# Money Follows the Person Rebalancing Demonstration

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

## 2022 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 Connecticut Department of Social Services (DSS) MyCommunityChoices website to explore the experiences of various groups of MFP participants, including those with a survey completed in 2022 and the 1 and 12 month surveys for the cohort of consumers who transitioned in 2021.

## 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. A participant's waiver or program determines which types of staff or services to ask about. Additional questions were added to the MFP HCBS CAHPS survey to further assess use of assistive devices and home modifications, self-direction, health care service use, depressive symptoms, finances, global satisfaction, and informal support. Consumers residing in a facility at the time of their survey answer about their experience with facility staff, as well as most of the other items covered in the full survey. The 2019-2020 MFP HCBS CAHPS Community and Institutional surveys are attached in Appendices A and B.

## B. Survey Administration

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

## C. Analysis

Key results are presented using established HCBS CAHPS composites and other key measures (Table 1; Appendix C). Individual items not included in these measures are also reported. This report uses the HCBS CAHPS scoring method to display the percentage of participants who gave the most positive or highest composite, global rating, or recommendation score. Descriptive results for all other survey questions are presented as frequencies and percentages.

Table 1. Key Measures*

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

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

## II. Results

Results are divided into five sections:

- Section 1: Survey and Respondent Characteristics for Surveys Completed in 2022

A total of 569 HCBS CAHPS surveys were completed with MFP participants in 2022: 300 1 month and 269 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 2022

This section presents select results from the 281 1 month surveys completed in 2022 with consumers residing in the community. HCBS CAHPS key results and areas of interest from the previous 2021 MFP HCBS CAHPS report, in particular case manager, health, and assistive devices, are shown.

- Section 3: Community Experiences from 1 Month to 12 Months Post-transition for Consumers Who Transitioned in 2021

The full set of both 1 month (n=340) and 12 month (n=258) MFP HCBS CAHPS surveys are available for consumers who transitioned in 2021. 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 examines 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 459 consumers who transitioned in 2021 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 2022 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 2022

A total of 569 HCBS CAHPS surveys were completed with MFP participants in 2022: 300 1 month and 269 12 month surveys (Table 1.1). Nine out of ten consumers (91%) were in the community at the time of their survey.

Table 1.1. Surveys Completed in 2022 by Setting

| | Community n (%) | Institution n (%) |
|---|---|---|
| 1 Month | 281 (93.7) | 19 (6.3) |
| 12 Month | 237 (88.1) | 32 (11.9) |
| All 2022 Surveys | 518 (91.0) | 51 (9.0) |

One month surveys were attempted to be completed between 30 and 45 days post-transition. On average, 1 month surveys were completed 38 days post-transition, and 12 month surveys were completed an average of 11.4 months post-transition (Table 1.2).

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

| | Minimum | Maximum | Mean | Standard Deviation |
|---|---|---|---|---|
| 1 Month Survey (Days) | 21 | 88 | 37.64 | 9.760 |
| 12 Month Survey (Months) | 11 | 13 | 11.35 | 0.535 |

Table 1.3 shows survey participants' home and community-based program at transition and at 1 and 12 months post-transition. Where the consumer is residing when the 1 month and 12 month surveys were completed is also specified. At each time point and setting, the greatest percentage of consumers transitioned with the Connecticut Home Care Program for Elders using agency-based services (CHCPE-AB), followed by consumers using Personal Care Assistant waiver agency-based services (PCA-AB).

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

| | At Transition n (%) | 1 Month Community n (%) | 1 Month Institution n (%) | 12 Month Community n (%) | 12 Month Institution n (%) |
|---|---|---|---|---|---|
| ABI waivers | 14 (2.6) | 10 (3.6) | 0 (0) | 3 (1.3) | 1 (3.1) |
| CHCPE-AB | 205 (36.0) | 96 (34.2) | 8 (42.1) | 84 (35.4) | 17 (53.1) |
| CHCPE-SD | 13 (2.3) | 6 (2.1) | 0 (0) | 6 (2.5) | 1 (3.1) |
| DDS waivers | 19 (3.3) | 7 (2.5) | 1 (5.3) | 11 (4.6) | 0 (0) |
| Katie Beckett | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Mental Health waiver | 15 (2.6) | 7 (2.5) | 2 (10.5) | 5 (2.1) | 1 (3.1) |
| MH State Plan | 52 (9.1) | 27 (9.6) | 1 (5.3) | 24 (10.1) | 0 (0) |
| PCA-AB | 125 (22.0) | 71 (25.3) | 3 (15.8) | 43 (18.1) | 8 (25.0) |
| PCA-SD | 60 (10.5) | 23 (8.2) | 2 (10.5) | 33 (13.9) | 2 (6.3) |
| PD State Plan | 44 (7.7) | 21 (7.5) | 2 (10.5) | 19 (8.0) | 2 (6.3) |
| RCH/Other | 22 (3.9) | 13 (4.6) | 0 (0) | 9 (3.8) | 0 (0) |

*See Appendix D for a complete list of acronyms

Table 1.4 shows survey and respondent characteristics for surveys completed in 2022. Similar to national trends, respondents who identified as White, non-Hispanic, and/or female were more likely to reside in an institution, compared to Black, Hispanic and/or male respondents (Travers et al., 2021). In all, proxies completed 22% of surveys in 2022, 5% lower than in 2021.

Table 1.4. Respondent and Survey Characteristics – Completed in 2022 by Time Point and Setting

| | | 1 Month Community N=281 n (%) | 1 Month Institution N=19 n (%) | 12 Month Community N=237 n (%) | 12 Month Institution N=32 n (%) |
|---|---|---|---|---|---|
| Survey Respondent | | | | | |
| | By self | 195 (69.4) | 15 (78.9) | 166 (70.0) | 22 (68.8) |
| | With assistance | 27 (9.6) | 1 (5.3) | 19 (8.0) | 0 (0.0) |
| | By proxy | 59 (21.0) | 3 (15.8) | 52 (21.9) | 10 (31.3) |
| Assistant Relationship | | | | | |
| | Spouse/partner | 8 (28.6) | 0 (0) | 5 (26.3) | 0 (0) |
| | Adult child | 8 (28.6) | 0 (0) | 6 (31.6) | 0 (0) |
| | Parent | 3 (10.7) | 0 (0) | 2 (10.5) | 0 (0) |
| | Attorney or legal representative | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| | Paid staff person | 3 (10.7) | 0 (0) | 0 (0) | 0 (0) |
| | Other | 6 (21.4) | 1 (100.0) | 6 (31.6) | 0 (0) |
| Proxy Relationship | | | | | |
| | Spouse/partner | 8 (13.6) | 1 (33.3) | 5 (9.6) | 1 (10.0) |
| | Adult child | 26 (44.1) | 2 (66.7) | 23 (44.2) | 6 (60.0) |
| | Parent | 9 (15.3) | 0 (0) | 8 (15.4) | 1 (10.0) |
| | Attorney or legal representative | 4 (6.8) | 0 (0) | 2 (3.8) | 1 (10.0) |
| | Paid staff person | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| | Other | 12 (20.3) | 0 (0) | 14 (26.9) | 1 (10.0) |
| How Person Assisted* | | | | | |
| | Answered some questions | 22 (78.6) | 1 (100.0) | 17 (89.5) | 0 (0) |
| | Restated/reminded/prompted for questions | 19 (67.9) | 1 (100.0) | 10 (52.6) | 0 (0) |
| | Translated questions | 0 (0) | 0 (0) | 2 (10.5) | 0 (0) |
| | Helped with use of assistive or communication equipment | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| | Other help provided | 3 (10.7) | 0 (0) | 0 (0) | 0 (0) |
| Survey mode | | | | | |
| | Telephone | 278 (98.9) | 17 (89.5) | 236 (99.6) | 32 (100.0) |
| | In-person | 3 (1.1) | 2 (10.5) | 1 (0.4) | 0 (0) |
| Survey used | | | | | |
| | English | 274 (97.5) | 19 (100) | 232 (97.9) | 30 (93.8) |
| | Spanish | 7 (2.5) | 0 (0) | 5 (2.1) | 2 (6.3) |

*Could assist in one or more ways

Demographics among the four groups showed some differences between survey setting and time point among gender (Table 1.5). Some notable differences are the increase in percentage of institutionalized participants who were male, from 26% at 1 month to 47% at 12 months.

Table 1.5. Demographics – Surveys Completed in 2022 by Time Point and Setting

| | | 1 Month | | 12 Month | |
|---|---|---|---|---|---|
| | | Community % | Institution % | Community % | Institution % |
| Age | | N=281 | N=19 | N=237 | N=32 |
| | <18 | <1.0 | 0.0 | 1.3 | 0.0 |
| | 18-44 | 14.9 | 15.8 | 8.4 | 9.4 |
| | 45-54 | 14.6 | 0.0 | 14.8 | 12.5 |
| | 55-64 | 30.2 | 36.8 | 30.4 | 18.8 |
| | 65-74 | 22.8 | 15.8 | 27.8 | 21.9 |
| | 75+ | 17.1 | 31.6 | 17.3 | 37.5 |
| Language | | N=280 | N=19 | N=235 | N=31 |
| | English | 81.1 | 94.7 | 83.8 | 83.9 |
| | Spanish | 1.4 | 0.0 | 1.7 | 6.5 |
| | Multilingual/Other | 17.5 | 5.3 | 14.5 | 9.7 |
| Race | | N=280 | N=19 | N=231 | N=30 |
| | White | 64.6 | 68.4 | 64.5 | 70.0 |
| | Black | 26.1 | 26.3 | 29.0 | 23.3 |
| | Other | 9.3 | 5.3 | 6.5 | 6.7 |
| Ethnicity | | N=280 | N=19 | N=235 | N=31 |
| | Non-Hispanic | 82.5 | 94.7 | 89.4 | 87.1 |
| | Hispanic | 17.5 | 5.3 | 10.6 | 12.9 |
| Education Level | | N=275 | N=18 | N=230 | N=31 |
| | < 8th Grade | 5.8 | 5.6 | 7.0 | 6.5 |
| | Some high school | 11.3 | 22.2 | 11.7 | 16.1 |
| | High school degree | 41.8 | 27.8 | 45.7 | 38.7 |
| | Some college | 29.5 | 33.3 | 23.0 | 29.0 |
| | 4 year college | 9.1 | 5.6 | 7.8 | 6.5 |
| | > 4 year degree | 2.5 | 5.6 | 4.8 | 3.2 |
| Gender | | N=281 | N=19 | N=237 | N=32 |
| | Male | 47.0 | 26.3 | 49.8 | 46.9 |
| | Female | 53.0 | 73.7 | 50.2 | 53.1 |

## Section 2. 1 Month Community Surveys Completed in 2022

This section presents select results from the 281 1 month surveys completed in 2022 with consumers residing in the community. Results include areas of interest from the 2021 report for comparison, in particular HCBS CAHPS key results, direct care staff, physical/mental health, assistive devices, and home modification items. Although not shown, similar data from the 19 1 month institutional surveys are available for any specific questions.

Consumers reported using a number of program services at 1 month after transition, especially care management services (80%) and personal care assistance (PCA) (61%) (Table 2.1). While most service use is similar to that reported at 1 month in 2021, use of PCA services decreased from 68% in 2021 to 61% in 2022. Case management service use increased from 74% in 2021 to 80% in 2022. "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 | 166 (60.6) |
| Behavioral health services | 4 (1.4) |
| Homemaking services or Homemaker-Companion** | 170 (62.0) |
| Care management services*** | 225 (80.1) |
| Job coach or vocational supports | 0 (0) |
| Recovery assistance services (MHW only) | 5 (71.4) |
| Community Service Provider (MHW only) | 6 (85.7) |
| None of these services | 14 (5.0) |

* Consumers can use more than one service

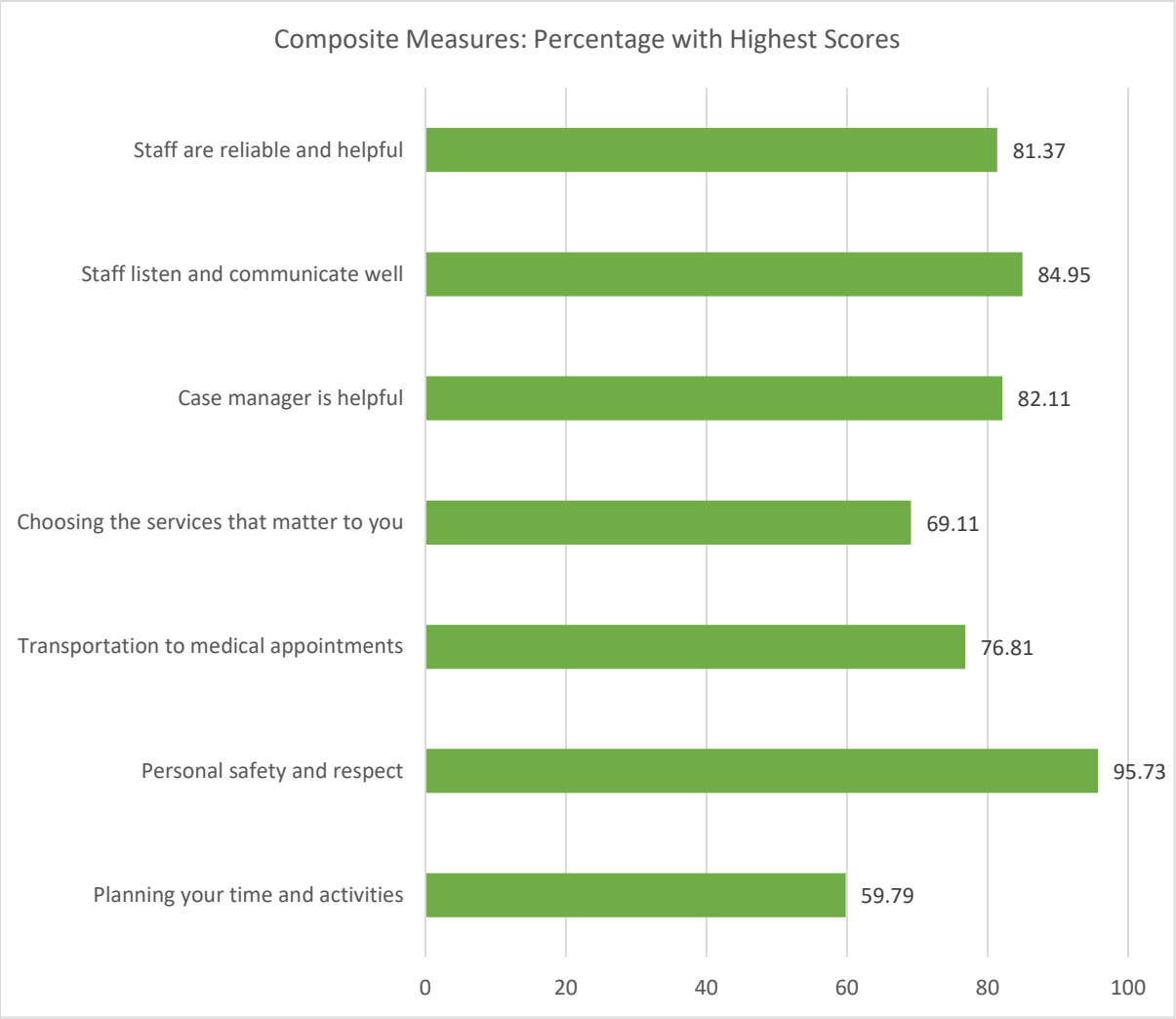
**Homemaking tasks can be provided by PCA or separate homemaking staff

***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 "planning your time and activities" once again received a noticeably lower score than the other composites, as just 60% of respondents gave this measure the highest score. Still, this represents an increase from 2021, when only 53% gave this composite the highest score. Choosing the services that matter to you also received a lower score than most of the other composites. While only 69% gave this composite the highest score, this is an increase from 65% in 2021. This composite includes items such as whether the care plan addresses what the participant views as important and their paid staff's knowledge of their care plan. Meanwhile scores for the staff and care manager composites went down this year. In 2022, 81% to 85% of respondents gave the highest scores to the staff and case manager composites, compared to 87% to 97% in 2021.

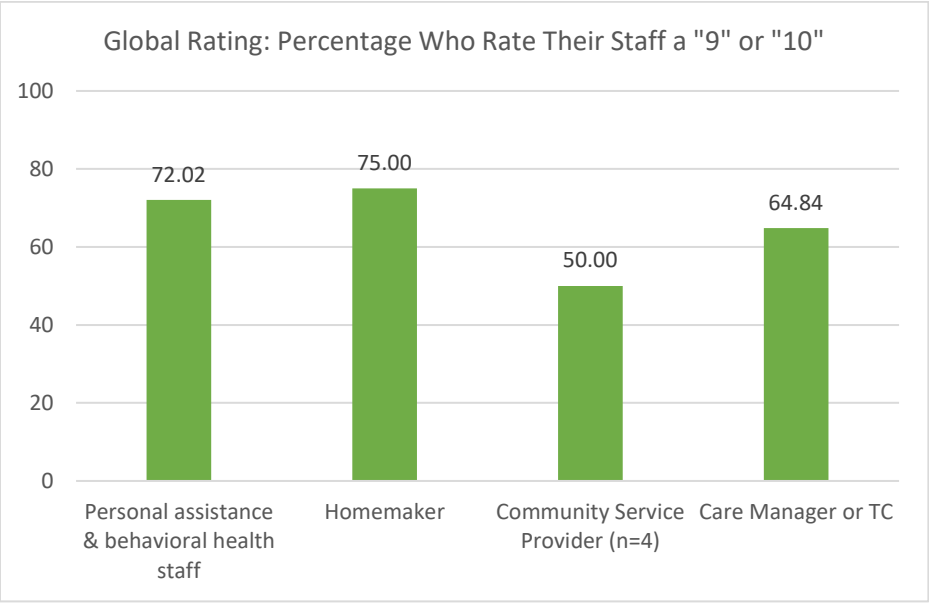
Figure 2.1. Composite Measures: Percentage with Highest Score*




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

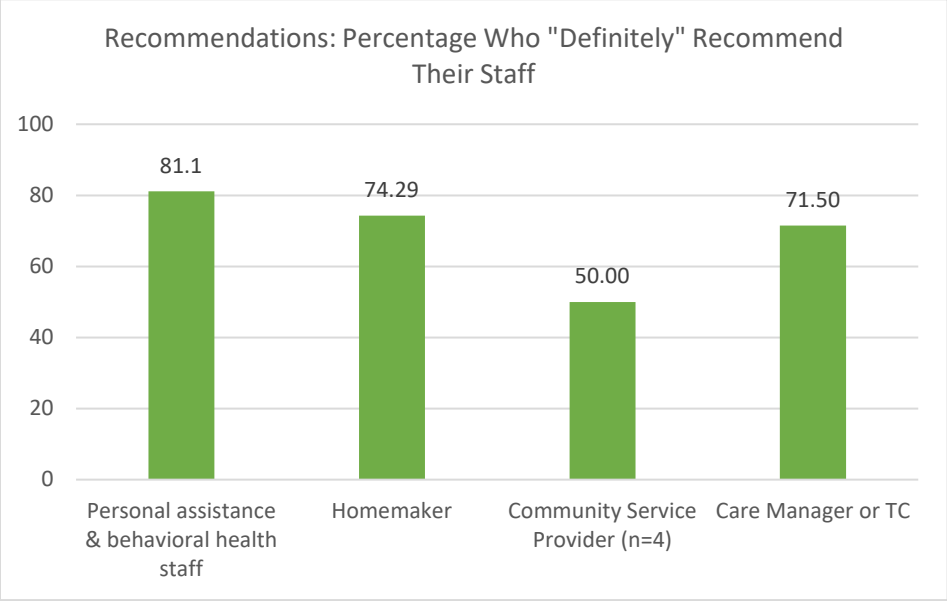
Figure 2.2 presents the percentage of consumers in the community who gave their staff the highest rating possible – a nine or ten, on a scale from zero to ten. Participants were more likely to give their homemaking staff or personal assistant/behavioral health staff a 9 or 10 (75%, 72% respectively) than their care manager/TC (65%). This trend continues in Figure 2.3, which shows the percentage of consumer who would "definitely" recommend their staff person.

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




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

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




Care manager

When asked about their care manager at 1 month, most participants (82%) knew who their care manager was, and 84% 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 | 225 (82.1) | 49 (17.9) |
| Able to contact care manager when need to | 184 (84.4) | 34 (15.6) |

In 2022, at one month post transition, positive experiences were noted, including:

> *Everything has worked out really well. I have noticed a big improvement since leaving the nursing home.*
>
> *My aide is very, very nice and so is my TC [name]. I am very happy with how things turned out.*
>
> *I am very grateful to be out of the nursing home. My TC is great – I was so impressed with everything she could get for me. Sometimes I get down when I think about my disability, but I just try to be grateful for what I have and pray.*
>
> *My live in aide is wonderful. He is a certified physician in his home country. I am very lucky to have him.*

Some respondents found that at one month post-transition the support from their MFP SCM or TC was not as they expected.

