (50.0)
No	185 (67.3)	4 (50.0)

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



Consumers with a reinstitutionalization by 1 month had much higher rates of falls, emergency room visits, and hospitalizations, which may have led to their subsequent return to a nursing facility by 1 month (Figure 6.8).

Figure 6.8. Falls, ER Visits, and Hospitalizations – Percentage Yes



### ***The Consumer Experience***

Case histories for each of the 9 consumers who experienced reinstitutionalization within 30 to 45 days post-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. Taken together, these provided a more complete picture of a consumer’s life pre and post-transition – describing a participant’s experiences in the community and for those who re-entered a facility, 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.

Six 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. Examples provide more insight into the consumer’s and family members’ experiences, as well as the often-overlapping issues contributing to reinstitutionalization.

#### **Consumer physical health decline post-transition**

As in 2022, physical health decline post-transition was a leading cause of reinstitutionalization within four to six weeks post-transition. Some consumers experienced acute medical incidents such as sudden difficulty breathing, while for others health conditions which were stable in the facility became worse once in the community. There were consumers who seemed to get progressively weaker after transition, losing the muscle strength needed to do necessary activities once in the community. For example, some consumers who needed assistance from just one person in the facility to perform physical activities such as stand and transfer began to need the assistance of two trained people once in the community. Additional factors in health decline included serious chronic and progressive conditions

such as congestive heart failure, while all three consumers who fell were injured. Other times it was not known why a consumer's physical health declined so rapidly after transition.

#### Lack of PCA or other non-medical home care services

Another reoccurring theme was lack of PCA or other non-medical home care services. For example, sometimes PCAs did not show up, did not do assigned tasks, or left early. Personality differences also contributed to staff turnover. Some consumers needed more paid help than was allowed in their care plan budget. Others began to need hands on assistance from more than one PCA to do certain everyday activities, such as getting up and sitting down. For some of these, the need for two caregivers fluctuated daily depending on physical health, making it especially difficult to provide this assistance.

Relying on only or two paid staff or PCAs without any back-up plan was also precarious, as experienced by one consumer who self-directed his services. His secondary PCA quit without notice while his primary PCA was on a family vacation. Without any other paid or family member back-up, he had to go back into a facility to receive the daily care he needed. Another consumer found upon transition that there was only one paid staff person at the small group home where she transitioned. After an incident, the paid staff person berated the consumer and told her to leave. Without any other place to go, the consumer returned to the nursing home until more supportive housing was found.

#### 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 other tasks. Informal support is especially important for consumers who live alone with no or limited paid supports. Regular check-ins or visits by friends or family can identify unanticipated issues and help resolve them before it becomes too much for the consumer or paid caregiver to handle. In addition, family are often the identified back-up in the care plan. At times consumers transition with health conditions requiring ongoing medical care which PCAs cannot provide, or consumers may need some extra assistance not included in their care plan budget. In cases like these, family members often agree to provide the additional care so their loved one can come home.

While unpaid family or friends can often give this extra help occasionally or in the short term, providing daily informal support is often too much. For example, one consumer's health declined to the point that she always needed a second person to help with hands on care. Family members would come help, but eventually providing daily care became too much for the family to continue. In other cases, family members or friends agreed before transition to provide assistance on a daily basis, but then did not follow through post-transition. For example, one consumer's family member was to provide hands on assistance in the evening after the PCA left. Unfortunately, within just a few weeks, this consumer found that their informal supporters did not provide the agreed upon care. This lack of this necessary informal support contributed to the subsequent reinstitutionalization of this consumer.

Any lack of paid services is especially difficult for consumers without readily available family members or friends to fill in the gaps. One self-directed consumer did not have any family or friends to call upon for informal assistance. He ended up going back into a facility when he suddenly found himself without any PCAs.

#### Falls

Multiple falls or falls resulting in 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 or walking without assistance, such as the consumer who fell on her way to the bathroom after her PCA left for the day. Two consumers who fell suffered bone fractures, which led to re-institutionalization.

### Consumer mental or behavioral health issues, including lack of mental health care

The worsening and exacerbation of one consumer's mental and behavioral health issues was a large factor in this consumer's reinstitutionalization post-transition. Although his mental health apprehensions were not debilitating while in the facility, he found that these challenges became overwhelming once in the community. Other factors contributing to an unstable life post-transition included lack of needed medications upon transition and physical and mental health incidents which lead to multiple emergency room visits and hospitalizations. Progress notes also indicate he received limited mental health support when in the community, primarily due to his multiple hospitalizations. He finally asked to go back into a skilled nursing facility.

