Money Follows the Person Rebalancing Demonstration

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

2024 Survey Results

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I. Introduction, Methods, and Analysis

As part of the comprehensive Money Follows the Person program (MFP) quality management strategy, 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 2024 and surveys completed for the cohort of consumers who transitioned in 2023.

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 six sections:

- Section 1: Survey and Respondent Characteristics for Surveys Completed in 2024

A total of 567 HCBS CAHPS surveys were completed with MFP participants in 2024: 310 1 month and 257 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 2024

This section presents select results from the 294 1 month surveys completed in 2024 with consumers residing in the community. HCBS CAHPS key results and areas of interest from the previous 2023 MFP HCBS CAHPS report, in particular case manager, health, and assistive devices, are shown for comparison.

- Section 3: Community Experiences from 1 Month to 12 Months Post-transition for Consumers Who Transitioned in 2023

A total of 575 MFP HCBS CAHPS surveys were completed with consumers who transitioned in 2023: 321 1 month and 254 12 month surveys. 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 482 consumers who transitioned in 2023 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 2024 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 2024

A total of 567 HCBS CAHPS surveys were completed with MFP participants in 2024: 310 1 month and 257 12 month surveys (Table 1.1). Setting indicates where the consumer was residing when the survey was completed. Over nine out of ten consumers (92%) were in the community at the time of their survey.

Table 1.1. Surveys Completed in 2024 by Setting

	Community n (%)	Institution n (%)
1 Month	294 (94.8)	16 (5.2)
12 Month	229 (89.1)	28 (10.9)
All 2024 Surveys	523 (92.2)	44 (7.8)

One month surveys are 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 2024: 1 Month and 12 Month Surveys

	Minimum	Maximum	Mean	Standard Deviation
1 Month Survey (Days)	24	91	37.76	9.683
12 Month Survey (Months)	11	13	11.28	0.524

Table 1.3 shows the home and community-based program of survey respondents by setting and time point. In 2024, 59-62% 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).

Table 1.3. Home and Community-Based Program – Surveys Completed in 2024 by Time Point and Setting*

	All Surveys n (%)	1 Month		12 Month	
		Community n (%)	Institution n (%)	Community n (%)	Institution n (%)
ABI waivers	7 (1.2)	4 (1.4)	0 (0)	3 (1.3)	0 (0)
CHCPE-AB	203 (35.8)	104 (35.4)	9 (56.3)	75 (32.8)	15 (53.6)
CHCPE-SD	20 (3.5)	10 (3.4)	0 (0)	8 (3.5)	2 (7.1)
DDS waivers	21 (3.7)	11 (3.7)	3 (18.8)	7 (3.1)	0 (0)
Katie Beckett	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Mental Health waiver	21 (3.7)	10 (3.4)	0 (0)	10 (4.4)	1 (3.6)
MH State Plan	62 (10.9)	34 (11.6)	1 (6.3)	25 (10.9)	2 (7.1)
PCA-AB	139 (24.5)	67 (22.8)	2 (12.5)	64 (27.9)	6 (21.4)
PCA-SD	39 (6.9)	21 (7.1)	1 (6.3)	17 (7.4)	0 (0)
PD State Plan	19 (3.4)	15 (5.1)	0 (0)	4 (1.7)	0 (0)
RCH/Other	36 (6.3)	18 (6.1)	0 (0)	16 (7.0)	2 (7.1)

*See Appendix D for a complete list of acronyms

Although most surveys were completed by the participant, one-fifth of all surveys were done by proxy, with someone else answering on behalf of the consumer (Table 1.4). Most often an adult child was the proxy or assisted with the survey by answering some of the questions for the consumer. 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 2024 by Time Point and Setting

		1 Month Community N=294 n (%)	1 Month Institution N=16 n (%)	12 Month Community N=229 n (%)	12 Month Institution N=28 n (%)
Survey respondent	By self	203 (69.0)	9 (56.3)	172 (75.1)	23 (82.1)
	With Assistance	28 (9.5)	0 (0)	19 (8.3)	1 (3.6)
	By Proxy	63 (21.4)	7 (43.8)	38 (16.6)	4 (14.3)
Survey mode	Telephone	287 (97.6)	13 (81.3)	221 (96.5)	22 (78.6)
	In-person	7 (2.4)	3 (18.8)	8 (3.5)	6 (21.4)
Survey used	English	283 (96.3)	16 (100)	219 (95.6)	28 (100)
	Spanish	11 (3.7)	0 (0)	10 (4.4)	0 (0)

Table 1.5 shows demographics among the four groups. Similar to national trends, participants residing in facilities were more likely to be age 65 or older, 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 2024 by Time Point and Setting

		1 Month		12 Month	
		Community	Institution	Community	Institution
		%	%	%	%
Age		N=294	N=16	N=229	N=28
	<18	1.4	0	2.6	0
	18-44	12.2	12.5	10.0	7.1
	45-54	15.0	6.3	12.7	3.6
	55-64	31.0	18.8	31.4	25.0
	65-74	19.7	31.3	26.6	32.1
	75+	20.7	31.3	16.6	32.1
Language		N=292	N=16	N=228	N=28
	English	81.2	93.8	82.0	89.3
	Spanish	2.4	0	3.5	0
	Multilingual/Other	16.4	6.2	14.5	10.7
Race		N=287	N=16	N=222	N=28
	White	58.2	62.5	59.0	71.4
	Black	31.7	31.3	32.4	25.0
	Other	10.1	6.3	8.6	3.6
Ethnicity		N=290	N=16	N=228	N=28
	Non-Hispanic	84.1	93.8	82.9	96.4
	Hispanic	15.9	6.3	17.1	3.6
Education Level		N=282	N=16	N=222	N=27
	< 8th Grade	9.6	18.8	9.0	3.7
	Some high school	13.1	12.5	14.4	7.4
	High school degree	42.9	50.0	43.2	63.0
	Some college	24.8	12.5	22.5	14.8
	4 year college	6.7	6.3	7.2	7.4
	> 4 year degree	2.8	0	3.6	3.7
Gender		N=294	N=16	N=229	N=28
	Male	49.3	31.3	53.3	28.6
	Female	50.7	68.8	46.7	71.4

Section 2. 1 Month Community Surveys Completed in 2024

This section presents select results from the 294 1 month surveys completed in 2024 with consumers residing in the community. Results include areas of interest from the 2023 report for comparison, including HCBS CAHPS key results, direct care staff, physical/mental health, assistive devices, and home modification items. Although not shown, similar data from the 16 1 month institutional surveys are available for any specific questions.

Consumers reported using several program services at 1 month post transition, especially care management (84%) and personal care assistance (PCA) services (68%) (Table 2.1). "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	192 (67.6)
Behavioral health services	2 (<1)
Homemaking services or Homemaker-Companion**	184 (64.8)
Care management services***	247 (84.0)
Job coach or vocational supports	0 (0)
Recovery assistance services (MHW only)	7 (70.0)
Community Service Provider (MHW only)	6 (60.0)
None of these services	6 (2.0)

* Consumers can use more than one service

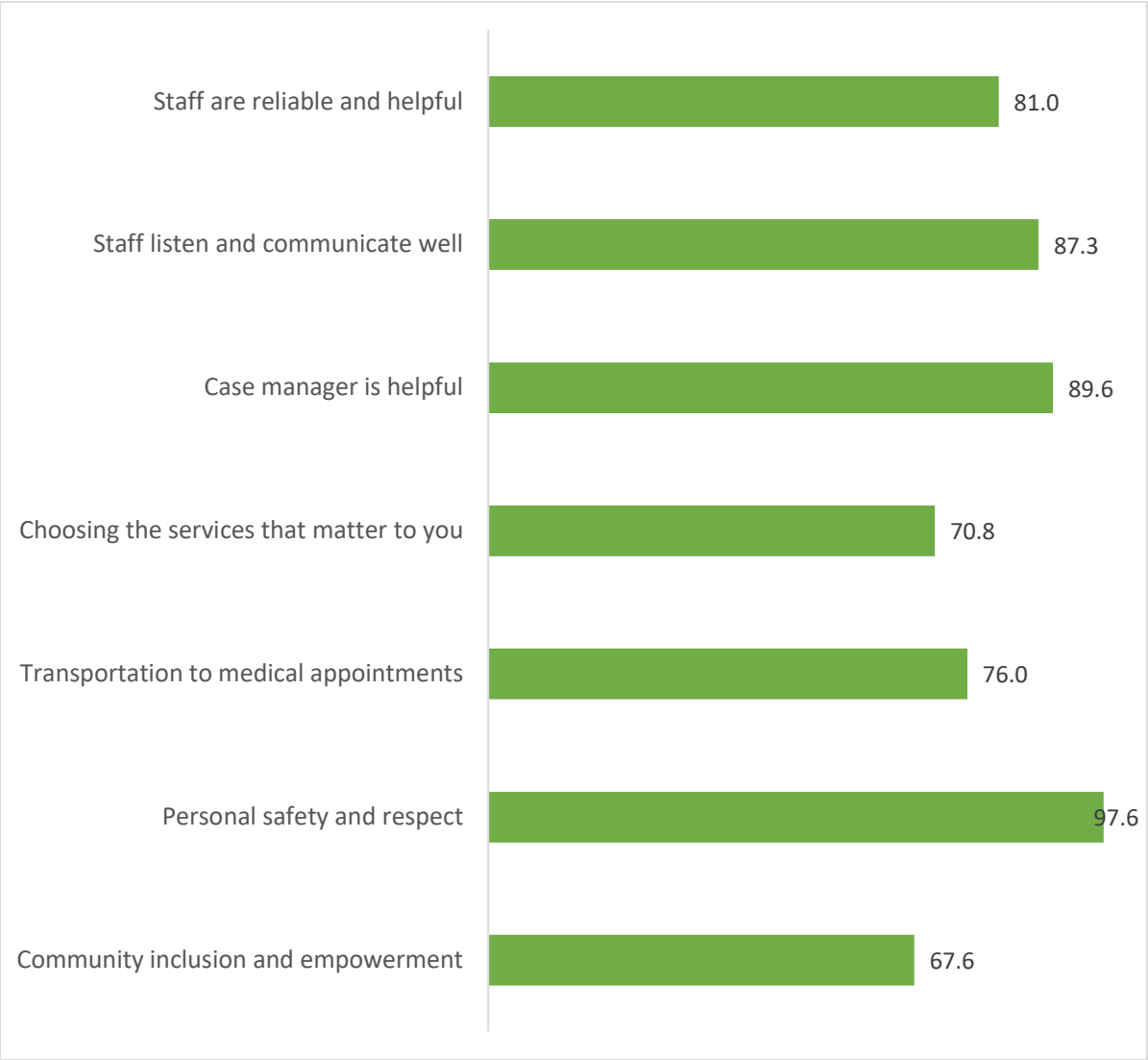
**Homemaking tasks can be provided by PCA or separate homemaking staff

***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 "Community inclusion and empowerment" (formerly called "planning your time and activities") once again received the lowest score among the composites, as just 68% of respondents gave this measure the highest score. Still, this represents an improvement over last year, when just 62% gave this measure the highest score. Respondents also gave notably lower scores to choosing the services that matter to you and transportation to medical appointments. Choosing the services that matter to you 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. Two-thirds of participants gave their homemaking staff, personal assistant/behavioral health staff, or care manager/TC a 9 or 10. Figure 2.3 shows the percentage of consumer who would "definitely" recommend their staff person. Interestingly, a higher percentage (>10%) of respondents definitely recommended their staff, compared to respondents who rated their staff a 9 or a 10.

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

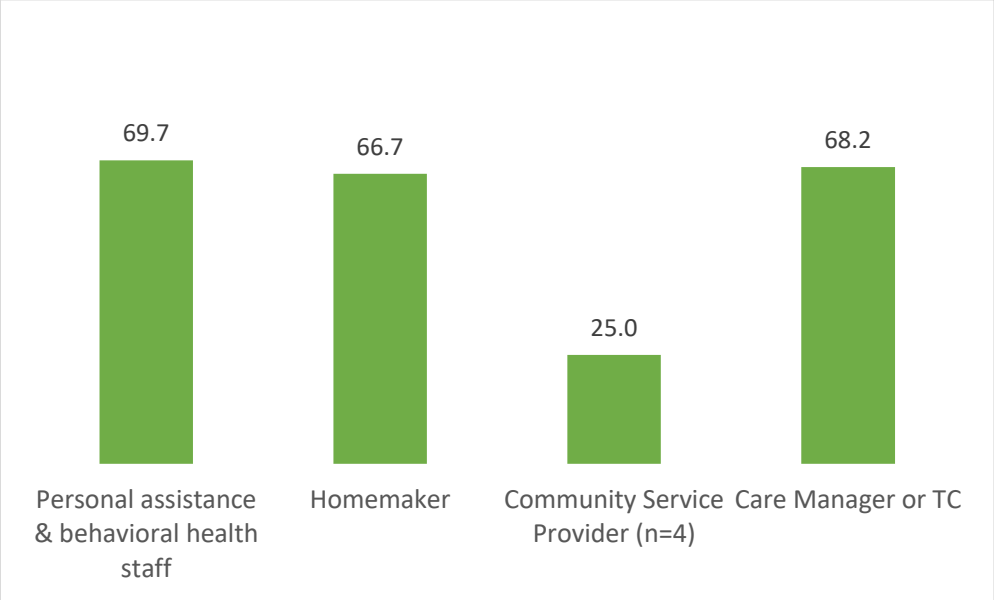
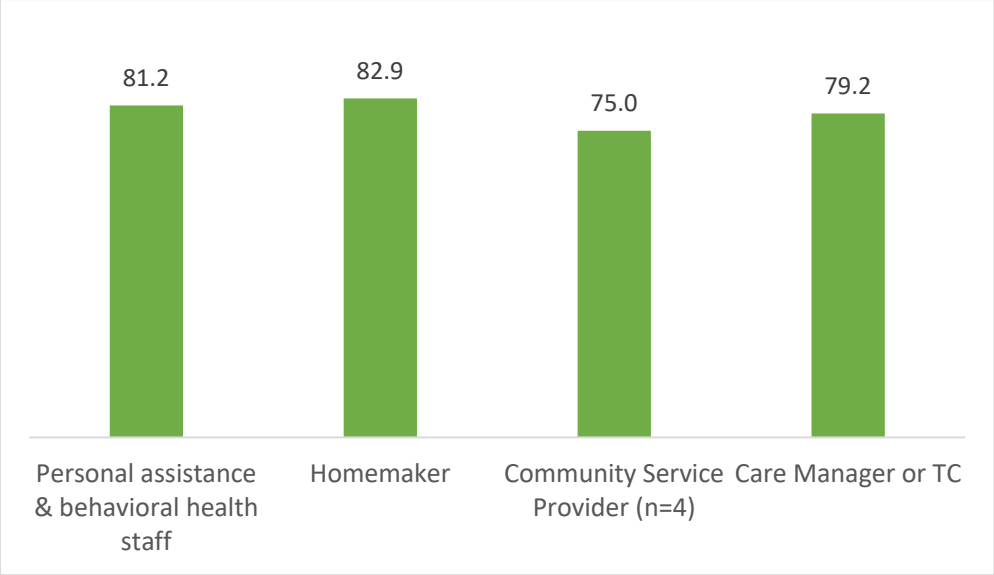


Figure 2.3. Recommendation: Percentage Who “Definitely” Recommend Their Staff



Positive comments about paid PCAs or other homecare staff include:

> *The service that the aides come from we have had issues with, but we have been able to rectify some of the issues with the aides that come now. The aides that come now are very good at their job, they come on time, and leave when they are supposed to. Sometimes they stay over to help [my mother] with her medicine and meals for when I need to take over.*
>
> *His main PCA is amazing and always helping him with his needs. The agency needs a good secondary plan for when his primary aide cannot come or needs a fill in on her off days. They lack that leadership and I find myself having to call from states away to inform them that there is no one there to help my brother or the person there is making a mess and not helping. Other than that, he is very happy with his life at the moment."*

Care manager

When asked about their care manager at 1 month, most participants (90%) knew who their care manager was, and 92% 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	264 (90.1)	29 (9.9)
Able to contact care manager when need to	239 (92.3)	20 (7.7)

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

> *The case workers are very helpful. They were able to set up a few things that really helped us in the transition for my grandmother to be in the home. They do regular check ins to make sure there is nothing else they can do.*
>
> *I really appreciate the work done by my care mangers. The whole program and what it is there for, everything was hands down phenomenal. They all fought for me to get this done.*
>
> *The program worked really well from me from beginning to end. Everyone was really accommodating and knowledgeable. Sometimes you have to be patient for a callback, but they are busy and they have been mostly accessible. My whole transition team was awesome, everybody was great.*
>
> *I've been doing the program with my mom, and the housing and transition workers have been amazing. The program is good. Some things do take time but no complaints because the people I have worked with are on top of things.*

Still some respondents reported that at one month post-transition they did not have the support they needed from their MFP SCM or TC. These respondents expressed confusion regarding all the different MFP staff working with them, who they are supposed to contact, and difficulty contacting the TC or SCM.

> *It's a good program, but they need to call you back when you leave messages. It's been very hard for me to do things on my own after this stroke. I call (my SCM) and nobody returns my calls. I need more PCA hours. I have good help on the weekdays, but I need somebody on the weekend. It is very hard for me to do things on my own right now.*
>
> *The main issue I had with MFP was feeling like communication was not good. I did not feel like all the MFP staff were on the same page and I felt like I didn't know what was going on. But other than that I had a good experience with the program and I really like my apartment. My TC is good.*
>
> *They need to focus on following through with the people that they take on instead of taking on more people they can't handle. Aside from getting me into my apartment, I have no idea what to do next. I don't know how I'm going to get my Social Security back. I am disabled, and I don't know how to get a person to help me with my laundry or get my medications. I don't even know who my contact person is to help me with these things through the program. UConn sent me a nice bright yellow postcard to do this survey, I think that's what Money Follows the Person should be doing to let me know who I can contact for assistance.*

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 PCA hours and lack of consistent staff to be especially problematic.

I wish there was more help. We need a better bed for him. We need more PCA hours. They make it complicated. They give a certain number of hours for PCA and nursing services. PCA and nursing hours should be interchangeable.

When I get a new aide, I hate explaining everything over and over again. That really bothers me. Sometimes they send me a fill in aide, and I have to explain everything or sometimes there is a language barrier which is annoying.

Several consumers reported financial concerns 1 month post-transition, such as not enough money for food, rent, electricity, or transportation.

[TC name] has been great. I'm really happy I got to go back to my home, and my daughter gets paid to help me which is awesome. Money is still a struggle. I need to eat as much organic food as possible because of the cancer, and it's very hard to afford it even with food stamps. But I try to stay positive. I'm very grateful.

Some relied on friends or family members to fill in and provide the extra support needed to live in the community.

I have been paying out of pocket for a lot of [my child's] purchases. I pay for her food and I still need a dresser for her downstairs. I am confused about who to go to for these issues.

They say there should only be one worker at a time but my child needs two people, so I need to be there most of the time.

Physical and Mental Health

Consumers reported better physical health in this year: 34% of consumers rated their physical health as fair or poor, compared to 42% in 2023 (Figure 2.4). Still some consumers expressed difficulty getting to their doctor appointment or obtaining their prescriptions which was concerning, especially given the poor health of many of these consumers.

MFP has been great, but there have been some major challenges once [my son] came home. Transportation is a huge issue right now. We were assured this was part of his discharge plan, and now that he is home, MFP says it wasn't clearly stated and there has been no resolution. He has no transportation service as of now and has been unable to get a neurological exam as that provider does not make house visits like the other providers.

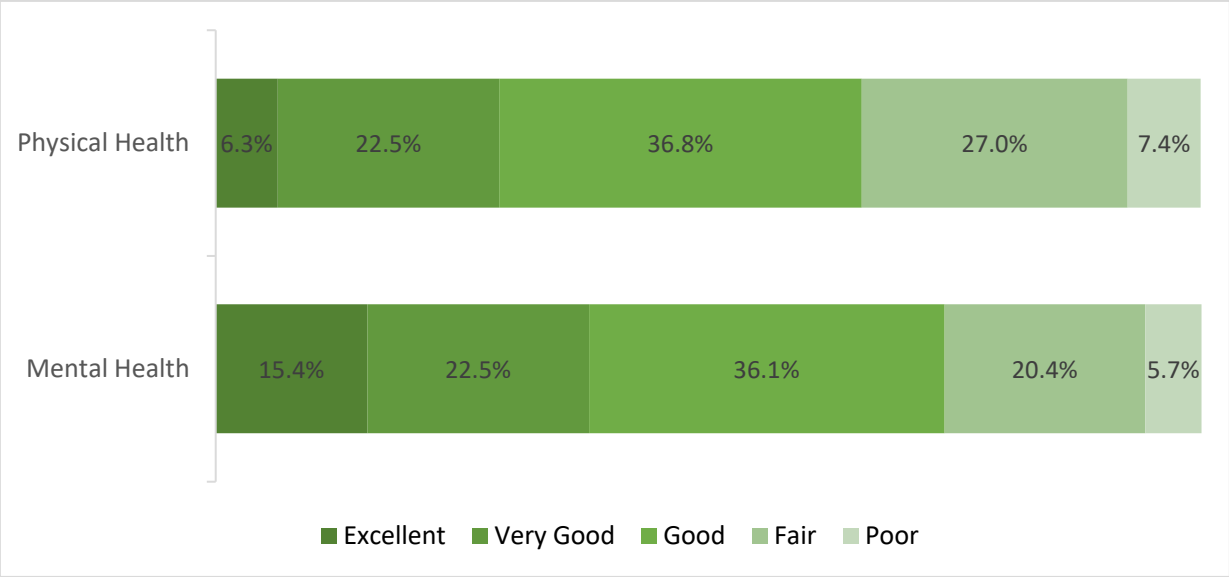
In comparison to 2023, consumers reported better overall mental or emotional health –74% said their mental health was good or better. Still, one-quarter (26%) of consumers reported having at least one depressive symptom in the last month. For some respondents, issues with where they now live, such as transitioning to a different city or to an assisted living facility, contributed to their poor mental health.

Being in Hartford isn't great for me. The area is not really handicap accessible and all my doctors are in Naugatuck. Same with my friends. It's been a really tough transition. I have no money, no one to come into my apartment to help me, which I really need, and there's nothing to do. I can't leave the apartment by myself and I'm going to lose my mind from boredom.

I'm very sad. I wish I had my own apartment, not just an assisted living facility. I told my kids to never put me in one of these places. I had six kids and nobody has time for me. I want to go out to the stores and not just have things brought to me. I still need curtains but nobody wants to bring me to the store – I like to pick out my own curtains. I would like to get counseling again. I would like to know why I am on so many medications and need some clarification on why I am on so many. Because I cannot see, I used to get tapes sent to me with six to eight stories on them, and I haven't gotten any of these since I was in the nursing home.

At 1 month post-transition, 11% of community consumers reported falling since transition, a decrease from the 15% in 2023. However, there was an increase this year from 18% to 21% for those who used the emergency room in the month post-transition.

Figure 2.4. Self-Reported Physical and Mental Health

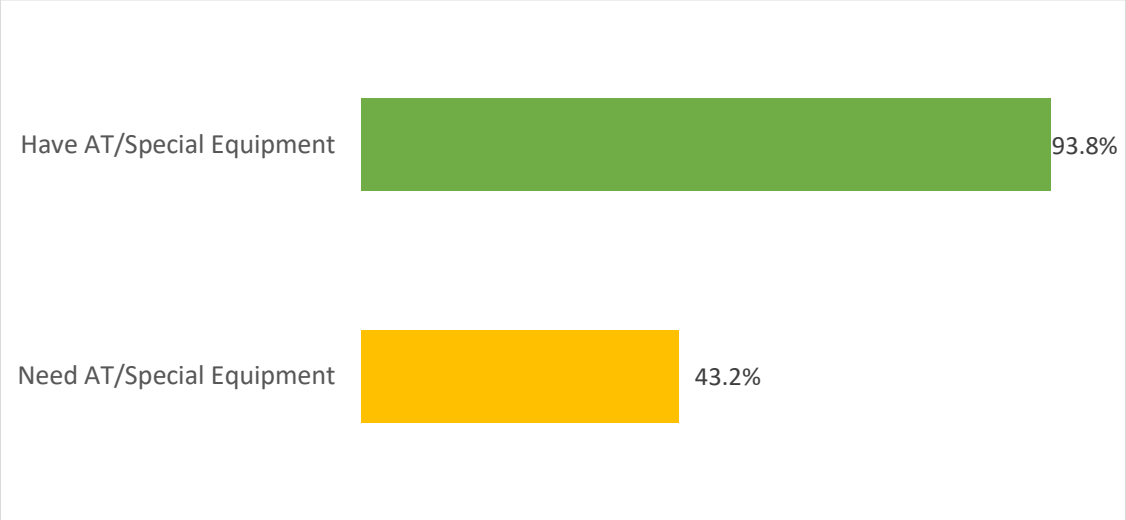


Assistive Technology and Special Equipment

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 (43%) consumers reported lacking some type of assistive device, equipment, or home modification needed for them to live in the community at the 1 month survey (Figure 2.5). Although 2024 did not see an increase compared to 2023, this number has risen steadily over the past 3 years – 24% of consumers in 2021, 34% in 2022, and 42% in 2023 reported a need for some type of device or modification 1 month post-transition.

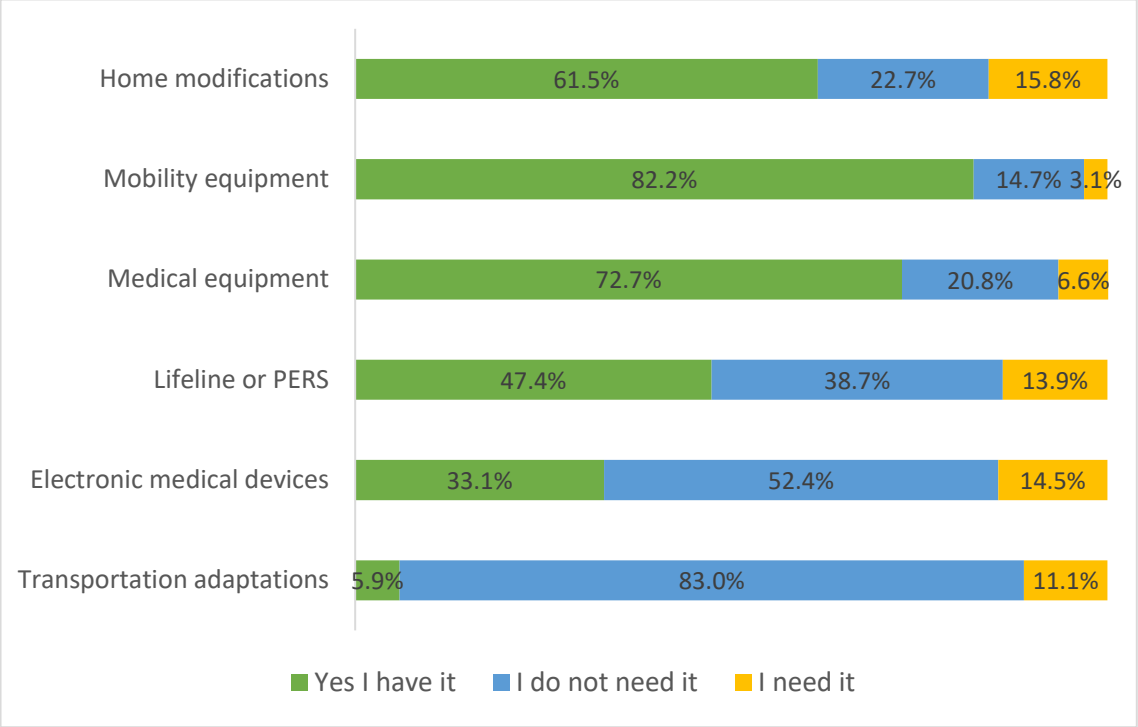
Figure 2.5. Have or Need any Type of Assistive Devices, Home Modifications, or Special Equipment



Consumers most often reported having mobility equipment (82%), special medical equipment (73%), or home modifications (62%) (Figure 2.6). When asked what type of equipment or devices they still needed, 11-16% of consumers still needed home modifications, a personal emergency response system (PERS), electronic medical devices, or transportation adaptations 1 month post transition. Lack of home modifications, such a railing or ramp made it difficult to leave the house, while others needed medical equipment such as a hospital bed or shower chair. Comments included:

> *My biggest concern right now is getting out of my house to go to medical appointments. I have steep stairs, and MFP assessed them and are unable to get a ramp placed there. I get transportation to medical appointments covered by my insurance but only from the street to the office. I would have to pay out of pocket for EMTs to bring me to the vehicle as I am unable to walk down the stairs. I am hoping to get into senior housing – I have already applied.*
>
> *[MFP] told [my mother] that she was going to receive something for her to stand up, but she hasn't received one. She also needs a recliner.*
>
> *I think the program should be freelance. There should be enough funding when to transition an acute care patient who is very dependent. There should be more help with obtaining funding or modifications for vehicles to be able to transport.*
>
> *I really need assistance with getting a van lift. I tried reaching out to [SCM/TC] for assistance but they aren't really helpful in that aspect. I wish I had a little more guidance when it comes to getting that for my mother.*

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 2023

This section reports the experiences of consumers who transitioned in 2023 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 482 consumers transitioned in 2023. Altogether, they completed 575 HCBS CAHPS surveys: 321 1 month and 254 12 month surveys (Table 3.1). The majority (93%) of surveys were completed with consumers residing in the community. This resulted in 310 1 month and 226 12 month community surveys completed for consumers who transitioned in 2023. Section 3 reports data from these 536 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 prior 3 months.