> *I couldn't get an answer from [SCM]. I've had to call the manager in order for her to return any of my calls. I asked about adult day programs. They said MFP doesn't do that and I was told to go to the senior center. I asked about a respite program, I was told that MFP does not provide that and that there aren't any respite hours available for [consumer].*
>
> *The MFP staff/team has not really been helpful. I've talked to so many different people- I can't keep them straight and don't know who is who. The day my grandmother transitioned home was the TC's first day. … There was so much that went wrong and things that should have been set up a long time ago that weren't set up. They didn't get any of the medical equipment they said they would. This last month has been hard. Financially, the only thing keeping us above water is the fact that I can get paid to be her caregiver.*

Other expressed concerns included not enough paid supports, issues with direct care staff, transportation, and need for socialization. Consumers found not having enough hours in their care plan and staffing consistency to be especially problematic. Some relied on family members to fill in for paid support.

> *I could use more help on the weekends. I don't have anyone for those days, and it's really hard to do things on my own. Not to mention it's lonely not having anyone to talk to. I have a lot of anxiety about how things are going to go in the future.*
>
> *The RA has been inconsistent. He does a good job when he's here, but he often has a "reason" why he can't come that day. I would like to have more consistency.*
>
> *The only reason my aide isn't a 10 is because of the language barrier. We make it work, and she is very helpful – it's just really hard to communicate.*
>
> *My aides did not work out. They were constantly changing, and I could not get a consistent aide. A lot of them were lazy and did not want to work, and they expected us to provide them with food. The final straw was the last aide that made her own sandwich and grabbed a water bottle and sat on the couch. They just could not follow my directions, and I couldn't take it anymore.*

*Luckily my husband is able to provide care for me, and I asked them to stop sending the PCAs. I think that the aides are not paid well, and it gives them no reason to want to do a good job.*

*I do not understand why I did not receive more hours. I had to fight to keep my 63 hours. My cousin is helping me, but he's not getting paid yet. I hope that I can receive more hours because I'm quadriplegic.*

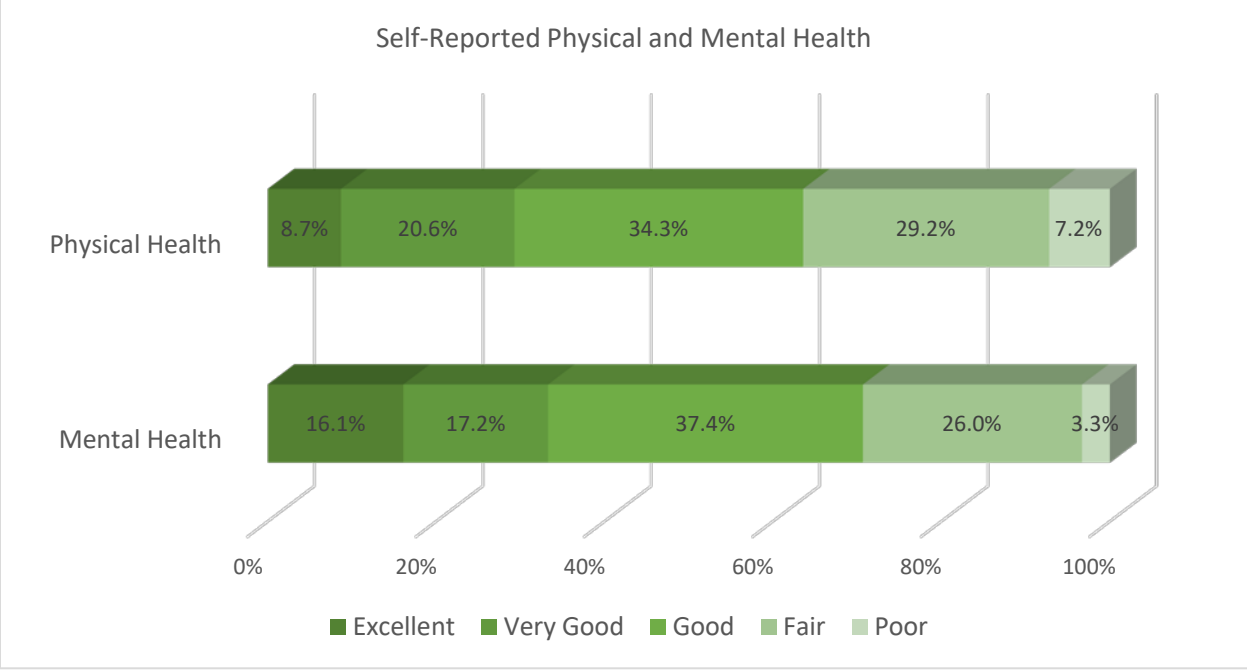
Physical and Mental Health

Figure 2.4 shows that when interviewed one month post-transition, the majority of community consumers rated their physical and mental health as good or better (64% and 71% respectively). However, more consumers reported feelings of depression this year: 36% of consumers residing in the community at 1 month reported depressive symptoms in 2022, compared to 29% in 2021. One comment in particular highlighted the intersection of transportation, social activities, and emotional health:

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

At 1 month post-transition, 19% of community consumers reported falling since transition – up from 14% in 2021. About one-quarter (24%) had used the emergency room.

Figure 2.4. Self-Reported Physical and Mental Health

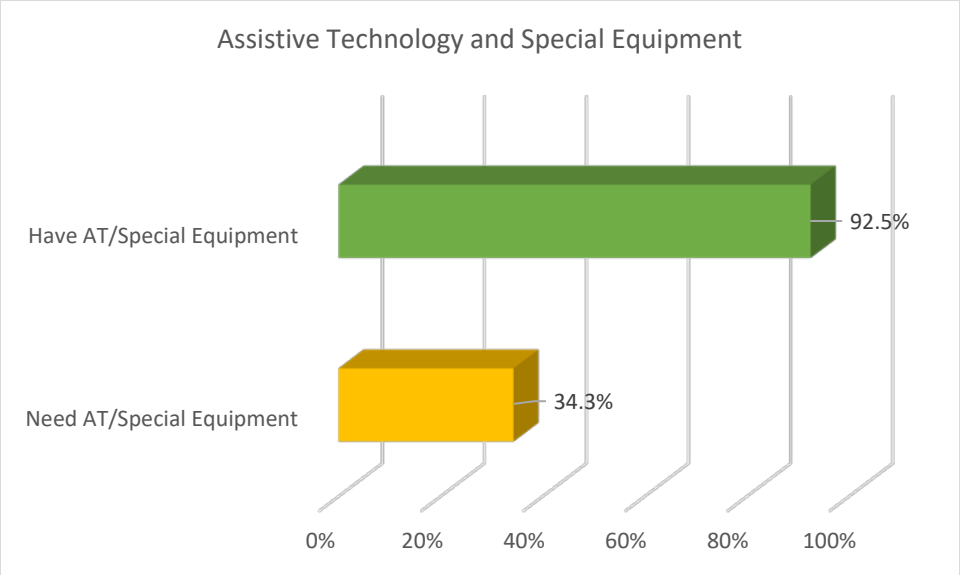



Assistive Technology and Special Equipment

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 HCBS 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 93% of consumers reported having at least one type of assistive device or special equipment, 34% of consumers reported lacking some type of assistive device, equipment, or home modification needed for community living at the 1 month survey (Figure 2.5). This number is much higher than in 2021, when 24% reported a need for some type of device or modification 1 month post-transition.

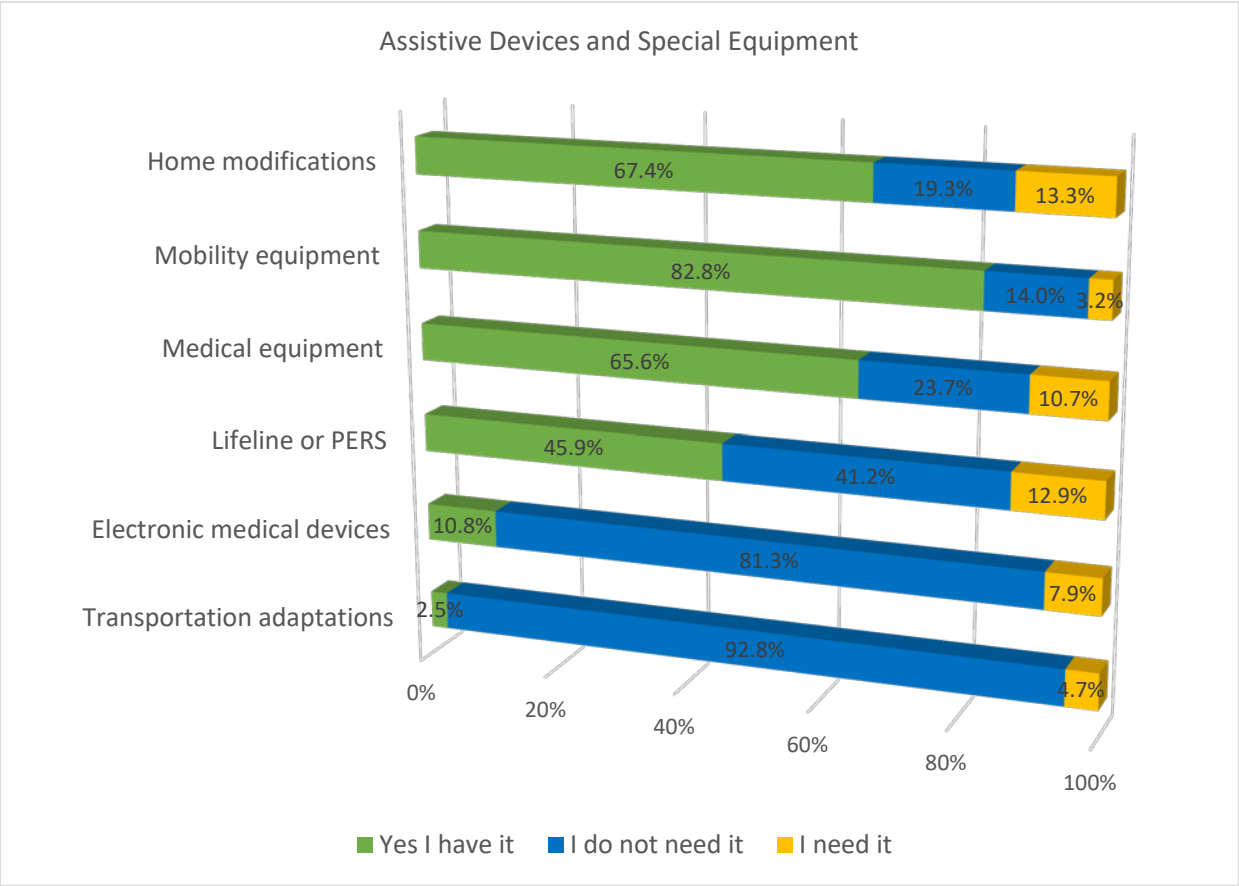
Figure 2.5. Have or Need any Type of Assistive Devices, Home Modifications, or Special Equipment




Consumers most often reported having mobility equipment (83%), home modifications (67%), or special medical equipment (66%) (Figure 2.6). When asked if they needed certain equipment, 11-13% of consumers still needed some type of special medical equipment, a personal emergency response system (PERS), or home modifications. Comments included:

> *I need a reacher if possible because my hands don't work well, and when nobody is here I have to wait to pick up something I dropped.*
>
> *I need a shower chair and a raised toilet seat because I can't sit on the toilet. They haven't gotten me a shower chair yet and I am upset about that. I haven't taken a shower since I've been here.*
>
> *I wish we could get more hours and certain equipment such as the blood pressure cuff, roll-in shower, and the Sera lift to make it easier to transfer my son. The manual crank lift is difficult.*
>
> *I'm waiting on a ramp to be installed. It's hard to leave my house right now without it. I don't know what the hold-up is.*

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 2021

This section reports the experiences of consumers who transitioned in 2021 and were living in the community at the time of their 1 month or 12 month survey. It explores questions such as, what are these consumers' lives like at one year after transition compared to 1 month after leaving the facility? What are their experiences with their HCBS paid supports early and later in their post-transition journey? Sections 4 and 5 describe this group by waiver status and type of service to answer the questions: are there any notable differences between consumers on a waiver and those using state plan services? How do the experiences of consumers using agency-based services differ from those using self-directed supports?

### *Respondent sample*

A total of 459 consumers transitioned in 2021. Altogether, they completed 598 HCBS CAHPS surveys: 340 1 month and 258 12 month surveys (Table 3.1). The majority (91%) of surveys were completed with consumers residing in the community, a decrease of 1% from the previous year. This resulted in 317 1 month and 227 12 month community surveys completed for consumers transitioned in 2021. This section reports data from the 544 1 and 12 month community surveys. For the 1 month survey, consumers described their experience since transition; for the 12 month survey, consumers described their experience in the last 3 months.

Table 3.1. Surveys Completed for 2021 Transitions by Time Point and Survey Setting

| | Community Surveys n (%) | Institution Surveys n (%) | Settings Combined n (%) |
|---|---|---|---|
| 1 Month | 317 (93.2) | 23 (6.8) | 340 (100.0) |
| 12 Month | 227 (88.0) | 31 (12.0) | 258 (100.0) |
| Both Time Points | 544 (100.0) | 54 (100.0) | 598 (100.0) |

### *Home and Community-Based Services Use*

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

Only use of care management services showed a noticeable difference from 1 month to 12 months, decreasing from 75% at 1 month to 49% at 12 months. This is not unexpected as some MFP consumers may not have much case management support at 12 months after transition. After six months, MFP case management services are usually reduced to monthly check in calls by the TC.

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

| | 1 Month n (%) | 12 Month n (%) |
|---|---|---|
| Personal care assistant/attendant services | 210 (66.2) | 148 (65.2) |
| Behavioral health services | 0 (0) | 1 (<1) |
| Homemaking services or Homemaker-Companion | 188 (59.3) | 138 (60.8) |
| Care management services | 239 (75.4) | 112 (49.3) |
| Job coach or vocational supports | 0 (0) | 0 (0) |
| Recovery assistance services (MHW only) | 5 (62.5) | 3 (60.0) |
| Community Service Provider (MHW only) | 1 (12.5) | 3 (60.0) |
| None of these services | 21 (6.6) | 29 (12.8) |

* Consumers can use more than one service

## A. HCBS CAHPS Key Results

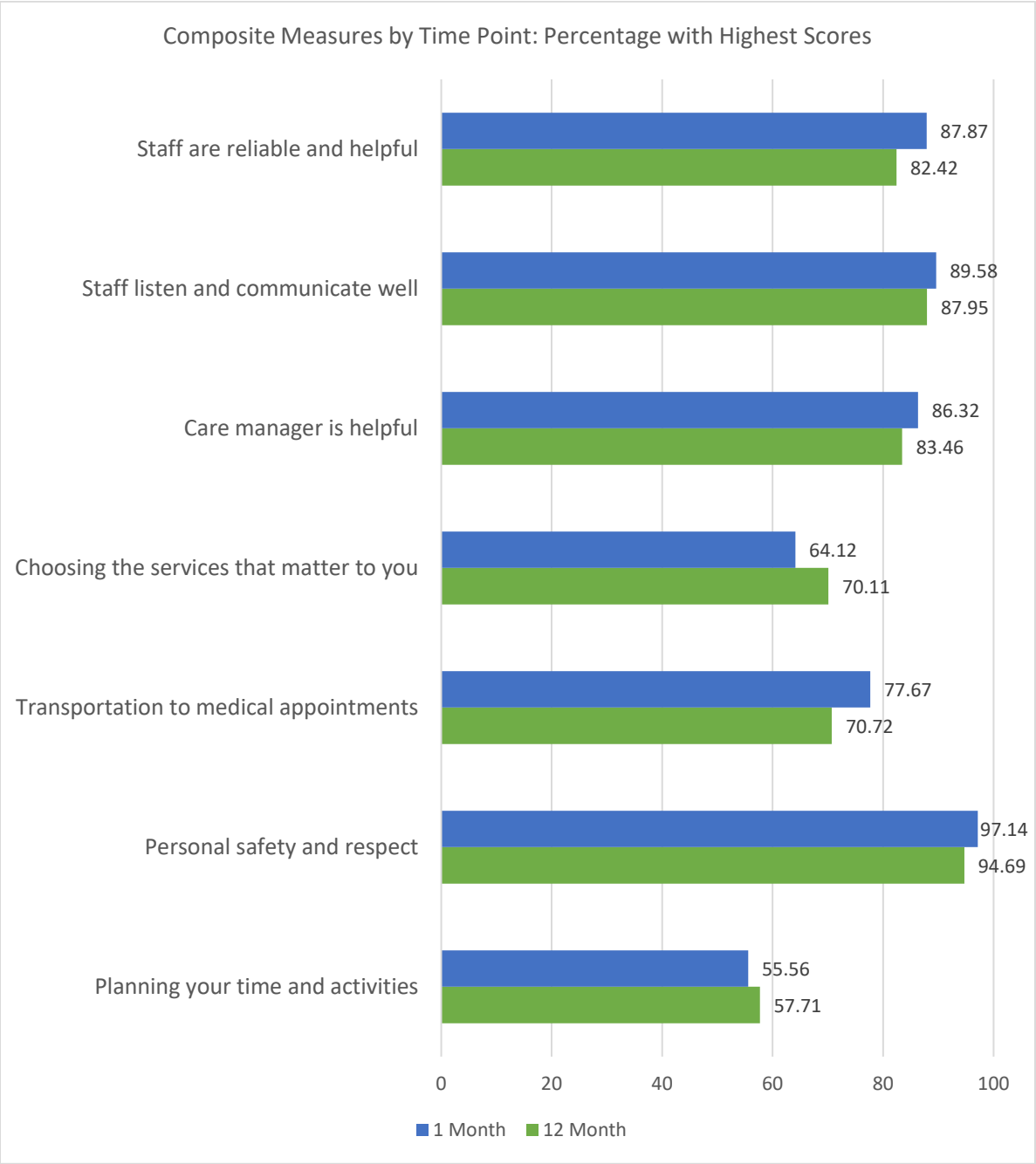
The HCBS CAHPS survey key results include 7 composite measures, staff global ratings, staff recommendations, unmet need for services, and physical safety.

### *Composite measures*

Figure 3.1 shows the percentage of participants at each time point who gave the most positive answer for each composite item. Although the majority of consumers at either timepoint gave the most positive answer for the composite item staff are reliable and helpful, the percentage decreased from 88% at 1 month to 83% at 12 months. Other notable differences from 1 to 12 months include a decrease in the transportation to medical appointments composite score from 1 month (78%) to 12 months (71%). The percentage of consumers who reported the highest score for the composite choosing the services that matter to you increased over time, from 64% at 1 month to 70% at 12 months. Consumers expressed ongoing frustration with the limited availability of reliable medical transportation. Issues ranged from missing intake appointments, having to forgo dialysis, and waiting longer to see a doctor about a prescription because they missed their appointment.

> *I missed my first doctor's appointment because VEYO never showed up, and that appointment was going to allow me to get my meds. Now, I have to wait until January for another appointment, and I have to go even longer without my meds. It's crazy.*
>
> *VEYO transportation is awful. They had forgotten to enter my paperwork for dialysis. Because of this I missed a whole week of dialysis. Logisticare was a better transportation company.*
>
> *VEYO, which I stopped using, was not sending the appropriate transportation to bring me to my doctor's office. I feel like my recovery process is on hold because I don't have the appropriate transportation.*

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




## *Global Ratings*

Global ratings for PCA staff and homemaking staff remained stable over time, with a slight shift in participants rating their care managers higher at 12 months. At both 1 and 12 months, 70% to 72% of community participants rated their PCAs/RAs/ILSTs or their homemaking staff a 9 or 10 (Figure 3.2). Sixty-four percent of participants gave their care managers a nine or ten at 1 month; this increased to 68% at 12 months. Positive comments about PCAs include:

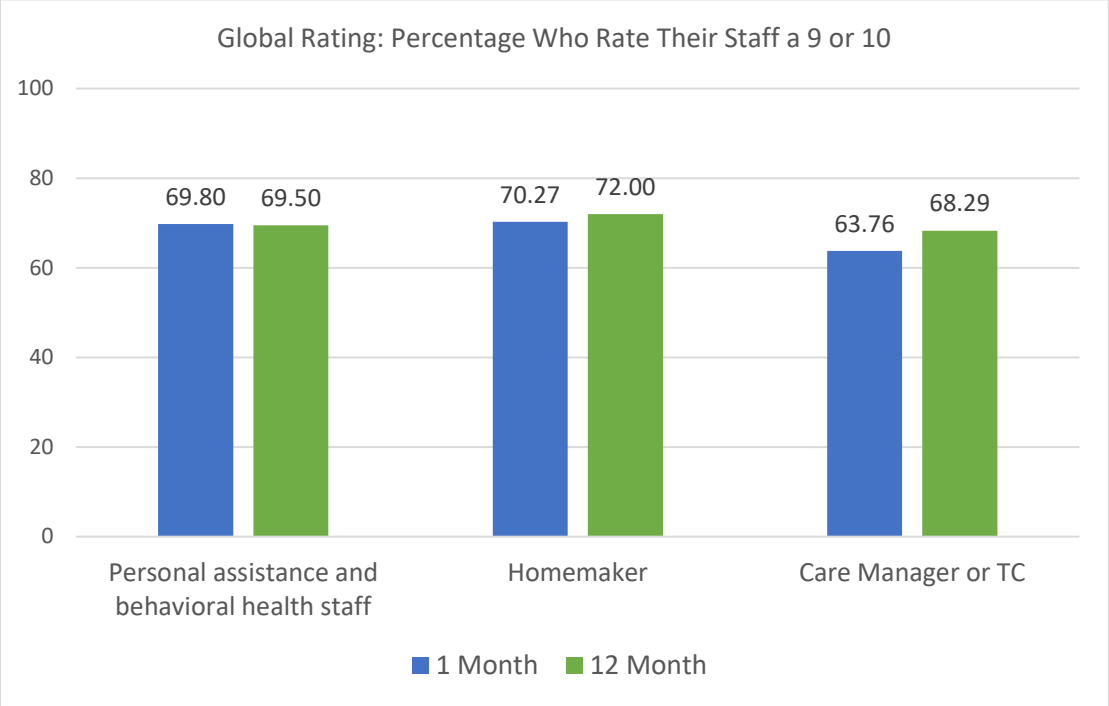
> *Thankfully the aide we have now has been great. I can tell her only focus is taking care of my mom.*

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

*I've gone through a lot, but I'm sober and I have a great caregiver who is literally like my mother and grandmother reincarnated. It must have been meant to be.*

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

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




At the same time, many consumers shared the multiple issues they have experienced with getting assistance, such as staffing turnover, lack of training, difficulty finding staff, issues with managing multiple staff, lack of home care agency communication, and needing more assistance. Consumers or family members often thought that staff would assist or do specific tasks, but once the staff were there found that was not the case.