### Decline in cognition

One consumer experienced a sudden decline in her cognition post-transition which led to her reinstitutionalization.

A substantial portion of consumers who were either always in the community or who had ever experienced reinstitutionalization by 1 month were not in good health. Surprisingly in this small group of reinstitutionalized consumers, they reported better physical health – 38% of reinstitutionalized consumers reported fair or poor health, compared to 44% of consumers always in the community since transition. This is despite the greater rates of falls, emergency room use, and hospitalizations reported by reinstitutionalized consumers. Mental health results were more predictable. Consumers who had been reinstitutionalized by 1 month reported worse mental health, had greater rates of depressive symptoms, and were much less happy with how they lived their life. Qualitative themes most commonly associated with either a short or long-term reinstitutionalization for these consumers included physical health decline post-transition, lack of PCA and other nonmedical HCBS, lack of or limited family or informal support, falls, and consumer mental or behavioral health issues.

## **III. Conclusions and Recommendations**

A total of 571 HCBS CAHPS surveys were completed with MFP participants in 2023: 323 1 month and 248 12 month surveys. The rate at which proxies completed surveys continues to drop and is now almost at pre-pandemic levels (proxy rate across all surveys: 17.7% 2023, 16.6% 2019).

### ***1 Month Community Surveys Completed in 2023***

This section examined data from the 312 1 month surveys completed in 2023 with community residing consumers. Planning your time and activities continues to be the lowest performing composite, which again indicates an area for program improvement. There was a notable increase in the percentage of consumers who knew who their TC or care manager was (90%, up from 82%) and who could contact them when needed (89%, up from 84%). Being able to reach your TC or care manager may be one reason for the increase in consumers who rate their care manager a 9 or 10 (71%, up from 65%) and would definitely recommend them to family or friends (77%, up from 72%).

Another notable finding was the increased unmet need for assistive devices, equipment, or home modifications. At 1 month post-transition, 42% of consumers said they still needed at least one or more of these items, compared to one-third of consumers in 2022. 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.

## ***1 and 12 Month Community Surveys Completed with Consumers Who Transitioned in 2022***

A total of 422 consumers transitioned in 2022. Altogether, they completed 548 HCBS CAHPS surveys: 302 1 month and 246 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=502), 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 after 3 months any MFP “case management” is reduced to monthly check in calls by the TC.

Similar to 2021 and 2022, community residing participants gave three composites comparatively low scores at both 1 and 12 months: medical transportation, choice of services, and especially planning your time and activities. Despite these generally lower ratings, there was positive change in this last composite over the previous year, as the percentage who gave planning your time and activities the highest score at 12 months increased from 58% in 2022 to 64% in 2023. The 1 month score for choosing the services which matter to you increased from 64% in 2022 to 70% in 2023, although it remained the second lowest performing composite. 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.

Consumers at both 1 and 12 months post-transition commented on the difficulties they had with their PCA and homemaking services. Similar to previous years, lack of trained, good quality staff and staff turnover were most frequently mentioned. Respondents expressed frustration when the PCAs or homemakers would not do basic tasks needed by the consumer such as provide personal care or housekeeping. Consumers were left doing the best they could, while family and friends often took the initiative to provide the care themselves. Consumers also remarked on communication difficulties with the home care agencies. Staff turnover and a shortage of available caregivers exacerbated the problems.

There is a critical need in Connecticut for high quality, consistent HCBS staff. Connecticut continues to face challenges recruiting and retaining people to work as PCAs or in other home care positions. In addition, nonmedical homecare agencies provide much of the PCA, homemaker, and companion staff, but oversight as to the quality of care provided is lacking. Without an influx of well-qualified and motivated paid caregivers, consumers who rely on paid caregivers for their independence may find it increasingly difficult to stay in the community.

Six out of ten consumers at either time point received assistance around the house from either family or friends. Family or friends often play a significant role in keeping their loved ones in the community, by providing hands-on care, social and financial support, or other assistance such as transportation. Without appropriate staff support, these informal caregivers often found themselves helping more than expected, causing some caregivers to be too overwhelmed to maintain this level of assistance. Informal caregivers are an essential part of the HCBS system, and increased support is needed in order for them to continue in this role.

Unsurprisingly, between 38-40% of consumers reported fair to poor physical health at either time point. Consumers also reported high levels of fair to poor mental health. By 12 months post-transition one-third of community consumers rated their mental or emotional health as fair or poor, and over a



third reported depressive symptoms. Still, when asked if they were happy or unhappy with the way they lived their life, between 72-76% of consumers said they were happy.