Table 3.1. Surveys Completed for 2023 Transitions by Time Point and Survey Setting

	Community Surveys n (%)	Institution Surveys n (%)	Settings Combined n (%)
1 Month	310 (96.6)	11 (3.4)	321 (100)
12 Month	226 (89.0)	28 (11.0)	254 (100)
Both time points	536 (93.2)	39 (6.8)	575 (100)

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 82% at 1 month to 58% 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	209 (69.4)	155 (71.4)
Independent Living Skills Trainer (ILST) (ABI waiver only)	1 (<1)	1 (<1)
Homemaking services or Homemaker-Companion	202 (67.1)	155 (71.4)
Care management services	255 (82.3)	130 (57.5)
Job coach or vocational supports	0 (0)	0 (0)
Recovery assistance services (MHW only)	5 (55.6)	4 (44.4)
Community Service Provider (MHW only)	7 (77.8)	6 (66.7)
None of these services	12 (3.9)	28 (12.4)

*Consumers can use more than one service

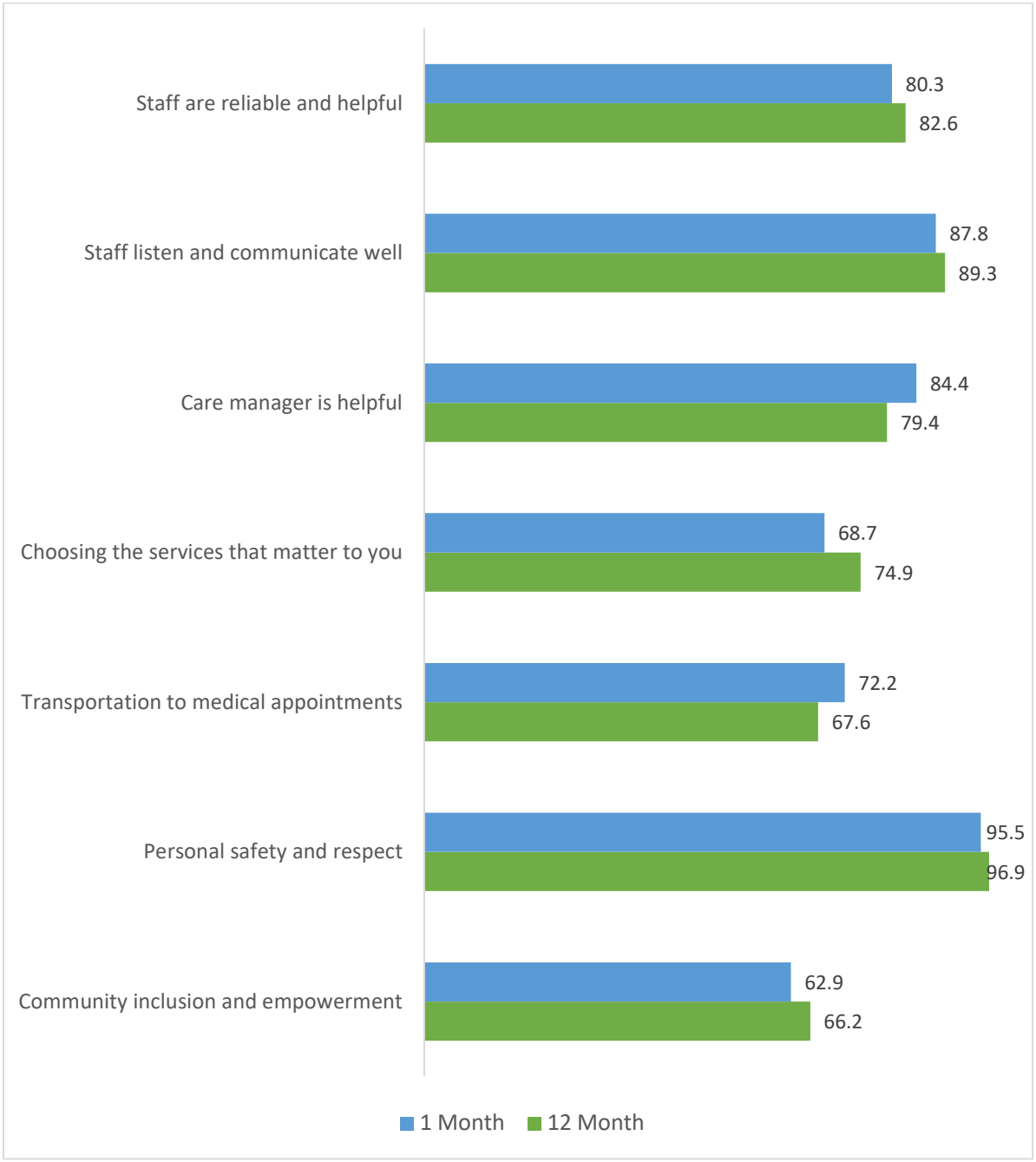
A. HCBS CAHPS Key Results

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 time points gave the highest scores to personal safety and respect, followed by both staff and care manager composites. As in previous years, consumers gave the composite community inclusion and empowerment the lowest score. Only 63-66% of consumers gave the highest score for this composite. While the care manager is helpful composite declined from 1 to 12 months, more people reported that they were choosing the services that matter to them at 12 months than at 1 month.

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



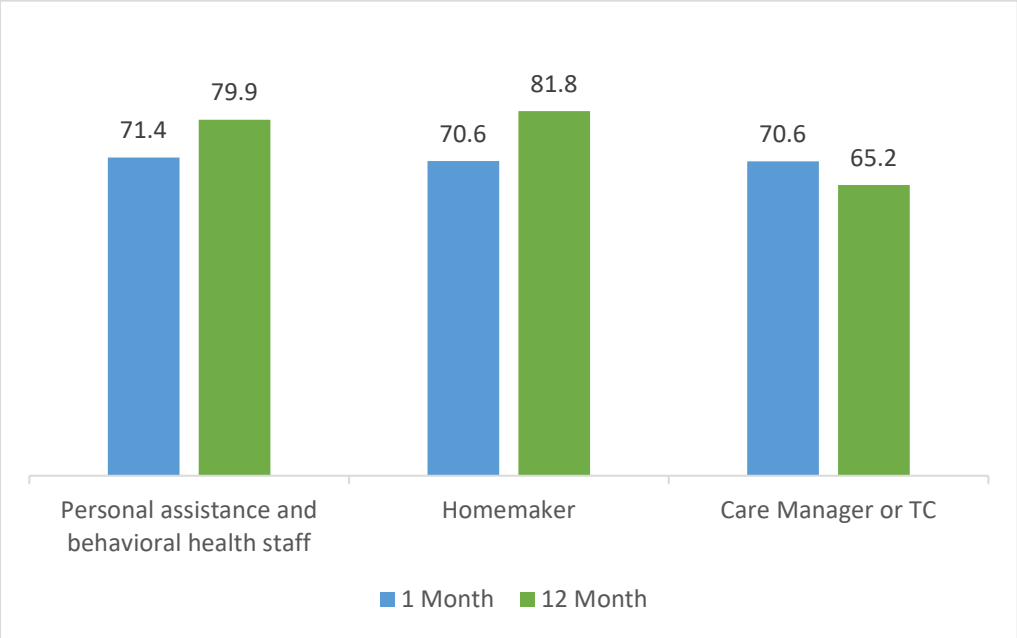
*"Staff" combines all PCA, ILST, recovery assistant (RA), community service provider (CSP), homemaking, companion, life skills coach, and community mentor staff

Global Ratings

Global ratings for PCA/RA/ILST staff and homemaking staff show a noticeable increase from 1 month to 12 months. (Figure 3.2). Meanwhile, care manager ratings fell from 71% at 1 month to 65% at 12 months. Positive comments about PCAs or other HCBS staff included:

> *Everything's been good. I appreciate it and I thank God that I got this help. I probably would not have made it if I didn't. (12 month)*
>
> *I really like my aide. She's the best. (1 month)*
>
> *I adore my home health aide - she is a total machine and such a delight to be around. I have no complaints. (12 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 staff turnover, lack of basic training, difficulty finding staff, quality of work, inappropriate behavior, and language barriers. Consumers also expressed dissatisfaction with the home care agencies themselves, especially lack of staff supervision and communication. One repeated comment was the lack of even a phone call to tell them that the scheduled aide would not be coming and they had no one else to send. Consumers felt the agencies should be responsible for the quality of the staff and providing adequate supervision. Consumers also commented that they needed more assistance than what could be provided by MFP.

> *If he could get the aide to stay off the phone that would be a nice thing. That is an issue we have had with all aides. (1 month)*
>
> *The aides do the bare minimum, I caught one of them sleeping on the couch and one left halfway through the shift to change her pants but never came back. (1 month)*
>
> *My aide does not know how to do certain tasks like the laundry or cooking, or clean the oxygen tank. (12 month)*
>
> *I would like staff or agency to call me directly if their schedule changes. (1 month)*

[The agency should] have the PCA not use the phone or smoke in my house. The agency the PCA comes from does not care about the patients. They should stay all the hours they have scheduled. (12 month)

I wish I had an aide longer than a few months or several months at a time. (12 month)

None of the aides have brain injury experience so it would be nice to have someone that is trained. There are limited hours and no overnight coverage which makes no sense for someone who is 24/7 care. (12 month)

The agency needs backup aides, and those aides did not know what to do, like the personal care I needed. The company did not tell them what to do, and then they find out when they get here. My mother who is 85 years old has needed to help when aides did not show. I don't want my mother to get hurt [helping me]! (1 month)

Her transportation is an issue. We want an aide to drive. The agency said it would happen and it has not after 6 weeks. (1 month)

Some consumers found that Community First Choice (CFC) was a better fit for them. A couple of consumers remarked that they were switching from agency-based to CFC because of their dissatisfaction with either the home care agency itself or the PCAs provided by the agency. As in previous years, self-directing consumers reported multiple issues with GT Independence (GTI) such as staff not getting paid on time, lack of responsiveness and difficulty navigating the self-hire process. This prevented or delayed consumers getting the PCA help they needed.

We have been trying to hire our own aides because working with the agencies has not been good. We've had some good staff, but most are completely unreliable or unwilling to do the necessary tasks. Working with GTI has been a nightmare and is like applying for Medicaid all over again. We have aides that have been trained, followed all the instructions, but still have not been paid by GTI. (12 month)

I appreciate the help that I got from this program for my daughter. She would not have been able to come home without it. I'm so glad also that I can hire people that already know and love my daughter to care for her. I don't have to worry about her care when I'm not here. (1 month)

I have called GTI three times and no reply. I did what I had to do and have not heard back. (1 month)

I did not have a good experience with the one [agency provided] aide I had for one day. I have been trying to self-hire my friend who has been voluntarily helping me every day for the past month. (1 month)

Some respondents expressed their frustration with MFP regarding the home care agencies MFP recommended or referred them to. These respondents cautioned that unless the home care 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.

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 them have people with enough experience or training to care for someone who is bed bound and cannot do any basic personal care, like 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 sit on the couch and change and clean my mom when she needs it. Nothing else. And I can't find that basic care. (1 month)

I think it would be great if Money Follows the Person or the Agency on Aging could vet the companies they pay for respite care a little better. I think that would benefit all the people who provide that care. When I was in the police academy last year, I had to leave to go change [my mother] during work because there was no one there who could change her. It seems like all of them are not adequately trained or staffed. I had to show them because they did not know how to change a bariatric diaper, and neither did I but I just used basic common sense to figure it out. They should adequately staff their Money Follows the Person people so they have someone available to answer questions so an ambulance doesn't need to be called for that patient. It is not very efficient if you ask me. Connecticut kind of falls short when taking care of their elderly if you ask me. (12 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.

We could only qualify for 8 hours a day or a live-in aide, but we didn't have a place for a live-in, so my husband who is disabled has been taking care of me for the remainder of the time which isn't great. (12 month)

I have called them [MFP staff] multiple times and no answers to why we never get a call back. They are way too busy. It cannot deliver what it is going to do. I feel like they have not done anything that we are aware of. We have not had anyone come to the home and provide us with resources. It took us four months to receive food stamps. I had to take care of it – the case workers did not help. They expected [my husband] to fill out the form, and he can't do that. We found the Disabilities Network has been very good, but that was not Money Follows the Person. (12 month)

There is a slight language barrier. The aides have heavy accents and sometimes it is hard to understand. One we can communicate 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 she 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. (1 month)

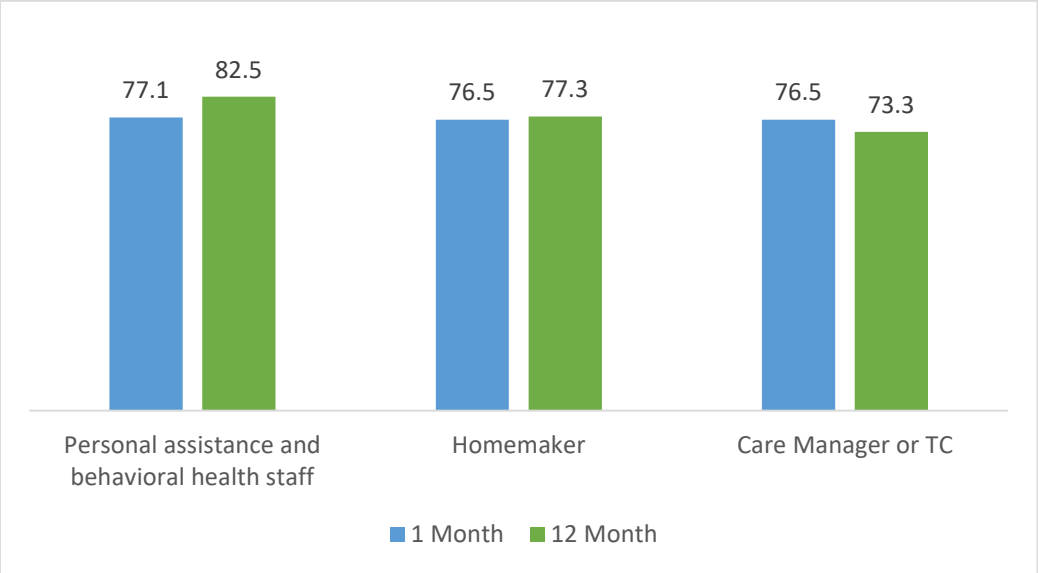
[He is] not receiving PCA services from the state. He has dementia and is a wander risk. he needs someone to help him go to the grocery store and help clean. We have hired and paid for PCA services out of pocket, but he really needs services from the state. (1 month)

Staff Recommendations

Despite issues with paid staff, Figure 3.3 shows that a high percentage of consumers at both 1 and 12 months (77-83%) would "definitely" recommend their PCAs/RAs/ILSTs to family or friends. Positive comments about SCMs and TCs included:

> *[TC name] and [Housing Coordinator (HC) name] 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)*
>
> *[TC name] has been wonderful and I appreciate MFP help. I don't know how I would ever pay them back. (1 month)*
>
> *The program worked really well for me from beginning to end. Everyone was really accommodating and knowledgeable. Sometimes you have to be patient for a callback, but they are busy and they have been mostly accessible. My whole transition team was awesome, everybody was great. (1 month)*
>
> *I am grateful for MFP and how they support me. They call when I go to the hospital and they care. I can talk to them. They help me if I don't understand until I do. They don't get mad, but will continue to help me understand. (12 month)*
>
> *I'm very grateful for everything that the TC and HC has done for [me]. [I am] very, very pleased with all of the work that they have done for [me]. [They were] phenomenal throughout the whole process. Even though their part of the process is completed, they still are checking on [me]. (1 month)*
>
> *My Housing Coordinator was so helpful in helping me to find an apartment and get my benefits. She was great and I always felt like I could call her. (12 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.

Table 3.3. Self-reported Assistance with Everyday Activities

Needs assistance with:	1 Month n (%)	12 Month n (%)
Personal care	165 (79.3)	129 (81.7)
Meals or eating	174 (82.9)	136 (86.1)
Taking medications	127 (60.8)	92 (58.2)
Using the toilet	108 (51.7)	86 (54.4)
Housekeeping or laundry	203 (69.1)	161 (72.2)

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, 21 participants (9% of those with PCAs or homemakers) indicated one or more unmet need: 7 for personal care, 5 for taking medications, 6 for using the toilet, 6 for meals or eating, and 7 for household tasks. At 12 months, 9 participants (5% of those with PCAs or homemakers) indicated one or more unmet need: 3 for personal care, 2 for taking medications, 5 for using the toilet, 3 for meals or eating, and 3 for household tasks (separate items, consumers can report more than one).

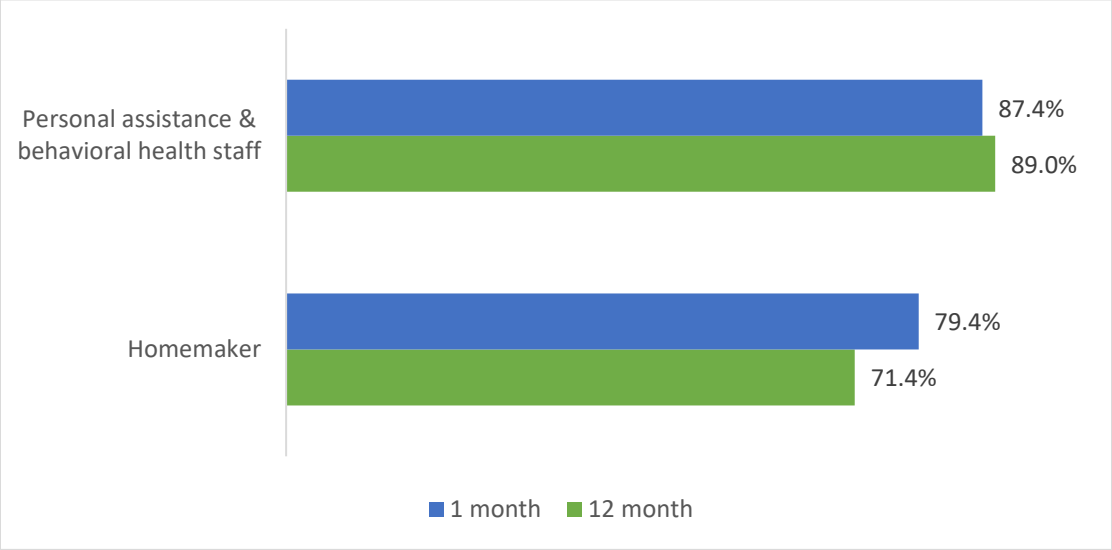
Participants not receiving personal assistance were asked if they always had the assistance they needed for bathing/dressing, meals, medications, and toileting. Eleven individuals at 1 month (11% of those asked) and seven participants at 12 months (11% of those asked) had an unmet need for one or more of these tasks. At both 1 and 12 months, no participants reported staff having hit them or hurt them.

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 (88% 1 month, 90% 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 (79%) to 12 months (71%) (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

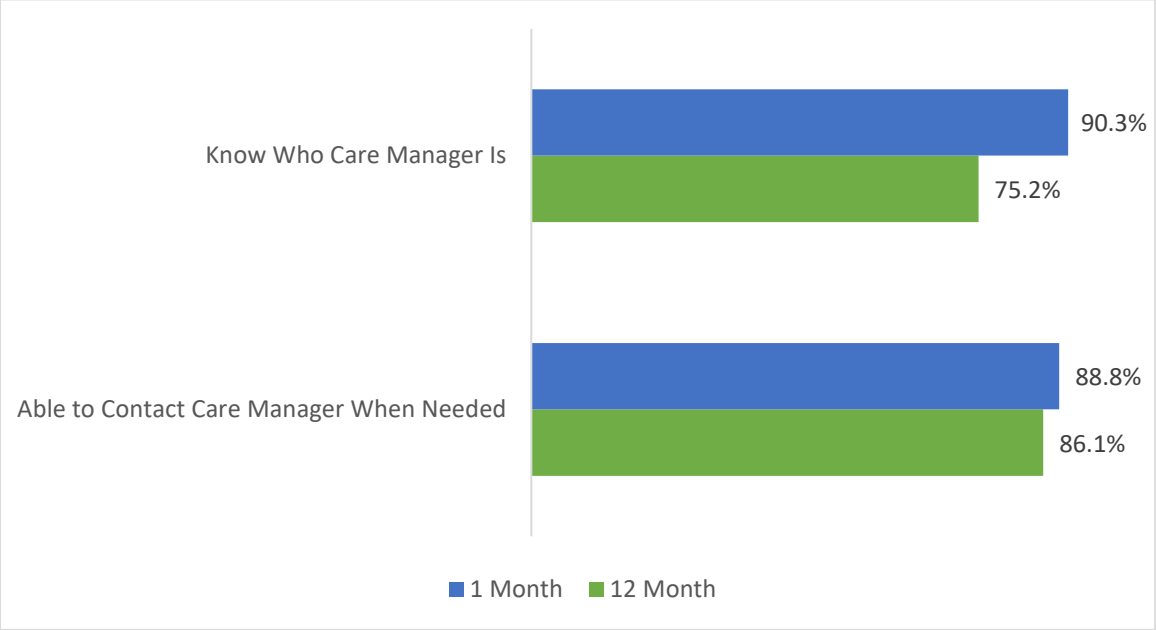
Care Managers and Care Plans

When asked if they knew who their care manager was, 90% of consumers at 1 month and 75% of consumers at 12 months said they did (Figure 3.5). This significant drop over the year reflects 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. Last year, 82% of consumers at 1 month said they knew who their care manager was, indicating an improvement in this area. Most (86-89%) consumers at either time point were able to contact their care manager when they needed to.

Comments indicated that for some consumers or family members, communication with their care managers or TCs was difficult. Respondents frequently commented on the change in their care managers, and how that made it difficult to know whom to call. 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.

> *[I] haven't heard back from TC or SCM at all and desperately need answers on care related items. (1 month)*
>
> *Case managers need to be willing to see their clients in person. My lady said I lived too far away and could not help me. That shouldn't be the case, she never even saw my face. (12 month)*
>
> *They should provide info and phone numbers so that we can reach our case managers. (1 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. Before you told me I could call my case manager I didn't know that I could reach out to her. I did speak with her on the phone earlier because she called me, and she let me know in the next month I'll be assigned a different case manager. I don't understand why they would assign someone new again. (1 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 (62% 1 month, 48% 12 month), while 62-64% of consumers had asked for help with changing services over the year (Figure 3.6). Some consumers had not thought about asking their care managers for help with equipment until they were asked if they had done so in the interview.

> *I need help getting a shower chair. I do not know who to contact. (1 month)*
>
> *I had a few aides that I did not like, but the one that we had for the past 2 weeks has been excellent. I need a new walker and I did not realize that I could ask my case manager about this. (1 month)*

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

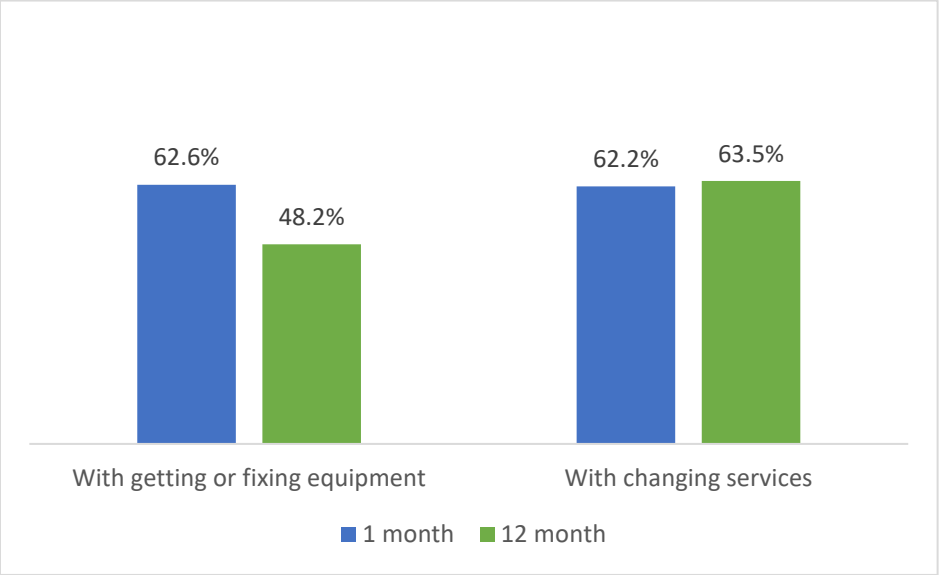
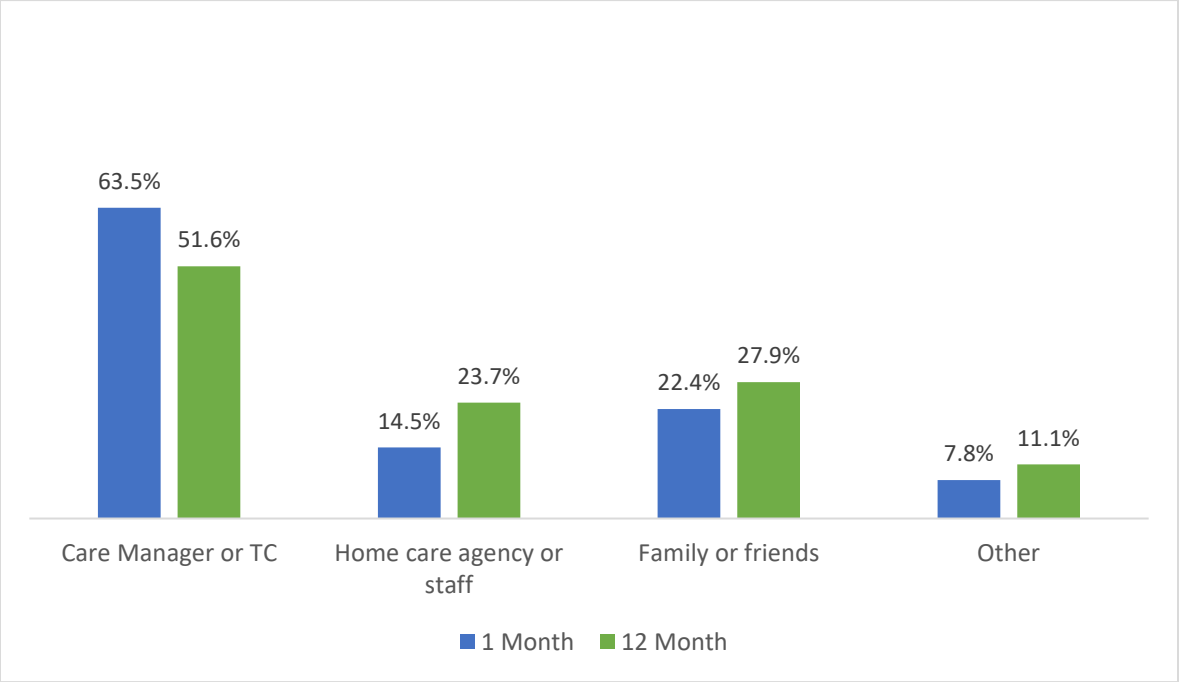


Figure 3.7 shows that at both 1 and 12 months, consumers would most likely contact their care manager for changes to their care plan, followed by contacting family or friends.

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



*Can name more than one

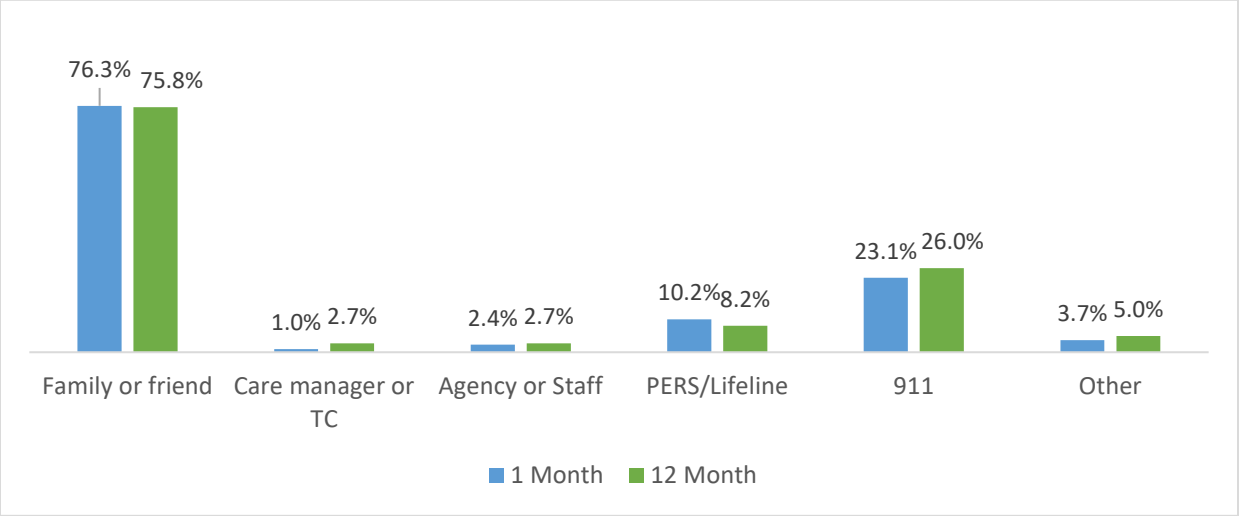
Consumers also mentioned needing more support than was in their care plan or not getting the paid services they expected or needed.

> *His care plan is not being fully executed in the community and therefore [his] needs are not being met. (1 month)*
>
> *I need more PCA hours or at least split hours because there are times when I am stuck without help with toileting.(1 month)*
>
> *[There are] untrained aides. The budget approves items that aren't needed but doesn't approve things that are needed such as hospital bed – there's been no way to weigh [my] son since being home. I had to purchase our own suction unit for his tracheostomy. He needs 24 hour care and he receives 11. (1 month)*
>
> *He wants more hours from aides so that he can go out and socialize. (12 month)*
>
> *The only thing is we needed more PCA hours if possible, but other than that they did really good. They definitely helped me and walked me through. (12 month)*
>
> *This program has done nothing for me. They got me food and helped furnish my place at the beginning and that was it. I was never given a person, came into this blindfolded. They didn't even help me get this place. I did my own application. I filled out an application for a homemaker to do my laundry over 10 months ago and still haven't heard back. I have a broken hip and it's impossible for me to do that on my own. They need to get it together. (12 month)*

Emergency Contact

Most consumers reported that they were likely to contact family or friends in case of an emergency (76%), followed by 911 (Figure 3.8).