*The PCA agencies are terrible, I have PCAs coming in saying that they were hired as companions only, and my mom needs more help than that. They don't know how to change a diaper.*

*As a caregiver my biggest issue is the merry-go-round of PCAs that are provided on the weekends. Most of them do not know what they should be doing, specifically for my mom having a catheter. Some have lost the catheter; some have not placed it well. All these things can cause an infection, and in fact, my mother is in the hospital now with a UTI.*

*The communication between the aides and the service is not good. A lot of them show up not knowing anything about my wife's condition... They [home care agency] don't do anything to make sure the person who comes is prepared. The scheduling is also crazy. The turnover we have had is crazy. We've had so many people in and out, but we cannot find anyone consistent. It's been really tough on us. We never know what we're going to get.*

*PCA services have been a nightmare. We had a PCA who had a history of stealing medicine from a nursing home she used to work at, and sure enough we found that she was stealing meds from my mother. She then had moved all her belongings into our mom's house and had changed her residence and address to my mom's. She was found to be smoking pot in my mom's house. We had her removed and then had to call the police on her because she was threating my wife by phone and on social media. This person was on the news and in the newspapers and still employed at this agency. PCAs are a liability if they lack care and interest. The job is not for them; this is a job that you have to know and love doing, not just have to make money.*

*My father is not currently receiving PCA services. The home health agency is stating that they do not have enough personnel. Also, for the past 3 months, PCAs were so sporadic that it was as if my father did not have any services at all.*

*We have had so many issues while being a part of this program. The agencies that MFP work with are terrible, and the aides are just as bad usually. I don't know if it's the aides themselves or the lack of training. I complain to the agencies, and they do nothing. They always have an answer or an excuse.*

*It has been really rough for me this first month. I am bed bound and need help with everything. I feel like the first night I was home, I was just left to fend for myself. The aide they sent me did not speak any English and we could not communicate. I have endless stories about all the crazy things that happened with the aides. It's like they don't have common sense. They would cook for themselves and not even think about me or ask if I was hungry or offer me some of what they would make. I'm not sure if they're not used to working with someone of a sound mind, but that's what it felt like. One time the replacement aide did not show up, and the aide that was supposed to be leaving could not stay so I was left by myself. The agency office said that this would not happen and sure enough it did. They even said that if something like this happened, the office staff are all trained and would come out to assist me. Of course, when the time came, they "didn't have anyone to send." They just tell you want you want to hear.*

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

*There is a lot of paperwork that really delays the process of getting the things we need. It's really too much for one person and a lot of it is very complicated. Also, [consumer] was only approved for 30 minutes of PT, and she really needs an hour. There is a bunch of equipment and braces that she needs to be set up with, and by the time the PT has them on, they only have a remaining 15 minutes with her and that is not enough time to see results.*

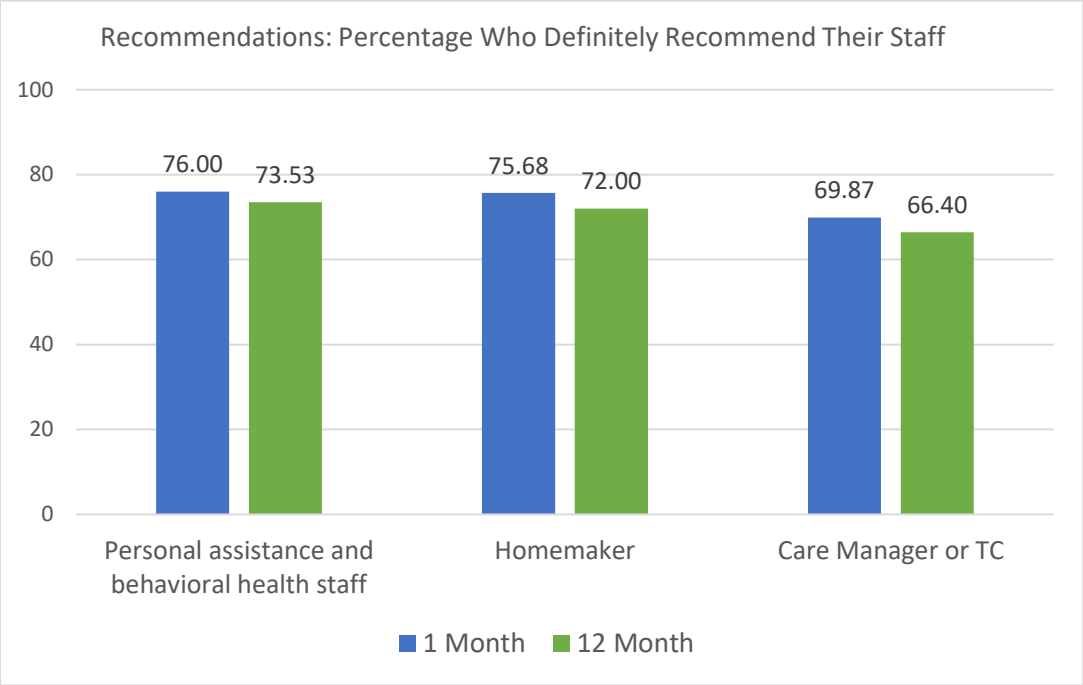
*Since I joined this program, I was told that I would have aides to help me in my apartment. Here I am one year later, having done the paperwork that they asked me to do, six different times, and now when my case is about to close they tell me that I don't qualify for aides because I have figured out ways to care for myself in the meantime. … I had to figure out how to bathe myself, how to make food for myself, and how to do the little things that I can do. It doesn't mean that I'm doing them safely or the most effective way. It is not at all easy for me to do those things. My apartment is a mess because there are so many things I can't do for myself. I have boxes that I can't do anything with because I can't reach the places where I want to put them. Having an aide would change my life in 24 hours. I know there are people on this program that have aides that don't even want them or need them, and I'm here begging for some help and can't get it. I am so frustrated and disappointed.*

*This has not been easy. I honestly didn't think it was a good idea for my mom to come home. Right now she is not able to have a live-in PCA because of our apartment situation, but that's what she really needs. As of right now I'm still not convinced that having her here is better than at the nursing home. There have been staffing issues that make this very difficult. The agency doesn't have enough people hired and if someone can't come in, they often don't have someone to cover. The hardest part is staffing.*

### *Recommendations*

The percentage of consumers who would "definitely" recommend their PCAs, homemaking staff, or case managers all dropped between 2 to 4 percent from 1 month to 12 months (Figure 3.3). The most noticeable difference was shared between homemaking staff (76% to 72%) and care manager (70% to 66%) recommendations. This shows a slight departure between consumers who rated their care managers a 9 or 10, which increased at 12 months, and those who would definitely recommend their care managers to family or friends.

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




## B. Unmet Need and Physical Safety

Consumers who reported receiving paid assistance with any kind of personal care or behavioral health were asked if they needed help with four everyday activities: personal care (dressing/bathing), meals, medications, and using the toilet (Table 3.3). Those who reported receiving homemaking services were considered to need help with housekeeping tasks such as cleaning or laundry. Over 85% of consumers at both 1 and 12 months reported receiving assistance with personal care, such as dressing or bathing, or making meals/eating.

Table 3.3. Self-reported Assistance with Everyday Activities

| Needs assistance with: | 1 Month n (%) | 12 Month n (%) |
|---|---|---|
| Personal care | 185 (88.5) | 126 (88.1) |
| Meals or eating | 180 (86.1) | 127 (88.8) |
| Taking medications | 119 (56.9) | 83 (58.0) |
| Using the toilet | 124 (59.9) | 83 (58.0) |
| Housekeeping or laundry | 188 (62.9) | 138 (63.9) |

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, eighteen participants (10%) indicated one or more unmet need: 5 for personal care, 1 for taking medications, 5 for using the toilet, 3 for meals or eating, and 4 for household tasks. At 12 months, eight participants indicated one or more unmet need: 2 for personal care, 2 for taking medications, 2 for using the toilet, and 2 for household tasks (separate items, consumers can report more than one).

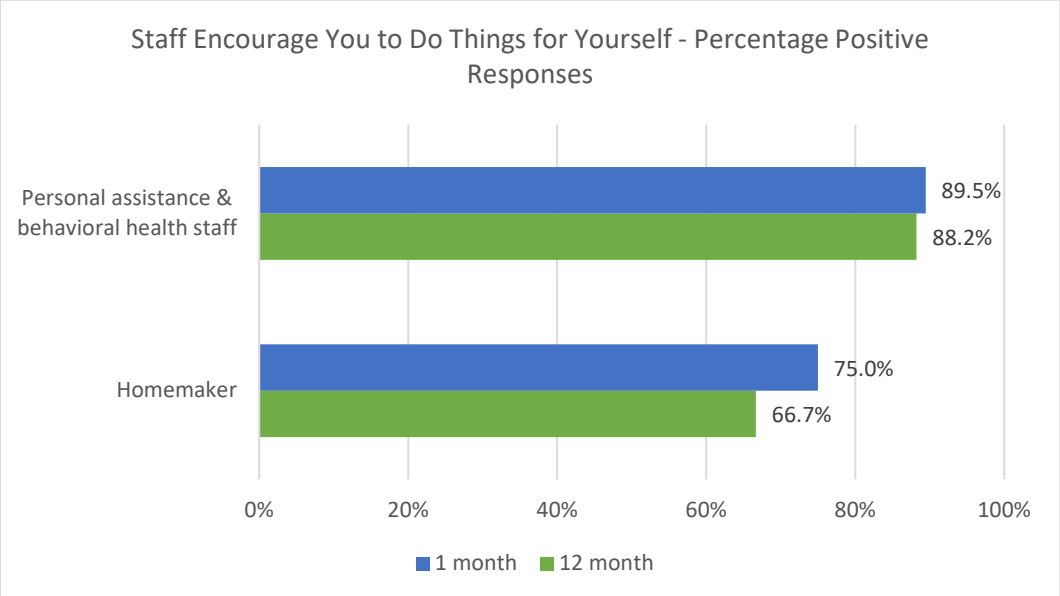
Participants not receiving personal assistance were asked if they always had the assistance they needed for bathing/dressing, meals, medications, and toileting. Nine individuals at 1 month (10% of those asked) and sixteen participants at 12 months (11% of those asked) had an unmet need for one or more of these tasks. There were no reports of any staff members hitting or hurting participants at either 1 month or 12 months.

## 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 (96% 1 month, 93% 12 month). A majority of participant agreed that their staff encouraged them to do things for themselves, especially at 1 month. Homemaking staff however, experienced a noticeable drop from 1 month (75%) to 12 months (67%) (Figure 3.4).

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

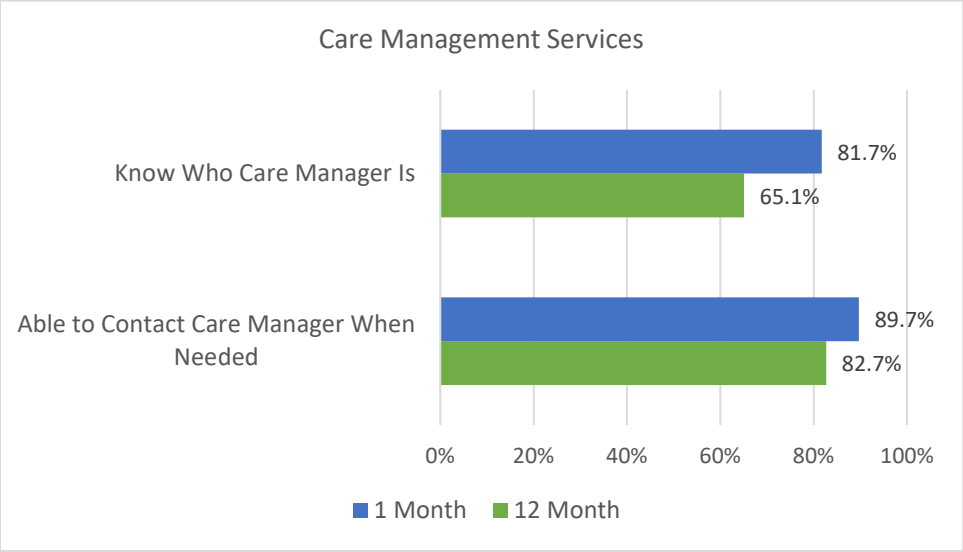


### *Care Managers and Care Plans*

When asked if they knew who their care manager was, 82% of consumers at 1 month and 65% of consumers at 12 months said they did (Figure 3.5). This significant drop is reflective of the structure of the MFP program. After 6 months, consumers do not have any SCM services, and TC services are reduced to one telephone call a month. Most of these consumers at either time point were able to contact their care manager when they needed to. That 18% of consumer at 1 month did not know who their care manager is, even though they have at least a TC, is concerning. Comments indicated that for some consumers or family members, there was confusion about who to turn to for assistance, even just one month after transition.

> *It's very confusing and hard to keep track of all the different people from MFP and elsewhere. I'm not sure who my care manager is, and I know that there has been a lot of people switching and replacing.*
>
> *I don't think I've had a conversation with [name]. I don't know who the care manager is right now.*

Figure 3.5. Care Management Services - Percentage Positive Responses




Consumers asking their care managers or TCs for assistance with changing services or getting or fixing specialized equipment decreased over the year (Figure 3.6). One consumer's daughter expressed issues with staff turnover and wondered how people without responsive care managers like hers deal with these challenges.

> *It is a fabulous program. Without it [my mother] would be in a nursing home. The nursing home was a heartache. Overall, it has been amazing to have her home and in her own home. Most people have been fabulous, the people she initially had. Staffing has a high turnover – it is fast and people move around. Establishing relationships is hard, which should be a big part of the program. Without the responsiveness from the care management, it's a challenge. I wonder how some other people maneuver through these challenges.*

Figure 3.7 shows that consumers would most likely contact their care manager for changes to their care plan, followed by contacting family or friends(can name more than one person).

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

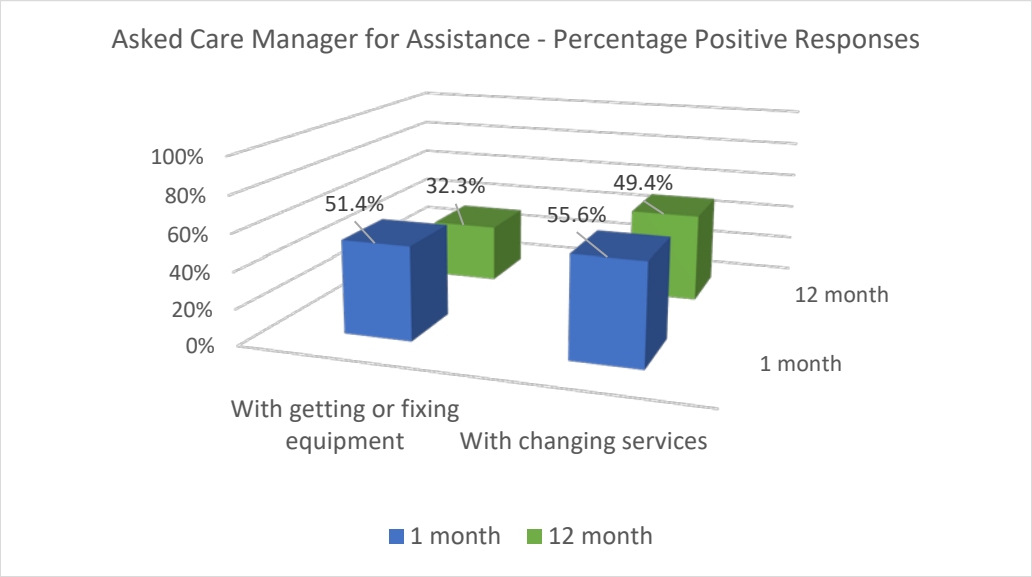
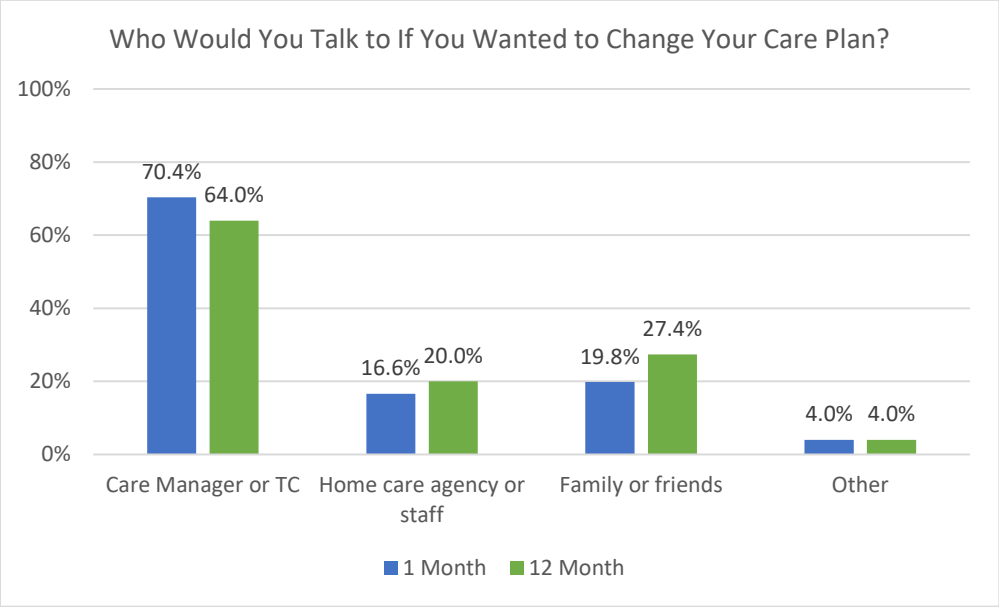



Figure 3.7. Who Would You Talk to if You Wanted to Change Your Care Plan?*

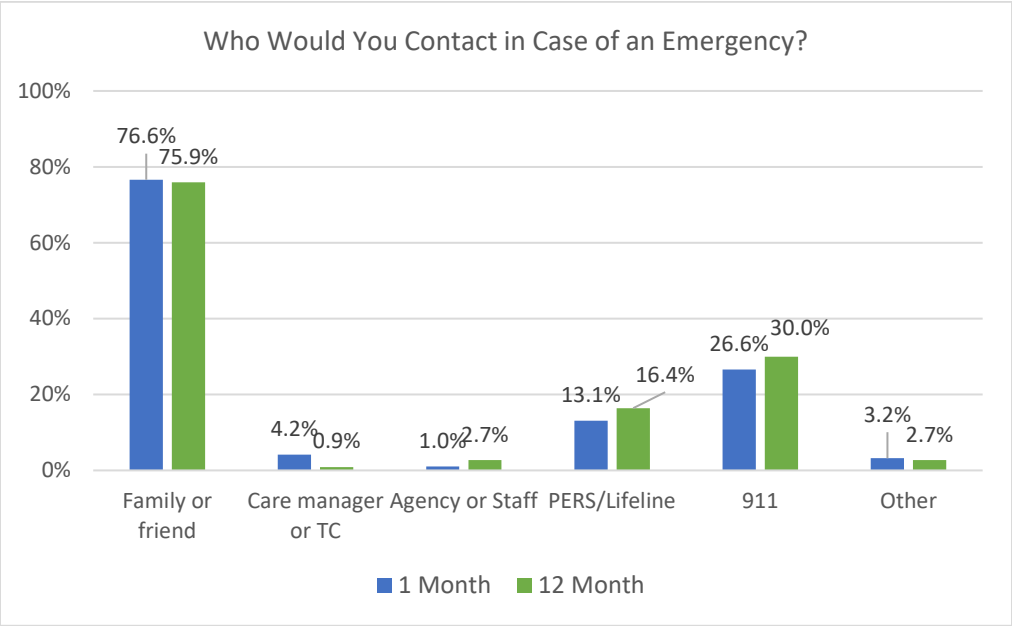



*Can name more than one

## *Emergency Contact*

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

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




*Can name more than one

## D. Self-Direction

Almost all consumers at either time point reported they used agency-based services (Figure 3.9). The percentage of who hired their own family members as staff increased from 39% at 1 month to 44% at 12 months (Figure 3.10; see Section 4 for a more in depth look at self-directed consumers). While at 1 month 22% of consumers reported they picked the people who help them, at 12 months that increased to 30% (Table 3.4).