Comments indicated that becoming part of one's new community can be challenging. Some consumers expressed struggles with loneliness and lack of social connection, especially the almost 60% of consumers living alone. 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. Proactively 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, or even connect those newly transitioned with interested consumers who transitioned previously.

Use of assistive devices, special equipment, and home modifications are common among MFP consumers – 92-94% at either time point reported having at least one of these. Still, 34-37% of consumers at either time point lacked some type of device or modification needed to live in the community, an increase of almost 10% from 2022. At 1 month post-transition, between 11-13% of consumers still needed home modifications, a PERS, or special medical equipment. 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 completed through MFP. Obtaining needed home modifications, special medical equipment, and assistive devices 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.

When asked about finances, nearly one-third (31%) of participants said they did not have enough money to make ends meet. Comments indicated that food insecurity including not enough food stamps continued to be of great concern in 2023, as it was in both 2021 and 2022.

### ***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 2022 were divided 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). Waiver consumers composed 80% of both the 1 month and 12 month samples. 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 use shows this contrast, especially at 12 months, where 76% of waiver consumers reported using some type of personal care assistance, compared to only 9% of state plan consumers. In addition, by 12 months post transition, half of state plan consumers reported using no services, compared to just 5% of waiver consumers.

The difference in use of and experience with case management services between the two groups over time was striking. When 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. Consumers often identify their TC or SCM as their case manager at 1 month post-transition. Historically state plan consumers reported much lower case management services use, even at just 1 month post transition. This year state plan use of case management services at 1 month jumped from 54% in 2022 to 74% in 2023, which is very close to the waiver consumer rate (80%).

Although at 1 month 81% of both groups of consumers gave the highest score for the case manager is helpful composite, by 12 months 87% of waiver consumers gave the highest score for this composite,

compared to only 67% of state plan consumers. State plan consumers gave a much higher rating for the composite planning your time and activities at both 1 and 12 months. The reasons for this difference are not clear, but it is not due to a difference in physical health, as state plan consumers reported similar or worse physical health compared to waiver consumers.

Consistent with last year's report, state plan consumers reported less social support overall. State plan consumers were more likely to live alone and less likely to get help from family or friends around the house. State plan consumers were also less satisfied with their living arrangements and less likely to feel safe where they live. Unlike last year, there were some notable differences in depressive symptoms between the two groups. At 1 month, waiver consumers were more likely to report depressive symptoms, but by 12 months post transition, this had reversed and state plan consumers reported more depressive symptoms. The increased likelihood of living alone along with less social support and family involvement could all be factors contributing to the higher rating of depressive symptoms for state plan consumers one year post-transition.

Despite waiver consumers reporting higher rates of emergency room visits, hospitalizations and nursing home readmissions at 12 months, state plan consumers' physical health declined by 12 months compared to waiver consumers. Almost half (49%) of state plan consumers reported fair or poor health at 12 months, compared to 38% of waiver consumers. Noticeably more waiver consumers reported having home modifications, mobility or medical equipment, or a PERS unit at both 1 and 12 months. This may be an effect of the greater functional needs of waiver consumers, given waiver consumers must meet facility level of care. It could also be that waiver consumers have greater access to these items, especially given state plan consumers reported a greater unmet need for both a PERS and medical equipment at 12 months.

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

Community living consumers who transitioned in 2022 were stratified by service type into those using agency-based services versus self-directed consumers who hire their own staff. At 1 month, 86% of consumers reported used agency-based services, while just 14% self-directed their services. By 12 months, use of self-directed services increased to 21%. Self-directed consumers were more likely to use PCA services at both timepoints, but less likely to use case management services at 12 months despite having equal access to TC and SCM services post-transition. Consumers using self-direction must be able to manage their own services, or have a family member or friend do it for them, which might factor into self-reported use of 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. Self-directed consumers were much more likely than agency-based consumers to report that their staff were reliable and helpful and listened and communicated well. 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. Overall, self-directed consumers reported higher ratings for all the composite measures as well. Still, despite these positive benefits of self-direction, use of agency-based services at 1 month post-transition has grown substantially over the past 4 years, from 69% in 2020 to 86% in 2023, likely driven by the addition of agency-based services to the PCA waiver.

As in previous years, agency-based consumers were much more likely to live alone and be over age 65: by 12 months, agency-based consumers were twice as likely to be 65 or older. Not surprisingly given this age difference, agency-based consumers were less likely to report very good or excellent physical health and more likely to report experiencing a fall. Despite this, by 12 months, self-directed consumers reported higher emergency room, hospitalization, and reinstitutionalization rates. In particular, by one year post-transition, self-directed consumers were almost twice as likely to be reinstitutionalized

either short or long term. This may reflect the need for enhanced back-up services for self-directed consumers who are responsible for hiring their own back-up staff to cover if their PCA cannot come to work, instead of relying on an agency to send a replacement.