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



*Can name more than one

D. Self-Direction

The majority of consumers at 1 month (89%) and 12 months (94%) reported they used agency-based services to hire their aides (Figure 3.9). Three-quarters of consumers who self-directed their own services hired family members to help them. (Figure 3.10; see Section 4 for a more in-depth look at self-directed consumers). At 1 month, 19% of all consumers reported they picked the people who are paid to help them, which increased to 32% at 12 months (Table 3.4).

Figure 3.9. How Do You Hire Your Aides?

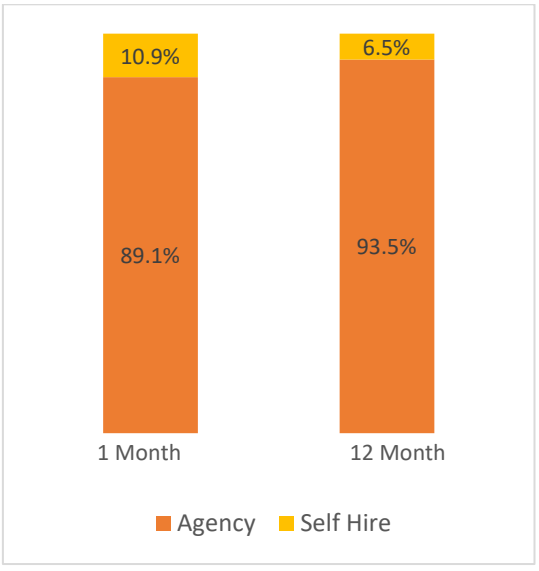


Figure 3.10. Employs Family Members

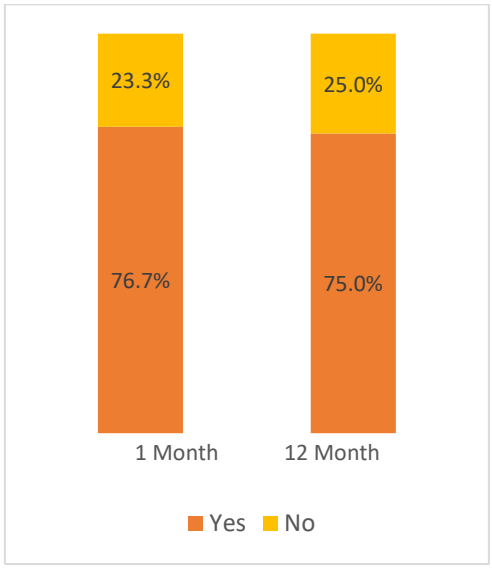


Table 3.4. Do You Pick the People Who Are Paid to Help You?

	1 Month n (%)	12 Month n (%)
Yes	48 (19.0)	60 (32.3)
No	205 (81.0)	126 (67.7)

E. Living Situation and Social Support

As shown in Table 3.5, living situation and family/friends living nearby was similar between time points. Although 58-63% of consumers at either time point lived alone or without other adults, approximately 71% of all consumers at either time point 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 74-75% of consumers who did not live alone resided with family members at either time point. Unfortunately, not all consumers living alone had nearby informal support – 19% of consumers living alone at 1 month and 15% 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, 62% of consumers reported this assistance at 1 month, which decreased to 57% 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.

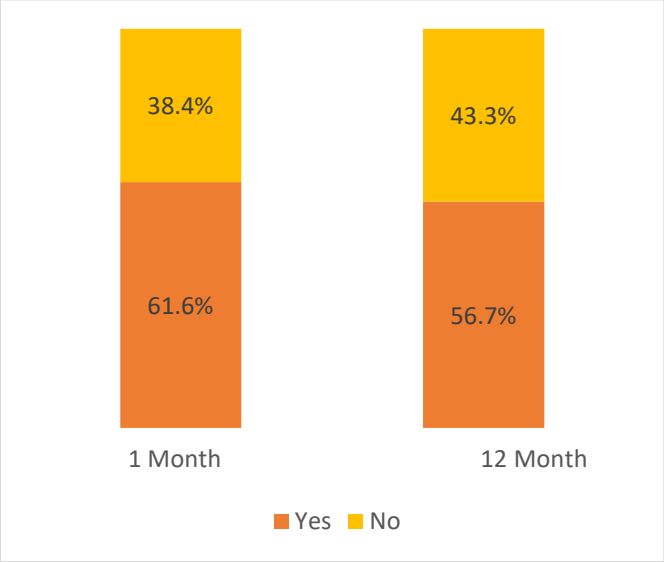
> *I'm looking for a female companion. I need to lose weight first. But I want someone in my life. (1 month)*

Table 3.5. Living Situation and Social Support*

		1 Month %	12 Month %
Number of adults living in household		N=309	N=224
	1	57.9	63.4
	2-3	37.2	33.0
	4+	4.9	3.6
Lives with family member/s		N=130	N=81
	Yes	73.9	75.3
	No	26.2	24.7
Lives with non-family		N=130	N=81
	Yes	30.0	32.1
	No	70.0	67.9
Family member/s live nearby		N=309	N=225
	Yes	71.5	70.7
	No	28.5	29.3
Friend/s live nearby		N=309	N=224
	Yes	51.1	54.4
	No	48.9	44.6
Can see nearby family		N=221	N=157
	Yes	90.5	93.6
	No	9.5	6.4
Can see nearby friends		N=158	N=124
	Yes	91.1	92.7
	No	8.9	7.3

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

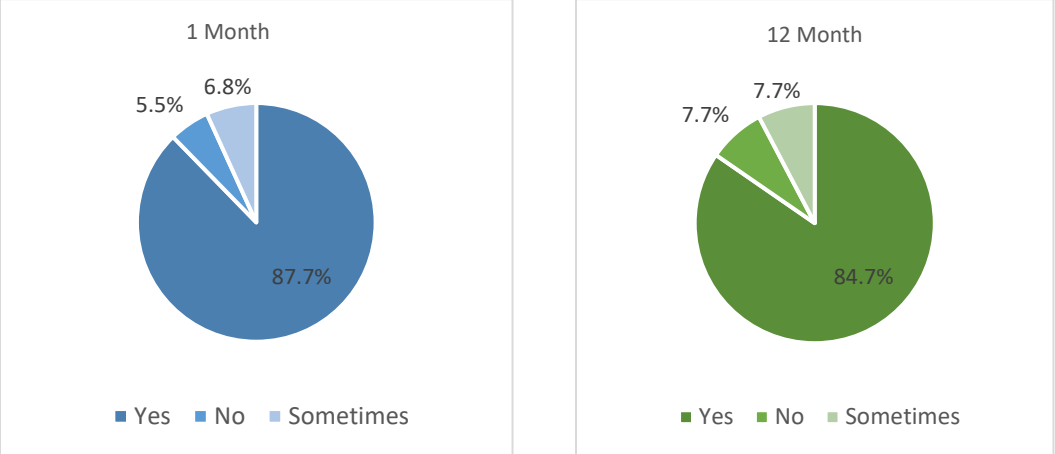
Figure 3.11. Assistance from Family or Friends Around the House



The majority of consumers at both time points said they liked where they live (88% 1 month; 85% 12 month). The percentage of those who liked where they lived at 12 months increased from 2023, when only 79% said they liked where they live. Additionally, almost all consumers (95% 1 month, 92% 12 month) felt safe where they live. Many respondents indicated how happy they were just to have their own place. Respondents also appreciated the help they received from MFP, especially with setting up their new place. One consumer expressed gratitude to his MFP transition team and for his new home in the community:

> *When I walked into this apartment for the first time, I had a fully furnished home, a house full of groceries, and a whole team of people waiting there for me like a welcome home party. I love it here. It's quiet all day, I have nice neighbors, and the location is great. This program helped me get out of the nursing home and back on my feet, and my health has only gotten better. I am a patient person and very happy to be where I am at now. (12 month)*

Figure 3.12. Do You Like Where You Live?



On the other hand, consumers also expressed dissatisfaction with their community residence, housing coordinator, or the housing process. Housing is one of the top challenges for consumers when planning to transition back into the community from a facility (UConn Center on Aging, 2023). Even with housing coordinators and financial assistance, it is difficult to find affordable, accessible housing, especially given the high housing and 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.

> *They are a good program – I got the help I needed to leave. But I don't like where I live now. The landlord is always complaining about me and my friends/family even though I don't cause any problem. I'll be happier when I find a new place. Not sure how to get the help I need in the new place, but I will call my housing director. (1 month)*

> *I haven't had any help. The voucher is useless if you don't qualify for a place to live. I don't have a place to live right now. (12 month)*

> *I feel that my Housing Coordinator I have was not helpful at all. She wasn't helping me find places or suggesting anything, I was doing it all on my own, and then when I found a place it was hard to get her connected with the place and get the security deposit. It was all very frustrating with her. (1 month)*

Limited housing options meant that consumers sometimes found themselves living farther away from their friends or family or in adverse living situations. Several comments called out the interconnection of living situation, location, transportation, social support, and mental health.

> *I really wanted to be in Middletown which is where all my family and friends are. I told them that for 10 months before I left the nursing home and then they stuck me in Meriden. Meriden has no transportation and my disabled brother has to come from Middletown to bring me out which is a lot for him. If I was in Middletown, I could do things on my own and be more independent. Not being in Middletown is the main thing that impacts me right now. It makes me depressed. I'm talking to a psychologist right now. (12 month)*

> *I do not want to stay here at the [Residential Care Home]. There is no hot water. I want my dogs, cats, and birds back when I move into an apartment. (1 month)*

> *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. (1 month)*

F. Physical Health

Physical Health, Falls

One quarter of consumers rated their physical health as very good or excellent at both time points (26% 1 month, 25% 12 month) (Figure 3.13). At the same time, between 39-43% of consumers at either time point 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. One consumer remarked on his own health and how it limited his ability to be out in the community, “I would like to get stronger to take the town bus with the aide.” Some consumers found it difficult to manage their health conditions once in the community, even with support from visiting nurses or family.

> *There’s been a delay in requesting and receiving visiting nurse services. I contacted [my father's] care manager who is having trouble obtaining these services for him. Now I must check his vitals and determine his medication dose, which makes me feel stressed and scared for his safety. (1 month)*

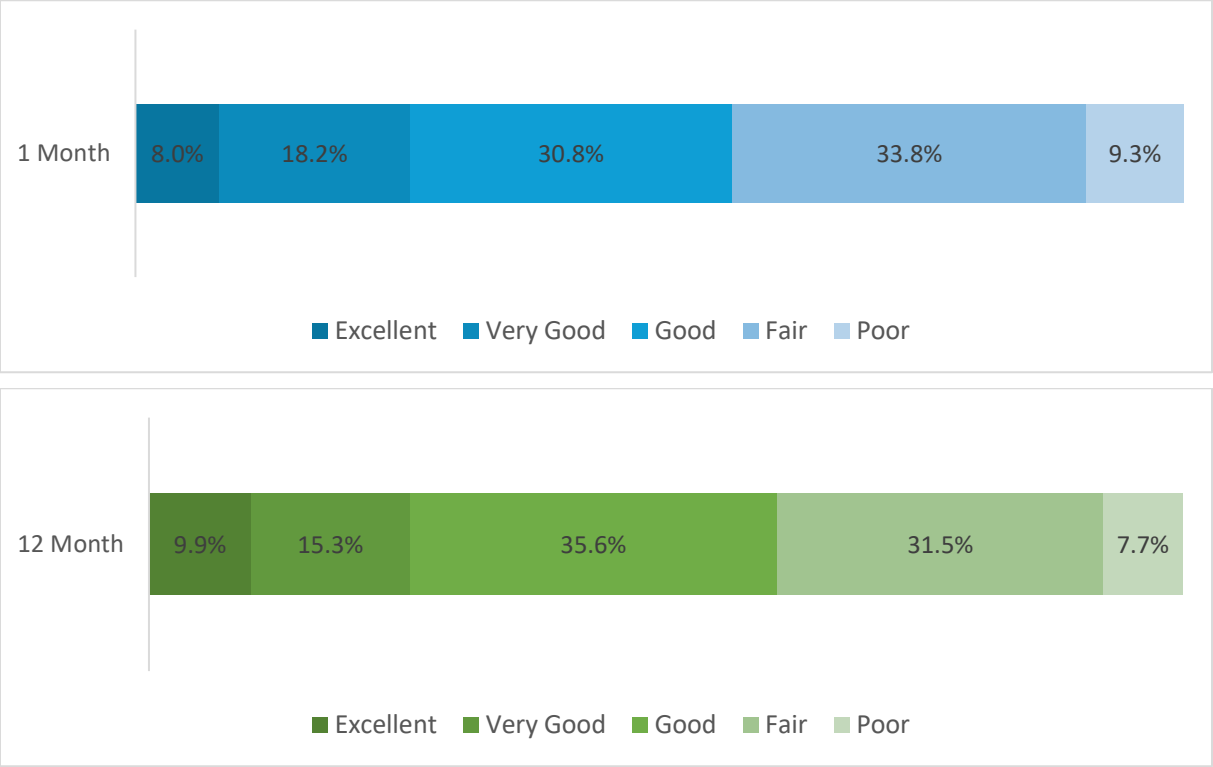
> *I've been having problems getting my prescriptions filled, and I feel sick because it has been over a week. (1 month)*

I want enough physical therapy. The first team of physical therapists they give you do not stick around long, but they are terrific, and I would like to keep them as long as possible. I am not going to be able to get out of bed without good PT. (1 month)

For others, getting devices like a pill box from MFP and weekly nursing in their care plan made all the difference in managing their health:

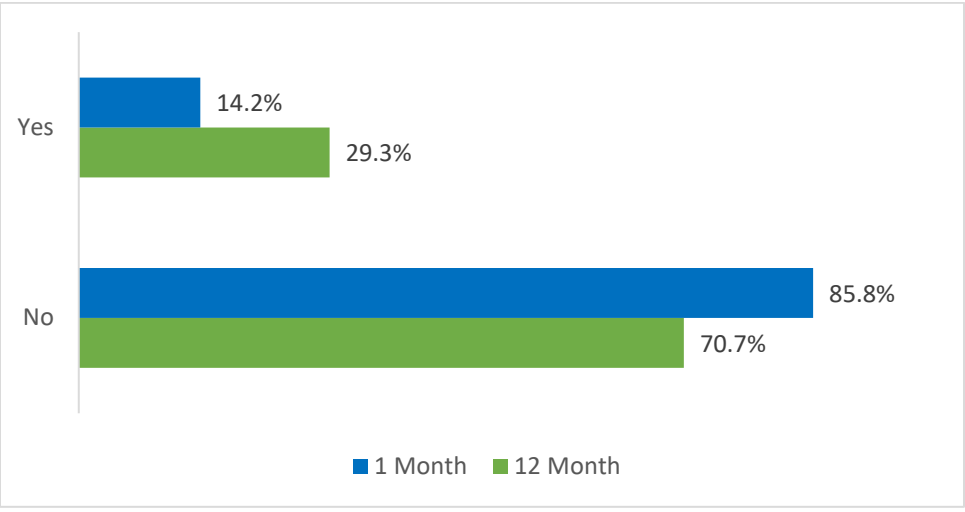
All I have to say is I am really pleased with the nursing coming in. I have the meds in control with the pill box – they have been amazing. I think everyone could use a program like this to help transition…. It has been very helpful. (1 month)

Figure 3.13. Self-Reported Physical Health



Fourteen percent of consumers reported falling between transition and their 1 month survey (Figure 3.14). This percentage increased to 29% by the 12 month survey, which is not surprising due to the longer timeframe (since transition to 1 month, 1 month survey to 12 months) (Figure 3.14).

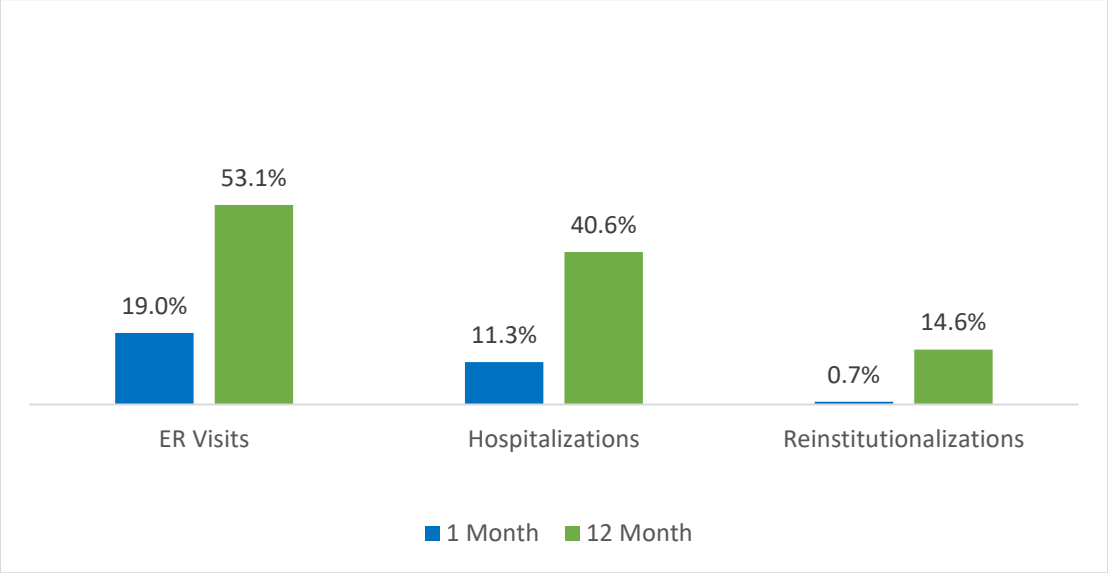
Figure 3.14. Falls



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). Fifty-three percent of participants interviewed at 12 months had used an emergency room, and 41% had been hospitalized. By 12 months, 15% of consumers were reinstitutionalized, either short or long term. Compared to 2023, consumers had lower rates of all three metrics at 1 month in 2024, but higher rates of all three at 12 months.

Figure 3.15. Emergency Room Visits, Hospitalizations, and Reinstitutionalizations



G. Mental Health

Mental Health

Self-rated mental and emotional health increased slightly over time: at 1 month, 34% of consumers rated their mental or emotional health as very good or excellent, compared to 38% at 12 months (Figure 3.16). This represents a positive increase in self-reported mental health compared to last year when 32% of community consumers reported very good or excellent mental health at 12 months. Between 28-32% of consumers reported poor to fair mental or emotional health at either time point.

Rates of depression decreased slightly over time. One out of three (33%) consumers reported depressive symptoms at 1 month, which decreased to 28% at 12 months (Figure 3.17). The 1 month rate is notably higher than in the general population: in 2023, 26% of adults in Connecticut reported symptoms of depression (National Center for Health Statistics, 2020-2023).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 would like to start working with a psychiatrist or therapist.” 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. One conservator remarked on the absence of specialized mental health care for consumers who need this support:

> *Social services should have a psychiatric unit for these patients. She came out of the nursing home with behavioral issues. When she goes to the case manager to ask for neuropsychologist for medication changes, the case manager says that there is no neuro specialist covered under this program. (1 month)*

Figure 3.16. Self-Reported Mental Health

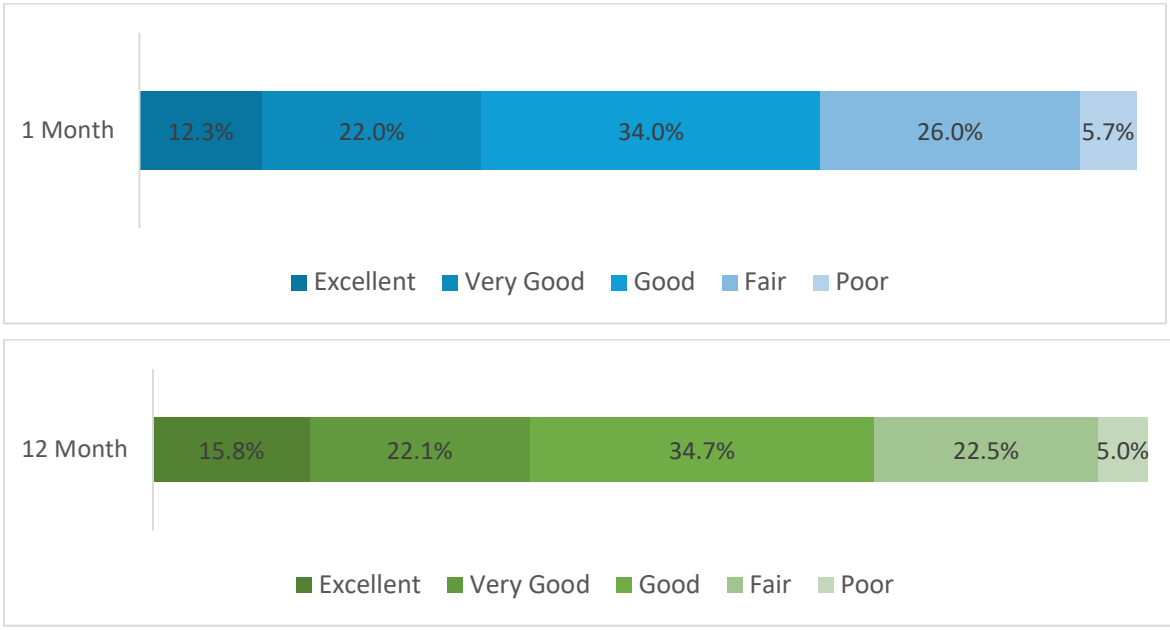
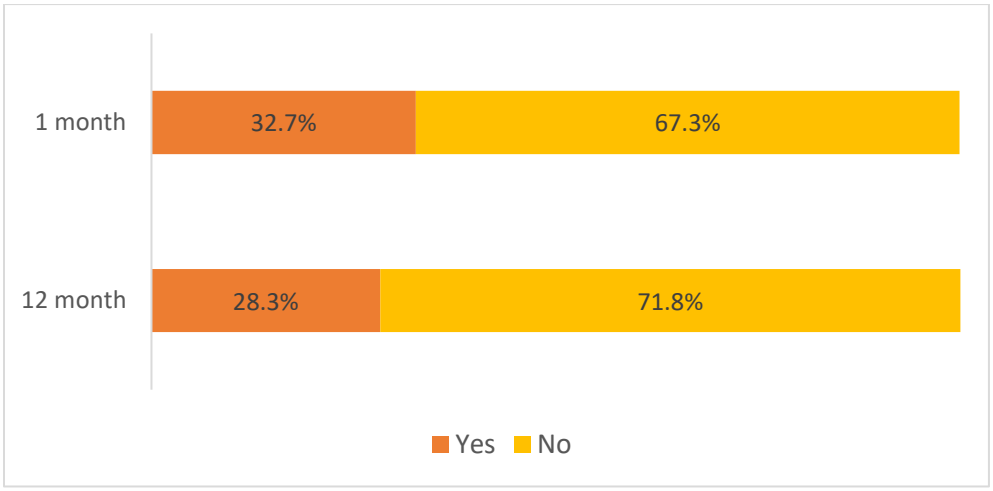


Figure 3.17. Depressive Symptoms*

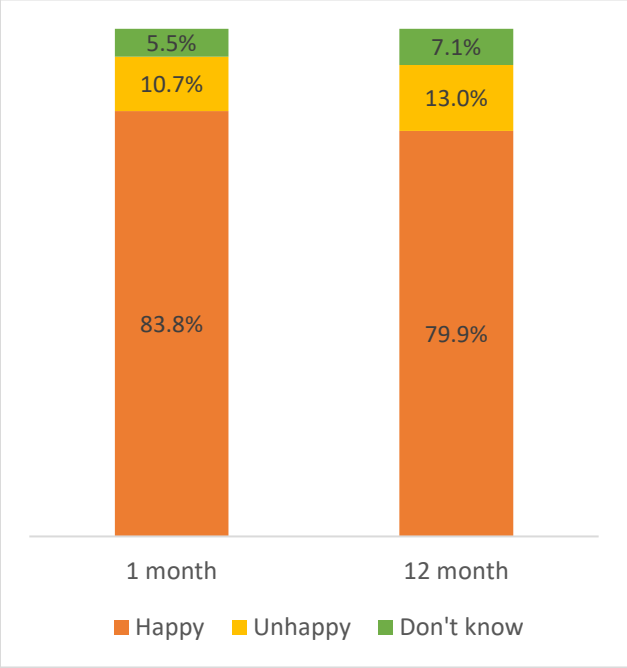


*Depressive symptoms were determined using the Patient Health Questionnaire (PHQ-2) (Whooley et al., 1997).

Overall Quality of Life

Global life satisfaction stayed stable once in the community. Between 80-84% of consumers reported feeling happy with the way they live their life at both 1 and 12 months (Figure 3.18). These rates are higher than in 2023, when 72% of consumers at 1 month and 76% at 12 months reported being happy with their life..

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



H. Assistive Devices, Medical Equipment, Home Modifications

The majority (95% at 1 month and 96% at 12 months) of consumers reported having at least one type of assistive device, special equipment, or home modification (Figure 3.19). However, 47% of consumers at 1 month and 40% at 12 months said they lacked some type of device or modification needed for community living. This represents a substantial increase from 2023 at 1 month post transition – in 2023 34% of consumers reported missing some type of device or modification at 1 month after transition.

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 also be in place by transition. Some comments included:

> *We didn't have a clear understanding of how he would be transported when he got home. I found out later we could have applied for the wheelchair while at his facility so when he was discharged it would go with him. (1 month)*
>
> *He needs grab bars and a new hospital bed. (1 month)*
>
> *I also have not been able to get into my shower without an accessible shower and shower chair. (1 month)*
>
> *[I'm] having trouble getting my pen needles for insulin and test strips. (12 month)*
>
> *I do not have a Hoyer lift and have not been able to get out of bed for the past month. (1 month)*
>
> *I need new catheter bags. The nurse says they have plenty, but it leaks and they are old and dirty. (1 month)*

Sometimes medical insurance or budget limitations in different care plans made it difficult to get the proper equipment to help a person live in the community, such as the daughter who would need to pay out of pocket for materials that support a Hoyer lift:

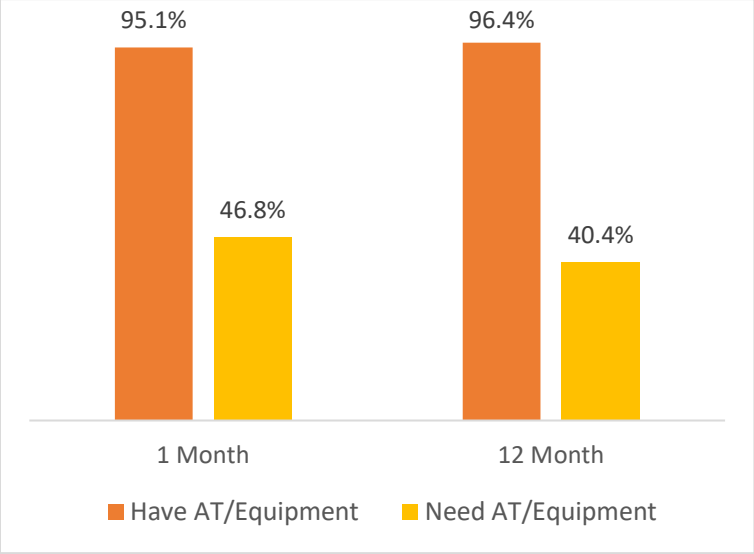
My mother needs a Hoyer and more supplies for the aides that are not covered by insurance or the program. I need to pay out of pocket for these extra costs. (1 month)

There is so much confusing paperwork. My insurance has not approved my PCA services or my medical transportation, so I have been taking the bus. I need an updated ID as well. Also, I need my walker, grab bars and a raised toilet seat. (1 month)

Another comment indicated how a person's care plan budget can affect their getting items needed to safely stay in the community, and how not having simple things, like a phone, limits a person's engagement in their community:

I need grab bars in my shower, but they are not covered in my plan. I am scared that I will hurt myself in the shower. I am waiting for my phone to come in. I need my phone before I can receive recovery assistance and apply for jobs. (1 month)

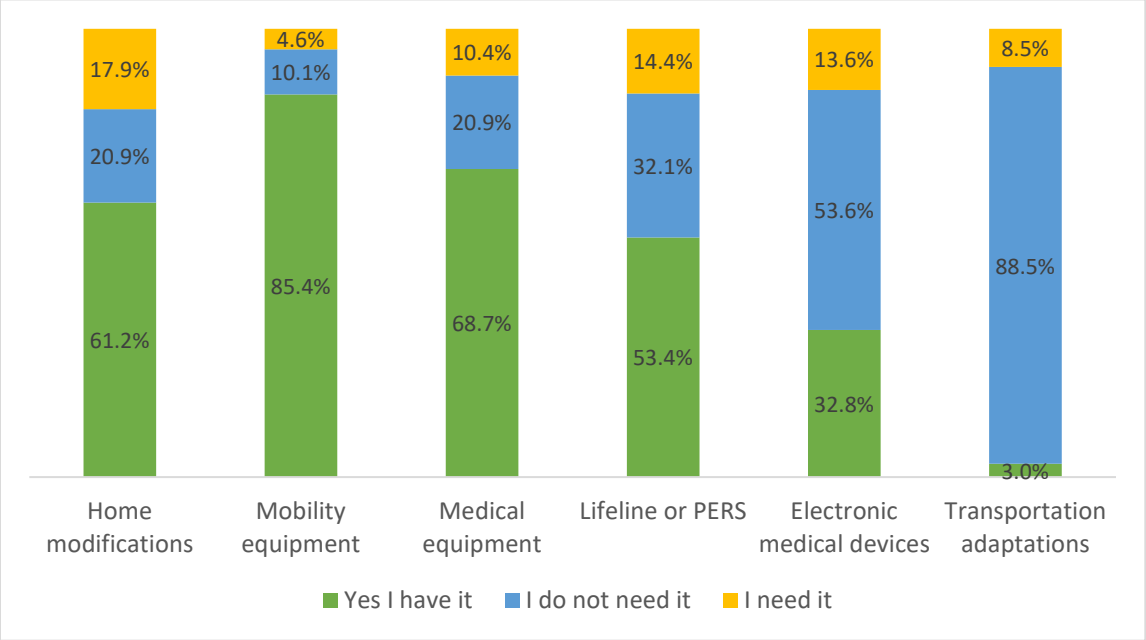
Figure 3.19. Have or Need any Type of Assistive Device, Home Modification, or Special Equipment – Percentage Positive Responses



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 53-59% of consumers at either 1 or 12 months reported having one.