Figure 3.9. How Do You Hire Your Aides?

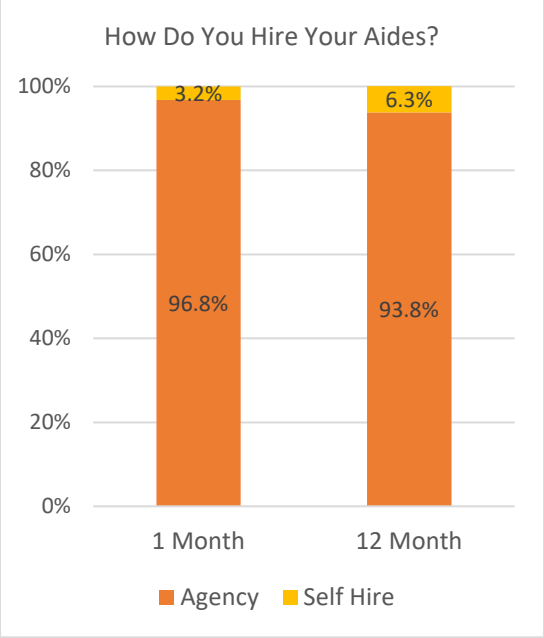



Figure 3.10. Employ Family Members

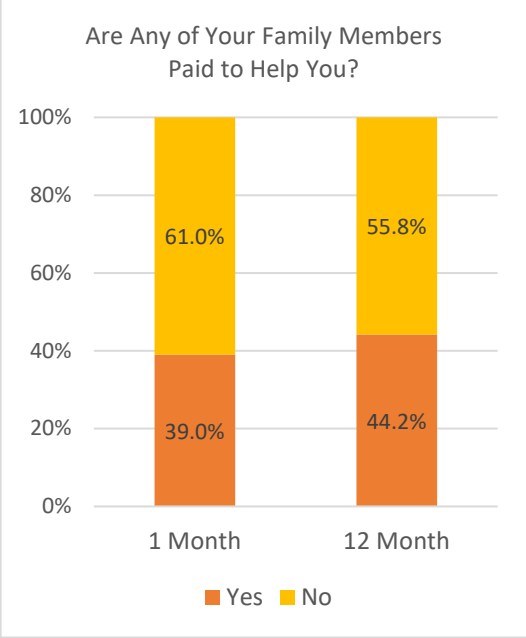


Table 3.4. Do You Pick the People Who Are Paid to Help You?

| | 1 Month n (%) | 12 Month n (%) |
|---|---|---|
| Yes | 55 (22.0) | 53 (29.6) |
| No | 195 (78.0) | 126 (70.4) |

## E. Living Situation and Social Support

Although 52%-55% of consumers at either time point lived alone or without other adults, 70-74% of all consumers had a family member who lived nearby (Table 3.5). Most consumers who had nearby family members or friends could see them when they wanted to. In addition, the majority of consumers who did not live alone, resided with family member(s) at either time point. Between 56-62% of consumers at either time point reported receiving assistance around the house from either family or friends (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 wish I could meet more new people. [Town] has a lot of narrow-minded people in this town. The senior center was a bad experience, very noisy and rude. This is not a friendly place to live. It is hard to make friends here; nobody is friendly here.*

> *This program has been really helpful for us, and we are so grateful to have [our son] home. However, there is a lot of room for improvement. This program was supposed to allow [our son] to rejoin the community; however, he has basically been stuck in this house for the last 365 days. This program and all other state programs need to do a better job of covering PT because that's what really allows someone to rejoin the community.*

Table 3.5. Living Situation and Social Support*

| | | 1 Month % | 12 Month % |
|---|---|---|---|
| Number of adults living in household | | N=4316 | N=224 |
| | 1 | 52.2 | 54.5 |
| | 2-3 | 36.4 | 37.1 |
| | 4+ | 11.4 | 8.5 |
| Lives with family member/s | | N=151 | N=103 |
| | Yes | 75.5 | 72.8 |
| | No | 24.5 | 27.2 |
| Lives with non-family | | N=151 | N=103 |
| | Yes | 31.8 | 30.1 |
| | No | 68.2 | 69.9 |
| Family member/s live nearby | | N=314 | N=225 |
| | Yes | 70.1 | 74.2 |
| | No | 29.9 | 25.8 |
| Friend/s live nearby | | N=315 | N=225 |
| | Yes | 47.9 | 48.9 |
| | No | 52.1 | 51.1 |
| Can see nearby family | | N=220 | N=167 |
| | Yes | 94.1 | 92.2 |
| | No | 5.9 | 7.8 |
| Can see nearby friends | | N=151 | N=110 |
| | Yes | 88.1 | 92.7 |
| | No | 11.9 | 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

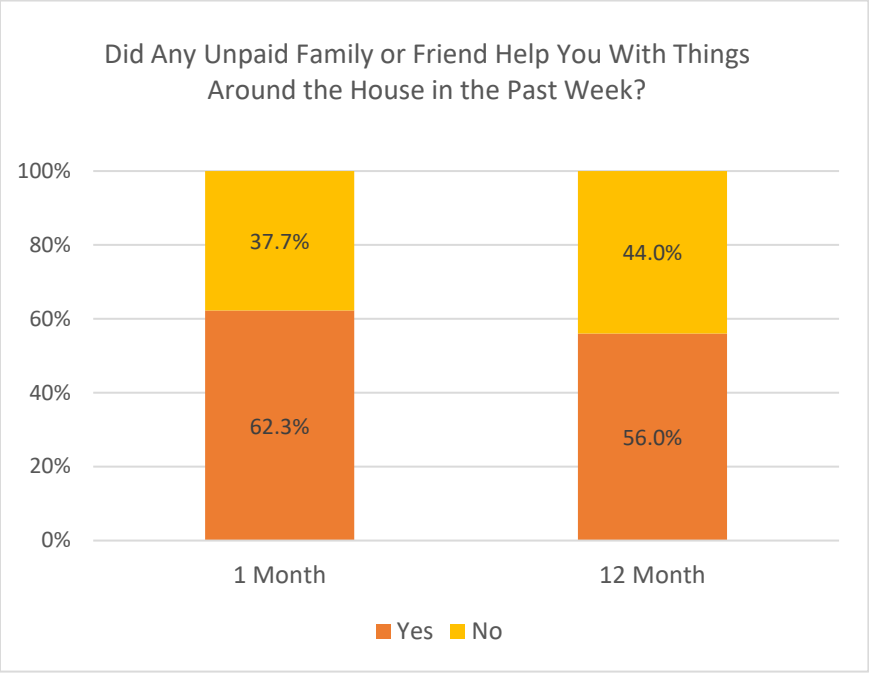
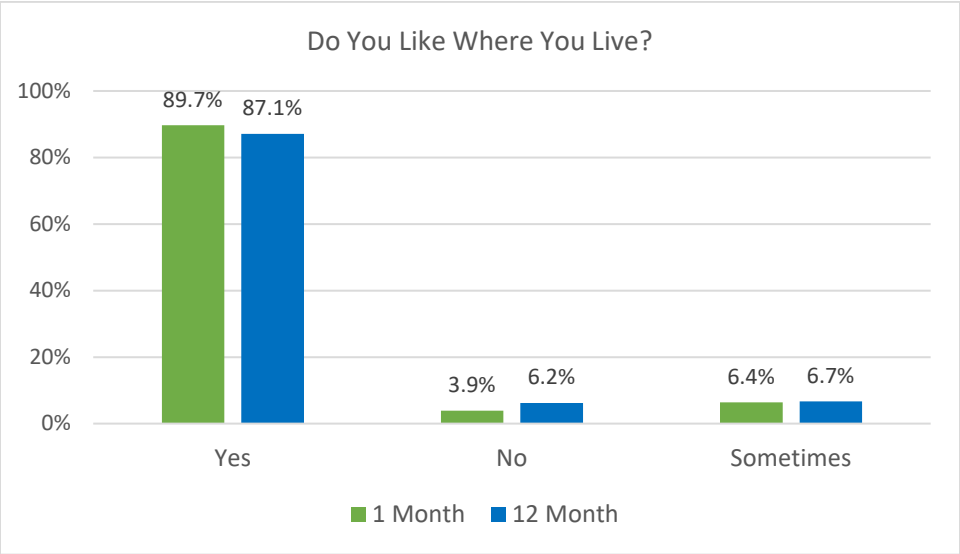


Figure 3.12 shows that the majority of consumers at either time point said they liked where they live 90% 1 month, 87% 12 months). Almost all consumers at both 1 month (96%) and 12 months (93%) felt safe where they live. A few consumers expressed the following:

> *I was in the nursing home for four years, and I am so happy to be out of there in my own place.*
>
> *This place is great – I am so happy.*

Figure 3.12. Do You Like Where You Live?



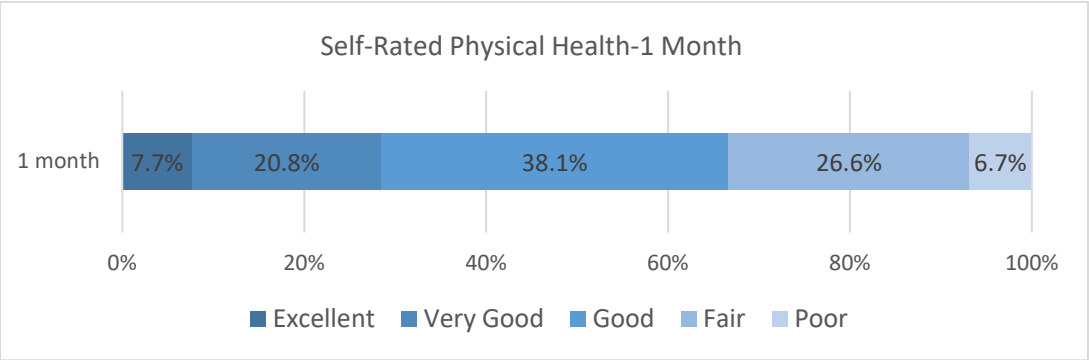

## F. Physical Health

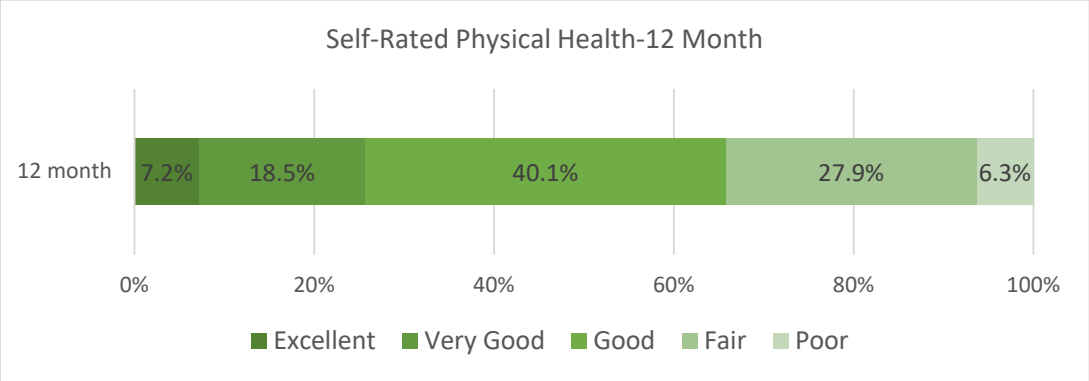
### *Physical Health, Falls*

Self-rated physical health declined slightly over time: at 1 month, 29% of consumers rated their physical health as very good or excellent, compared to 26% at 12 months (Figure 3.13). One consumer spoke to the challenges they face not having everything they need set up before being discharged home and the limits that places on them as someone with physical disabilities.

> *It's frustrating because when I got home, I have stepped backwards instead of forward. I need changes done to my toilet seat in the bathroom so that I can do my necessities in the bathroom not in my bed. I do not have an appropriate wheelchair or motorized chair to give me mobility in the home or outside in the community; I cannot physically go into my physician's office. PCAs really can control your progress and life, because if they do not work out you are stuck.*

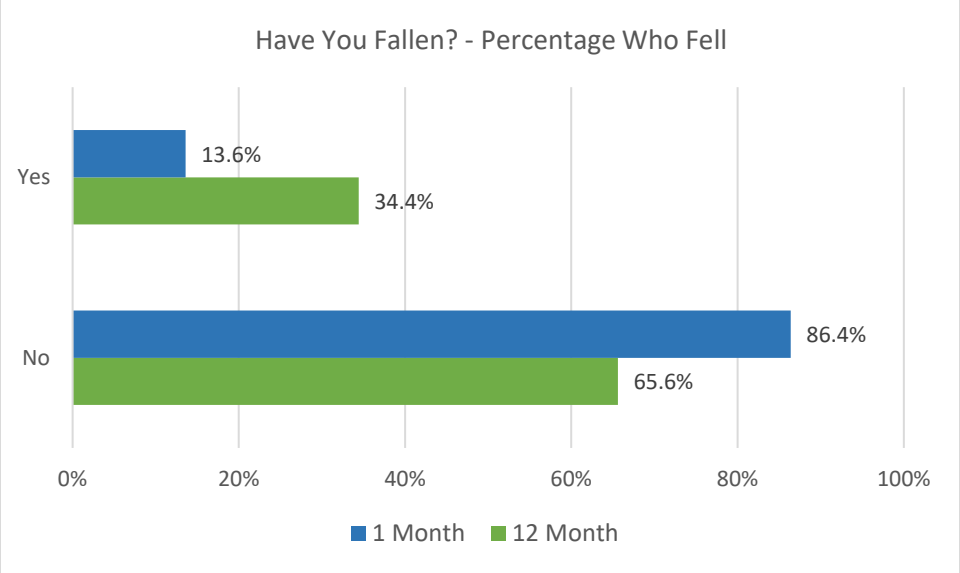
Figure 3.13. Self-Reported Physical Health




Fourteen percent of consumers reported falling between transition and their 1 month survey (Figure 3.14). This percentage increased to 34% by the 12 month survey, which is not surprising due to the longer timeframe (since transition to 1 month, since 1 month survey to 12 months) (Figure 3.14).

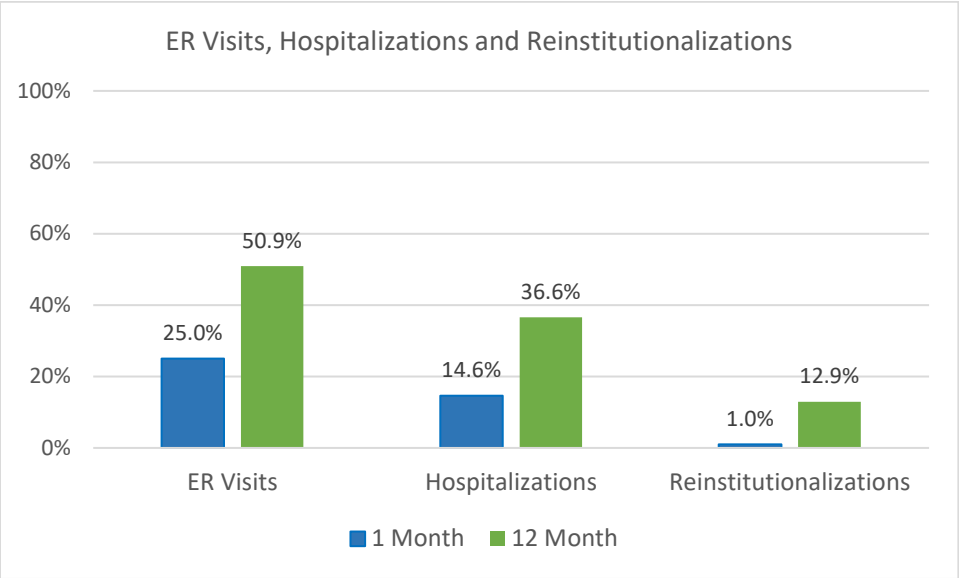
Figure 3.14. Falls



### *Emergency Room, Hospital and Facility Use*

As can be expected, emergency room (ER) and hospital use were also reported more often at 12 months due to the longer timeframe (Figure 3.15). Fifty one percent of participants interviewed at 12 months had used an emergency room, and 37% had been hospitalized. By 12 months, 13% of consumers were reinstitutionalized, either short or long term.

Figure 3.15. Emergency Room Visits, Hospitalizations, and Reinstitutionalizations




## G. Mental Health

### *Mental Health*

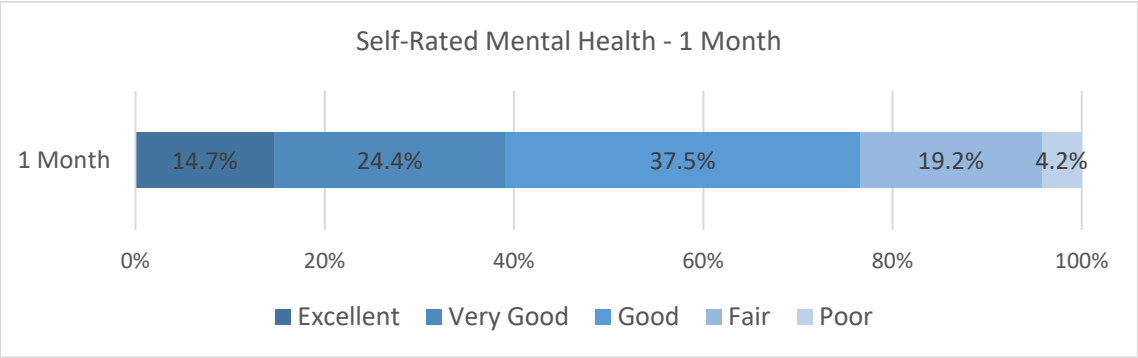
Self-rated mental and emotional health declined only slightly over time: at 1 month, 39% of consumers rated their mental or emotional health as very good or excellent, compared to 37% at 12 months (Figure 3.16). Still, between 23-26% of consumers reported poor to fair mental or emotional health at either timepoint.

Rates of depression increased over time. Thirty percent of consumers reported depressive symptoms at 1 month, which increased to 35% at 12 months (Figure 3.17). These rates are higher than in the general population: in 2020, 24.2% of adults in Connecticut reported symptoms of depression (National Center for Health Statistics, 2020-2021).

These data indicate a need for enhanced mental and emotional support post-transition. 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.