### ***The Reinstitutionalization Effect***

#### **Consumers who transitioned in 2022**

This section examined the history and effect of readmission to a facility by tracking consumers from transition through their 1 or 12 month survey. Consumers who transitioned in 2022 were followed from transition through 1 year post-transition to determine reinstitutionalization at four time points after transition. After excluding consumers either missing or deceased, within 1 month after transition, 8% of participants had returned to a facility for either a short or long-term stay. Unsurprisingly given the longer length of time, one quarter (25%) of consumers had been in a facility between the 1 month and 12 months survey, a 7% decrease from the previous year. At 12 months post-transition, the percentage who remained reinstitutionalized dropped to 15%.

Select results showed that consumers reinstitutionalized at 12 months rated all staff, safety, medical transportation, and planning time and activities composites lower than consumers residing in the community at 12 months. Unlike previous years, self-reported overall physical and mental health were very similar between the two groups. Still, reinstitutionalized consumers reported much higher rates of depressive symptoms and were significantly less likely to be happy with their lives.

#### **Consumers who transitioned in 2023**

Next, reinstitutionalization for consumers who transitioned in 2023 and completed a 1 month survey (n=285) was explored. Only 3% (n=9) of these consumers were reinstitutionalized at the time of their 1-month survey. This re-institutionalization rate for 2023 transitions is less than half the rate for 2022 transitions, when 7% of consumers who completed a 1-month survey were reinstitutionalized either short or long term by that time. Those who were reinstitutionalized by 1 month were more likely to be older, female, and White compared to those who were never reinstitutionalized. Consumers reinstitutionalized by 1 month reported better physical health, but worse mental health, more depressive symptoms, and increased unhappiness. Reinstitutionalized consumers also reported greater rates of emergency room visits and hospitalizations.

Consumers who had transitioned in 2023 and had experienced a reinstitutionalization by their 1 month survey were examined in more detail. Qualitative analysis identified common circumstances or issues associated with facility readmission. Six 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 included physical health decline post-transition, lack of PCA or other home care services, lack of family or informal support, falls, mental health or behavioral issues, and decline in cognition.

### ***Final Thoughts***

Although faced with a variety of challenges, from insufficient staff to health challenges and missing medical equipment or home modifications, most consumers were happy to be back in the community. 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:

*I appreciate the program because I haven't been independent in a long time, and this helps me, even though living by yourself is another challenge. Otherwise, the staff from MFP are really good and they give 100% and really try and get you housing. (12 month)*

*It was wonderful. It got me all set up. They were extremely helpful. I would not be able to do this without MFP. (1 month)*

*I think this program has helped her be at home and gave her the dignity to stay at home instead of being in a nursing home. (12 month)*

*They [TC, SCM, HC] did an excellent job transitioning me into my new home because at the rate that I was going I would have been in the facility the rest of my life. The facility social worker was helpful in the process, but I had to do a lot of advocating for myself. I never doubted though that these MFP people mean business because they were always on point. (1 month)*

*This is a great program, and it has made a difference in my aunt's life. She wouldn't be alive if it wasn't for this program. (12 month)*

## IV. References

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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?

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

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

---

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

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

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

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

9. What do you call the person or people who 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?

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

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

12. What do you call the person who 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 . . .

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

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

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

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

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

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

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

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

- <sup>1</sup>  YES
- <sup>2</sup>  NO → GO TO Q20
- <sup>-1</sup>  DON'T KNOW → GO TO Q20
- <sup>-2</sup>  REFUSED → GO TO Q20
- <sup>-3</sup>  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?

- <sup>1</sup>  YES → GO TO Q19
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW → GO TO Q19
- <sup>-2</sup>  REFUSED → GO TO Q19
- <sup>-3</sup>  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 . . .

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

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

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

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

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

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

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

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

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

<sup>-3</sup>  UNCLEAR RESPONSE

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

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

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

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

### GETTING NEEDED SERVICES FROM 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 . . .

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

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

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

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

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

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

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

38a. Sometimes staff cannot come to work on a day that they are scheduled. In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that *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 . . .

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

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

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

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

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

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

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

46. Using any number from 0 to 10, where 0 is the worst help from {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
- <sup>-1</sup> DON'T KNOW
  - <sup>-2</sup> REFUSED
  - <sup>-3</sup> UNCLEAR RESPONSE

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

- <sup>1</sup> Excellent,
- <sup>2</sup> Very good,
- <sup>3</sup> 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

<sup>-3</sup>  UNCLEAR RESPONSE

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

Would you say . . .