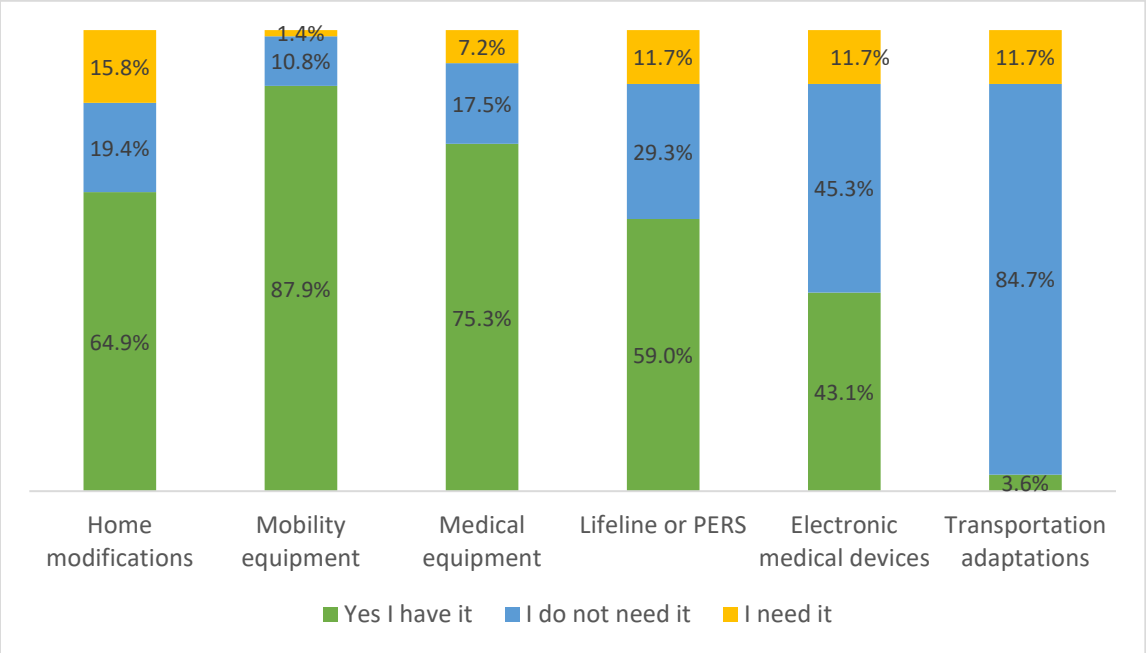
At 1 month post-transition, consumers most commonly needed home modifications (18%), a PERS (14%), or an electronic medical device (14%). Overall there were small decreases in rates of unmet need from 1 to 12 months across all categories but one, transportation adaptation, which rose 3%.

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, the vast majority of participants reported having internet access at their homes, and most (71% to 80% respectively) consumers owned a computer, tablet, or smart phone (Figures 3.22 and 3.23).

Figure 3.22. Internet Devices

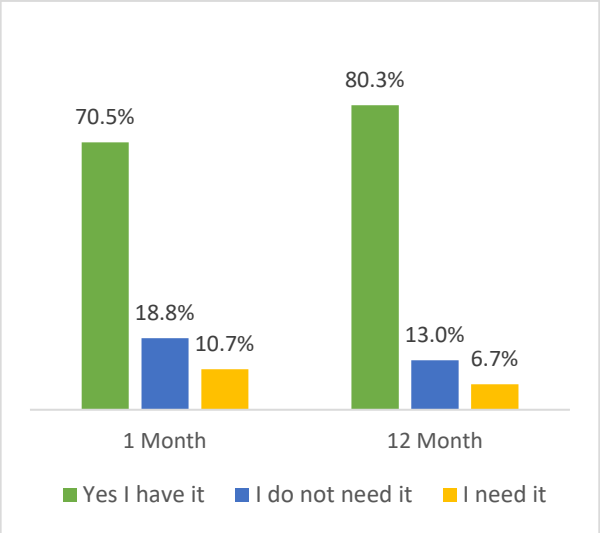
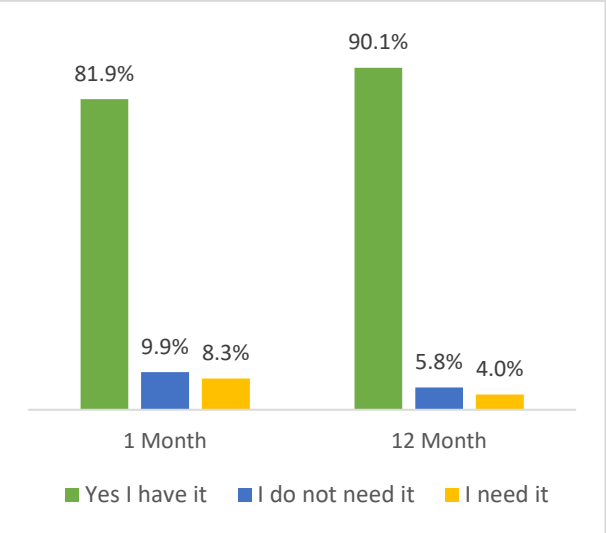


Figure 3.23. Internet Access



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 = 23 n (%)	12 Month N = 20 n (%)
Excellent	6 (26.1)	5 (23.8)
Very Good	8 (34.8)	7 (33.3)
Good	6 (26.1)	4 (19.1)
Fair	0 (0.0)	4 (19.1)
Poor	3 (13.0)	1 (4.8)

Table 3.7. Day Program Rating

	1 Month N = 4 n (%)	12 Month N=8 n (%)
Excellent	1 (25.0)	5 (62.5)
Very Good	0 (0.0)	2 (25.0)
Good	2 (50.0)	0 (0.0)
Fair	0 (0.0)	1 (12.5)
Poor	1 (25.0)	0 (0.0)

Finances, Employment, and Volunteering

At both time points, more than one quarter of consumers reported not having enough money to make ends meet (Figure 3.24). Food insecurity was mentioned by several participants, whether caused by lack of money, food stamps, transportation, or paid/unpaid support.

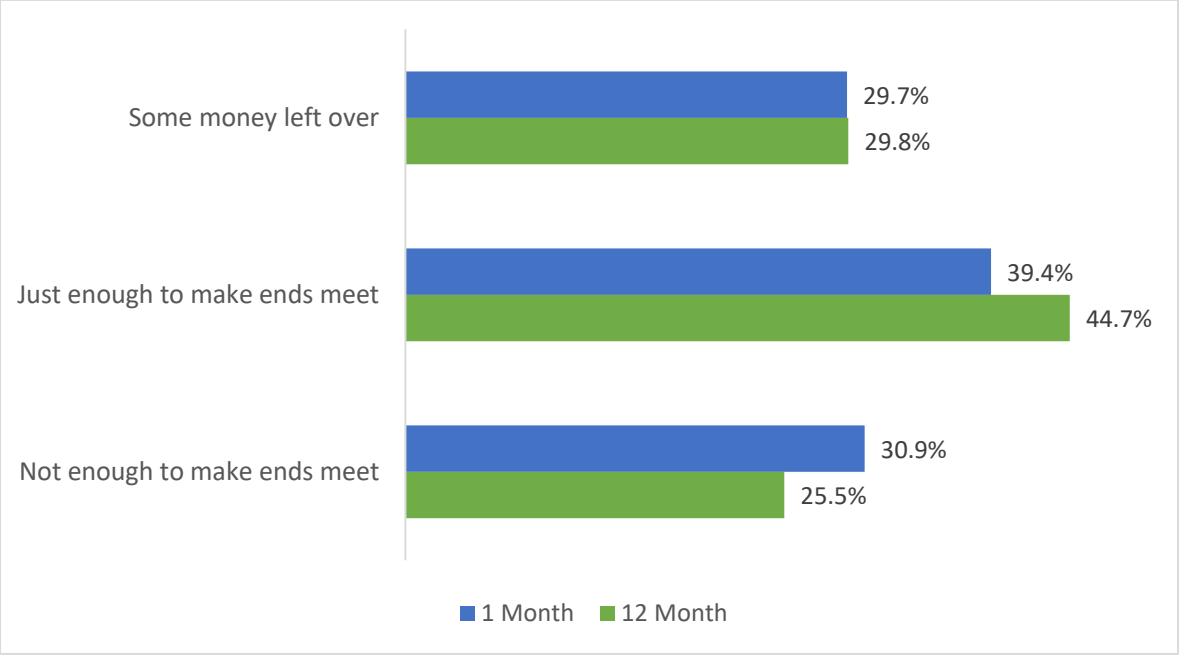
> *I would like to get food stamps and meals on wheels. (1 month)*
>
> *I just would like to get services, like getting food services or information about food banks because at the end of the month it gets a little tight. But other than that I don't have any issues. (12 month)*
>
> *I have not received my SAGA money and I cannot pay my bills. I have been in contact with care managers. (1 month)*

I would like to know if I can get help with cash assistance – I don't have money to pay my bills. I only get $20 of food stamps. I got my electricity turned on but I have no income to pay for it. (1 month)

Family members sometimes found themselves stepping in and paying for supplies or other items needed by their loved to live in the community.

The supply is terrible – he is home but is not getting his diaper supply. I have to go and buy stuff. The supply is not good. No diapers, no linen or lining for the bed. Those should be in place for the patient for when they come home. (1 month)

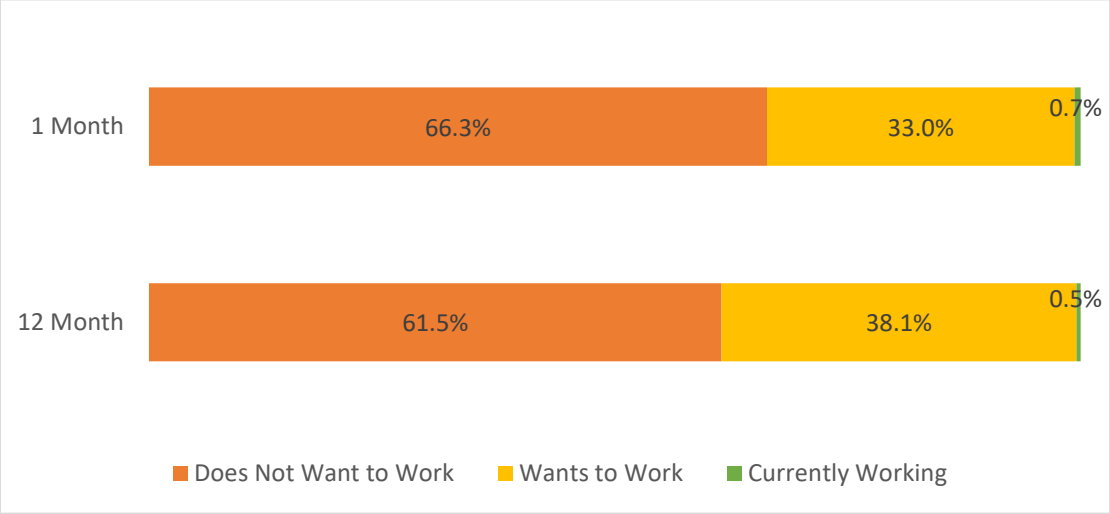
Figure 3.24. How Do Your Finances Usually Work Out at the End of the Month?



Employment and Volunteering

All community residing consumers aged 18 and older were asked questions regarding work status and employment goals (Figure 3.25). Although less than one percent of consumers were working, 33% of unemployed participants wanted to work at 1 month, increasing to 38% at 12 months. Having a job often increases independence and community involvement, and 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 "nothing is holding me back" as the reason for not working.

Table 3.8. Most Common Reasons for Not Working

	Would like to work		Does not want to work	
Most Common Reasons for Not Working	1 Month N= 99 n (%)	12 Month N= 83 n (%)	1 Month N= 200 n (%)	12 Month N= 134 n (%)
Health Concerns	80 (80.8)	66 (79.5)	130 (65.0)	85 (60.4)
Transportation	7 (7.1)	10 (12.0)	5 (2.5)	7 (5.2)
Nothing/Do not want to work	7 (7.1)	4 (4.8)	57 (28.5)	42 (31.3)

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 39% at 1 month and 31% 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

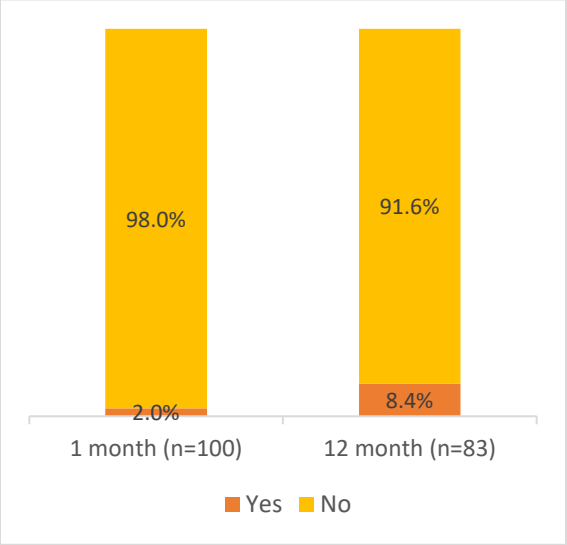
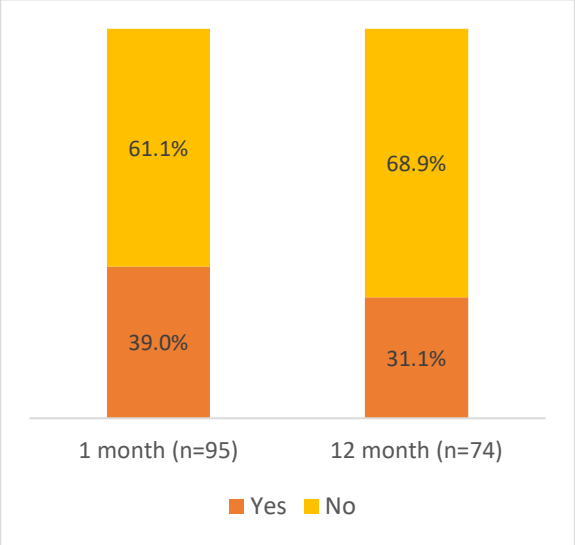
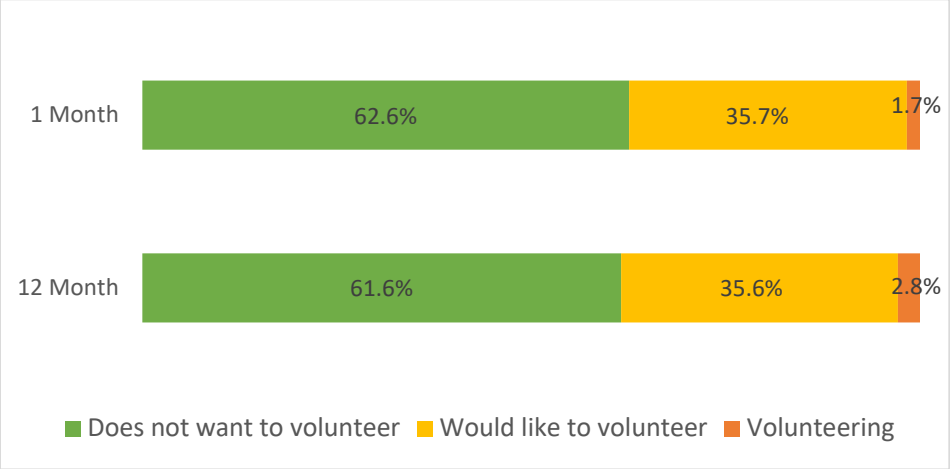


Figure 3.27. Aware of Employment Assistance



The percentage of consumers interested in volunteer work remained the same from 1 month to 12 months at 36% (Figure 3.28). This shows an increase from what was reported in the previous year, where just 22-30% of consumers wanted to volunteer at both 1 and 12 months. 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.

> *I am so blessed. I found this place to live and MFP people really helped me get the things I needed. They got me set up with cash assistance which is so helpful. My aide is wonderful. I prayed that I would get someone good and my prayers were answered. (1 month)*
>
> *The program was a lifeline for us [husband and caregiver wife]. (12 month)*
>
> *I am grateful for this program, I do not know how I would be without them. (1 month)*

It has been great. It was a big help when [my father] came home. I know the case managers will still help. (12 month)

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. Multiple consumers commented on how long the transition process took.

There was a lot of miscommunication when transitioning out of the facility. I didn't depend on them. I understood it would take long, but they told me they could help me out then I had to stay in the facility longer. (1 month)

It took two years to find housing to transition out of the nursing home. [TC name] 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 card. (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.

[There is] poor communication and inability to reach case manager. She is supposed to do check ups on me but she doesn't. The transition coordinator has been helpful and I just want a new case manager. (12 month)

We were not given a pamphlet with everything to expect, who to call, what to do. It's been like throwing stones in the air and trying to catch them. It is disorganized and should have been in print. I feel like [care manager] is always busy so I try to do what I can do to help her, but we need a handbook. (1 month)

Program structural guidelines could also be frustrating to consumers, and limitations regarding the transition budget were mentioned on several occasions. Another consumer 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. Several people mentioned that the furniture or other items bought by MFP did not fit or easily broke.

I don't have a microwave. I have some pots and bed and couch which I am thankful for but it would have been nice to get a microwave. (1 month)

[My transition] budget has not been utilized accurately and I was told I had $1700 left. Then cleaning supplies were purchased, and now there is no money left. The furniture they bought in the beginning is all broken and nobody can come and fix it. (12 month)

Everything is good, but I wish they [had] considered my size when they got me my bed. I do not fit in my bed. They should take that into consideration when getting furniture. (1 month)

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 2023 were separated into those who met the requirements for a Medicaid HCBS waiver at transition and those who were not eligible for a waiver. Consumers accepted to a waiver (waiver consumers) were eligible for an HCBS waiver at transition. Waiver consumers comprised 77% of the 1 month and 80% of the 12 month samples (Table 4.1). Consumers not accepted to a waiver transitioned using state plan or other community Medicaid services. Referred to here as state plan consumers, they comprised the remaining 23% and 20% of the community surveys, respectively. 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	240 (77.4)	181 (80.1)
State Plan	70 (22.6)	45 (19.9)
All programs	310 (100)	226 (100)

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 or other waiver requirements and often do not need extensive assistance with activities of daily living (ADLs). Therefore, 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, 85% of waiver consumers reported using some type of personal care assistance, compared to only 17% of state plan consumers. While there was a small difference in case management use at 1 month, by 12 months there was a large gap between the two groups, with 62% of waiver consumers reporting the use of case management services, compared to 38% 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	197 (85.3)	12 (17.1)	148 (86.0)	7 (15.6)
Behavioral health services	1 (<1.0)	0 (0)	1 (<1.0)	0 (0)
Homemaking services or Homemaker-Companion	185 (80.1)	17 (24.3)	146 (84.9)	9 (20.0)
Care management services	200 (83.3)	55 (78.6)	113 (62.4)	17 (37.8)
Job coach or vocational supports	5 (55.6)	0 (0)	4 (44.4)	0 (0)
Recovery assistance services (MHW only)	7 (77.8)	0 (0)	6 (66.7)	0 (0)
Community Service Provider (MHW only)	0 (0)	0 (0)	0 (0)	0 (0)
None of these services	3 (1.3)	9 (12.9)	8 (4.4)	20 (44.4)

* Consumers can use more than one service

Waiver and state plan consumers were the same age on average (61 years old). State plan consumers were more likely to be male (Table 4.3).

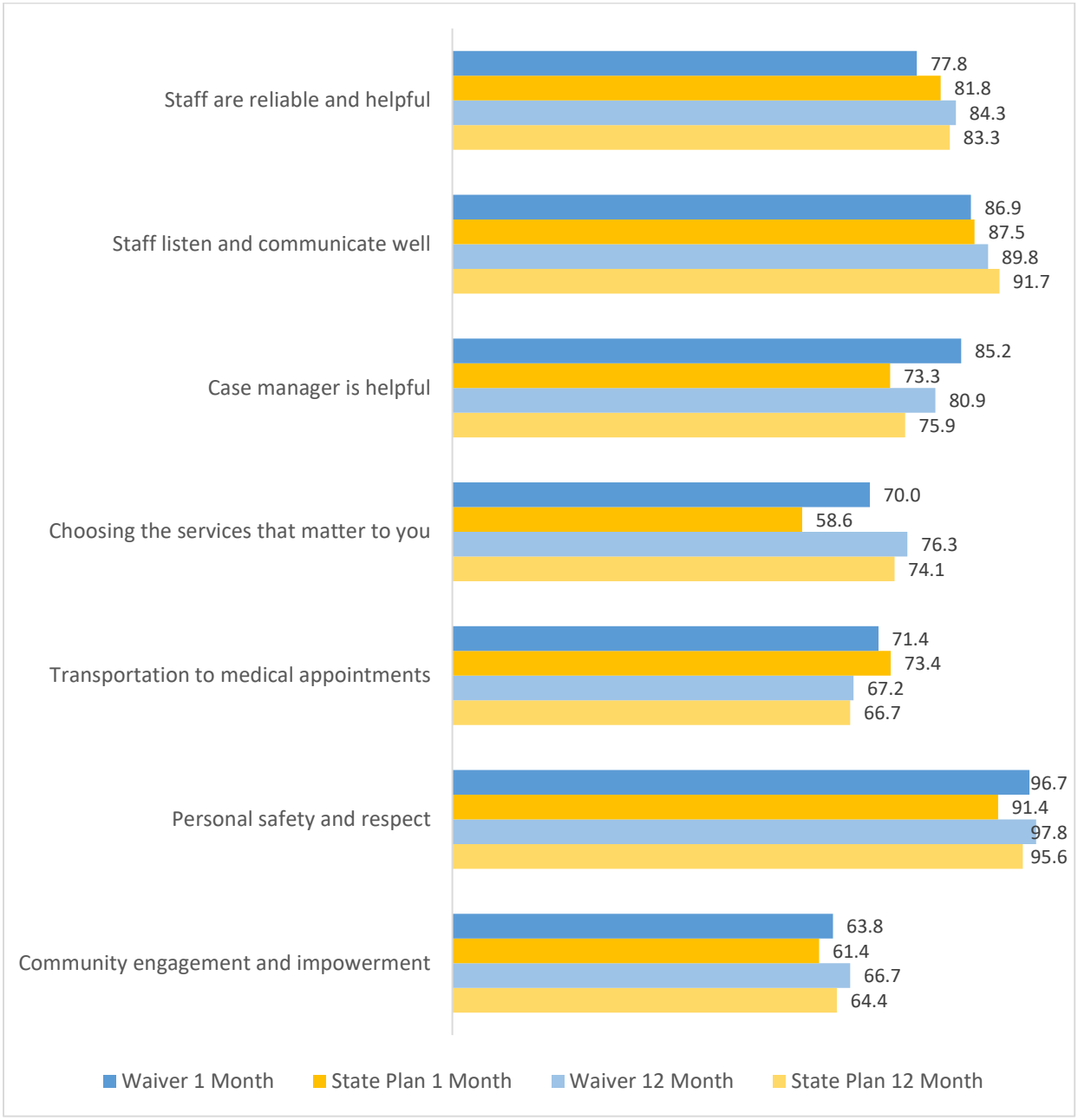
Table 4.3. Demographics – Waiver/State Plan by Time Point

		1 Month		12 Month	
		Waiver %	State Plan %	Waiver %	State Plan %
Age		N=240	N=70	N=181	N=45
	<18	<1.0	5.7	1.1	6.7
	18-24	1.7	0	2.2	0.0
	25-34	3.3	2.9	2.2	2.2
	35-44	4.2	7.1	5.5	6.7
	45-54	12.5	20.0	13.3	15.6
	55-64	28.8	45.7	27.1	51.1
	65-74	27.9	12.9	30.4	11.1
	75+	21.3	5.7	18.2	6.7
Gender		N=240	N=70	N=181	N=45
	Male	46.3	65.7	49.7	66.7
	Female	53.8	34.3	50.3	33.3

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

Two of the composite measures showed noticeable differences between the two groups (Figure 4.1). At 1 month, 70% of waiver consumers gave the highest scores for the composite choosing the services that matter to you, compared to 59% of state plan consumers. This likely reflects the limited services available to state plan consumers, compared to those on a waiver. Waiver consumers were also much more likely to report their care manager was helpful at 1 month post transition, even though both waiver and state plan consumers have Transition Coordinator (TC) services at this time.

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



Waiver consumers were much more likely to give higher global ratings to their case managers at both 1 and 12 months (Figure 4.2). The large difference even at 1 month may indicate the benefit of having a Specialized Care Manager (SCM) post transition. Unlike waiver consumers, SCM services do not always continue after transition for state plan consumers. Waiver consumers were also more likely to "definitely recommend" their case managers at both 1 and 12 months (Figure 4.3). 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.