> *I've been waiting for this since 2016 – I'm finally in my own apartment. It was a little rough at first. I found myself alone, and thinking of who I have and not have in my life. But I'm getting better*
>
> *I don't think I need the caregiver because I can do basically everything for myself. But they must think I need her because she always comes. I get lonely though when she is not here, so I'm always glad to get the company.*
>
> *I need to be around more people – be more social.*

Figure 3.16. Self-Reported Mental Health



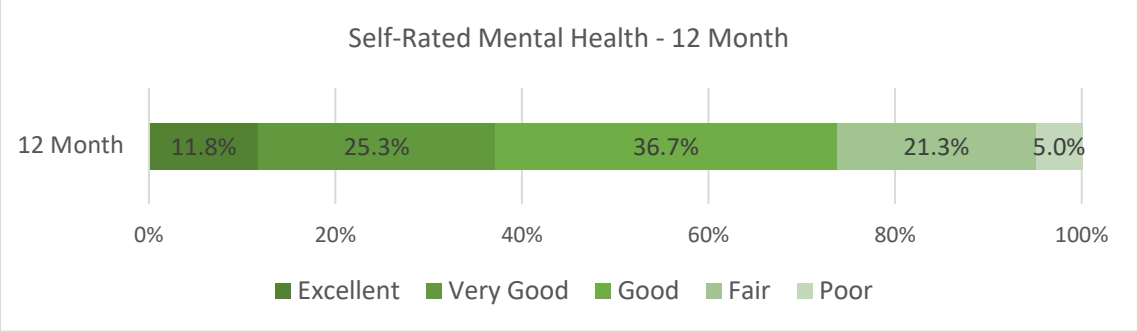
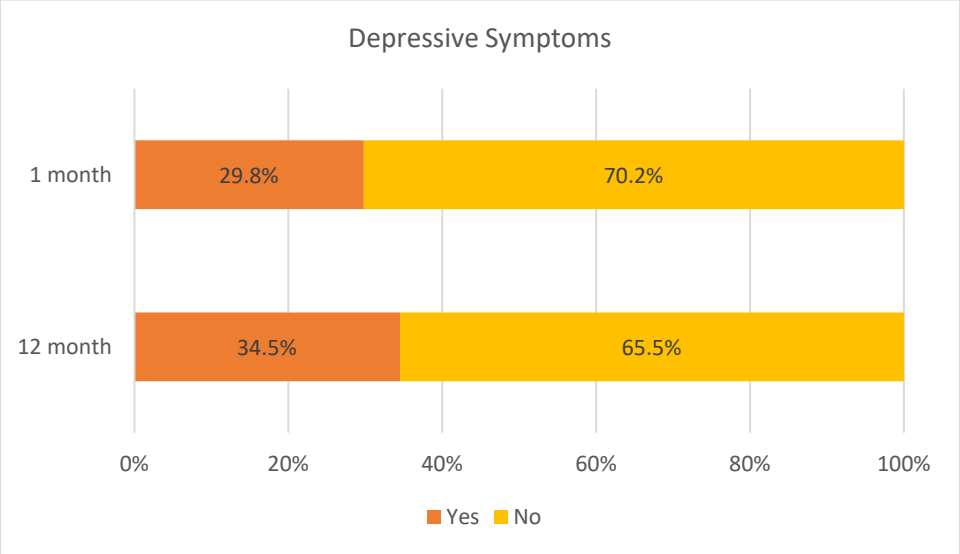




Figure 3.17. Depressive Symptoms*



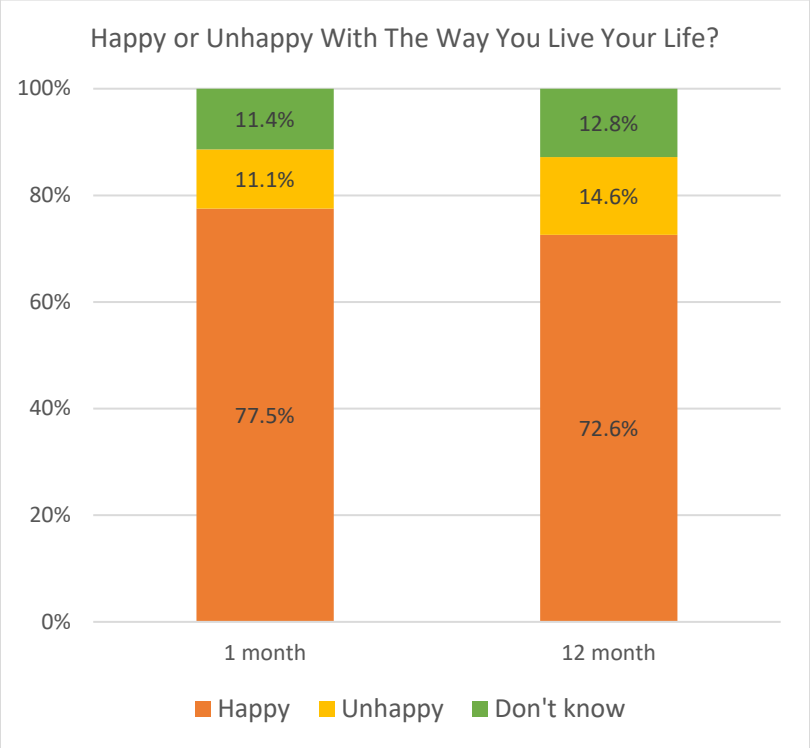

*Depressive symptoms were determined using the Patient Health Questionnaire (PHQ-2) (Whooley et al., 1997).

### *Overall Quality of Life*

Although the majority of consumers were happy with the way they live their life, global life satisfaction declined over the year post transition. At 1 month 78% of community residing consumers said they were happy with their lives; this dropped to 73% at 12 months (Figure 3.18). Commented one consumer:

> *I am very happy here. I wish I was in my actual home, but things have changed, and I have to adapt. I like my apartment, and I know I will get more used to it with time.*

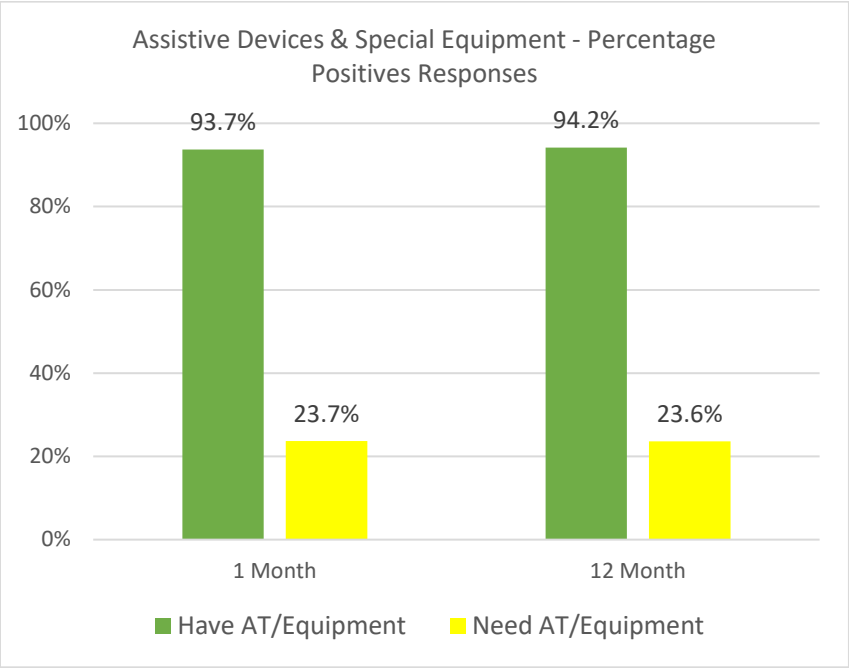
Figure 3.18. Happy or Unhappy with the Way You Live Your Life




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

The vast majority (94% at 1 month and 12 months) of community consumers reported having at least one type of assistive device, special equipment, or home modification (Figure 3.19). At the same time, data show that at both time points, 24% of consumers lacked some type of device or modification needed for community living.

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 43-55% of consumers at either 1 or 12 months reported having one.

At 1 month post-transition, consumers most commonly still needed a PERS (11%), home modification (10%), or special medical equipment (7%). At 12 months, 11 percent of consumers reported they still needed home modifications. Compared to 1 month after transition, a greater percentage of consumers reported needing electronic medical devices and transportation aides at 12 months. Comments indicated that multiple factors affected the continued need for necessary equipment or home modifications. Not having necessary home modifications or equipment can jeopardize one's ability to live successfully in the community, and providing these before or soon after transition should continue to be a program goal.

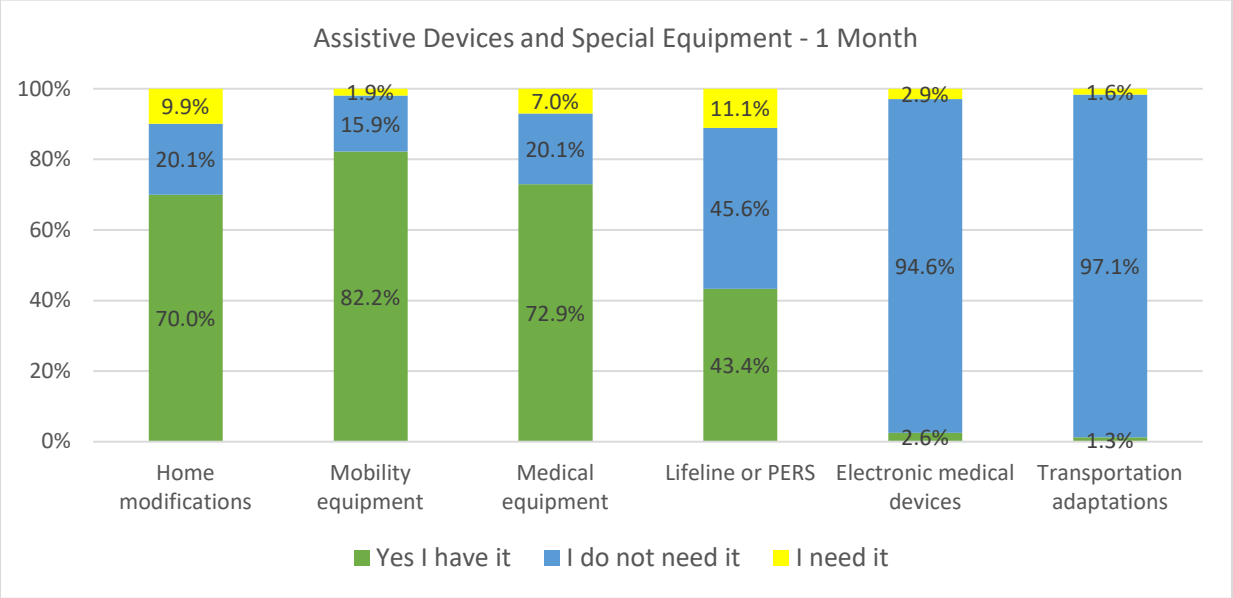
> *We've had a lot of trouble with the nursing home not following through with things they're supposed to order. They wait till last minute for everything, and then my husband ends up not having the things he needs. He was just in the hospital because he's supposed to have this vest thing that keeps the mucus from forming in his lungs. Well, the nursing home never ordered it, and we are still waiting, and this ER-hospital stay could have been completely avoided.*
>
> *My father needs a ramp. I'd say that is something I'd like to add – to get him a ramp suitable for the weight of the wheelchair and individual.*
>
> *They told me they were going to get my mom a ramp, months later I hadn't heard anything and asked what was going on, they told me it was never ordered? Why? This person said it was this person's job, and that person said it was that person's job... I don't care who's job it is it just needs to be done. My mom needed other equipment like a wheelchair, a hospital bed... MFP didn't help get any of that. I ordered it all myself.*

*He's looking for residence on his own. The apartment that MFP found for him, is not handicapped accessible.*

*The nursing home was supposed to set me up with grab bars and a new wheelchair, but I haven't gotten those things.*

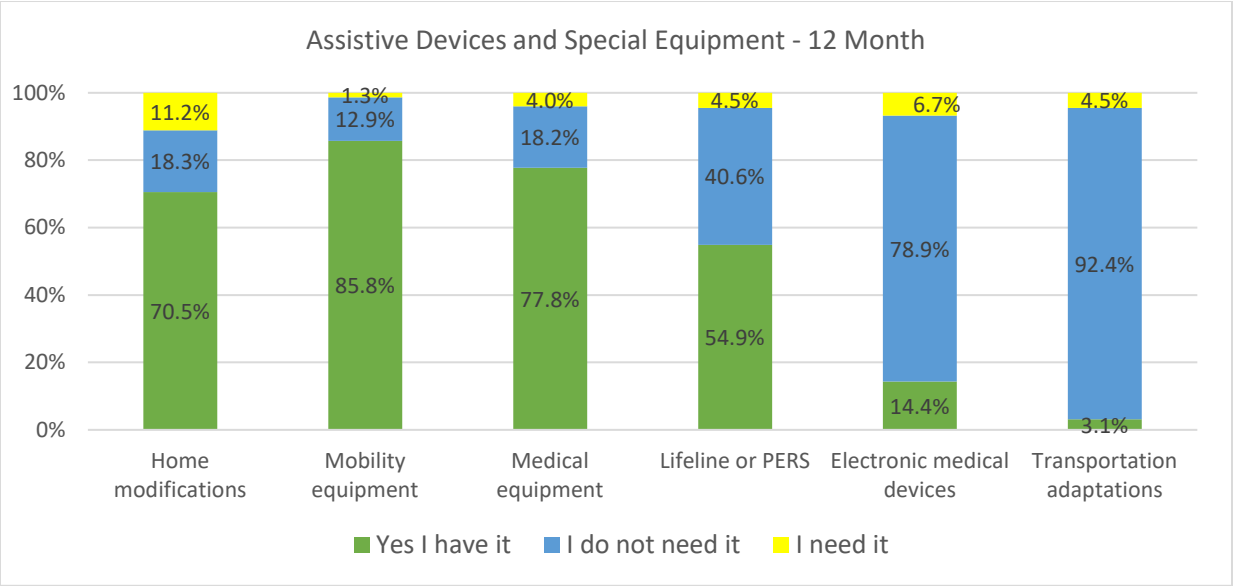
*Only last week did they install the grab bar on one side of toilet, and I still need to get a higher toilet seat, shower bench or shower chair.*

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




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

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



At both 1 and 12 months post-transition, more than 80% of participants reported having internet access at their home, and approximately 70% of consumers owned a computer, tablet, or smart phone. Overall, less than 6% of consumers at 1 month or 12 months said they needed some type of internet capable device, and at 1 year post-transition, just 6% of consumers still needed internet access (Figures 3.22 and 3.23).

Figure 3.22. Internet Devices

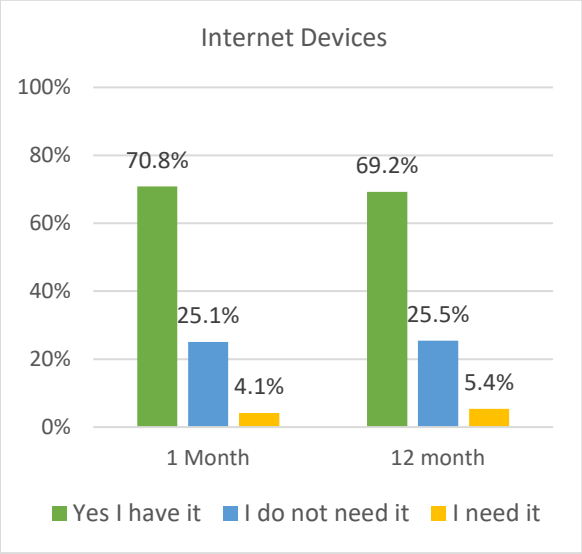
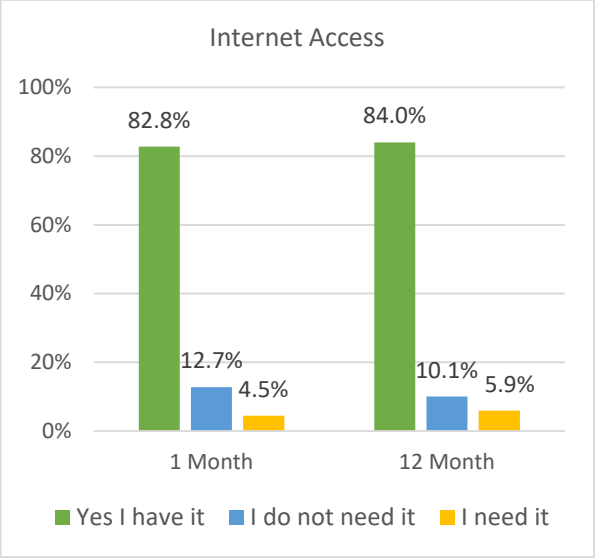



Figure 3.23. Internet Access




## I. Other Services

Only 45% of participants at 1 month, and 49% at 12 months, reported using a van or transportation service for medical and/or nonmedical services. This is an increase from last year, when just 38% of participants said they used a van or transportation service at 1 month. 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=25 n (%) | 12 Month N=16 n (%) |
|---|---|---|
| Excellent | 4 (16.0) | 3 (18.8) |
| Very Good | 6 (24.0) | 5 (31.3) |
| Good | 9 (36.0) | 5 (31.3) |
| Fair | 4 (16.0) | 2 (12.5) |
| Poor | 2 (8.0) | 1 (6.3) |

Table 3.7. Day Program Rating

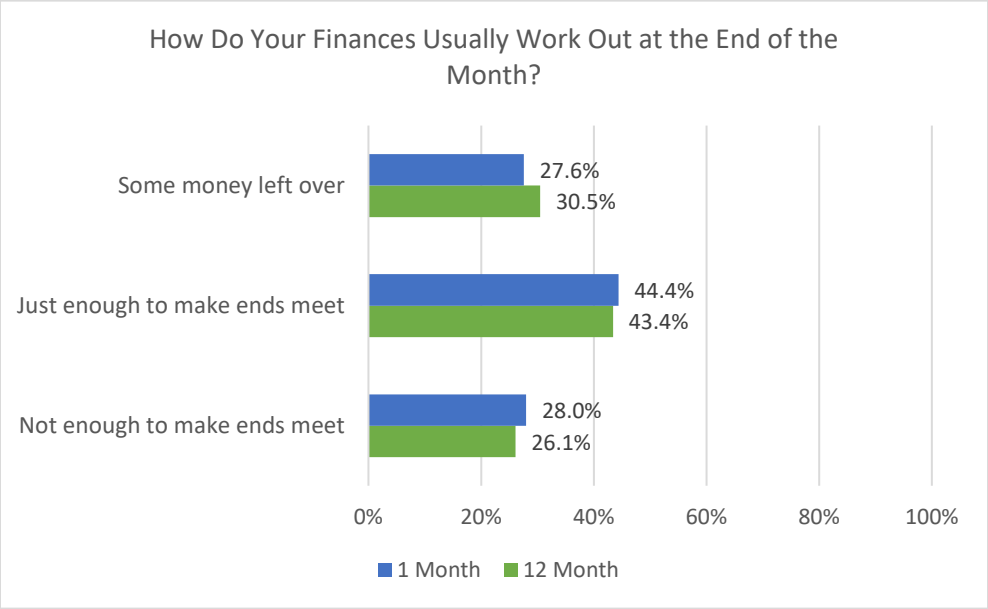
| | 1 Month N=6 n (%) | 12 Month N=14 n (%) |
|---|---|---|
| Excellent | 0 (0.0) | 3 (21.4) |
| Very good | 0 (0.0) | 8 (57.1) |
| Good | 4 (66.7) | 2 (14.3) |
| Fair | 1 (16.7) | 1 (7.1) |
| Poor | 1 (16.7) | 0 (0.0) |

## J. Finances, Employment, and Volunteering

Over one quarter of consumers did not have enough money to make ends meet at either time point (Figure 2.24). Food insecurity was mentioned by several participants, whether caused by lack of or inadequate food stamps, transportation, or paid/unpaid support.

> *I am in great need of food. Lack of money to buy food. Aides do not drive and need someone to drive me places, especially the store.*
>
> *I wish the state would pay for an air conditioner because it is needed.*
>
> *I need more assistance with food. I would really like to get food stamps. We would also like to move to a bigger apartment.*
>
> *I have no extra money to pay for a Lifeline, even though I'm afraid of falling and could use it. But I had to send it back when I received it because I could not afford the $30 a month.*

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

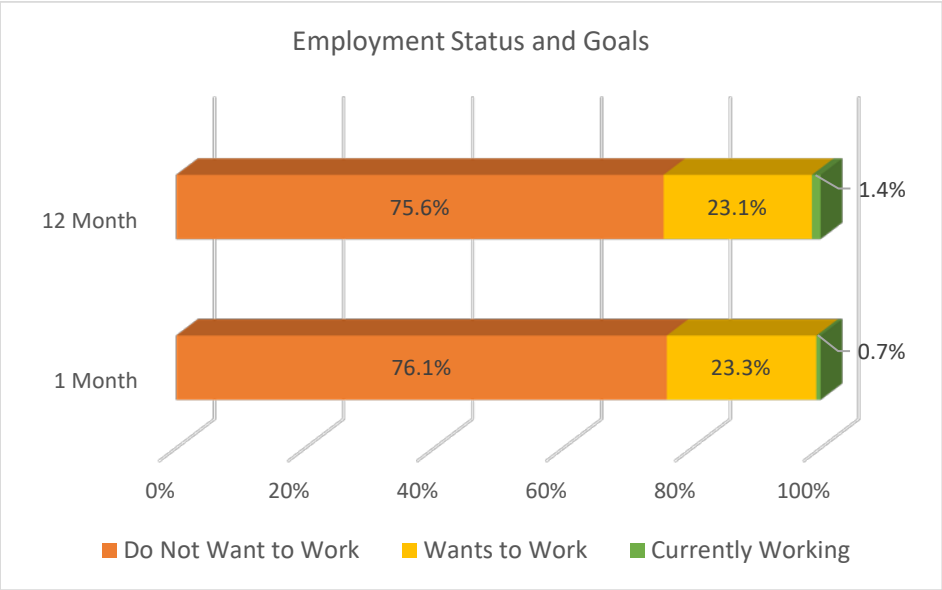



### *Employment and Volunteering*

All community residing consumers aged 18 and older were asked questions regarding work status and employment goals (Figure 3.25). Although very few consumers were working, 23% of unemployed participants at both 1 month and 12 months wanted to work. These rates are lower than in 2021, when 25% of 1 month and 29% of 12 month consumers wanted to work. Having a job often increases independence and community involvement. Connecting consumers who want to work with existing state and town employment supports is an area to focus on. Commented one consumer:

> *I was hoping they [MFP] would help me find a job better or help me navigate things better.*

Figure 3.25. Employment Status and Goals




Not surprisingly, when asked what was holding them back from working, health and disability-related concerns were the most frequently reported reason for not working, especially for participants who wanted to work (Table 3.8). Few to no participants who wanted to work reported that training/education, looking but can't find work, potential loss of benefits, or employment resources were challenges to employment. Compared to unemployed participants who wanted to work, participants who did not want a job were much more likely to say retirement or "nothing is holding me back" as the reason for not working.