<sup>1</sup>  Excellent,

<sup>2</sup>  Very good,

<sup>3</sup>  Good,

<sup>4</sup>  Fair, or

<sup>5</sup>  Poor?

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

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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*} . . .

<sup>1</sup>  Definitely no,

<sup>2</sup>  Probably no,

<sup>3</sup>  Probably yes, or

<sup>4</sup>  Definitely yes?

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

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

## HOME-DELIVERED MEALS, ADULT DAY PROGRAM

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

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

<sup>1</sup>  Excellent,

<sup>2</sup>  Very good,

<sup>3</sup>  Good,

<sup>4</sup>  Fair, or

<sup>5</sup>  Poor?

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

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE or DID NOT USE HOME-DELIVERED MEAL SERVICE

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

<sup>1</sup>  Excellent,

<sup>2</sup>  Very good,

<sup>3</sup>  Good,

<sup>4</sup>  Fair, or

- 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?

- <sup>1</sup>  YES, Please specify relationship/s \_\_\_\_\_
- <sup>2</sup>  NO
- <sup>-1</sup>  DON'T KNOW
- <sup>-2</sup>  REFUSED
- <sup>-3</sup>  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]

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

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

ALTERNATE VERSION: 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 . . .

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

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]

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

**COMMUNITY INCLUSION AND EMPOWERMENT**

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

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

- <sup>1</sup> YES
- <sup>2</sup> NO → GO TO Q76
- <sup>-1</sup> DON'T KNOW → GO TO Q76
- <sup>-2</sup> REFUSED → GO TO Q76
- <sup>-3</sup> UNCLEAR RESPONSE → GO TO Q76

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

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

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

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

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

- <sup>1</sup> YES
- <sup>2</sup> NO → GO TO Q78
- <sup>-1</sup> DON'T KNOW → GO TO Q78



- 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		
<b>16a. Building or home modifications</b> , such as entrance ramps, wide doorways, roll-in shower, grab bars, stair glide, etc.					

<b>16b. Mobility equipment</b> , such as walker, cane, manual or electric wheelchair, scooter, etc.					
<b>16c. Special medical equipment</b> , such as a hospital bed, Hoyer or transfer lift system, shower chair, raised toilet seat, commode, etc.					
<b>16d. Lifeline, PERS, or a 24 hour life alert system.</b>					
<b>16e. Electronic devices to monitor your health or share health information electronically</b> , 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.					
<b>16f. Transportation aids</b> , such as a lift van, adaptive driving controls, etc.					
<b>16g. Internet capable devices</b> , like a computer, a smart phone, or a tablet.					
<b>16h. Internet access</b> 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 . . .

- <sup>1</sup> Excellent,
- <sup>2</sup> 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

- <sup>2</sup> Some high school, but did not graduate
- <sup>3</sup> High school graduate or GED
- <sup>4</sup> Some college or 2-year degree
- <sup>5</sup> 4-year college graduate
- <sup>6</sup> More than 4-year college degree
- <sup>-1</sup> DON'T KNOW
- <sup>-2</sup> REFUSED
- <sup>-3</sup> UNCLEAR RESPONSE

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

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

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

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

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

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

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

- <sup>1</sup> Asian Indian → GO TO Q92
- <sup>2</sup> Chinese → GO TO Q92
- <sup>3</sup> Filipino → GO TO Q92
- <sup>4</sup> Japanese → GO TO Q92
- <sup>5</sup> 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

<sup>-3</sup>  UNCLEAR RESPONSE

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

<sup>1</sup>  YES

<sup>2</sup>  NO

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

<sup>-2</sup>  REFUSED

<sup>-3</sup>  UNCLEAR RESPONSE

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

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

*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?

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

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

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

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

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

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

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

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

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

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

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

F7. Relationship to participant:

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

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

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

**END OF SURVEY**

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

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



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

\* Question added by Connecticut

## Appendix D. Acronyms

ABI	Acquired Brain Injury waiver
ADL	Activities of daily living
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
CSP	Community service provider
DDS	Department of Development Services
DSS	Department of Social Services
EBT card	Electronic Benefits Transfer card
ER	Emergency room
HC	MFP Housing Coordinator
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
MH State Plan	Mental Health State Plan
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
PD State Plan	Physical Disability State Plan
PERS	Personal emergency response system
RCH	Residential care home
RA	Recovery assistant
SAGA	State-Administered General Assistance
SCM	MFP Specialized Care Manager
SNAP	Supplemental Nutrition Assistance Program
TC	MFP Transition Coordinator