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

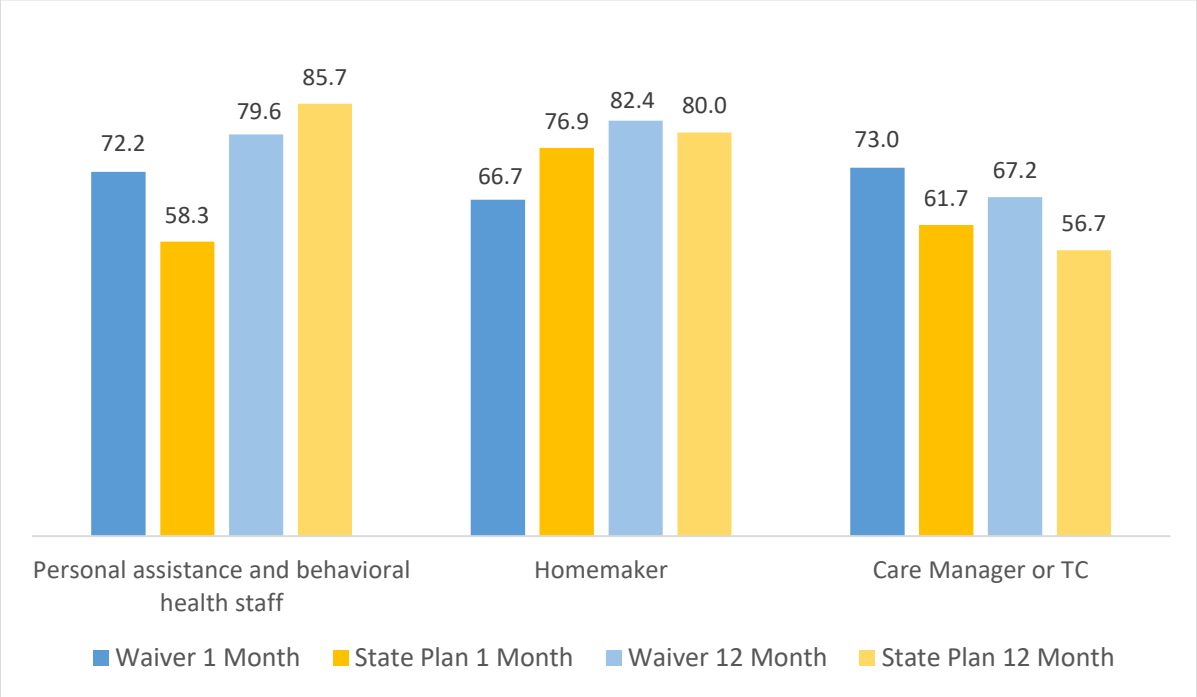
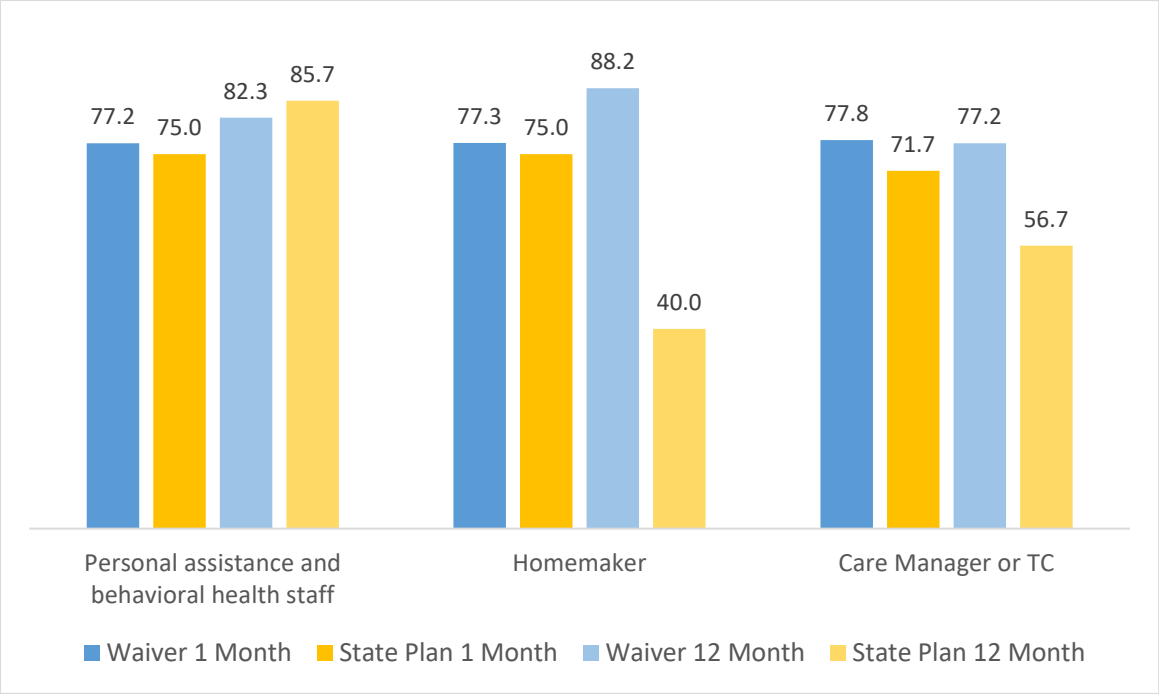


Figure 4.3. Recommendations by Waiver vs. State Plan: Percentage Who "Definitely" Recommend Staff



Case Manager Items

At 1 month post-transition, nine out of ten waiver and state plan consumers reported knowing their case manager or service coordinator, compared to approximately 80% 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

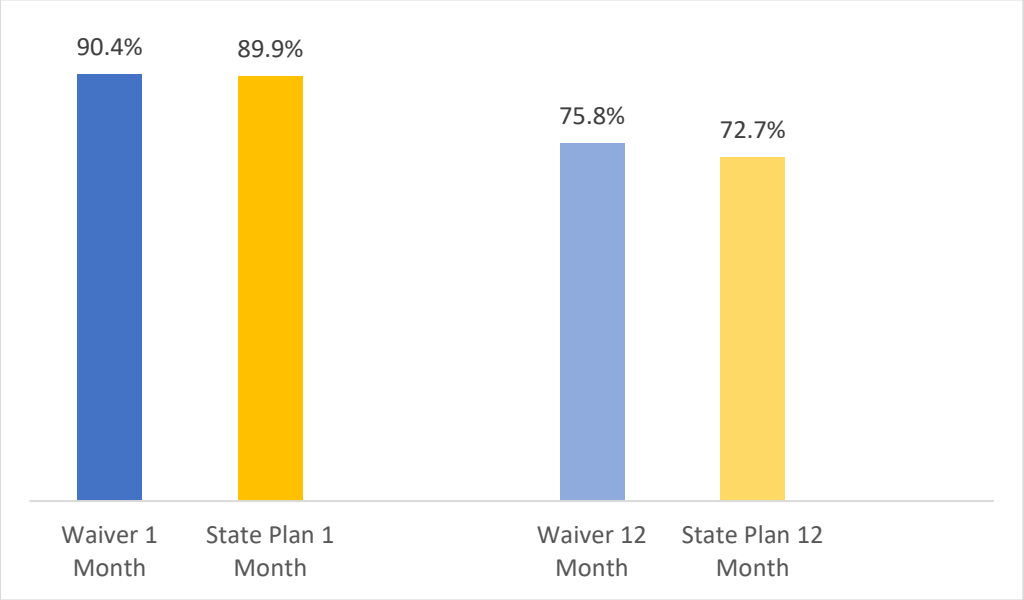
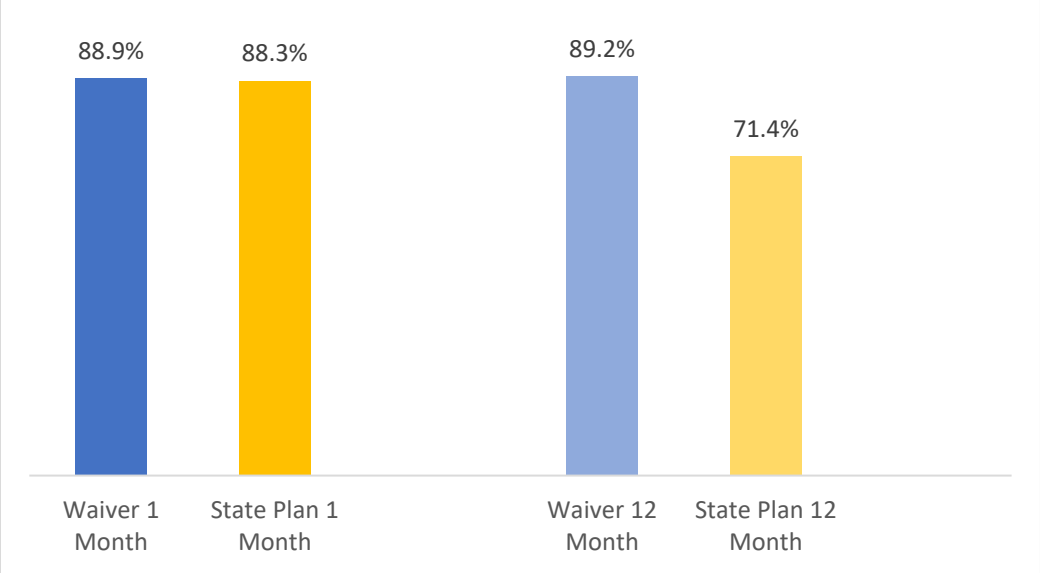
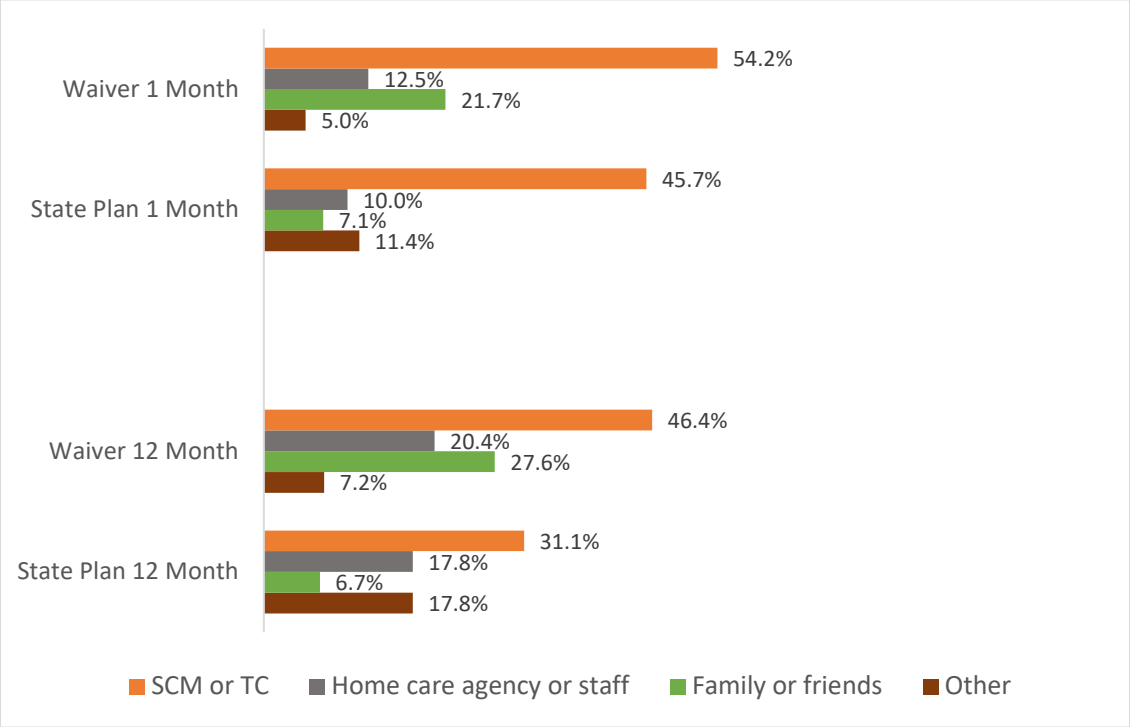


Figure 4.5. Able to Contact Case Manager, Waiver vs. State Plan



Similar to previous years, waiver consumers were more likely to talk to their TC or SCM if they wanted to change their care plan (Figure 4.6). Overall, waiver consumers reported having more resources to turn to if they wanted changes to their services. Notably, at 12 months post transition, 28% of waiver consumers said they would turn to their family or friends for this assistance, compared to just 7% of state plan consumers.

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



*Can name more than one

Living Situation and Social Support

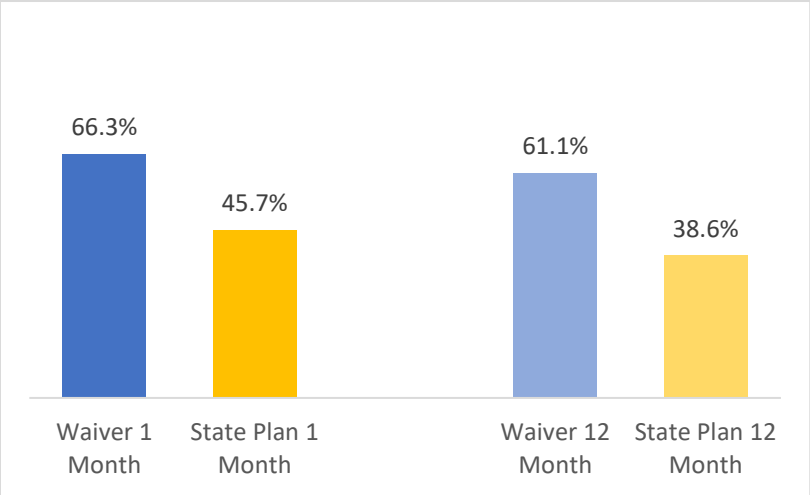
Overall, consumers with state plan services reported less social support than consumers who received services through a waiver. Consumers with state plan services were much more likely to live alone at both time periods – at 1 month 74% of consumers with state plan services lived alone, compared to 53% of waiver consumers (Table 4.4). State plan consumers were less likely to live with family or have nearby family or friends.

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=240	N=69	N=180	N=44
	1	53.3	73.9	60.0	77.3
	2-3	41.7	21.7	36.1	20.5
	4+	5.0	4.4	3.9	2.3
Lives with family member/s		N=112	N=18	N=71	N=10
	Yes	78.6	44.4	77.5	60.0
	No	21.4	55.6	22.5	40.0
Lives with non-family		N=112	N=18	N=71	N=10
	Yes	26.8	50.0	31.0	40.0
	No	73.2	50.0	69.0	60.0
Family member/s live nearby		N=240	N=69	N=180	N=45
	Yes	75.8	56.5	75.0	53.3
	No	24.2	43.5	25.0	46.7
Friend/s live nearby		N=240	N=69	N=180	N=44
	Yes	55.0	37.7	57.8	45.5
	No	45.0	62.3	42.2	54.5

Living with or near family members seemed to provide additional benefits. Compared to state plan consumers, waiver consumers were much more likely to report getting unpaid assistance around the house from family or friends at both 1 and 12 months (Figure 4.7).

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



When asked about where they lived, waiver consumers were consistently more likely to like where they live and feel safe living there (Figures 4.8 and 4.9).

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

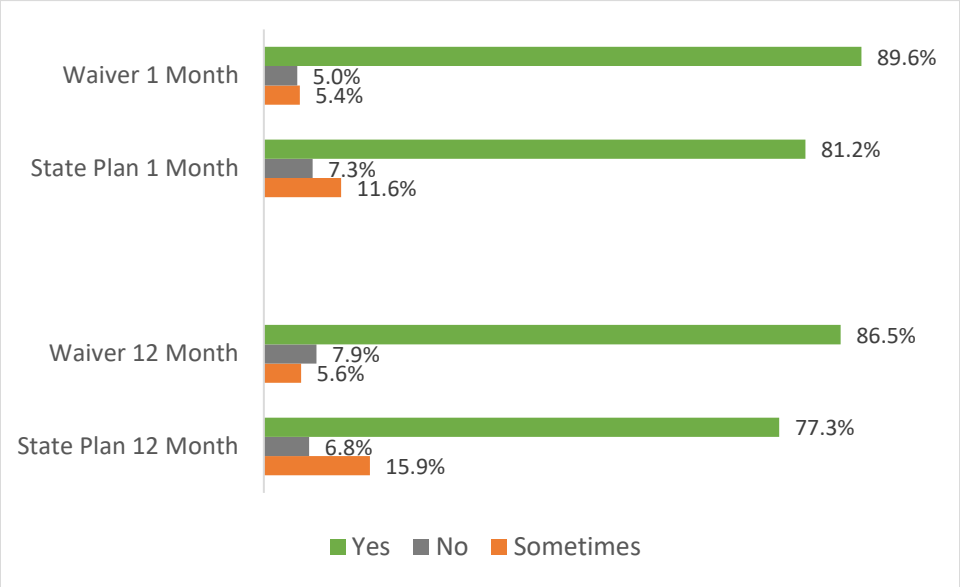
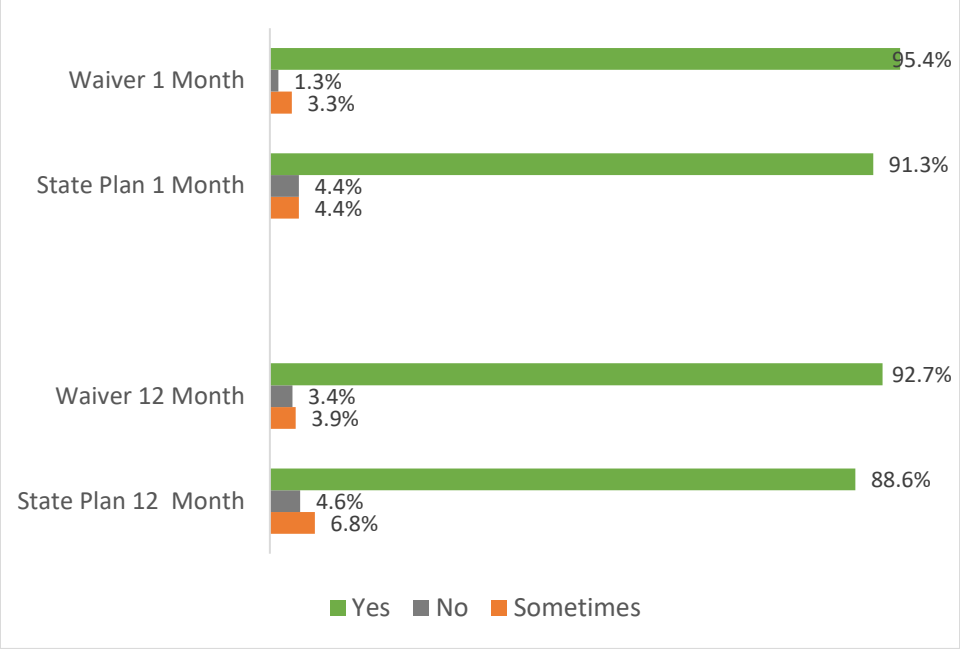


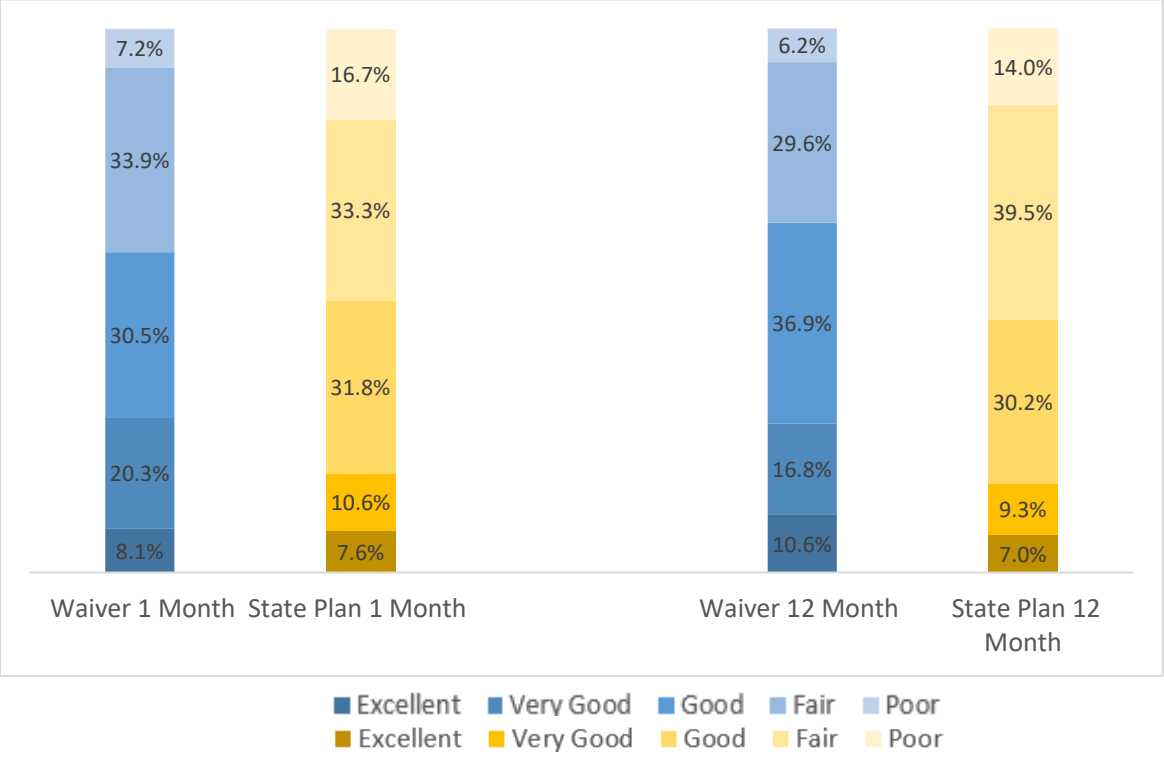
Figure 4.9. Do You Feel Safe Living Here? Waiver vs. State Plan



Physical Health

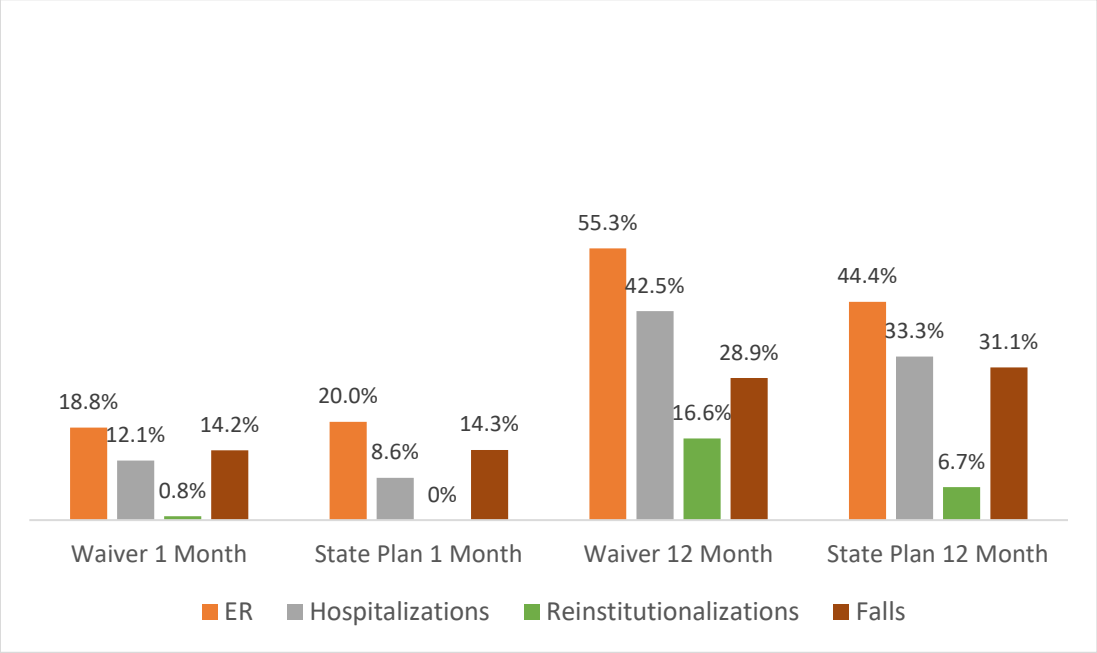
At one month, 41% of waiver consumers and 50% of state plan consumers rated their health as fair or poor (Figure 4.10). Waiver consumers' health did improve over time, as the percentage of waiver consumers reporting fair to poor health decreased to 36% by 12 months, while the percentage of state plan consumers with fair or poor health increased to 54%.

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



At 12 months, waiver consumers experienced more emergency room visits, hospitalizations, and reinstitutionalizations than state plan consumers, despite reporting better subjective health (Figure 4.11).

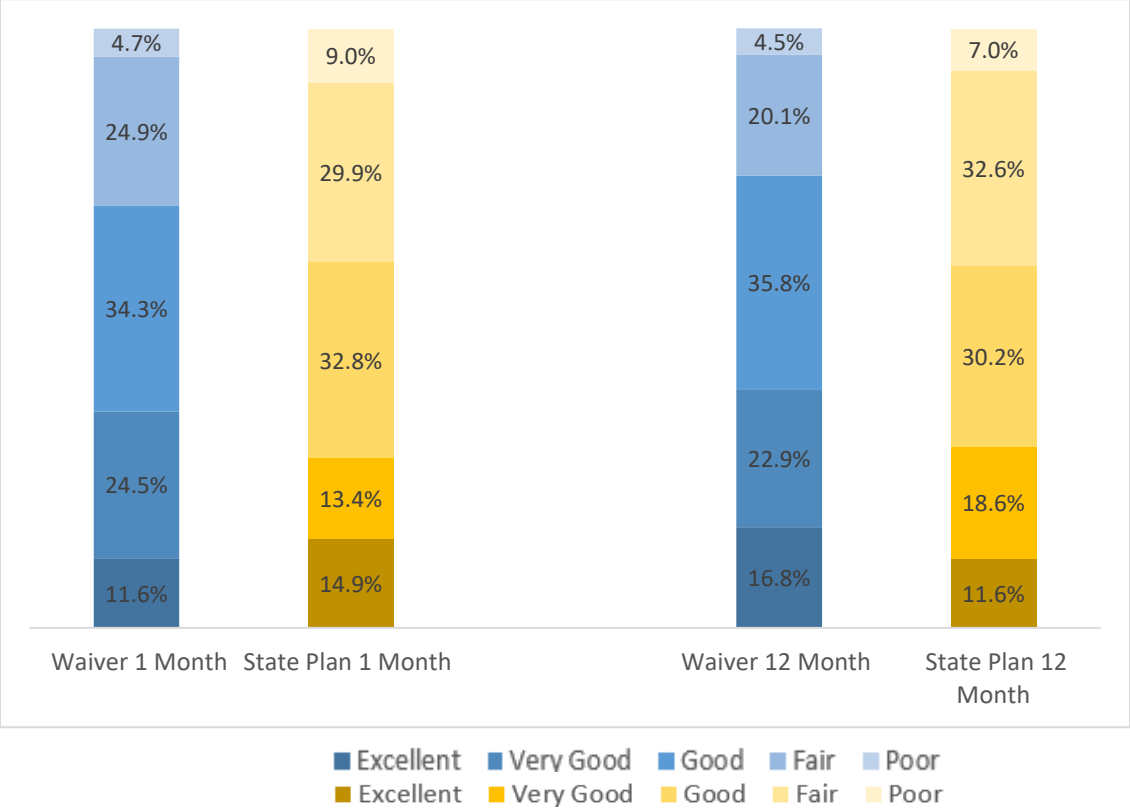
Figure 4.11. ER Visits, Hospitalizations, Reinstitutionalizations, and Falls: Waiver vs. State Plan



Mental Health

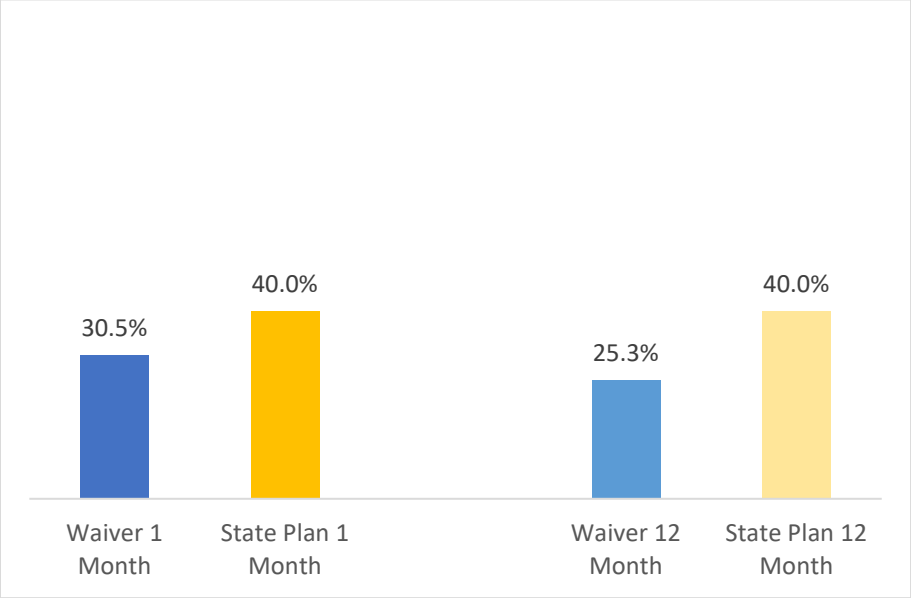
Differences were also seen with self-reported mental or emotional health status (Figure 4.12). Waiver consumers reported better mental health than state plan consumers at both time periods. For example, at 12 months, 76% of waiver consumers reported their mental health as good or better, compared to 60% of state plan consumers. This differs from 2023 when state plan consumers rated their mental health better than waiver consumers at 12 months.

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



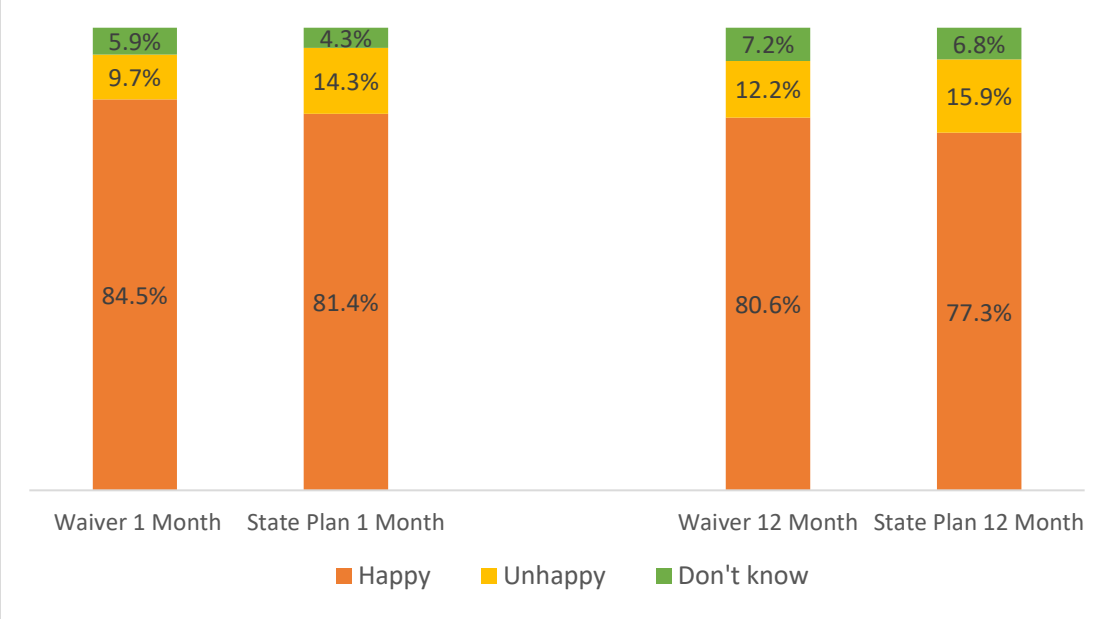
Consumers were asked whether they experienced depressive symptoms, characterized by a lack of interest in doing things and/or or feeling down, depressed or hopeless. Waiver consumer reported fewer depressive symptoms at both 1 and 12 months, which is consistent with the differences seen in self-reported mental health (Figure 4.13).

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



Still, 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 waiver consumers reporting being happy notably increased over last year – in 2023 71% reported being happy with the way they live their life, compared to 85% 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

Similar to previous years, noticeably more waiver consumers reported having home modifications, mobility or medical equipment, or a PERS unit at both 1 and 12 months (Table 4.5). 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 through their waiver services.