Table 3.8. Most Common Reasons for Not Working

| | Would like to work | | Does not want to work | |
|---|---|---|---|---|
| Most Common Reasons for Not Working | 1 Month N= 71 n (%) | 12 Month N= 51 n (%) | 1 Month N= 231 n (%) | 12 Month N= 166 n (%) |
| Health Concerns | 61 (85.9) | 42 (82.4) | 117 (50.7) | 84 (50.6) |
| Transportation | 5 (7.0) | 5 (9.8) | 5 (2.2) | 0 (0) |
| Retired | 0 (0) | 0 (0) | 32 (13.9) | 16 (9.6) |
| Nothing/Do not want to work | 3 (4.2) | 2 (3.9) | 91 (39.4) | 70 (42.2) |

Only 6% of unemployed participants at either time point had asked for assistance with finding a job (Figure 3.26). Of those who did not ask for help, only 21% at 1 month and 33% at 12 months knew there was assistance to help them find a job (Figure 3.27). Providing outreach to increase awareness of job assistance and encouragement to use these resources might help people who want to work become employed.

Figure 3.26. Sought Out Employment Assistance

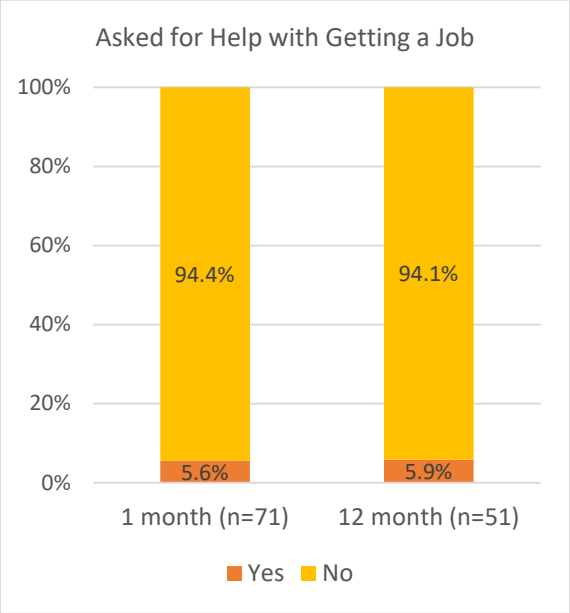
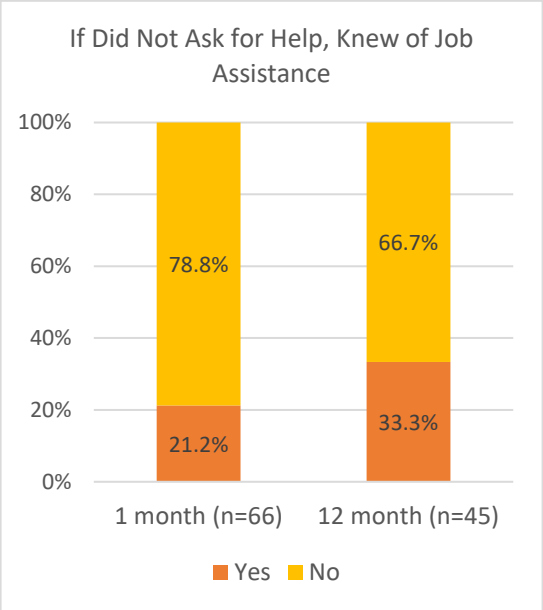



Figure 3.27. Aware of Employment Assistance




The percentage of consumers interested in volunteer work rose from 1 month to 12 months. Only 12% of consumers wanted to volunteer at 1 month, while 20% were interested at 12 months. This shows an increase in volunteering over last year, as in 2021 just 15% of consumers wanted to volunteer at 12 months. Consumers having more stability with their services and care needs may have contributed to the spike in interest by 12 months (Figure 3.28). Connecting these participants with volunteering opportunities would likely increase their community engagement and support overall well-being.

Figure 3.28. Volunteering Status and Goals

## 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 2021 were separated into those who met the requirements for a waiver at transition (waiver consumers) and those who were not eligible for a waiver. Consumers accepted to a waiver were eligible for waiver HCBS at transition. Waiver consumers comprised 78% of both the 1 month and 12 month samples (Table 4.1). The percentage of waiver consumers in our sample increased compared to last year, especially at 1 month (71% 2021; 78% 2022). Consumers not accepted to a waiver transitioned using state plan or other community Medicaid services. Referred to here as state plan consumers, they composed the remaining 22% of the community surveys. This section examines differences between these two groups of consumers. Data is shown by waiver/state plan and by survey time point. Only select data is shown to focus on any pronounced differences.

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

| | 1 Month n (%) | 12 Month n (%) |
|---|---|---|
| Waiver | 248 (78.2) | 176 (77.5) |
| State Plan | 69 (21.8) | 51 (22.5) |
| All programs | 317 (100.0) | 227 (100.0) |

### *Services and Select Demographics*

At transition, waiver consumers are eligible for various waiver services to assist them with daily living tasks. Meanwhile, most state plan consumers need no ongoing assistance with these tasks and receive limited or no HCBS. Table 4.2 highlights differences in self-reported service use between the two groups. For example, at 1 month, 82% of waiver consumers reported using some type of personal care assistance, compared to only 12% of state plan consumers.

Use of case management services is also quite different, even soon after transition. Waiver case managers are not assigned to waiver consumers until 3 to 12 months post-transition. However, MFP TCs provide case management services to waiver and state plan consumers for at least the first 1 to 3 months post-transition. Still, state plan consumers were much less likely to report using case management services at just 1 month post transition – 82% of waiver consumers reported using case management at 1 month post transition, compared to 54% of state plan consumers. Although SCM services may end soon after transition for some state plan consumers, TC services does not. It is not clear why TCs are apparently less involved with non-waiver consumers just a few weeks after transition. It may also be that state plan consumers do not consider TCs to be case managers.

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

| | 1 Month | | 12 Month | |
|---|---|---|---|---|
| | Waiver n (%) | State Plan n (%) | Waiver n (%) | State Plan n (%) |
| Personal care assistant/attendant services | 197 (82.1) | 8 (11.6) | 139 (81.3) | 6 (11.8) |
| Behavioral health services | 1 (<1.0) | 2 (2.9) | 2 (1.2) | 0 (0) |
| Homemaking services or Homemaker-Companion | 176 (73.3) | 12 (17.4) | 129 (75.4) | 9 (17.6) |
| Care management services | 202 (81.5) | 37 (53.6) | 101 (57.4) | 11 (21.6) |
| Recovery assistance services (MHW) | 5 (62.5) | 0 (0) | 3 (60.0) | 0 (0) |
| Community Service Provider (MHW) | 1 (12.5) | 0 (0) | 3 (60.0) | 0 (0) |
| Job coach or vocational supports | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| None of these services | 1 (<1.0) | 20 (29.0) | 8 (4.5) | 31 (60.8) |

* Consumers can use more than one service

As in previous years, waiver consumers are more likely to be older, with the average age being 64, compared to average age of 55 for state plan consumers. State plan consumers are also more likely to be male (Table 4.3).

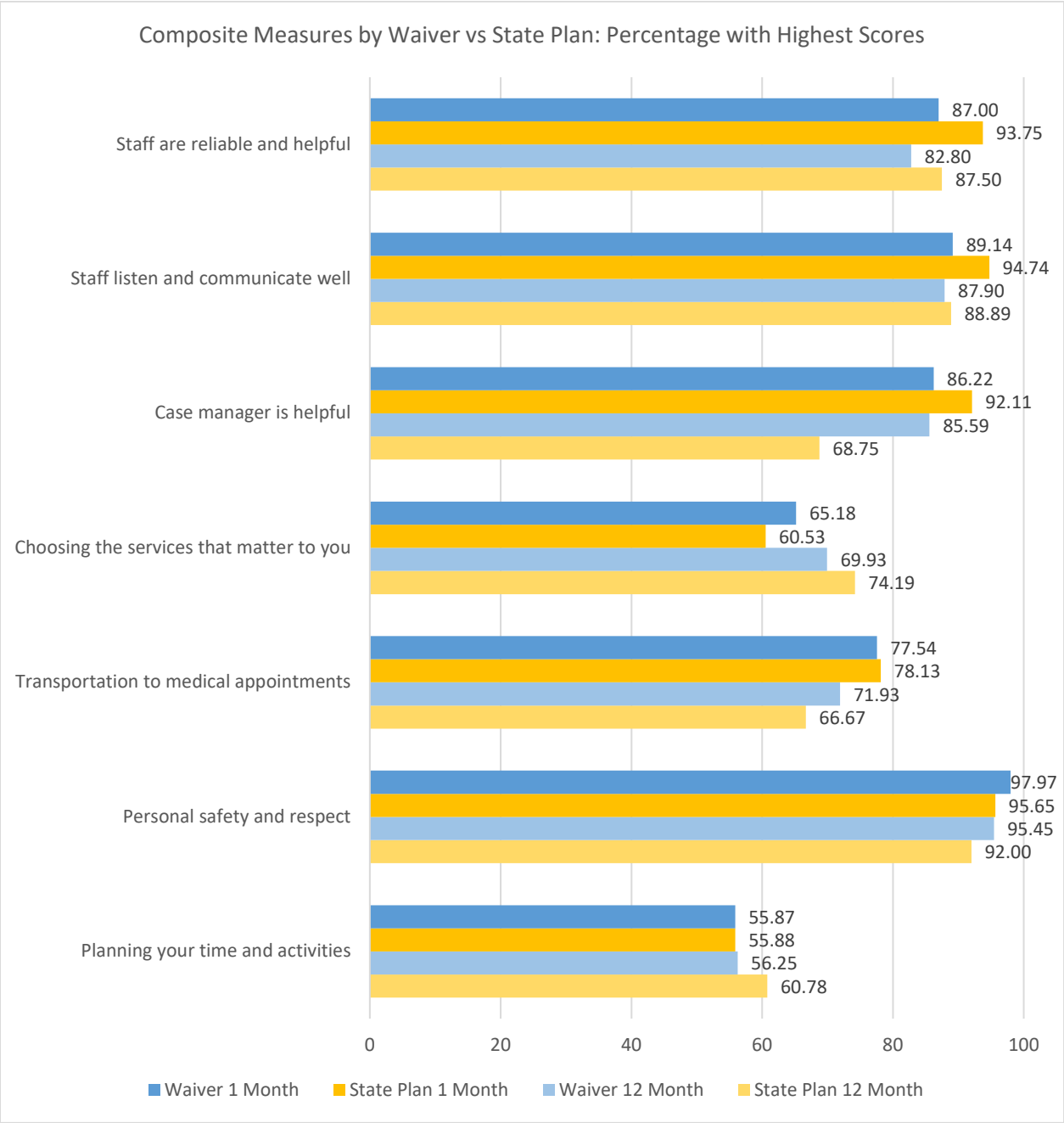
Table 4.3. Demographics – Waiver/State Plan by Time Point

| | | 1 Month | | 12 Month | |
|---|---|---|---|---|---|
| | | Waiver % | State Plan % | Waiver % | State Plan % |
| Age | | N=248 | N=69 | N=176 | N=51 |
| | <18 | <1.0 | 4.3 | 1.1 | 3.9 |
| | 18-24 | <1.0 | 0.0 | <1.0 | 2.0 |
| | 25-34 | 2.4 | 7.2 | 2.8 | 7.8 |
| | 35-44 | 3.6 | 4.3 | 4.0 | 2.0 |
| | 45-54 | 15.3 | 20.3 | 11.9 | 25.5 |
| | 55-64 | 25.8 | 42.0 | 28.4 | 35.3 |
| | 65-74 | 31.0 | 15.9 | 32.4 | 15.7 |
| | 75+ | 20.2 | 5.8 | 18.8 | 7.8 |
| Gender | | N=248 | N=69 | N=176 | N=51 |
| | Male | 45.2 | 69.6 | 44.9 | 72.5 |
| | Female | 54.8 | 30.4 | 55.1 | 27.5 |

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

Several of the composite measures showed noticeable differences between the two groups (Figure 4.1). At 1 month, state plan consumers gave the staff and care manager composites noticeably higher scores than waiver consumers. However, at 12 months, 86% of waiver consumers gave the highest score for the care manager composite, compared to only 69% of state plan consumers.

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




Although both groups gave very similar global ratings for PCAs, homemaking staff, and case managers at 1 month, at 12 months waiver consumers rated their PCAs and case managers higher (Figure 4.2). However, state plan consumers were more likely to definitely recommend their PCAs at 12 months, and their care managers at both 1 and 12 months (Figure 4.3).

Comparing percentage differences between these populations has some limitations, given the small number of state plan consumers who reported using PCA and homemaking services in particular. For example, at 12 months, only 6 state plan consumers had PCA/behavioral health staff and 9 used homemaking services (Table 4.2).

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

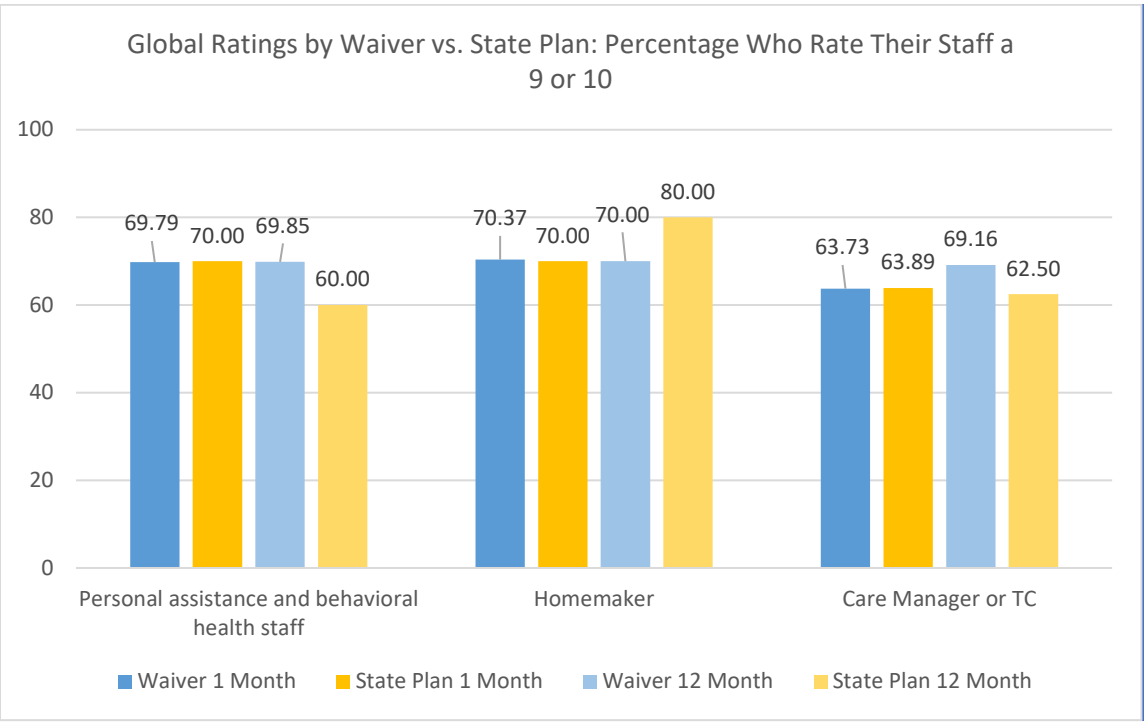
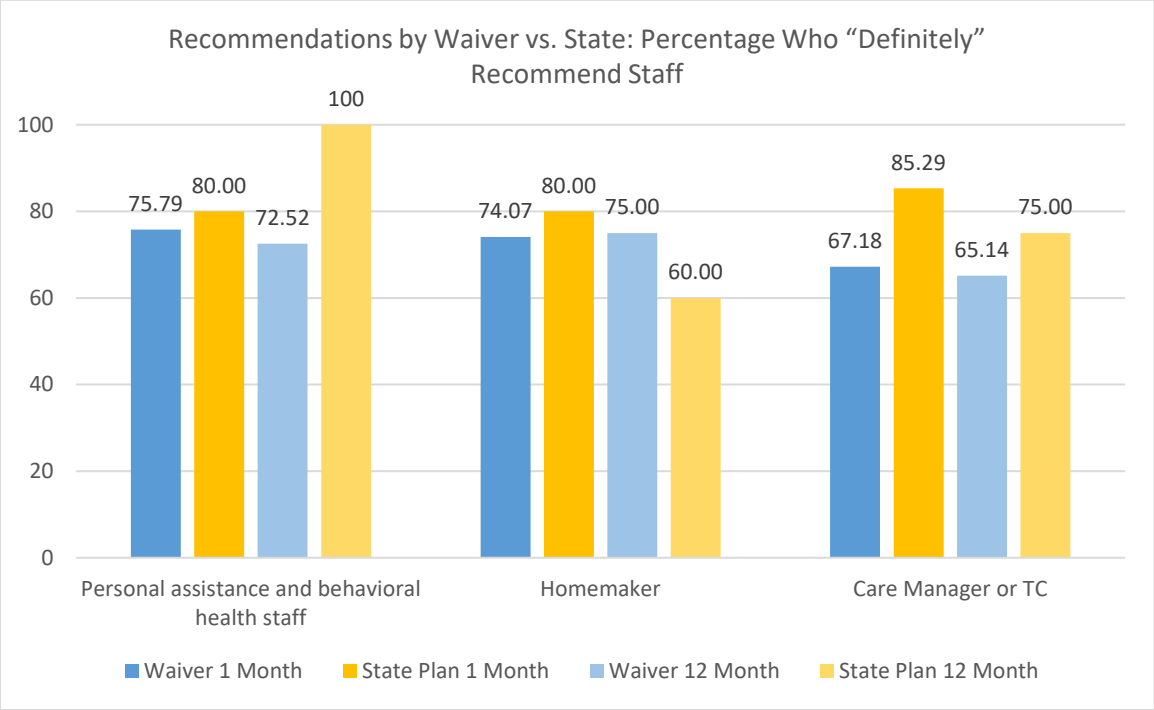



Figure 4.3. Recommendations by Waiver vs. State Plan: Percentage Who "Definitely" Recommend Staff



### *Case Manager Items*

Not surprisingly, by one year post transition, a noticeably lower percentage of state plan consumers reported knowing their case manager or service coordinator (Figure 4.4). However, unlike last year, state plan consumers with a care manager were more likely to be able to reach this person when they needed to at both 1 and 12 months (Figure 4.5). It is not clear what caused this change from the previous year.

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

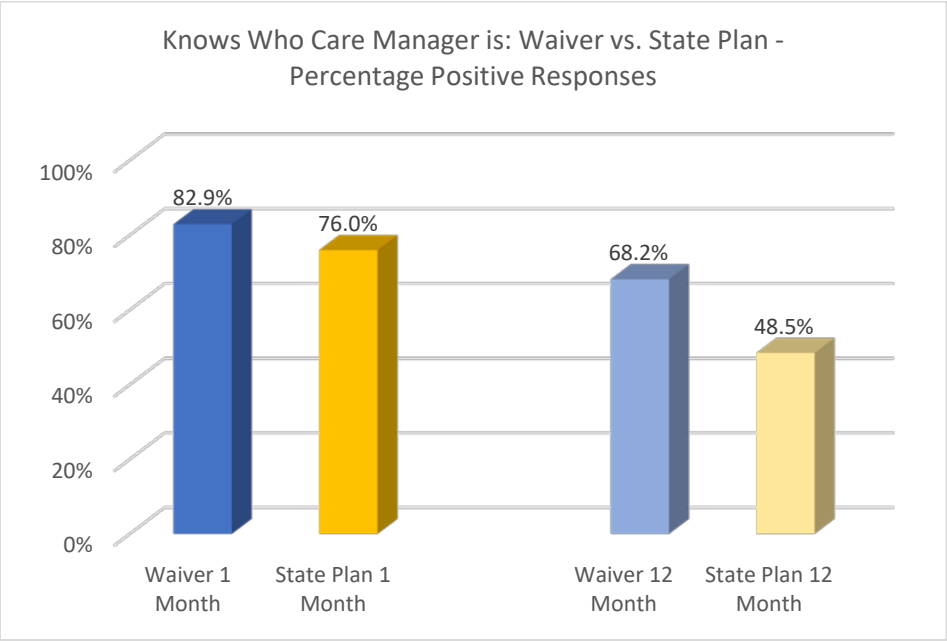
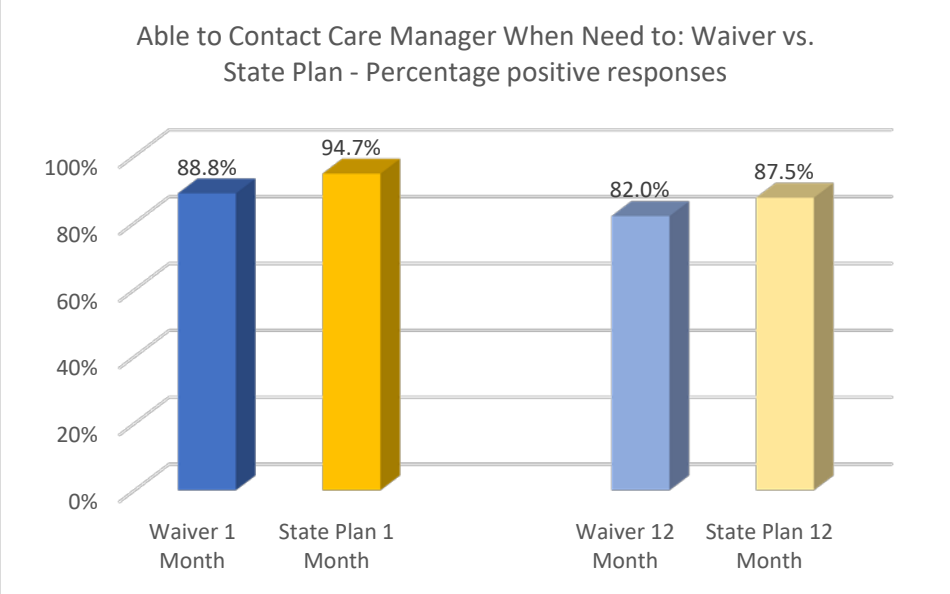
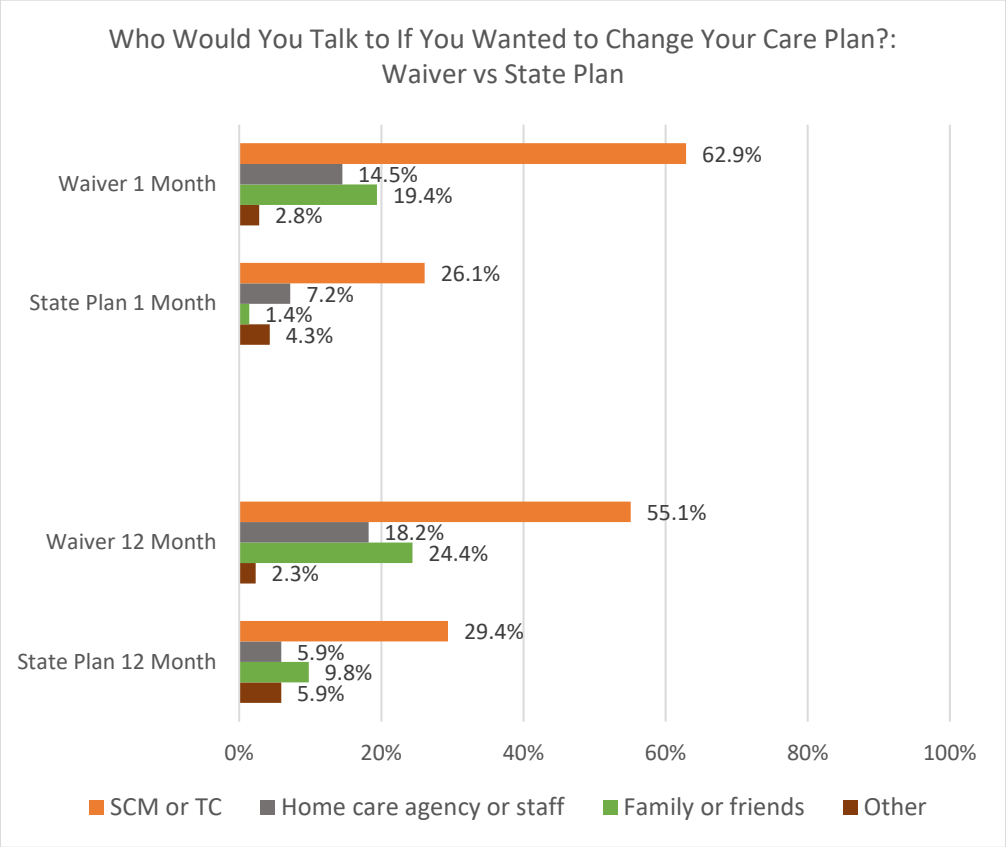



Figure 4.5. Able to Contact Case Manager, Waiver vs. State Plan



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

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




## *Living Situation and Social Support*

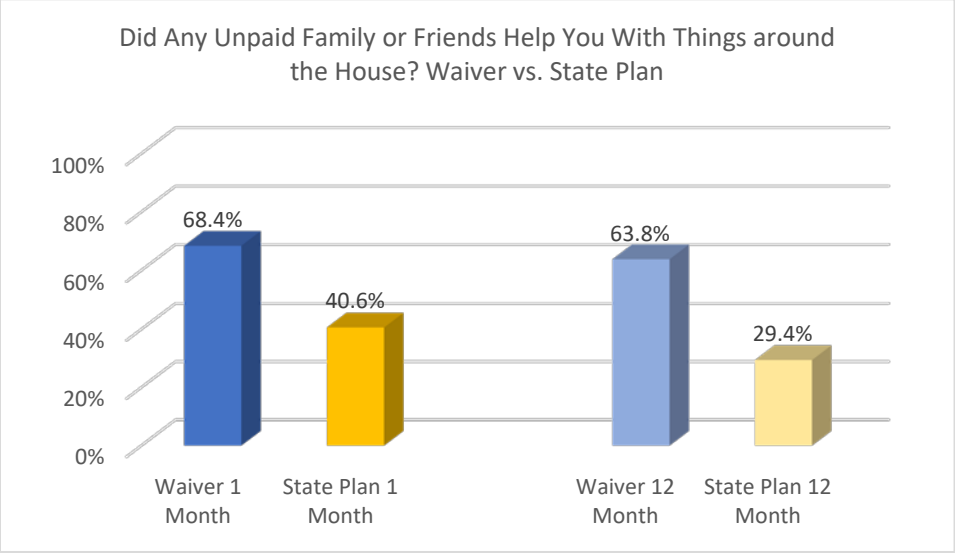
Overall, consumers with state plan services reported less social support than consumers who received services through a waiver. Consumers with state plan services were much more likely to live alone. For example, 65% of consumers with state plan services lived alone at 1 month, compared to 49% of waiver consumers (Table 4.4). State plan consumers were also less likely to either live with family or have family members who lived nearby.

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

| | | 1 Month Waiver % | 1 Month State Plan % | 12 Month Waiver % | 12 Month State Plan % |
|---|---|---|---|---|---|
| Number of adults living in household | | N=247 | N=69 | N=175 | N=49 |
| | 1 | 48.6 | 65.2 | 49.7 | 71.4 |
| | 2-3 | 41.3 | 18.8 | 42.3 | 18.4 |
| | 4+ | 10.1 | 15.9 | 8.0 | 10.2 |
| Lives with family member/s | | N=127 | N=24 | N=88 | N=15 |
| | Yes | 81.9 | 41.7 | 78.4 | 40.0 |
| | No | 18.1 | 58.3 | 21.6 | 60.0 |
| Lives with non-family | | N=127 | N=24 | N=88 | N=15 |
| | Yes | 27.6 | 54.2 | 27.3 | 46.7 |
| | No | 72.4 | 45.8 | 72.7 | 53.3 |
| Family member/s live nearby | | N=247 | N=67 | N=175 | N=50 |
| | Yes | 73.3 | 58.2 | 76.6 | 66.0 |
| | No | 26.7 | 41.8 | 23.4 | 34.0 |
| Friend/s live nearby | | N=248 | N=67 | N=175 | N=50 |
| | Yes | 48.4 | 46.3 | 46.9 | 56.0 |
| | No | 51.6 | 53.7 | 53.1 | 44.0 |

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

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



At 1 month waiver consumers were more likely to like where they live than state plan consumers (92% to 81% respectively), but by 12 months that gap had closed (Figure 4.8). Although 95% of both waiver and state plan consumers reported feeling safe at 1 month, that shifted by 12 months when nearly 100% of waiver consumers felt safe where they lived compared to 88% of state plan consumers. Note that all of these consumers were living in the community at the time of these interviews; this analysis excludes those in institutional settings.

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

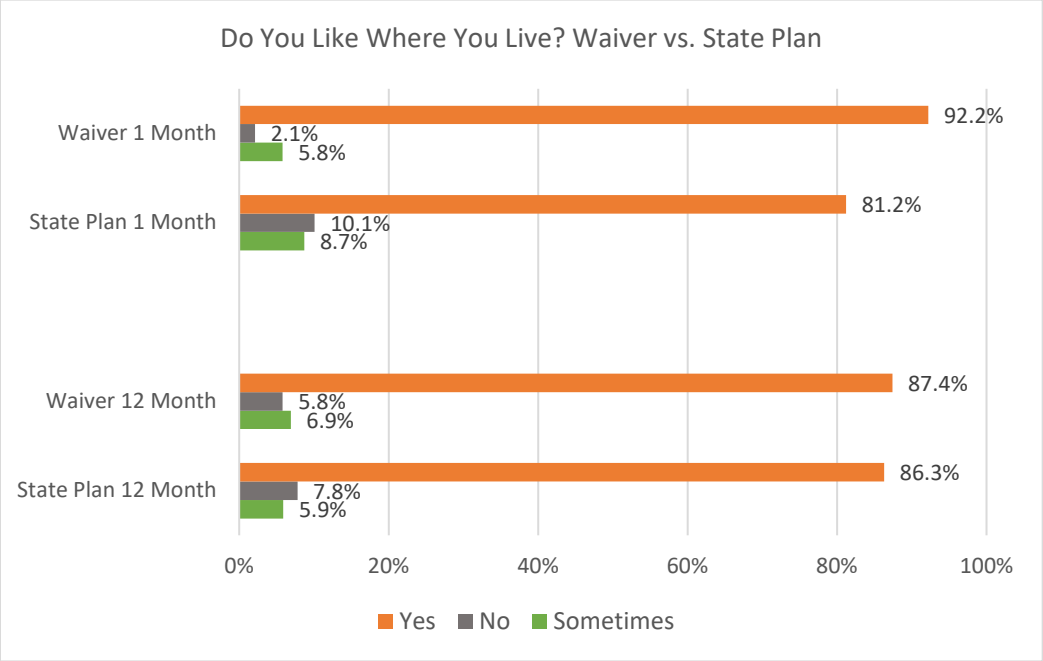
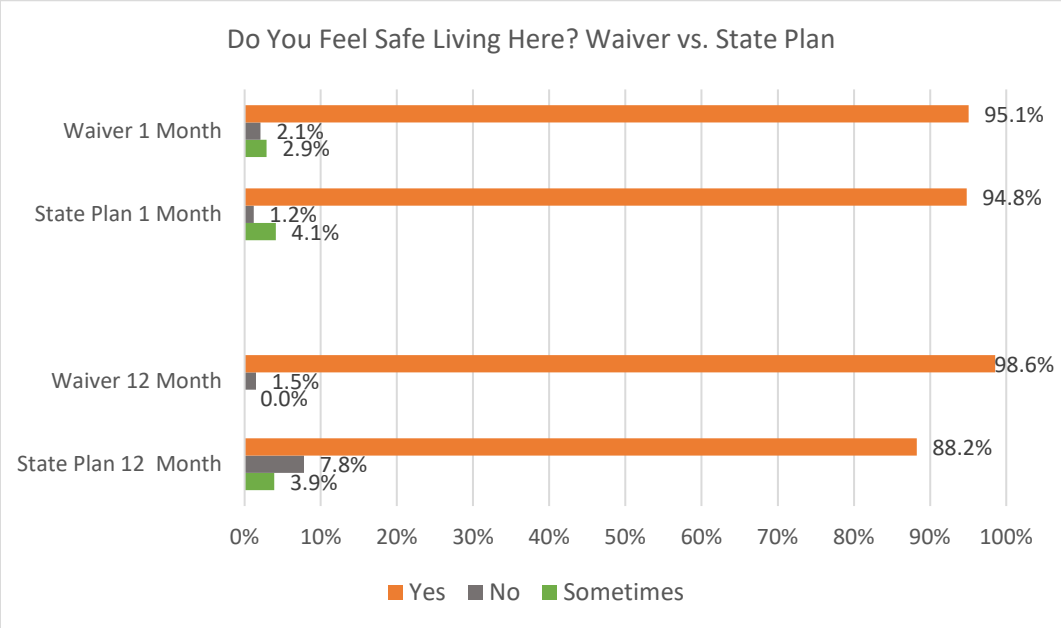


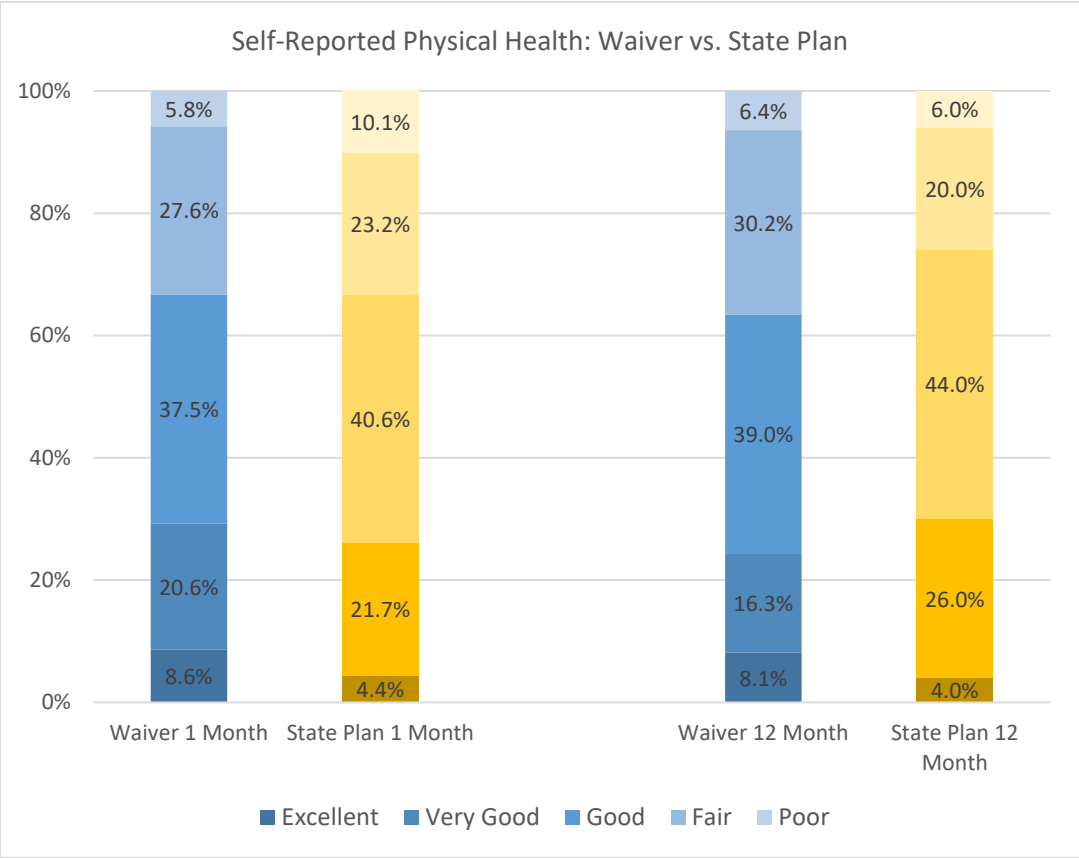

Figure 4.9. Do You Feel Safe Living Here? Waiver vs. State Plan



### *Physical Health*

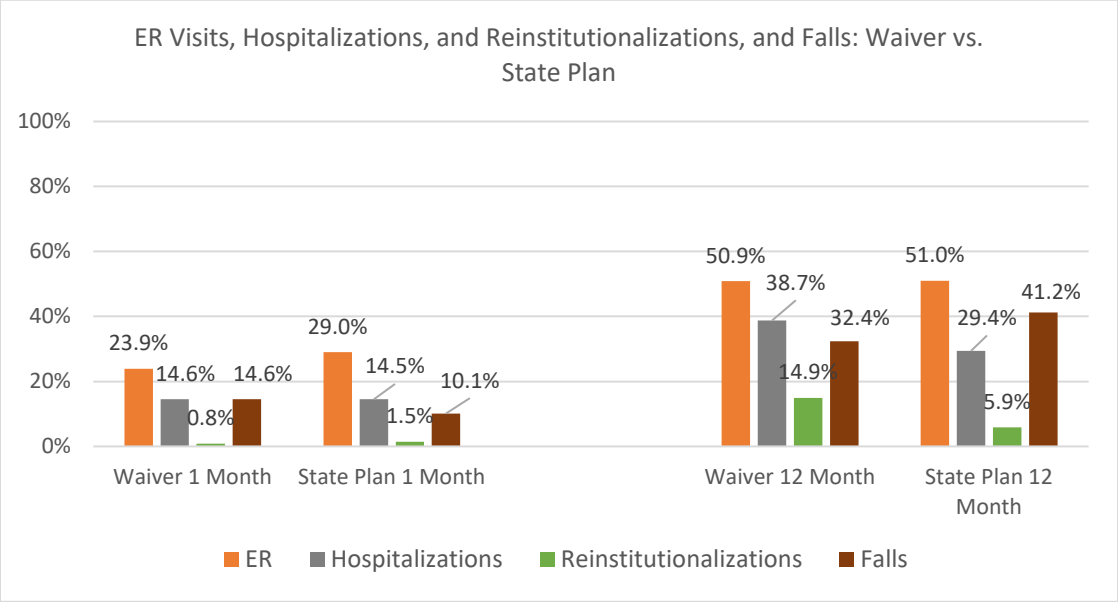
When asked to rate their physical health, one third (33%) of both waiver and state plan consumers reported poor or fair physical health at 1 month (Figure 4.10). By 12 months, state plan consumers reported an improvement in their overall physical health, while waiver participants' health worsened. Age and functional status differences between the two groups may contribute to these findings.

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




Rates of emergency room visits, hospitalizations, nursing home readmissions, and falls showed some between group differences with few identifiable trends (Figure 4.11). Although both groups had equivalent rates of emergency room use at 12 months, these visits lead to greater rates of hospitalization and subsequent short-term reinstitutionalization for waiver consumers.

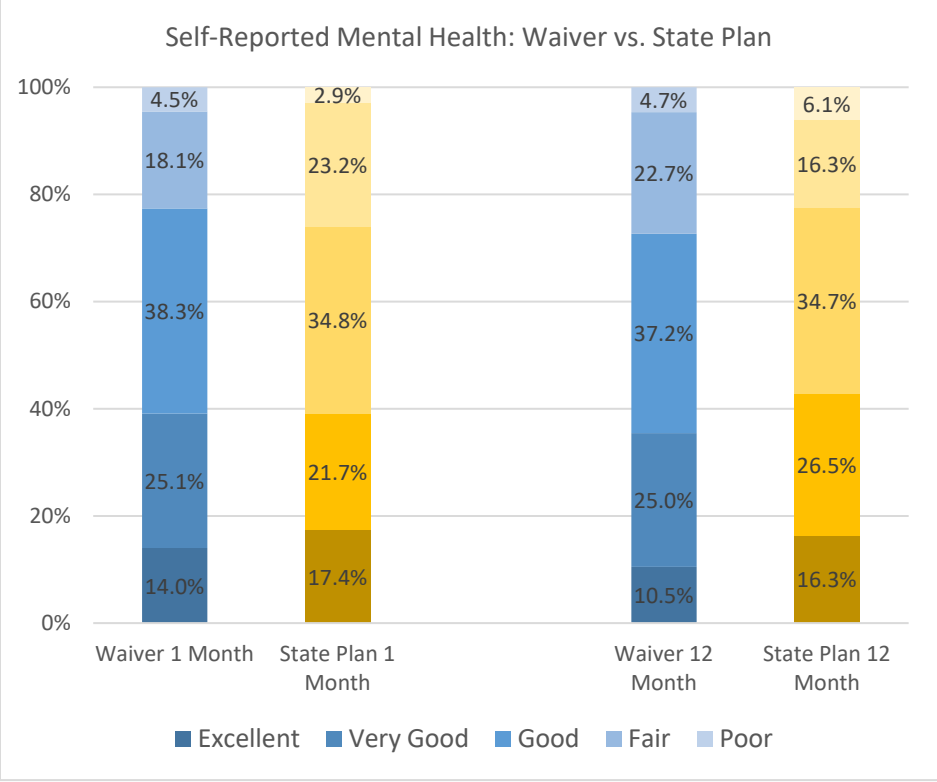
Figure 4.11. ER Visits, Hospitalizations, Reinstitutionalizations, and Falls: Waiver vs. State Plan




## *Mental Health*

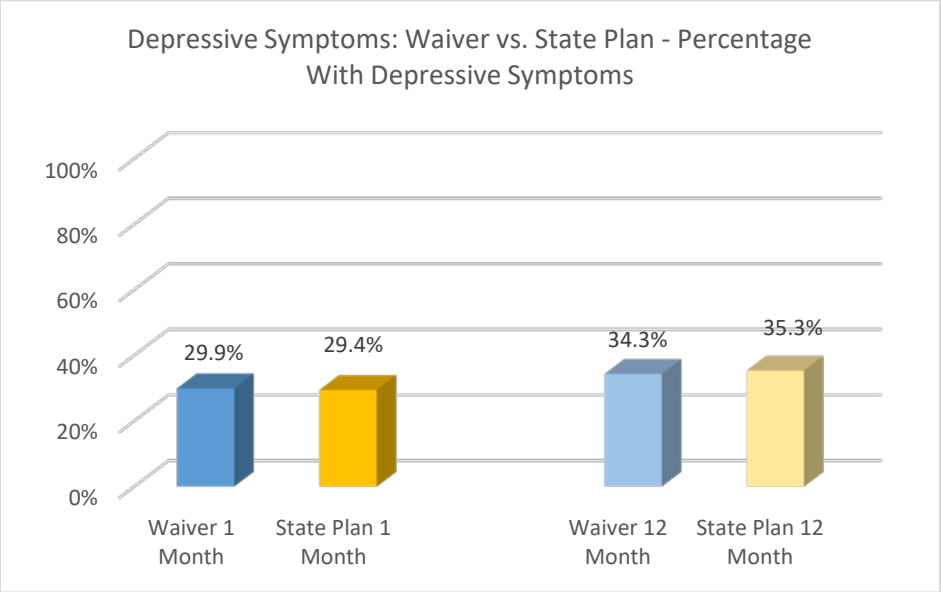
There were minimal differences reported between the two groups when comparing reported mental or emotional health status this year (Figure 4.12). At 12 months, state plan consumers reported slightly better mental health than waiver consumers – 78% of state plan consumers reported their mental health as at least good, compared to 73% of waiver consumers. This differs from 2021 when state plan consumers reported much poorer mental health than waiver consumers at 12 months.