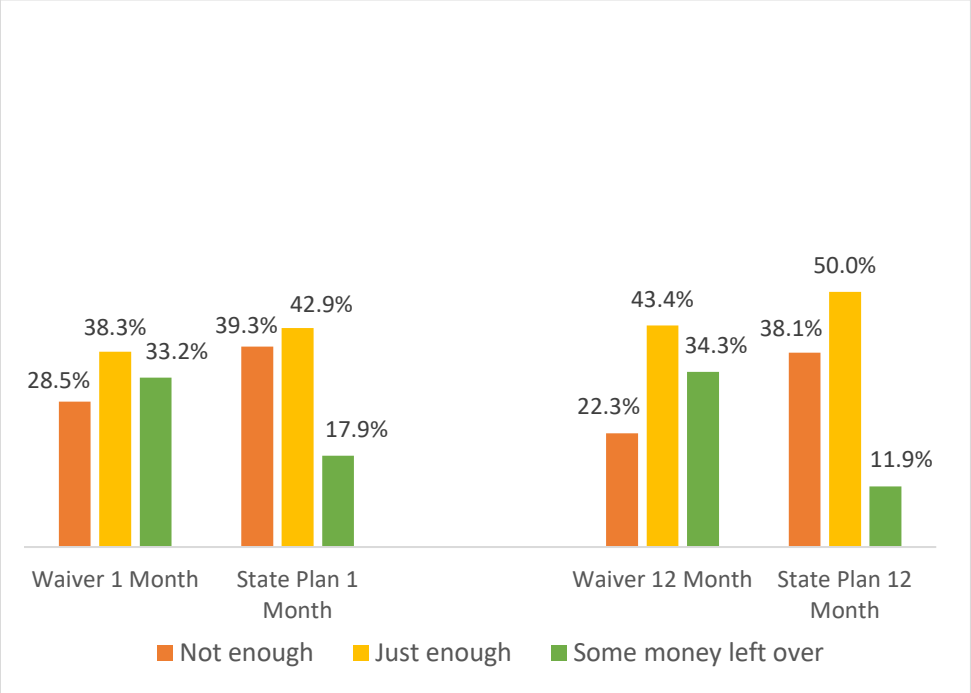
Table 4.5. Special Equipment and Assistive Devices: Waiver vs. State Plan

		1 Month Waiver %	1 Month State Plan %	12 Month Waiver %	12 Month State Plan %
Home modifications		N=238	N=69	N=180	N=42
	I have it	64.7	49.3	70.0	42.9
	I do not need it	16.4	36.2	13.9	42.9
	I need it	18.9	14.5	16.1	14.3
Mobility equipment		N=239	N=69	N=180	N=43
	I have it	90.0	69.6	90.0	79.1
	I do not need it	5.9	24.6	9.4	16.3
	I need it	4.2	5.8	0.6	4.7
Medical equipment		N=238	N=69	N=180	N=43
	I have it	78.6	34.8	81.1	51.2
	I do not need it	11.3	53.6	11.1	44.2
	I need it	10.1	11.6	7.8	4.7
Lifeline or PERS		N=237	N=68	N=179	N=43
	I have it	65.8	10.3	69.3	16.3
	I do not need it	22.4	66.2	21.8	60.5
	I need it	11.8	23.5	8.9	23.3
Internet capable devices		N=239	N=69	N=179	N=44
	I have it	71.1	68.1	81.0	77.3
	I do not need it	18.8	18.8	12.3	15.9
	I need it	10.0	13.0	6.7	6.8
Internet access		N=236	N=67	N=179	N=44
	I have it	86.0	67.2	92.7	79.6
	I do not need it	8.9	13.4	5.0	9.1
	I need it	5.1	19.4	2.2	11.4

Finances

Although both waiver and state plan consumers faced financial hardship at each time point, state plan consumers reported much worse finances (Figure 4.15). Almost 40% of state plan consumers reported not having enough money to make ends meet across the year after transition, compared to 29% (1 month) and 22% (12 month) of waiver consumers.

Figure 4.15 How Do Your Finances Usually Work Out at the End of the Month?



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

Community living consumers who transitioned in 2023 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 88% of consumers used agency-based services, while just 12% 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 5 years, from 69% in 2020 to 88% in 2024.

Services and Select Demographics

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

	1 Month n (%)	12 Month n (%)
Agency-based	212 (87.6)	137 (79.2)
Self-directed	30 (12.4)	36 (20.8)
Total	242 (100)	173 (100)

Compared to agency-based consumers, self-directed consumers reported greater use of personal care and homemaking services at both 1 and 12 months (Table 5.2). Self-directed consumers were more likely to use case management services at 1 month; by 12 months use of case management services did not differ between the 2 groups.

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	175 (85.4)	28 (93.3)	114 (89.1)	36 (100)
Behavioral health services	1 (<1.0)	0 (0)	1 (<1.0)	0 (0)
Homemaking services or Homemaker-Companion services	166 (81.0)	26 (86.7)	115 (89.8)	31 (86.1)
Care management services	176 (83.0)	28 (93.3)	88 (64.2)	23 (63.9)
Recovery assistance services (MHW only)	5 (71.4)	0 (0)	4 (44.4)	0 (0)
Community Service Provider (MHW only)	6 (85.7)	0 (0)	6 (66.7)	0 (0)
Job coach or vocational supports	0 (0)	0 (0)	0 (0)	0 (0)
None of these services	0 (0)	0 (0)	0 (0)	0 (0)

* Consumers can use more than one service

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

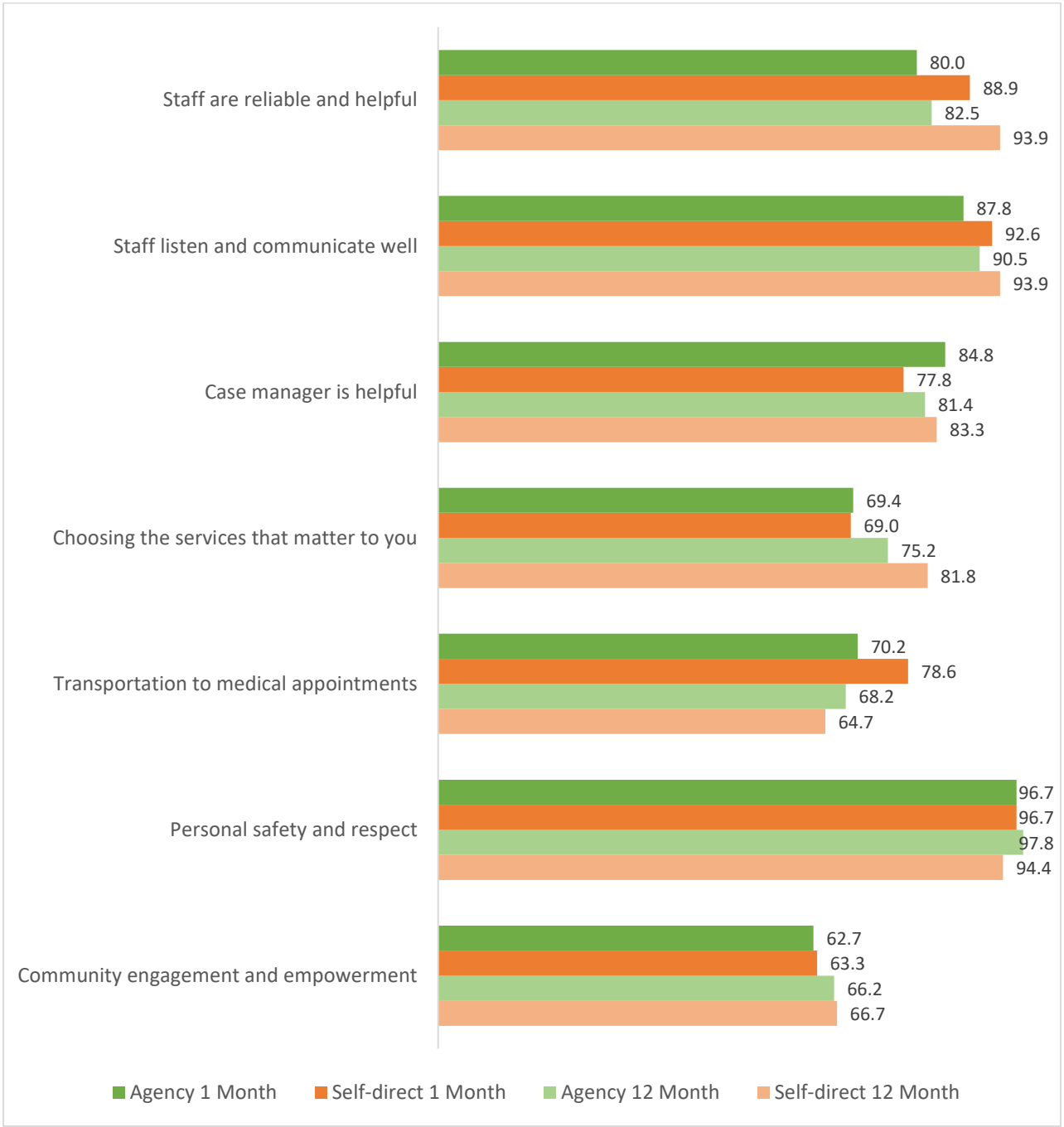
Table 5.3. Demographics: Agency vs. Self-direct

		1 Month		12 Month	
		Agency %	Self-direct %	Agency %	Self-direct %
Age		N=212	N=30	N=137	N=36
	<18	0.0	3.3	0.0	13.9
	18-24	<1.0	6.7	<1.0	8.3
	25-34	3.8	6.7	1.5	11.1
	35-44	5.2	3.3	5.1	5.6
	45-54	11.8	16.7	11.7	16.7
	55-64	33.0	16.7	27.7	25.0
	65-74	24.1	36.7	32.8	11.1
	75+	21.2	10.0	20.4	8.3
Gender		N=212	N=30	N=137	N=36
	Male	49.1	36.7	56.2	38.9
	Female	50.9	63.3	43.8	61.1

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

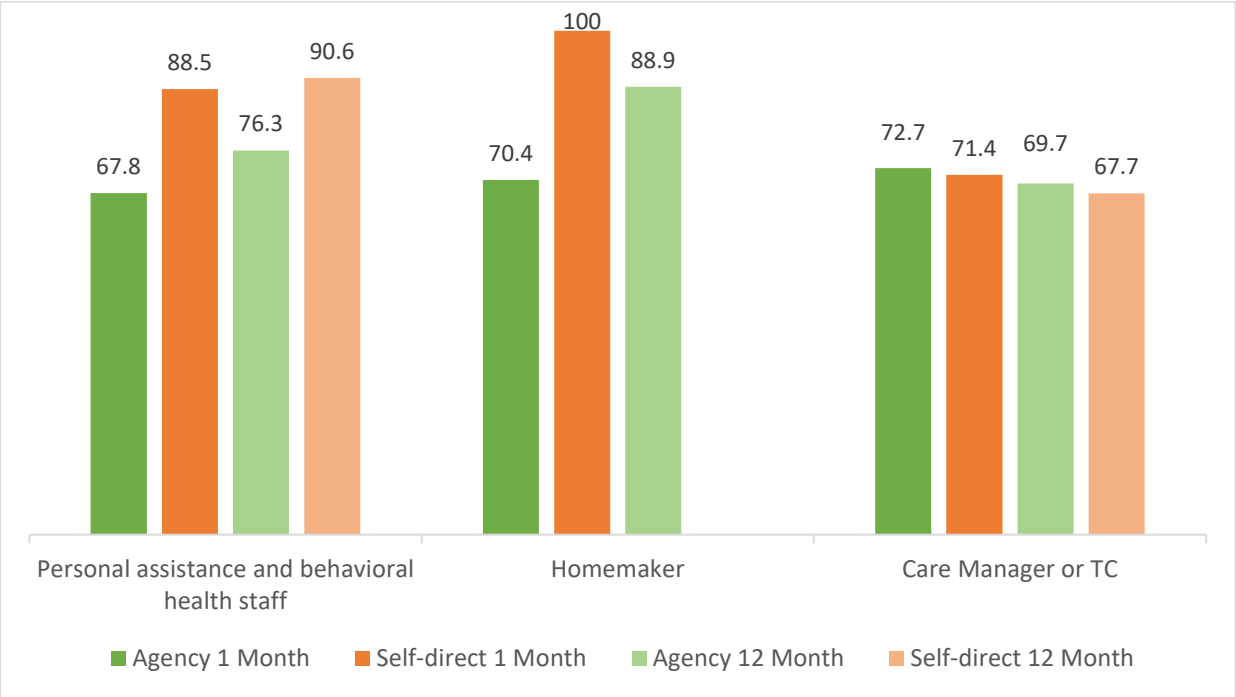
Several differences in the composite measures existed between agency-based and self-directed consumers, with few identifiable trends (Figure 5.1). Self-directed consumers were more likely than agency-based consumers to report that their staff were reliable and helpful and listened and communicated well. By 12 months, more self-directed consumers (82%) reported that they chose the services that matter to them.

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



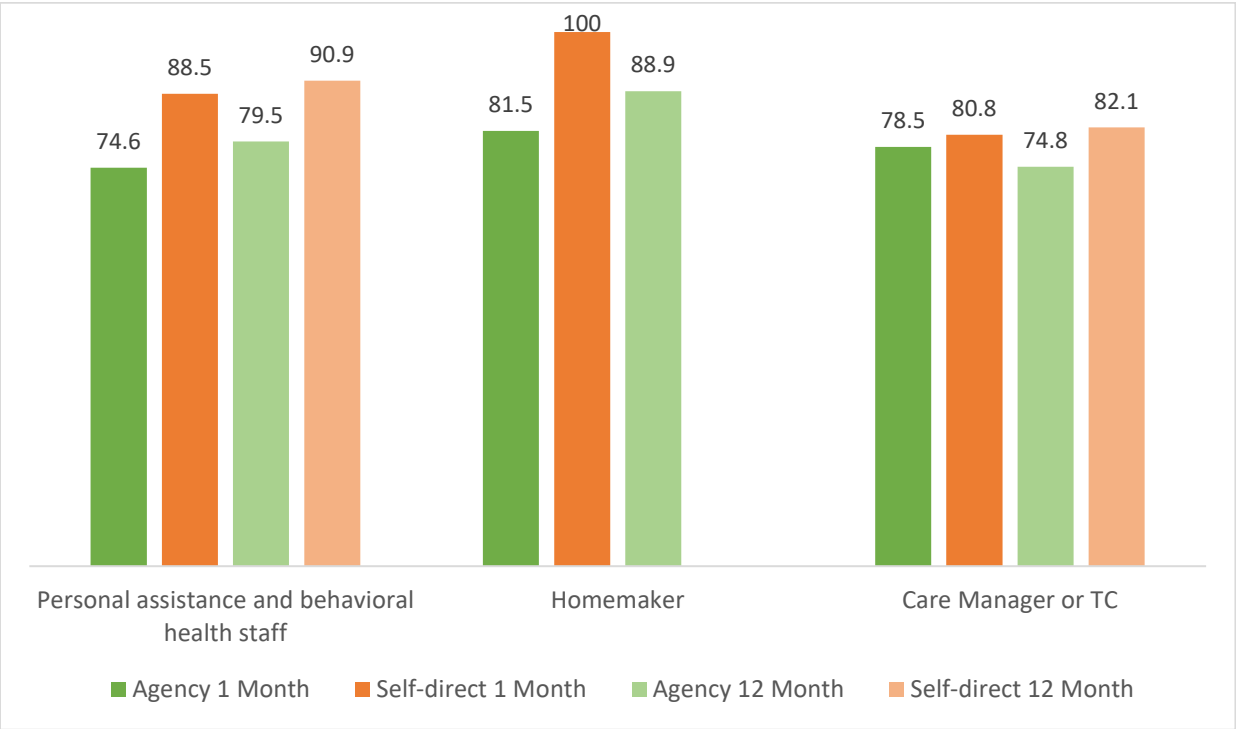
Staff ratings and recommendations also showed some marked differences between the two groups of consumers (Figure 5.2). In particular, at 1 and 12 months after transition, self-directed consumers rated their personal care staff notably higher than agency-based consumers. Because most self-directed consumers 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=0 12 month), which limits group comparisons for this particular service.

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 at both 1 and 12 months (Figure 5.3).

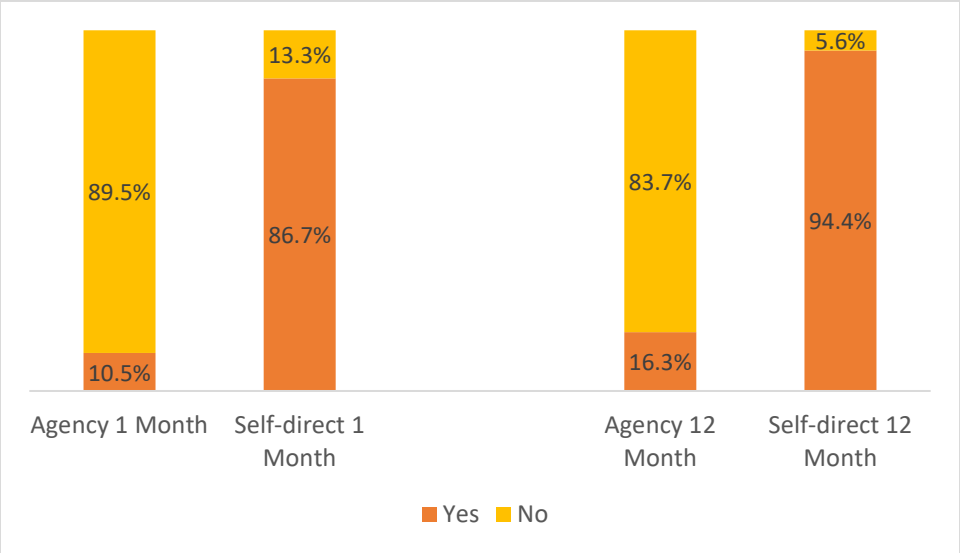
Figure 5.3. Recommendations by Agency vs. Self-direct: Percentage Who "Definitely" Recommend Staff



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



Assistance with Everyday Activities

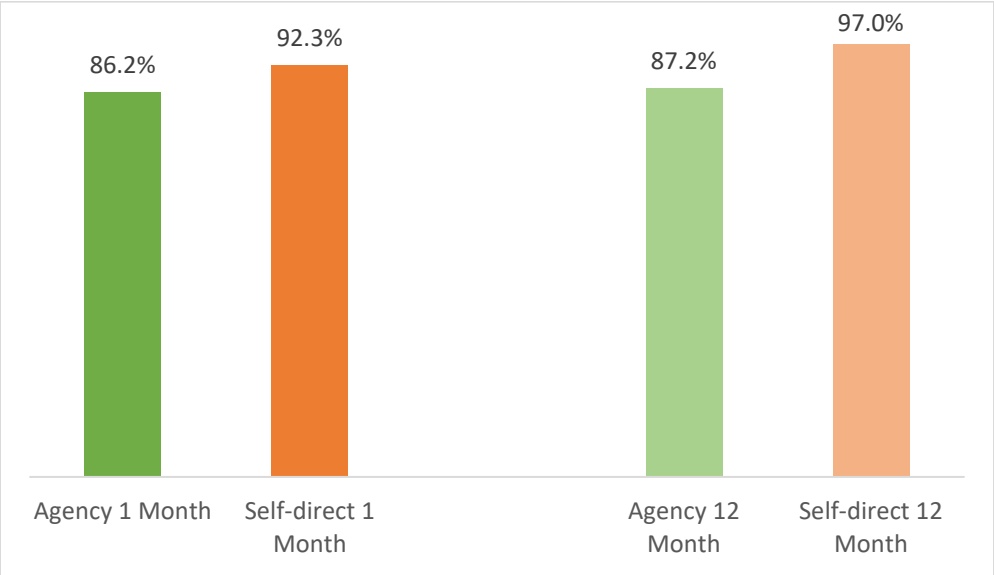
Consumers who received personal care assistance were asked what tasks they needed assistance with. As seen in Table 5.4, greater percentages of self-directed consumers reported needing assistance with all activities at both 1 and 12 months.

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

Needs assistance with:	1 Month Agency Based n (%)	1 Month Self-direct n (%)	12 Month Agency Based n (%)	12 Month Self-direct n (%)
Personal care	136 (76.8)	26 (100)	94 (79.0)	32 (91.4)
Meals or eating	145 (81.5)	24 (92.3)	98 (82.4)	34 (97.1)
Taking medications	102 (57.6)	20 (76.9)	65 (54.6)	25 (71.4)
Using the toilet	87 (49.2)	20 (76.9)	56 (47.1)	27 (77.1)
Housekeeping or laundry	166 (81.4)	26 (86.7)	121 (88.3)	31 (91.2)

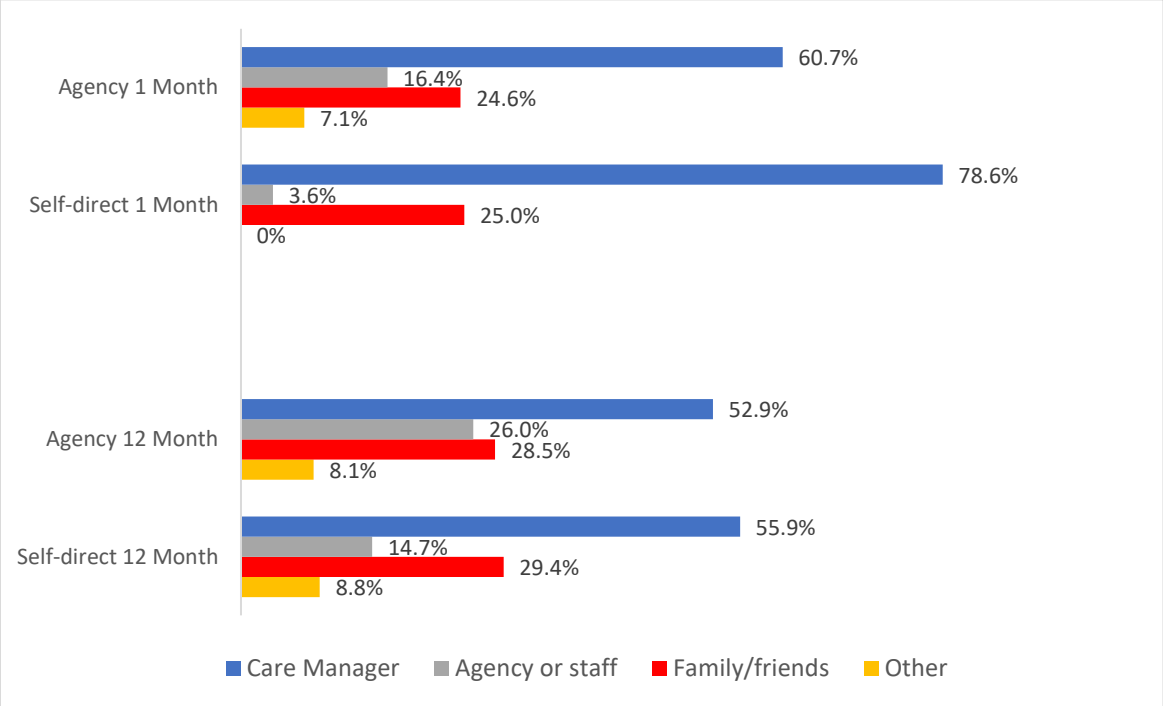
While the great majority of both populations said their PCAs encouraged them to do things for themselves if they could, at 12 months 97% of self-directed consumers felt this way, compared to 87% of agency-based consumers.

Figure 5.5. Do Your PCAs Encourage You to Do Things For Yourself? Agency vs. Self-direct (Percentage Yes)



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, followed by turning to family or friends (Figure 5.6). By 12 months, the percentage of agency-based and self-directed consumers who would contact their case manager to change their care plan dropped, while the percentage of these consumers who would contact their 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

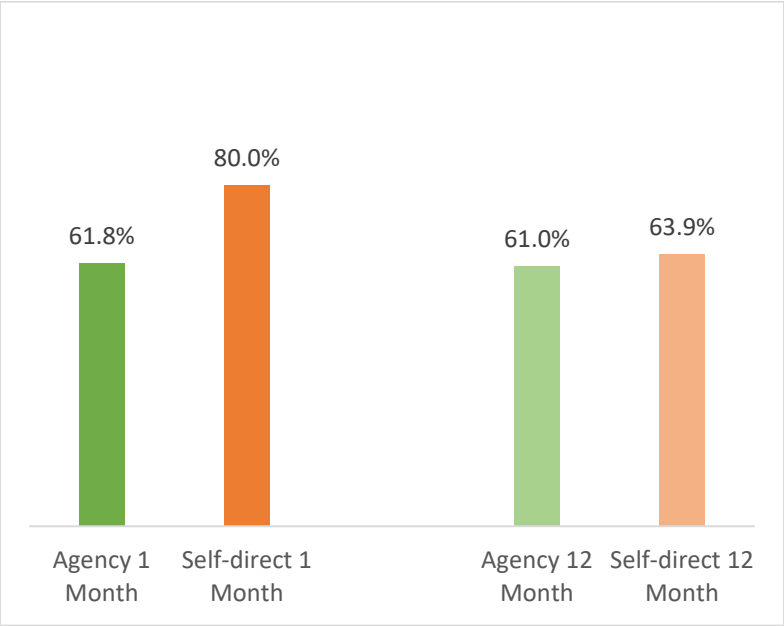
Household composition showed strong differences between the two groups of consumers (Table 5.5). For example, agency-based consumers were much more likely to live alone, especially at 12 months. Of the consumers who lived with someone, at both time points agency-based consumers were less likely to live with family, but much more likely to live with someone they were not related to, such as a live-in PCA. At both time points, a greater percentage of self-directed consumers had family or friends who lived nearby.

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=212	N=30	N=136	N=36
	1	56.1	43.3	64.7	38.9
	2-3	39.6	46.7	33.8	52.8
	4+	4.3	10.0	1.5	8.3
Lives with family member/s		N=93	N=17	N=48	N=22
	Yes	74.2	94.1	70.8	90.9
	No	25.8	5.9	29.2	9.1
Lives with non-family		N=93	N=17	N=48	N=22
	Yes	30.1	11.8	39.6	13.6
	No	69.9	88.2	60.4	86.4
Family member/s live nearby		N=212	N=30	N=136	N=36
	Yes	74.5	83.3	75.0	88.9
	No	25.5	16.7	25.0	11.1
Friend/s live nearby		N=212	N=30	N=136	N=36
	Yes	74.5	83.3	75.0	88.9
	No	25.5	16.7	25.0	11.1

Figure 5.7 shows that at 1 month post-transition, self-directed consumers reported receiving much more informal support from family and friends for household tasks. This is consistent with the higher rate at which family members live with self-directed consumers, as well as the greater percentage of nearby family or friends compared to agency-based consumers. Interestingly, at 12 months post-transition, self-directed consumers received much less help from family or friends, while the percentage of agency-based consumers receiving this assistance stayed stable.

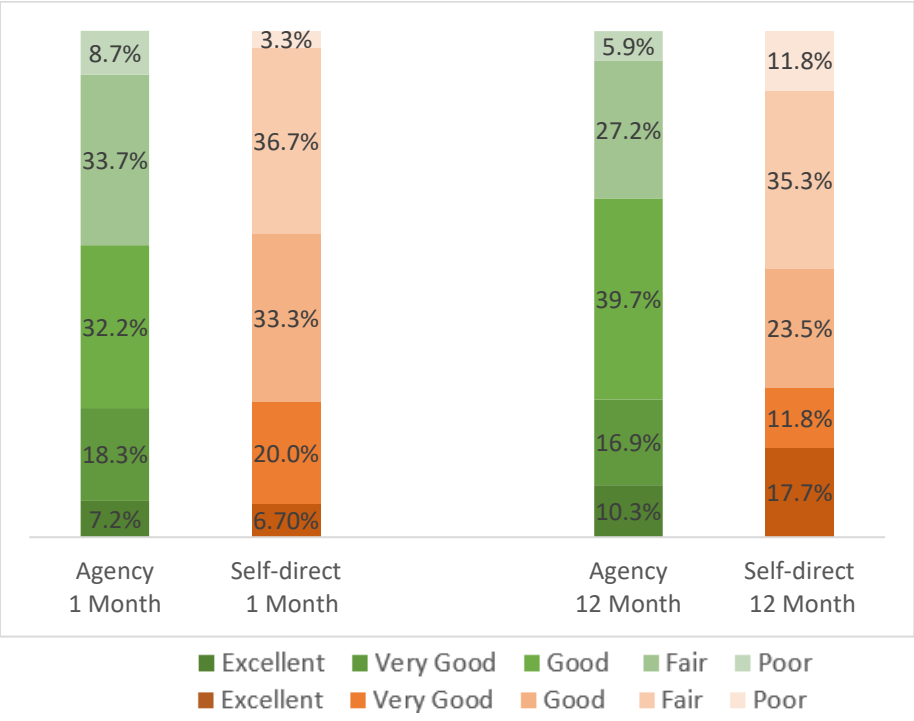
Figure 5.7. Assistance from Unpaid Family or Friends with Things Around the House: Agency vs. Self-direct (Percentage Yes)



Physical Health

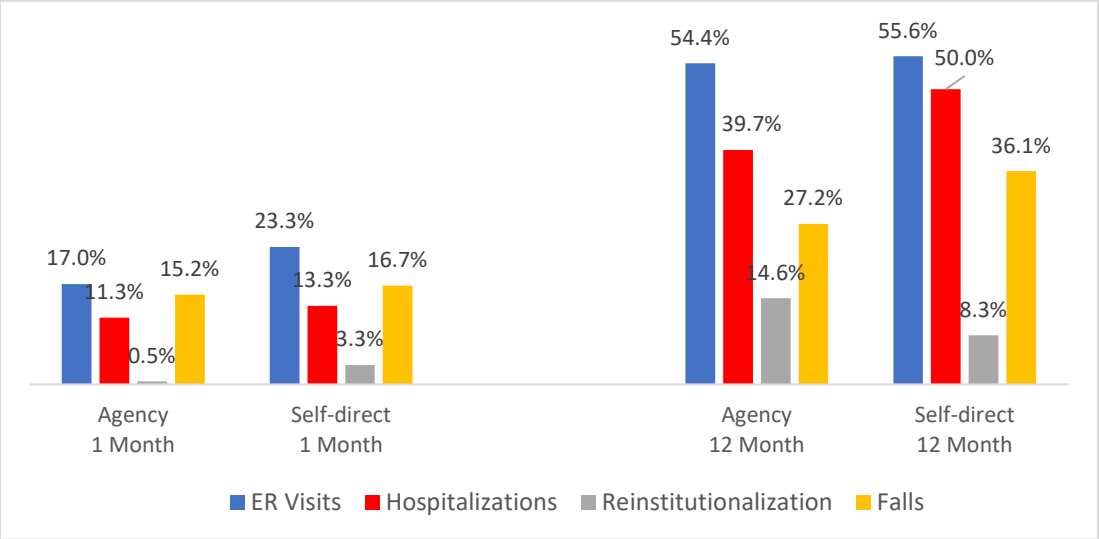
While self-reported health between the groups was pretty similar at 1 month, by 12 months, the health of self-directed consumers had worsened, while agency-based consumers were more likely to report good to excellent health. (Figure 5.8).

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). By 12 months, agency-based consumers were more likely to have experienced a reinstitutionalization, despite reporting better health, and having lower rates of both hospitalizations and falls compared to self-directed consumers.

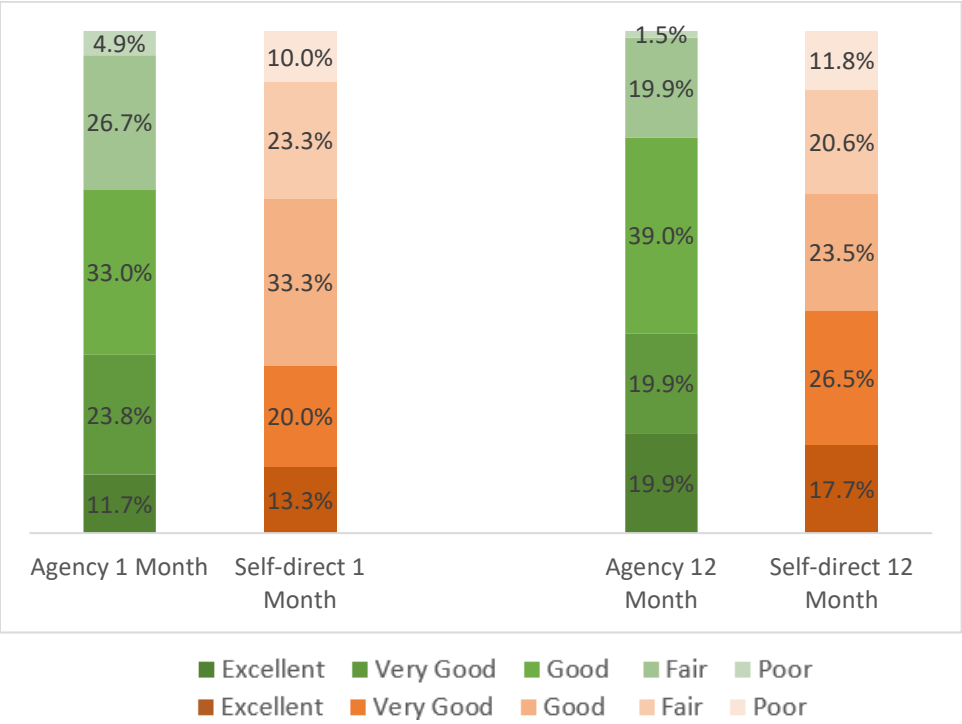
Figure 5.9. Emergency Room Visits, Hospitalizations, Reinstitutionalizations, and Falls: Agency vs. Self-direct (Percentage Yes)



Mental Health

Self-reported mental or emotional health showed an interesting change over time (Figure 5.10). While at 1 month agency-based and self-directed consumers reported similar rates of mental health, by 12 months agency-based consumers reported a much higher rate of good to excellent mental health compared to self-directed consumers. When asked about depressive symptoms, at 12 months self-directed consumers reported higher rates of depressive symptoms than agency-based consumers (data not shown). Still, compared to 2023, the mental health of self-directed consumers showed improvement over the previous year, as 68% of self-directed consumers reported good to excellent mental health in 2024, compared to 58% in 2023.

Figure 5.10. Self-Reported Mental Health: 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). Group differences in unmet need were greatest for home modifications, medical equipment, and internet devices. Most outstanding is that at 1 month, self-directed consumer reported a much greater need for home modifications: 17% agency-based and 40% self-directed reported they were missing needed home modifications. Both groups also reported an unmet need for various other types of these items, although differences were slight with no other 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=210	N=30	N=136	N=36
	I have it	65.7	53.3	70.6	58.3
	I do not need it	17.6	6.7	11.0	27.8
	I need it	16.7	40.0	18.4	13.9
Mobility equipment		N=211	N=30	N=136	N=36
	I have it	86.7	96.7	89.7	94.4
	I do not need it	7.6	3.3	10.3	2.8
	I need it	5.7	0.0	0.0	2.8
Medical equipment		N=210	N=30	N=136	N=36
	I have it	76.7	80.0	82.4	86.1
	I do not need it	13.3	3.3	11.0	5.6
	I need it	10.0	16.7	6.6	8.3
Lifeline or PERS		N=210	N=29	N=136	N=35
	I have it	62.9	62.1	70.6	57.1
	I do not need it	22.9	34.5	21.3	34.3
	I need it	14.3	3.5	8.1	8.6
Internet capable devices		N=211	N=30	N=135	N=36
	I have it	71.6	76.7	81.5	80.6
	I do not need it	18.5	16.7	12.6	11.1
	I need it	10.0	6.7	5.9	8.3
Internet access		N=211	N=30	N=136	N=35
	I have it	85.6	86.7	91.9	97.1
	I do not need it	9.1	3.3	6.6	0.0
	I need it	5.3	10.0	1.5	2.9

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 2023 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 (James et al., 2024). 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 482 consumers who transitioned in 2023 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=482 n (%)	Transition to 1 Month N=474 n (%)	1 Month Setting N=473 n (%)	1 Month to 12 Month N=396 n (%)	12 Month Setting N=397 n (%)
Community	482 (100)	441 (93.0)	443 (93.7)	290 (73.2)	339 (85.4)
Facility	0 (0)	33 (7.0)	30 (6.3)	106 (26.8)	58 (14.6)

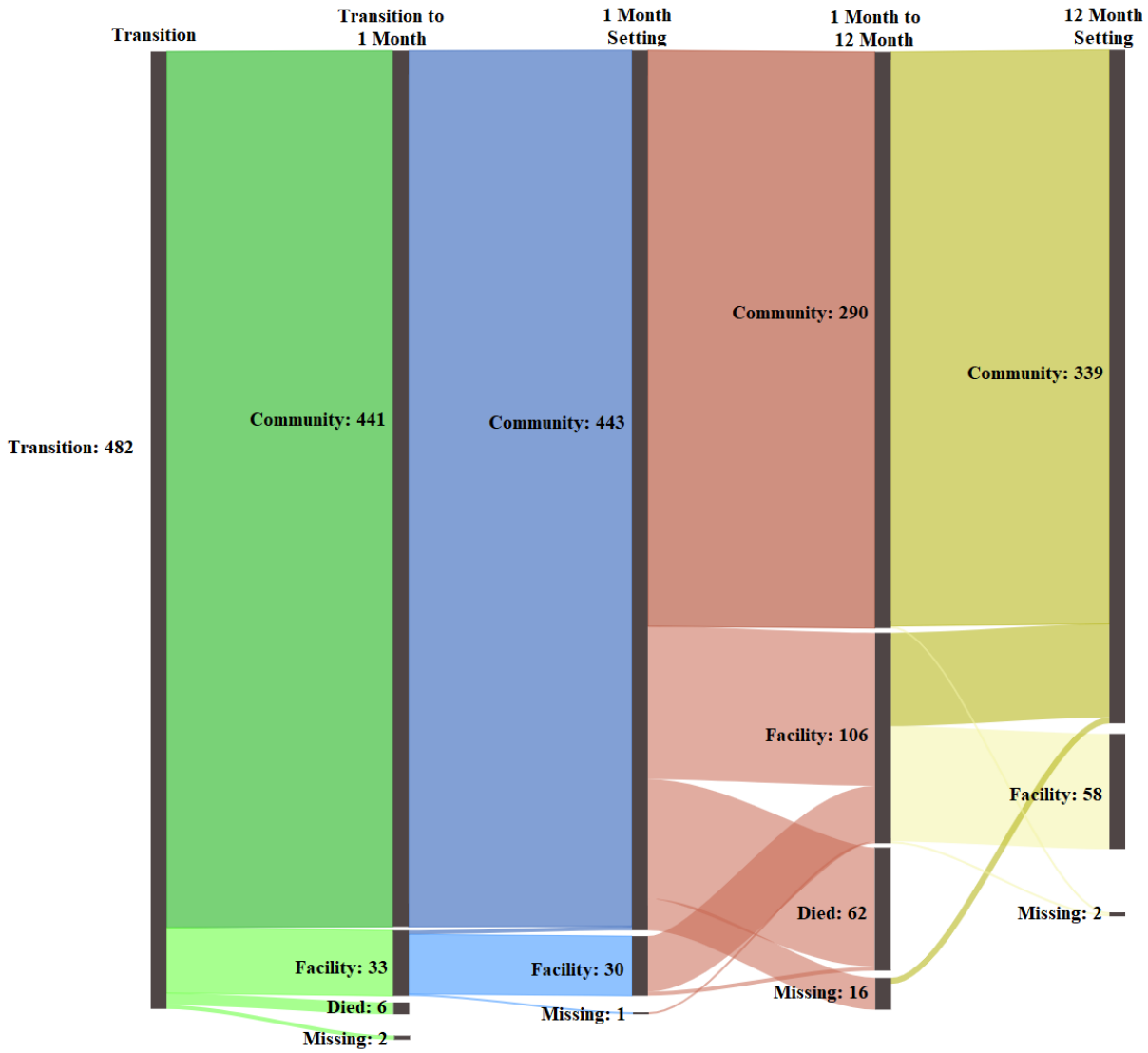
Sankey diagrams illustrate the flow and quantity of cases from one point to the next, or from one point through several different points of time. The proportion of cases determines the size of each flow relative to the total sample. In health policy research, Sankey diagrams often provide a visual aid 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 2023 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, 7% 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=3) discharges by 1 month post-transition, 6% 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 (27%) 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 2023 report, with one minor exception. The percentage of consumers who died between 1 to 12 months increased from 9% in 2023 to 13% in 2024.

Figure 6.1. Diagram of Participant Setting and Facility Use from Transition to 12 Months for 2023 Transitions

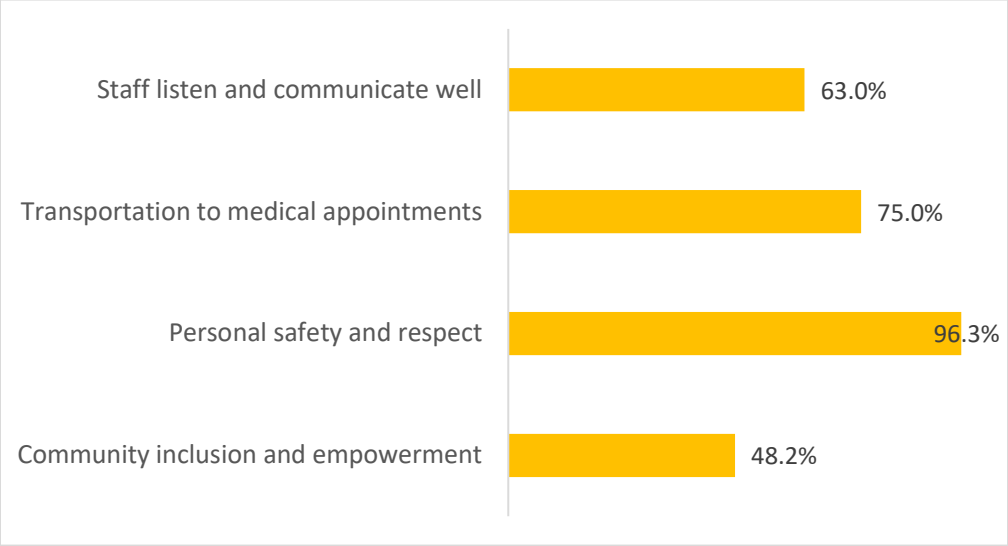


SankeyMATIC: A Sankey Diagram Builder for Everyone. http://sankeymatic.com

2023 12 Month Institution: Select Results

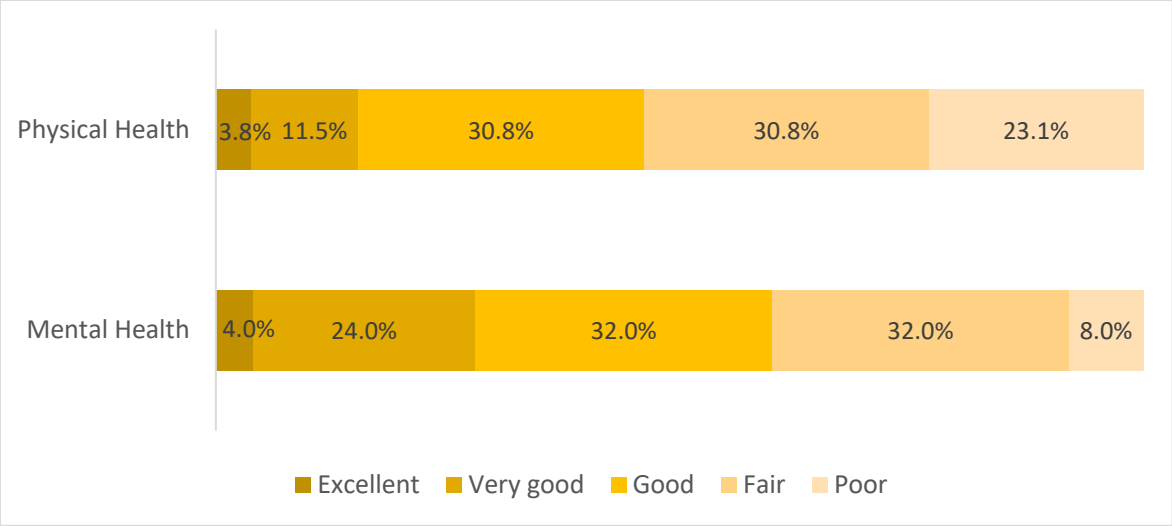
The following figures present 2024 survey data for the 27 consumers who transitioned in 2023 and were in a facility at 12 months. See Section 3 for comparative results for consumers in the community at 12 months. The percentage of consumers in a facility at 12 months who gave the highest score for personal safety and respect increased this year (86% 2023, 96% 2024), making it comparable to the personal safety and respect score given by community consumers at 12 months.

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



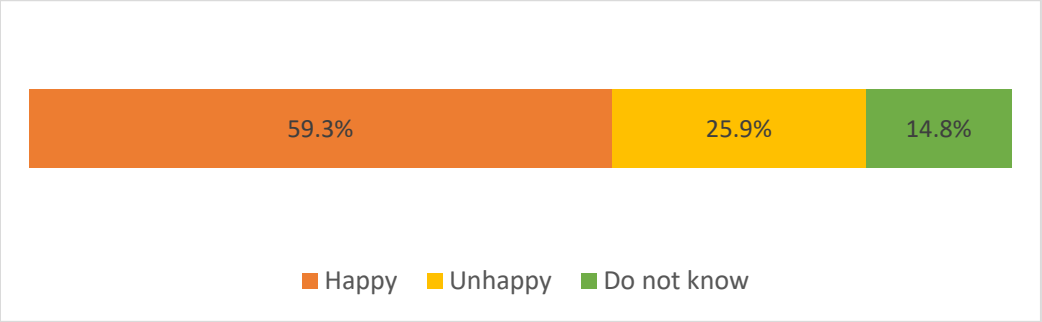
Not surprisingly, consumers reinstitutionalized at 12 months were in poor physical health – only 15% of reinstitutionalized consumers reported very good or excellent health (Figure 6.3). While over one-quarter (28%) rated their mental health as very good or excellent, depressive symptoms were common – almost half (48%) of consumers reinstitutionalized at 12 months reported depressive symptoms. Still this is an improvement over last year, when 67% of reinstitutionalized consumers reported depressive symptoms.

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



One-quarter (26%) of consumers reinstitutionalized said they were unhappy with the way they live their life (Figure 6.4). This is also an improvement over last year, when 41% were unhappy with the way they live their life.

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 2024

This section provides an overview of the experience of reinstitutionalization at one month post-transition for consumers who transitioned in 2024. 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 465 consumers transitioned in 2024. Of these, 274 consumers completed a 1 month survey before the end of the year. Almost all consumers (94.9%, n=260) 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 14 (5.1%) consumers who were in an institution at 1 month represent the total 1 month readmission rate (Table 6.2). This re-institutionalization rate for 2024 transitions is greater than the rate for 2023 transitions, when 3.2% of consumers who completed a 1 month survey were reinstitutionalized either short or long term by that time.

Table 6.2. Transitioned in 2024 – Experienced Reinstitutionalization by 1 Month Survey

	n (%)
Total 1 month surveys	274 (100)
Experienced readmission by one month survey	
No – Always in the community	260 (94.9)
Yes – Reinstitutionalized either short or long-term	14 (5.1)

Consumer Characteristics

Almost 80% of consumers reinstitutionalized by 1 month were waiver consumers (Table 6.3).

Table 6.3. Waiver or State Plan Status: Always Community vs. Ever Reinstitutionalized

Service Type	Always Community N=260 n (%)	Ever Reinstitutionalized N=14 n (%)
Waiver	203 (78.1)	11 (78.6)
State Plan	57 (21.9)	3 (21.4)
All programs	260 (100.0)	14 (100.0)

Reinstitutionalized consumers were also more likely to be older, female, less educated, and White compared to those who were never reinstitutionalized.

Table 6.4. Demographics: Always Community vs. Ever Reinstitutionalized

		Always Community n (%)	Ever Reinstitutionalized n (%)
Age			
	< 55	72 (27.7)	2 (14.3)
	55-64	83 (31.9)	3 (21.4)
	65-74	48 (18.5)	4 (28.6)
	75+	57 (21.9)	5 (35.7)
Race			
	White	144 (56.9)	8 (57.1)
	Black	84 (33.2)	5 (35.7)
	Other	25 (9.9)	1 (7.1)
Gender			
	Male	134 (51.5)	4 (28.6)
	Female	126 (48.5)	10 (71.4)
Education			
	< High school	57 (23.0)	5 (35.7)
	High school degree	108 (43.5)	6 (42.9)
	> High school	83 (33.5)	3 (21.4)

Physical and Mental Health at One Month

Consumers who were reinstitutionalized at 1 month post-transition were much more likely to be in fair or poor health (Figure 6.5). These consumers also reported worse mental health compared to consumers who had never been back to a facility (Figure 6.6). Consumers 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

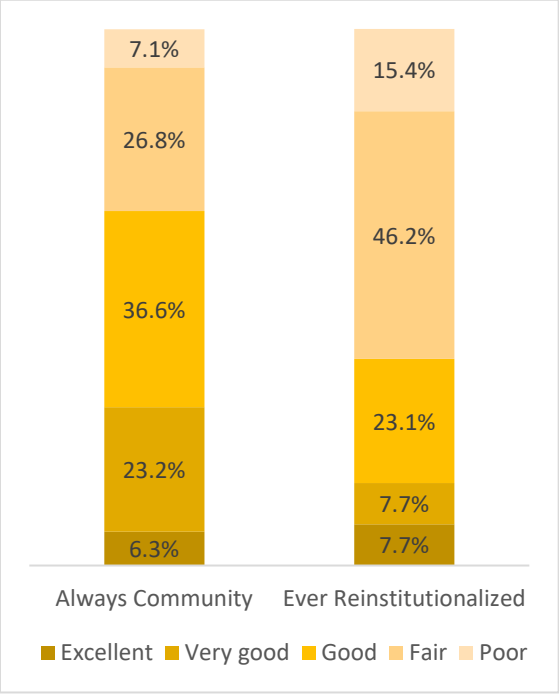


Figure 6.6. Self-Reported Mental Health

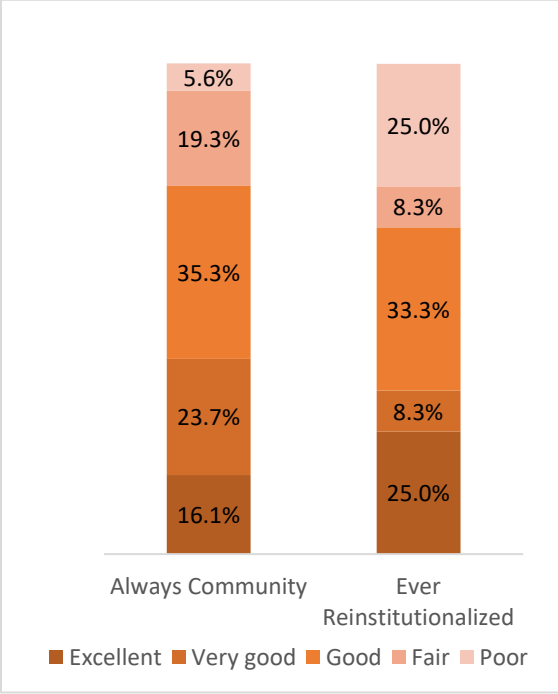
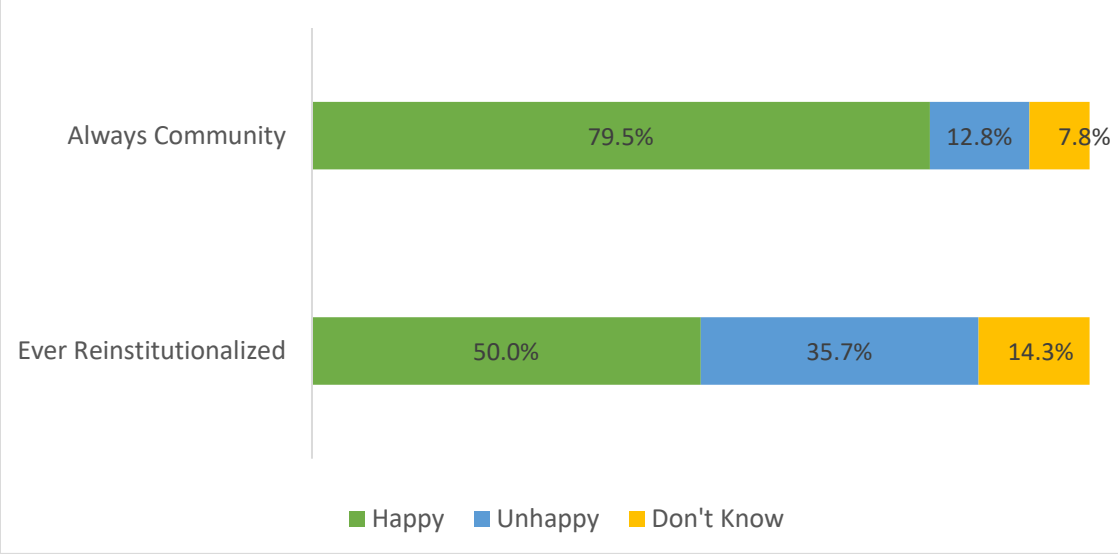


Table 6.5. Depressive Symptoms: Always Community vs. Ever Reinstitutionalized

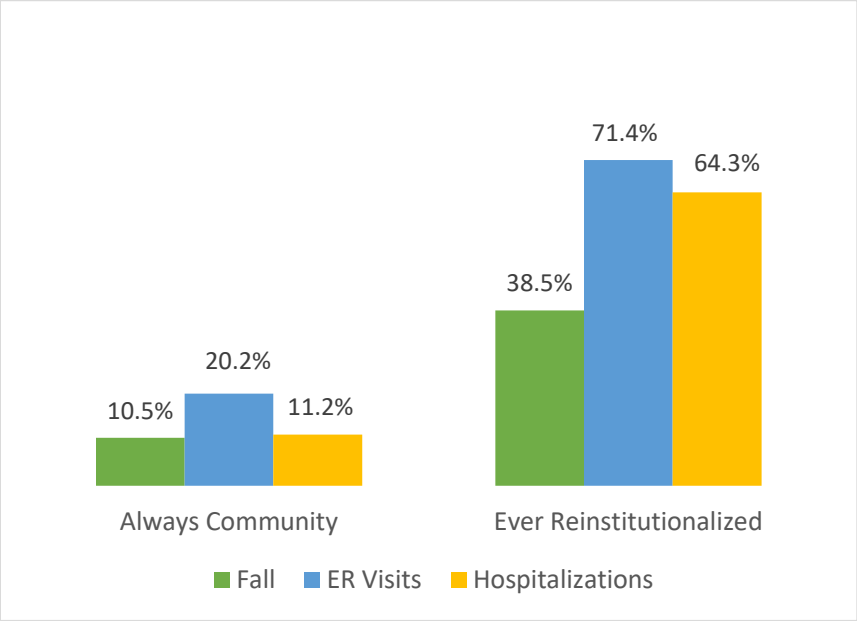
Depressive Symptoms	Always Community n (%)	Ever Reinstitutionalized n (%)
Yes	63 (24.6)	6 (46.2)
No	193 (75.4)	7 (53.8)

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 14 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.

Nine 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 member's experiences, as well as the often-overlapping issues contributing to reinstitutionalization.

Consumer physical health decline post-transition

As in 2023, physical health decline post transition was a leading cause of reinstitutionalization within four to six weeks post-transition. While some consumers experienced acute medical incidents such as a fracture, more often health conditions which were stable in the facility became worse once in the community. For example, some consumers who could walk independently with or without an assistive device at the facility began to need more and more assistance to do so in the community. Many of these consumers already have serious chronic and progressive conditions such as diabetes or kidney disease. Other factors in health decline included lack of professional medical care, relying on family members to provide complex care, worsening of wounds, falls with injury, lack of self-care, not taking medications as prescribed, and consumer mental health challenges.

Three consumers were hospitalized and then sent back to a facility due to wounds. Two consumers had wounds upon transition which got worse post-transition. Another consumer had recently healed wounds, but developed others once in the community. She could not stand and used a Hoyer lift with one person assisting for transferring. Her health conditions included COPD, mild cognitive impairment, and a recently healed coccyx wound, and phantom limb pain. She transitioned home with a hospital bed and Hoyer, continuing to live with her former spouse who also provided care between PCA shifts. Unfortunately, unlike the beds at the nursing home, once home the PCA found the hospital bed did not go low enough to allow for one person transfers. The husband then found he could not re-position her by himself when the PCA was not there, including through the night. The consumer developed very painful wounds on her coccyx which then required hospitalization and post-acute care.

Consumer self-care sometimes contributed to a physical health decline. It was particularly difficult for some consumers to manage their multiple medications, including glucose monitoring or injections, once in the community. This issue played a role in several consumers going back to the facility. Consumers come from an inpatient setting where medications are controlled and given out by a nurse without any consumer involvement. Once in the community, managing medications becomes the responsibility of the consumer or their family. The consumer must go see their primary providers to get their prescriptions, keep track of refills, and arrange to pick up the medications/medical supplies or get them delivered. Once their medications are obtained, then the consumer must take them as prescribed. For people with diabetes, this can involve checking their blood sugar and injecting insulin. If any bloodwork or urinalysis is needed, they have to proactively get this done.

Lack of PCA or non-medical home care services

Lack of PCA services, whether because of PCA call outs, consumer choice, frequency of need for assistance, consumer budget, or number of PCA hours approved, was a contributing factor for 5 consumers. Almost all of these consumers had split shifts, with several hours of PCA assistance in the morning and again in the evening. In some cases, consumers found they could not wait until the next PCA arrived to do things like get up or do personal care, and unfortunately fell while trying to do so.

Consumer physical and/or mental health decline could exacerbate this. For example, one consumer developed sores and needed to be turned throughout the night. Another consumer was ambulatory for short distances with a walker and assistance from one person to transfer in the facility, but once she got home, she could not walk without assistance, sat down, and could not get up. The PCA found that without the consumer working with her, she could not move or assist the consumer with getting up by herself – two PCAs would be needed. Such extensive two-person or throughout the night PCA assistance cannot be provided by MFP.

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, household tasks, or transportation. Informal support is especially important for consumers who live alone even if they have some paid support. Regular check-ins or visits by friends or family can identify unanticipated issues and help resolve them before they become 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 ongoing health conditions which require medical care that cannot be provided by PCAs, and family members agree to provide this care so their loved one can come home.

Some family or friends were willing to provide various types of support, but found that it was just too much for them for a variety of reasons. One family member who did not live with the consumer agreed to do daily specialized wound care. The consumer had dementia, and once home, the family member found themselves running the household and managing the finances in addition to doing the daily wound care, which became overwhelming for them. It was very hard for spouses in particular to realize

that they could not do everything needed to keep their spouse at home, and their loved one had to go back into a nursing home. In the progress notes, one SCM wrote this about a husband who found he could not do the physical care necessary in between the PCA shifts, “He is sad and thought things would get easier, but instead, things have gotten much harder.”

Falls

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 getting up or transferring without assistance, such as the consumer who fell transferring herself to the toilet after her PCA left for the day. Three of the five consumers who fell fractured either their femur or their pelvis, which then led to reinstitutionalization.

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

A worsening or exacerbation of mental or behavioral health issues led to reinstitutionalization for some consumers. Consumers whose behavioral issues were not debilitating in the facility suddenly found they could not manage their lives in the community. One consumer who transitioned to her own apartment felt so unsafe and suffered such extreme anxiety that she went to the emergency room with acute physical symptoms two times within three days of transition. The second time the symptoms were so severe she was admitted to the hospital. After ruling out all physical conditions, the hospital discharged her to a nursing facility.

Decline in cognition or poor judgment

Three consumers experienced a decline in cognition post transition which led to their reinstitutionalization. Several other consumers were not realistic or had limited insight into their ability to care for themselves or manage their households once in the community. This led to poor judgment and decisions which played a role in their going back to the nursing home.

One consumer had multiple health conditions, including right side paralysis, sliding scale insulin dependent diabetes, dialysis, and a recent lower limb amputation. Once home he did not manage his health or medications well, including his diabetes which lead to blood sugar swings. Despite needing extensive assistance, he often cancelled his PCAs, saying he did not need them or did not feel well. It was during one of those times when he fell trying to transfer himself to the toilet. This resulted in a fracture, requiring hospitalization and a return to a facility for more rehabilitation.

Medically complex with multiple morbidities

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

For example, one consumer was coming home after rehab for a broken ankle. She was using a walker and needed assistance with transfers for safety. Her other health conditions included COPD, oxygen dependence, incontinence, and osteoporosis. She had PCAs for several hours in the morning and evening while her husband assisted her during the day. Early in the morning she tried to get out of bed rapidly without assistance in order to make it to the bathroom on time. She ended up falling and broke

her femur which was weakened by osteoporosis. She required surgery and went from there to short term rehabilitation once again.

Intermediate Care Facility level of care

Three of these consumers had intellectual or developmental disabilities (IDD) as well as multiple medical and/or behavioral health care needs, and moved to Intermediate Care Facilities (ICFs) specialized for people with IDD. ICFs provide a higher level of support than a community living arrangement or group home such as 24 hour supervision, specialized programming, and some clinical and behavioral health support. These consumers needed a higher level of specialized supports and could not live in a traditional community group home.

Unstable transitions

MFP supports person-centered decision making and having choice about one's services, living situation, and other matters. The program is committed to providing everyone who prefers community living a chance to move out of the facility, and provides an array of supports to help make this a reality. It is also well known that most people want to live in the community and not in a nursing home. Consumers who have transitioned report a better quality of life and fewer depressive symptoms (Robison et al., 2015). Nonetheless, one theme identified this year was that of consumers leaving the nursing home under might be considered unstable or unsafe circumstances. The circumstances for these are all unique, with multiple factors playing a role.

In two cases, people who knew the consumer well including nursing home staff expressed concerns about the consumer being able to live in the community with the supports MFP could provide. These consumers had chronic conditions including cognitive impairment. In both cases the consumer very much wanted to leave the nursing home. Upon assessment, one consumer initially qualified for 4.5 hours of daily PCA assistance, although he could not answer what he would do in case of an emergency. The consumer's family, physical therapist and other staff said this was not enough even with informal supports, especially as the consumer would be living alone. Prior to transition the consumer's physical condition declined after a fall and hospital stay, and the assessor was granted a reassessment, which did not occur until after transition. Once in the community but before the second assessment was completed, the consumer's Parkinson's disease worsened, and his physical functioning, including his ability to care for himself and take his medications, further declined. This was exacerbated by his PCAs not always showing up. His family and home health agency team were all concerned for his safety and relayed this to the SCM. Three weeks post transition, at a scheduled occupational therapy (OT) session, the OT felt the consumer was too unsafe to be left alone and called the EMTs. He was hospitalized and discharged to a facility for short term rehabilitation.

Another consumer's health conditions included muscle weakness with pain, hypertension, fibromyalgia, and a behavioral health diagnosis. The consumer was using a wheelchair, but could walk a few steps using two canes. The consumer's family expressed concerns about the consumer going back home, as they felt the consumer had not managed well before his fall. The home was very cluttered with small paths through the rooms. However, the facility physical therapist determined it would be safe in its current condition as long as the consumer had more physical therapy to strengthen his legs. The consumer also agreed to have his family declutter his home, and when asked some days later, assured the TC this was going well.

The day of transition did not go as planned. When the TC arrived at the nursing home, the consumer was still in bed and none of his things were packed. The PCA ended up coming to the facility to help with packing. The TC overheard there was a monthly injectable medication, which had not been disclosed at the discharge meeting two weeks earlier. The TC called the SCM who said that can be done at a doctor's office and did not need to hold up transition. Once they arrived at the consumer's home, the TC found the home to be in just as bad shape as at the original evaluation. There was no place to sit due to items

piled up on all the chairs and only small paths to navigate through the rooms. When helping the consumer get settled, the PCA discovered the consumer's leg was bandaged. The consumer then told the TC that he had a blister break on his calf a few days ago which was getting daily care, but not to tell anyone. The TC notified the SCM who called the facility. The facility confirmed the consumer was getting daily wound care at this time, but had failed to tell the TC this at transition. The SCM advised the consumer to return to the nursing home, as the consumer's care plan did not include daily nursing, which now could not start until ordered by the community physician. The consumer refused saying he could take care of it himself. Without this daily nursing, the wound became infected and advanced to cellulitis in about a week. The home health nurse called the EMTs, and the consumer was hospitalized. The hospital then discharged him to a nursing home for short term rehabilitation as the infection was too severe to be treated in the community.

III. Conclusions and Recommendations

A total of 567 HCBS CAHPS surveys were completed with MFP participants in 2024: 310 1 month and 257 12 month surveys.

1 Month Community Surveys Completed in 2024

Section 2 of this report examined data from the 294 1 month surveys completed in 2024 with community residing consumers. Community inclusion and empowerment continues to be the lowest performing composite, which once again indicates an area for program improvement. Consumers reported better overall physical and mental or emotional health than in the previous year, although a considerable proportion of consumers still expressed concerns related to accessing medical care and depressive symptoms.

While the majority of consumers reported using assistive technology or special equipment, 42% of consumers reported lacking some type of equipment, home modification or assistive technology at 1 month post-transition. 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 2023

A total of 482 consumers transitioned in 2023. Altogether, they completed 575 HCBS CAHPS surveys: 321 1 month and 254 12 month surveys. Section 3 reported on the 1 and 12 month surveys completed with consumers residing in the community at the time of their survey (n=536), 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 prior 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 previous years, community residing participants gave three composites comparatively low scores at both 1 and 12 months: medical transportation, choice of services, and especially community inclusion and empowerment. Choice of services did show improvement by 12 months, with 75% of consumers reporting the ability to choose the services that matter to them compared to 69% of consumers at 1 month. 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.

Global ratings for their current PCAs and homemaking staff went up over time. By 12 months, 80-82% of consumers would rate their PC or homemaking staff a 9 or 10. In addition, between 77-83% of consumers would definitely recommend their PCAs or homemaking staff at either time point. Still, 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 expressed dissatisfaction with the home care agencies, especially the lack of staff supervision and communication. Meanwhile, a shortage of available caregivers only 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.

On the other hand, care manager ratings dropped slightly over time. This may reflect the structure of the program, as SCM support ends either at or within a few months of transition, and after 6 months, TC support is limited to a telephone call a month. Respondent comments indicated a need for better and more frequent communication. Respondents also remarked that TC and SCM turnover made it especially difficult for consumers to know whom to contact. Improved and more effective SCM and TC communication is an area which MFP could target for improvement.

Approximately 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 39-43% 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 more than one-quarter of community consumers rated their mental or emotional health as fair or poor, and a similar proportion of consumers reported depressive symptoms. Still, when asked if they were happy or unhappy with the way they lived their life, between 80-84% 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 58-63% 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 – 95-96% at either time point reported having at least one of these. Still, 40-47% of consumers at either time point lacked some type of device or modification needed to live in the community, reflecting a steady increase from previous years. At 1 month post-transition, between 14-18% of consumers still needed home modifications, a PERS, or electronic medical devices. 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 and personal care supplies 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, 26-31% 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 a great concern in 2024, as it has been in previous years.

Approximately 85% of consumers said they liked where they lived, and over 92% felt safe living there. Many respondents remarked on how happy they were just to have their own place. On the other hand, some consumers expressed dissatisfaction with their community residence, housing coordinator, or the housing process. Consumers also commented on their transition budget, specifically that the maximum allowable cost for many furniture items should be raised so better quality furniture which would last longer could be purchased.

Securing affordable, accessible housing in Connecticut is challenging. Needing community housing is one of the top challenges to transition, and the primary driver of length of time to transition (Robison et al., 2020). Connecticut has had a specialized CO staff person assigned to housing in the past, and should continue to fund this position along with housing initiatives in the future.

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 2023 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 comprised 77-80% of 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, as 85-86% of waiver consumers reported using some type of personal care assistance, compared to 16-17% of state plan consumers. In addition, by 12 months post transition, 44% of state plan consumers reported using no services, compared to just 4% 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 have typically reported much lower case management services use, even at just 1 month post transition. In the last 3 years state plan use of case management services at 1 month jumped from 54% in 2022, to 74% in 2023, and 79% in 2024, which is very close to the waiver consumer rate (83%). By 12 months post-transition, only 39% of state plan consumers reported using case management services, compared to 62% of waiver consumers.

Although at 1 month there was a 12% difference between waiver and state plan consumers for giving the highest score for the case manager is helpful composite, by 12 months that difference shrank to 5%, with waiver consumers reporting their care managers to be more helpful at each time point. In a more

notable display of this trend, waiver consumers gave a much higher rating for the composite choosing the services that matter to you at 1 month, but by 12 months the two groups had very similar ratings of this composite. Waiver consumers were more likely to highly rate and recommend their case managers than state plan consumers at both 1 and 12 months.

Consistent with the 2023 report, state plan consumers reported less social support overall. State plan consumers were much more likely to live alone, less likely to live near family or friends, 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. Waiver consumers reported better mental and emotional health at both time points and were also less likely to report depressive symptoms. The increased likelihood of living alone along with less social support and family involvement could all be factors contributing to the higher rate of depressive symptoms for state plan consumers one year after transition. Although both waiver and state plan consumers faced financial hardship at each time point, state plan consumers reported much worse finances, which may have negatively affected their mental health as well.

Despite reporting higher rates of emergency room visits, hospitalizations and nursing home readmissions at 12 months, waiver consumers reported better subjective physical health than state plan consumers. Approximately 27-28% of waiver consumers rated their health as very good or excellent at either time point, compared to 16-18% of state plan consumers. By 12 months post-transition, over half (54%) of state plan consumers rated their health as fair or poor, as did 36% 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 through their waiver plans.

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

Community living consumers who transitioned in 2023 were stratified by service type into those using agency-based services versus self-directed consumers who hire their own staff. At 1 month 88% of consumers reported using agency-based services, while just 12% 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. Unlike previous years, self-directed consumers were more likely to use case management services at 1 month. But by 12 months use of case management services did not differ between the 2 groups.

Self-directed consumers rated their personal care staff higher than agency-based consumers on all staff metrics at both time points. In particular, self-directed consumers were much more likely than agency-based consumers to report that their staff were reliable and helpful. 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. Still, despite these positive benefits of self-direction, use of agency-based services at 1 month post-transition has grown substantially over the past 5 years, from 69% in 2020 to 88% in 2024, likely driven by the addition of agency-based services to the PCA waiver.

Agency-based consumers were much more likely to live alone and at 12 months were more than twice as likely to be 65 or older. Surprisingly given this age difference, at 12 months agency-based consumers were more likely to report good to excellent physical health, and were less likely to be hospitalized or to report falling. Despite these differences, by 12 months, agency-based consumers reported much higher reinstitutionalization rates.

The Reinstitutionalization Effect

Consumers who transitioned in 2023

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 2023 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 7% of participants had returned to a facility for either a short or long-term stay. Unsurprisingly given the longer length of time, approximately one quarter (27%) of consumers had been in a facility between the 1 month and 12 months survey. At 12 months post-transition, the percentage who remained reinstitutionalized dropped to 15%.

Select results showed that consumers reinstitutionalized at 12 months rated the staff listen and communicate well and community inclusion and empowerment composites lower than consumers residing in the community at 12 months. Unlike previous years, reinstitutionalized consumers reported a higher rating for the transportation to medical appointments composite. Not surprisingly consumers reinstitutionalized at 12 months reported worse overall physical and mental health than community dwelling consumers. Reinstitutionalized consumers also experienced higher rates of depressive symptoms and were less likely to be happy with their lives.

Consumers who transitioned in 2024

Next, reinstitutionalization for consumers who transitioned in 2024 and completed a 1 month survey (n=274) was explored. Only 5% (n=14) of these consumers were reinstitutionalized at the time of their 1-month survey. This reinstitutionalization rate for 2024 transitions is comparable to the rate for 2023 transitions, when 3% 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 and female compared to those who were never reinstitutionalized. Consumers reinstitutionalized by 1 month reported much worse physical health, 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 2024 and had experienced reinstitutionalization by their 1 month survey were examined in more detail. Qualitative analysis identified nine common themes or circumstances or issues associated with facility readmission. 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, decline in cognition, medical complexity with multiple morbidities and unstable transitions.

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 am very pleased and happy with it. I am happy with the people and what they are doing. I am just very happy. Everyone has reached out and helped me. (1 month)*

> *Just keep on doing what you are doing, you guys are awesome. I didn't know what MFP was until the facility social worker introduced me to it. The people from MFP are impeccable, really helpful, and knowledgeable about what's out there. (1 month)*

This program has been a great experience. It's a relief my daughter was able to transition to this new group home which is so much better than where she was. So glad this program exists. (1 month)

This program was a tremendous help and a ray of hope for me in a time of need when I was pleading to get out of the nursing home. It was a long process but I am so glad to be where I am now. (1 month)

I think it has been very good for me and very helpful. It helped me to stay in my apartment after [the nursing home]. Without it I wouldn't have been able to stay in my apartment. (12 month)

Without the help of MFP assisting [my son's] case and providing these services, he would never have been able to live on his own. His chronic disease gets him down, but his being able to live on his own and care for himself definitely lifts his spirits. (12 month)

I am very pleased with the program – everything went good and helped jumpstart with my life all over again. You made it possible for me. (12 month)

I am so glad they took me on because it really helped me get back into the community. I don't think I could have done it without them. (1 month)

I am very thankful for them. I appreciate what they do for people to give us a chance. We would be stuck in there with nothing. I was able to get an apartment that was completely furnished. If it wasn't for them, I would have nothing. (12 month)

IV. References

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V. Appendices

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

HCBS CAHPS® survey

MFP Community survey

English

Instructions for Vendor

- The interview is intended as an interviewer-administered survey; thus all text that appears in initial uppercase and lowercase letters should be read aloud. Text that appears in **bold, lowercase letters** should be emphasized.

- Text in {*italics and in braces*} will be provided by the HCBS program's administrative data. However, if the interviewee provides another term, that term should be used in place of the program-specific term wherever indicated. For example, some interviewees may refer to their case manager by another title, which should be used instead throughout the survey.

- For response options of "never," "sometimes," "usually," and "always," if the respondent cannot use that scale, the alternate version of the survey with response options of "mostly yes" and "mostly no" should be used. These alternate response options are reserved for respondents who find the "never," "sometimes," "usually," "always" response scale cognitively challenging.

- For response options of 0 to 10, if the respondent cannot use that scale, the alternate version of the survey with response options of "excellent," "very good," "good," "fair," or "poor" should be used. These alternate response options are reserved for respondents who find the numeric scale cognitively challenging.

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

- Use program-specific terms. Where appropriate, add in the program-specific terms for staff (e.g., [*program-specific term for these types of staff*]) but allow the interviewer to modify the term based on the respondent's choice of the word. It will be necessary to obtain information for program-specific terms. State administrative data should include the following information:
    i. Agency name(s)
    ii. Titles of staff who provide care
    iii. Names of staff who provide care
    iv. Activities that each staff member provides (this will help with identifying appropriate skip logic)
    v. Hours of staff who come to the home

COGNITIVE SCREENING QUESTIONS

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

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

[1] ☐ YES
[2] ☐ NO → GO TO [Interviewer - Screening Failed]
[-1] ☐ DON'T KNOW → GO TO [Interviewer - Screening Failed]
[-2] ☐ REFUSED → GO TO [Interviewer - Screening Failed]
[-3] ☐ UNCLEAR RESPONSE → GO TO [Interviewer - Screening Failed]

2. How do they help you?

_____

[EXAMPLES OF CORRECT RESPONSES INCLUDE]

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

[-1] ☐ DON'T KNOW → GO TO [Interviewer - Screening Failed]
[-2] ☐ REFUSED → GO TO [Interviewer - Screening Failed]
[-3] ☐ UNCLEAR RESPONSE → GO TO [Interviewer - Screening Failed]

3. What do you call them?

_____

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

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

[-1] ☐ DON'T KNOW → GO TO [Interviewer - Screening Failed]
[-2] ☐ REFUSED → GO TO [Interviewer - Screening Failed]
[-3] ☐ UNCLEAR RESPONSE → GO TO [Interviewer - Screening Failed]

[Interviewer - Screening Failed]

[1] ☐ Continue anyhow
[2] ☐ End Survey

IDENTIFICATION QUESTIONS

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

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

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

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

_____

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

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

[1] ☐ YES
[2] ☐ NO → GO TO Q8
[-1] ☐ DON'T KNOW → GO TO Q8
[-2] ☐ REFUSED → GO TO Q8
[-3] ☐ UNCLEAR RESPONSE OR NOT APPLICABLE → GO TO Q8

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

_____

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

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

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

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

_____

[ADD RESPONSE WHEREVER IT SAYS "*homemaker"*]

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

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

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

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

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

_____

[ADD RESPONSE WHEREVER IT SAYS "*case manager"*]

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

ITEM AND RESPONSE—FOLLOW ALL ROWS THAT APPLY	**ACTION**
IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES), AND Q8 = NO, DON'T KNOW, REFUSE, UNCLEAR (HOMEMAKER SERVICES)	ASK Q13–Q36, AND Q48 ONWARD

ITEM AND RESPONSE—FOLLOW ALL ROWS THAT APPLY	**ACTION**
IF Q4 OR Q6 = YES (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES), AND Q8 = YES (HOMEMAKER SERVICES)	ASK Q13 ONWARD
IF Q4 AND Q6 = NO (PERSONAL ASSISTANCE OR BEHAVIORAL HEALTH SPECIALIST SERVICES)	SKIP Q13–36, Q57 AND Q79
IF Q8 = YES (HOMEMAKER SERVICES)	ASK Q37 ONWARD
IF Q10 = YES (HOMEMAKER AND PERSONAL ASSISTANCE STAFF SAME)	ASK Q13–Q36, Q39, Q40, AND Q48 ONWARD
IF Q11 = ANY RESPONSE (CASE MANAGER)	ASK Q48 ONWARD

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

__0 TO 10
[-1] ☐ DON'T KNOW
[-2] ☐ REFUSED

-3☐ UNCLEAR RESPONSE

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

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

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

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

GETTING NEEDED SERVICES FROM HOMEMAKERS

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

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

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

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

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

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

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

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

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

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

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

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

38b. In the last 3 months, how often did {*homemakers*} explain things in a way that was easy to understand? Would you say . . .

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

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

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

38c. In the last 3 months, did {*homemakers*} encourage you to do things for yourself if you could?

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

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

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

1☐ YES → GO TO Q41
2☐ NO
-1☐ DON'T KNOW → GO TO Q41
-2☐ REFUSED → GO TO Q41
-3☐ UNCLEAR RESPONSE 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 HOMEMAKER 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 HOMEMAKERS COMMUNICATE WITH AND TREAT YOU

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

__0 TO 10
[-1] ☐ DON'T KNOW
[-2] ☐ REFUSED
[-3] ☐ UNCLEAR RESPONSE

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

[1] ☐ Excellent,
[2] ☐ Very good,
[3] ☐ Good,

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

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

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

YOUR CASE MANAGER

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

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

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

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

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

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

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

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

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

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

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

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

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

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

__0 TO 10
[-1] ☐ DON'T KNOW
[-2] ☐ REFUSED

-3☐ UNCLEAR RESPONSE

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

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

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

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

HOME-DELIVERED MEALS, ADULT DAY PROGRAM

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

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

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

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

1☐ Excellent,
2☐ Very good,
3☐ Good,
4☐ Fair, or

5 ☐ Poor?
-1 ☐ DON'T KNOW
-2 ☐ REFUSED
-3 ☐ UNCLEAR RESPONSE or DID NOT USE AN ADULT DAY PROGRAM

CHOOSING YOUR SERVICES

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

1 ☐ **None** of the things that are important to you,
2 ☐ **Some** of the things that are important to you,
3 ☐ **Most** of the things that are important to you, or
4 ☐ **All** of the things that are important to you?
-1 ☐ DON'T KNOW → GO TO 57a
-2 ☐ REFUSED → GO TO Q57a
-3 ☐ UNCLEAR RESPONSE → GO TO Q57a
-4 ☐ NOT APPLICABLE → GO TO Q57a

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

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

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

Probes (*Use <u>only</u> 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 Heatlh/ABH to pay your aides?

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

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

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

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

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

TRANSPORTATION

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

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

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

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

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

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

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

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

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

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

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

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

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

PERSONAL SAFETY

The next few questions ask about your personal safety**.**

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

[1] ☐ FAMILY MEMBER OR FRIEND
[2] ☐ CASE MANAGER
[3] ☐ AGENCY THAT PROVIDES HOME- AND COMMUNITY-BASED SERVICES
[4] ☐ PAID EMERGENCY RESPONSE SERVICE (E.G., LIFELINE)
[5] ☐ 9–1–1 (FIRST RESPONDERS, POLICE, LAW ENFORCEMENT)

6☐ SOMEONE ELSE, PLEASE SPECIFY _____
-1☐ DON'T KNOW
-2☐ REFUSED
-3☐ UNCLEAR RESPONSE

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

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

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

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

1☐ YES
2☐ NO → GO TO Q68
-1☐ DON'T KNOW → GO TO Q68
-2☐ REFUSED → GO TO Q68
-3☐ UNCLEAR RESPONSE → GO TO Q68
-4☐ NOT APPLICABLE → GO TO Q68

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

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

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

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

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

[1] ☐ YES
[2] ☐ NO → GO TO Q71
[-1] ☐ DON'T KNOW → GO TO Q71
[-2] ☐ REFUSED → GO TO Q71
[-3] ☐ UNCLEAR RESPONSE → GO TO Q71
[-4] ☐ NOT APPLICABLE → GO TO Q71

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

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

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

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

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

[1] ☐ YES
[2] ☐ NO → GO TO Q74
[-1] ☐ DON'T KNOW → GO TO Q74
[-2] ☐ REFUSED → GO TO Q74
[-3] ☐ UNCLEAR RESPONSE → GO TO Q74
[-4] ☐ NOT APPLICABLE → GO TO Q74

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

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

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

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

COMMUNITY INCLUSION AND EMPOWERMENT

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

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

[1] ☐ YES
[2] ☐ NO → GO TO Q76
[-1] ☐ DON'T KNOW → GO TO Q76
[-2] ☐ REFUSED → GO TO Q76
[-3] ☐ UNCLEAR RESPONSE → GO TO Q76

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

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

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

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

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

[1] ☐ YES
[2] ☐ NO → GO TO Q78
[-1] ☐ DON'T KNOW → GO TO Q78

-2☐ REFUSED → GO TO Q78
-3☐ UNCLEAR RESPONSE → GO TO Q78

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

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

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you get together with these friends who live nearby? Would you say . . .
1☐ Mostly yes or
2☐ Mostly no?
-1☐ DON'T KNOW
-2☐ REFUSED
-3☐ UNCLEAR RESPONSE

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

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

ALTERNATE VERSION: In the last 3 months, when you wanted to, could you do things in the community that you like? Would you say . . .
1☐ Mostly yes or
2☐ Mostly no?
-1☐ DON'T KNOW
-2☐ REFUSED
-3☐ UNCLEAR RESPONSE

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

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

-3 ☐ UNCLEAR RESPONSE

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

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

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

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

EMPLOYMENT MODULE

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

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

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

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

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

1 ☐ BENEFITS → GO TO EM5
2 ☐ HEALTH CONCERNS → GO TO EM5
3 ☐ DON'T KNOW ABOUT JOB RESOURCES → GO TO EM5
4 ☐ ADVICE FROM OTHERS → GO TO EM5

5☐ TRAINING/EDUCATION NEED → GO TO EM5
6☐ LOOKING FOR AND CAN'T FIND WORK → GO TO EM5
7☐ ISSUES WITH PREVIOUS EMPLOYMENT → GO TO EM5
8☐ TRANSPORTATION → GO TO EM5
9☐ CHILD CARE → GO TO EM5
10☐ OTHER (_____) → GO TO EM5
11☐ NOTHING IS HOLDING ME BACK → GO TO EM5
-1☐ DON'T KNOW → GO TO EM5
-2☐ REFUSED → GO TO EM5
-3☐ UNCLEAR RESPONSE → GO TO EM5

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

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

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

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

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

1☐ YES → GO TO THE ABOUT YOU SECTION
2☐ NO → GO TO THE ABOUT YOU SECTION

-1 ☐ DON'T KNOW → GO TO THE ABOUT YOU SECTION
-2 ☐ REFUSED → GO TO THE ABOUT YOU SECTION
-3 ☐ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

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

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

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

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

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

1 ☐ EMPLOYMENT/VOCATIONAL STAFF/JOB COACH
2 ☐ CASE MANAGER
3 ☐ OTHER PAID PROVIDERS
4 ☐ OTHER CAREER SERVICES
5 ☐ FAMILY/FRIENDS
6 ☐ ADVERSTISEMENT
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 not have it**		**Do not know**	**Refuse**
		I do need it	**I do not need it**		
16a. Building or home modifications, such as entrance ramps, wide doorways, roll-in shower, grab bars, stair glide, etc.					

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

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

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

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

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

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

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

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

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

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

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

DMHAS QUESTIONS

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

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

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

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

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

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

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

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

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

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

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

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

ABOUT YOU

Now I just have a few more questions about you.

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

[1]☐ Excellent,
[2]☐ Very good,

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

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

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

84. What is your age?

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

ALTERNATE VERSION: In what year were you born?
_____ (YEAR)
-1☐ DON'T KNOW
-2☐ REFUSED
-3☐ UNCLEAR RESPONSE

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

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

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

1☐ 8th grade or less

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

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

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

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

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

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

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

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

1☐ Asian Indian → GO TO Q92
2☐ Chinese → GO TO Q92
3☐ Filipino → GO TO Q92
4☐ Japanese → GO TO Q92
5☐ Korean → GO TO Q92

6☐ Vietnamese → GO TO Q92
7☐ Other Asian → GO TO Q92
-1☐ DON'T KNOW → GO TO Q92
-2☐ REFUSED → GO TO Q92
-3☐ UNCLEAR RESPONSE → GO TO Q92

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

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

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

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

93. What is the language you speak at home?

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

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

1☐ 1 [JUST THE RESPONDENT] → END SURVEY
2☐ 2 TO 3
3☐ 4 OR MORE
-1☐ DON'T KNOW
-2☐ REFUSED
-3☐ UNCLEAR RESPONSE

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

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

-3☐ UNCLEAR RESPONSE

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

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

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

_____

_____

_____

Question 98 is not in MFP Follow-Up 2:

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

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

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

Name, address, and phone of person to contact:

First and last name: _____

Relationship to consumer: _____

Street: _____

Apt. _____

City: _____ State:_____ Zip: _____

Telephone: _____

Email address: _____

Best way to contact: _____

Contact notes: _____

END OF QUESTIONS

Thank you for completing this interview with me.

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

Alternative contact information:

Name: _____

Relationship:_____

Street Address: _____

Apt. or Unit: _____

City: _____

State: _____ ZIP: _____

Contact Phone: _____

If you wish to contact your care manager, the number for his/her agency is:
AASCC: 203-752-3040
CCCI Eastern region: 860-885-2960
CCCI North Central region: 860-257-1503
CCCI Northwest region: 203-596-4800
SWCAA: 203-333-9288
WCAAA: 203-465-1000
Autism waiver: 860-424-5865
Katie Beckett waiver: 860-424-5582
DMHAS: 866-548-0265

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

INTERVIEWER QUESTIONS

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

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

☐ Participant by his/herself
Participant telephone numbers: _____ → Go to F1

☐ Participant with assistance from another person.

If Assisted

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

First name: _____

Last name: _____

Telephone numbers: _____ → Go to F1

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

If Proxy:

Proxy Contact Information:

Proxy First name: _____

Proxy Last name: _____

Proxy Telephone numbers: _____ → Go to P1

P1. Relationship to participant – the proxy is the…

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

P2. Is the proxy also a legal representative?

- ☐ Yes
- ☐ No

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

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

F1. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

[1] ☐ YES
[2] ☐ NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

[1] ☐ YES
[2] ☐ NO → GO TO END OF SURVEY

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

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

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

[1] ☐ YES
[2] ☐ NO → GO TO END OF SURVEY

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

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

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

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

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

F8. Is the person who assisted also a legal representative?
☐ Yes → GO TO END OF SURVEY
☐ No → GO TO END OF SURVEY

END OF SURVEY

Interview done by:
☐ Telephone
☐ In-person
☐ Other: _____

Participant Information:
First name: _____
Middle name: _____
Last name: _____

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

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

- ☐ Yes
- ☐ No
- ☐ Do not know

Program:

- ☐ MFP

Community First Choice?

- ☐ Yes
- ☐ No
- ☐ Do not know

Name of interviewer: _____

Date Interview Complete: _____

Appendix B. HCBS CAHPS Institutional Survey Description

HCBS CAHPS Institutional Survey – UConn **2-13-2019**

Overall changes from the HCBS CAHPS Community survey:

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

Appendix C. CT MFP HCBS CAHPS® Composite Measures Items

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

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

* Question added by Connecticut

Appendix D. Acronyms

ABI	Acquired Brain Injury waiver
AT	Assistive devices or technology
CAHPS®	Consumer Assessment of Healthcare Providers and Systems
CHCPE	Connecticut Home Care Program for Elders waiver
CHCPE-AB	Connecticut Home Care Program for Elders waiver – Agency-based
CHCPE-SD	Connecticut Home Care Program for Elders waiver – Self-directed
COVID	Coronavirus disease
CSP	Community service provider
DDS	Department of Development Services
DSS	Department of Social Services
ER	Emergency room
HCBS	Home and community-based services
HCBS CAHPS® survey	Consumer Assessment of Healthcare Providers and Systems Home and Community-Based survey
ILST	Independent Living Skills Trainer
MFP	Money Follows the Person program
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
SCM	MFP Specialized Care Manager
TC	MFP Transition Coordinator