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



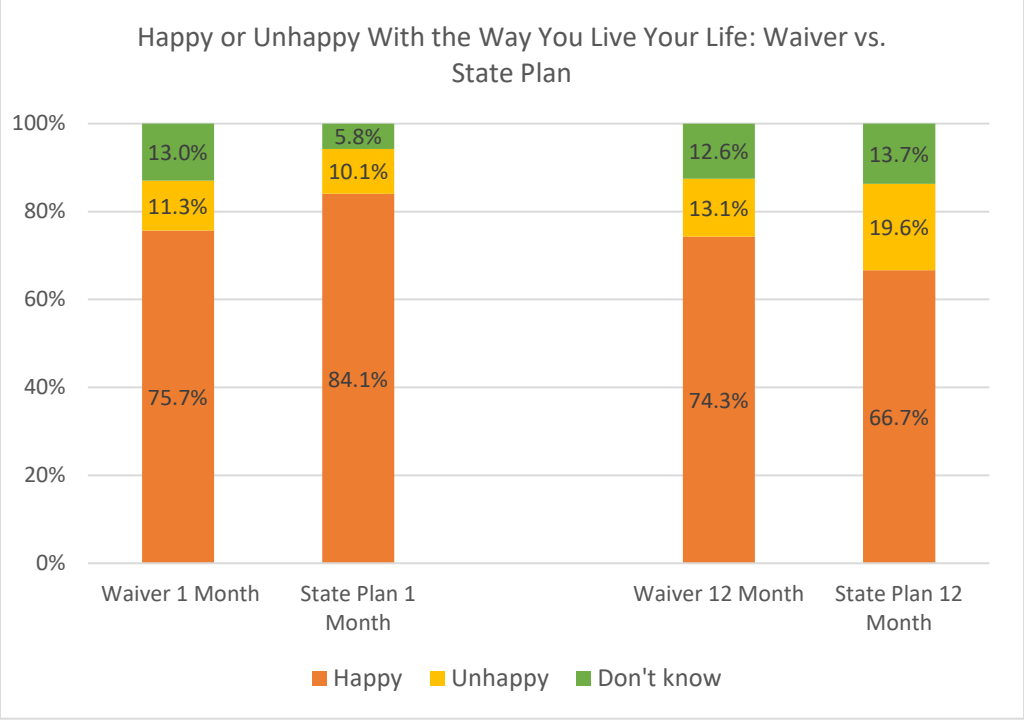
There was little difference in depressive symptoms reported by either waiver or state plan consumers at either time point (Figure 4.13).

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




As shown in Figure 4.14, the majority of both waiver and state plan consumers reported being happy with the way they live their life at either time point. However, while this rate stayed constant for waiver consumers over time, state consumers were much less happy at 12 months compared to 1 month.

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



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

As shown in Table 4.5, compared to state plan consumers, noticeably more waiver consumers reported having home modifications, mobility or medical equipment, or a PERS unit at both 1 and 12 months. This again may be an effect of the greater physical needs of waiver consumers. However, state plan consumers reported a greater unmet need for a PERS unit at both time points, and medical equipment at 12 months.

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

| | | 1 Month Waiver % | 1 Month State Plan % | 12 Month Waiver % | 12 Month State Plan % |
|---|---|---|---|---|---|
| Home modifications | | N=245 | N=68 | N=173 | N=51 |
| | I have it | 73.1 | 58.8 | 76.9 | 49.0 |
| | I do not need it | 16.3 | 33.8 | 12.1 | 39.2 |
| | I need it | 10.6 | 7.4 | 11.0 | 11.8 |
| Mobility equipment | | N=246 | N=69 | N=174 | N=51 |
| | I have it | 88.6 | 59.4 | 91.4 | 66.7 |
| | I do not need it | 9.4 | 39.1 | 6.9 | 33.3 |
| | I need it | 2.0 | 1.5 | 1.7 | 0 |
| Medical equipment | | N=245 | N=69 | N=174 | N=51 |
| | I have it | 80.4 | 46.4 | 87.9 | 43.1 |
| | I do not need it | 12.7 | 46.4 | 9.2 | 49.0 |
| | I need it | 6.9 | 7.3 | 2.9 | 7.8 |
| Lifeline or PERS | | N=247 | N=69 | N=173 | N=51 |
| | I have it | 52.6 | 10.1 | 65.3 | 19.6 |
| | I do not need it | 37.3 | 75.4 | 31.2 | 72.6 |
| | I need it | 10.1 | 14.5 | 3.5 | 7.8 |
| Internet capable devices | | N=247 | N=68 | N=174 | N=50 |
| | I have it | 68.4 | 79.4 | 69.0 | 70.0 |
| | I do not need it | 26.7 | 19.1 | 25.9 | 24.0 |
| | I need it | 4.9 | 1.5 | 5.2 | 6.0 |
| Internet access | | N=245 | N=69 | N=170 | N=49 |
| | I have it | 83.7 | 79.7 | 85.9 | 77.6 |
| | I do not need it | 12.7 | 13.0 | 9.4 | 12.2 |
| | I need it | 3.7 | 7.3 | 4.7 | 10.2 |

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

Community living consumers who transitioned in 2021 were next stratified by service type into those who used agency-based services and those who used self-directed services. This section examines differences between these two groups of consumers; data is shown by service type and by time point. To measure consumer self-direction, consumers living in the community were asked how their caregivers were hired, "Do your caregivers come from an agency, or do you or a family member find and hire your caregivers or aides?" The consumer's answer determined the category – agency-based consumers or self-directed consumers. Only participants who answered this question are included in this section.

As shown in Table 5.1, at 1 month 83% of consumers used agency-based services, while just 17% self-directed their services. By 12 months, use of agency-based services declined to 74%. Use of agency-based services at 1 month post-transition has grown over the past 3 years, from 69% in 2020 to 83% in 2022.

### *Services and Select Demographics*

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

| | 1 Month n (%) | 12 Month n (%) |
|---|---|---|
| Agency-based | 196 (82.7) | 122 (73.5) |
| Self-directed | 41 (17.3) | 44 (26.5) |
| Total | 237 (100.0) | 166 (100.0) |

Compared to agency-based consumers, self-directed consumers reported greater use of personal care services at both 1 and 12 months, and greater use of homemaking services at 12 months (Table 5.2). When asked about case management, a smaller percentage of self-directed consumers reported having case management services compared to agency-based consumers at either time point. Both agency-based and self-directed consumers have access to TC and SCM services post transition. It may be that some agency-based consumers consider someone at the home care agency, such as the scheduler, to be a case manager, especially given the care manager question on the survey refers the person who "helped make sure that you had all the services you needed."

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 | 158 (83.6) | 37 (90.2) | 100 (84.0) | 41 (93.2) |
| Behavioral health services | 2 (1.0) | 0 (0) | 2 (1.6) | 0 (0) |
| Homemaking services or Homemaker-Companion services | 142 (75.1) | 30 (73.2) | 91 (76.5) | 37 (84.1) |
| Care management services | 160 (81.6) | 30 (73.2) | 72 (59.0) | 23 (52.3) |
| Recovery assistance services (MHW only) | 5 (71.4) | 0 (0) | 3 (100.0) | 0 (0) |
| Community Service Provider (MHW only) | 1 (14.3) | 0 (0) | 0 (0) | 0 (0) |
| Job coach or vocational supports | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| None of these services | 1 (<1.0) | 0 (0) | 2 (1.6) | 1 (2.3) |

* Consumers can use more than one service

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

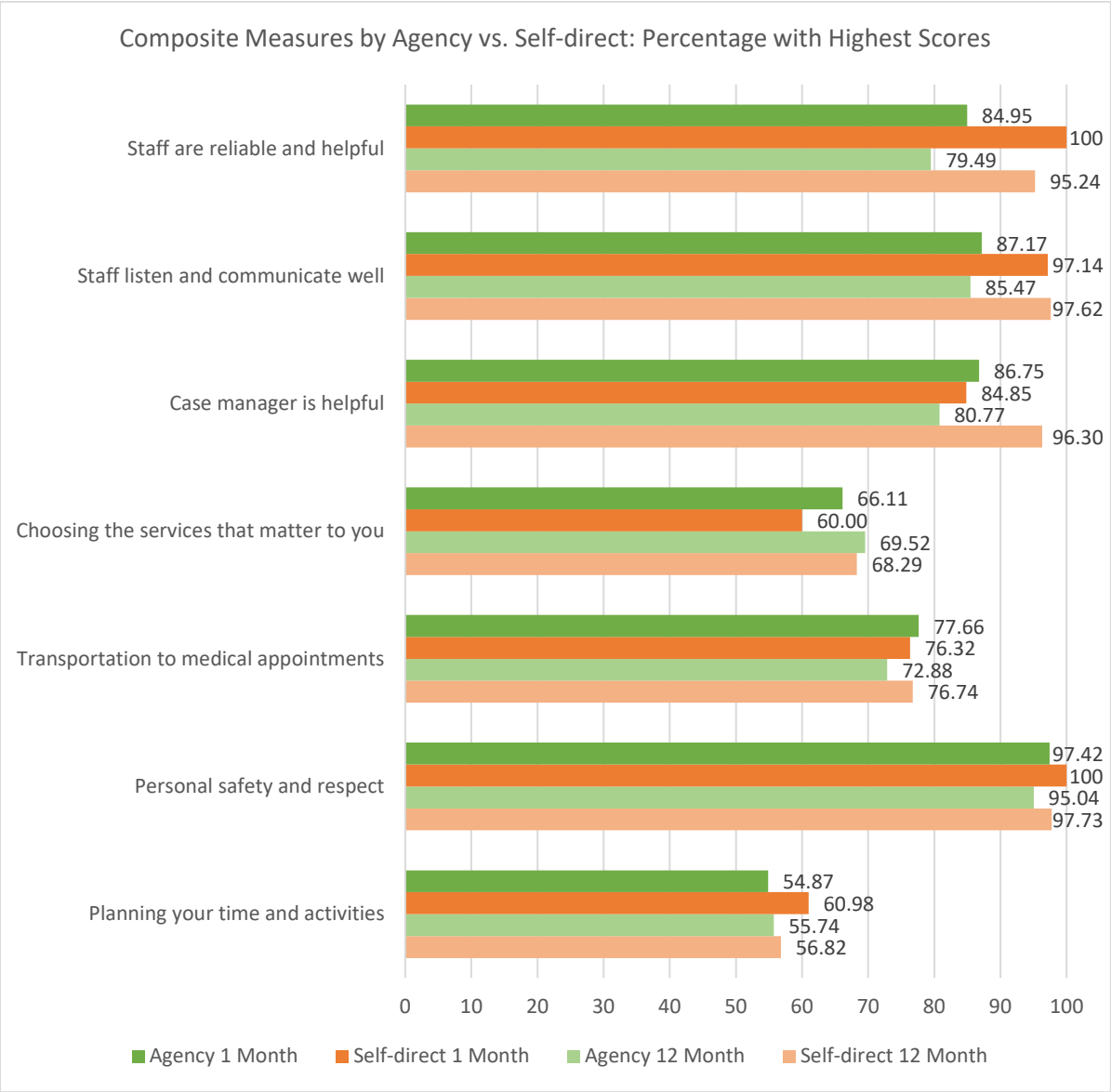
Table 5.3. Demographics: Agency vs. Self-direct

| | | 1 Month | | 12 Month | |
|---|---|---|---|---|---|
| | | Agency % | Self-direct % | Agency % | Self-direct % |
| Age | | N=196 | N=41 | N=122 | N=44 |
| | <18 | 0.0 | 2.4 | <1.0 | 2.3 |
| | 18-24 | <1.0 | 0.0 | 0.0 | 0.0 |
| | 25-34 | <1.0 | 7.3 | 1.6 | 6.8 |
| | 35-44 | 3.1 | 4.9 | 4.9 | 2.3 |
| | 45-54 | 15.8 | 24.4 | 12.3 | 13.6 |
| | 55-64 | 24.5 | 36.6 | 23.8 | 47.7 |
| | 65-74 | 33.7 | 14.6 | 32.8 | 20.5 |
| | 75+ | 21.9 | 9.8 | 23.8 | 6.8 |
| Gender | | N=196 | N=41 | N=122 | N=44 |
| | Male | 42.9 | 56.1 | 48.4 | 43.2 |
| | Female | 57.1 | 43.9 | 51.6 | 56.8 |

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

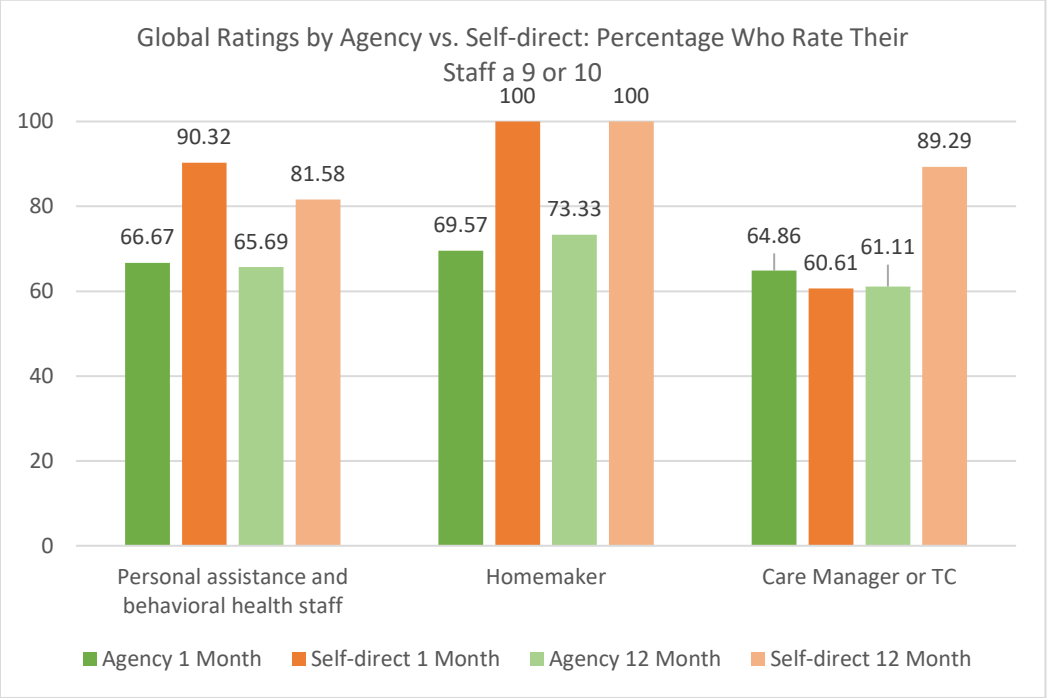
Several differences in the composite measures existed between agency-based and self-directed consumers (Figure 5.1). Self-directed consumers were much more likely than agency-based consumers to report that their staff were reliable and helpful, and that their staff listened and communicated well at both 1 and 12 months. The most notable difference was for the case manager is helpful composite at 12 months. While similar percentages of both agency-based and self-directed consumers gave the highest score to their case manager is helpful at 1 month, self-directed consumers had a significant increase at 12 months (81% agency vs. 96% self-direct). Meanwhile, at 1 month agency-based consumers more often gave the highest score to the composite “choosing the services that matter to you” compared to self-directed consumers.

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



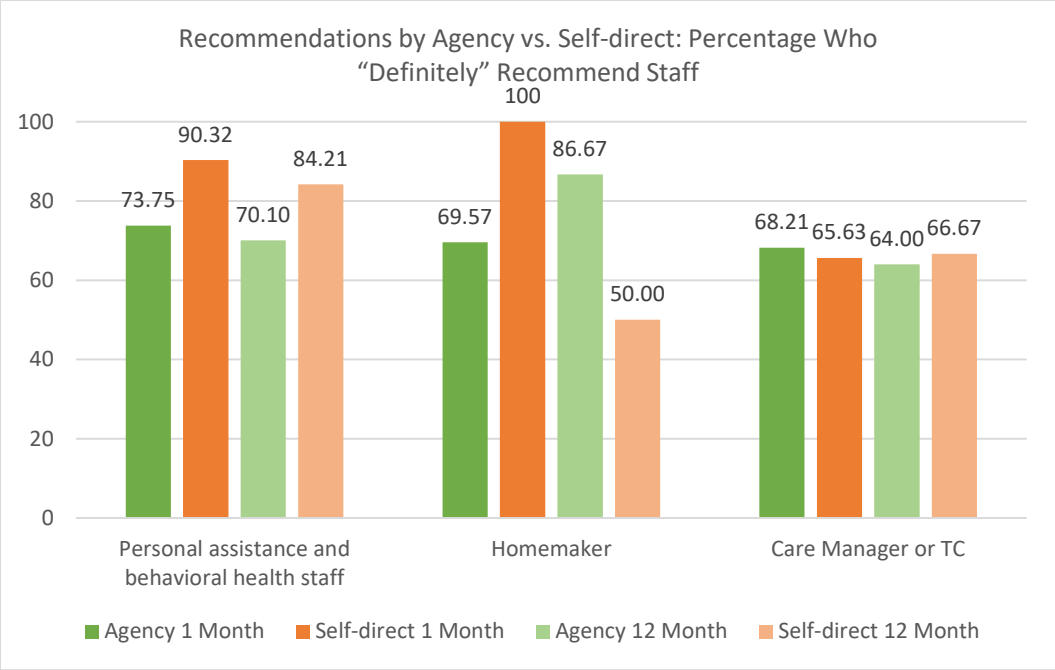

Staff ratings and recommendations also showed some marked differences between the two groups of consumers (Figure 5.2). In particular, at 1 and 12 months after transition, self-directed consumers rated their personal care and homemaking staff notably higher than agency-based consumers. Because most self-directed 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=4 1 month, n=4 12 month), which limits the comparison of homemaking services between agency-based and self-directed consumers. Self-directed consumers were much more likely to rate their care managers a 9 or 10 than agency-based at 12 months. It is not clear why self-directed consumers experienced such a drastic increase in how they rated their case managers, especially as the percentage who “definitely” recommend their case managers did not increase during this same time period (Figure 5.3).

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 and homemaking staff at either time point. Unexpectedly, self-directed consumer homemaking staff recommendations fell at 12 months.

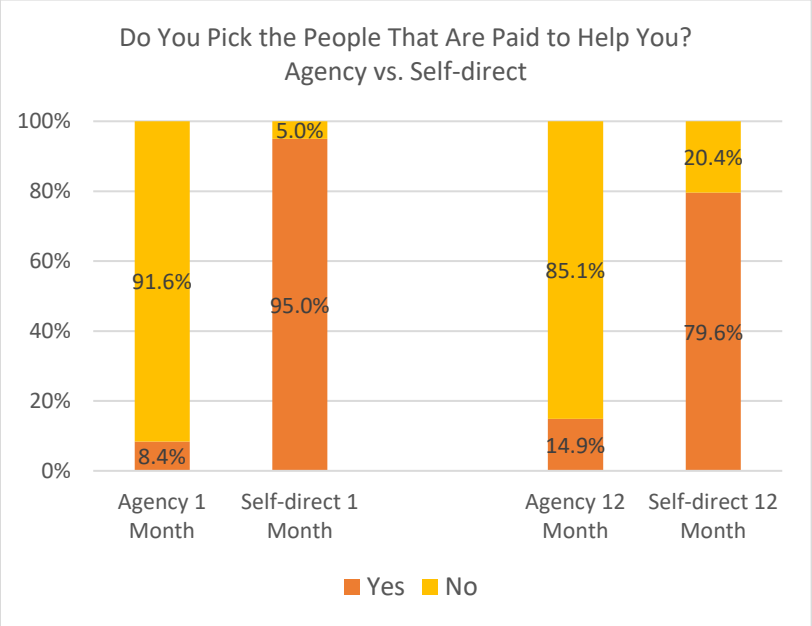
Figure 5.3. Recommendations by Agency vs. Self-direct: Percentage Who "Definitely" Recommend Staff



### *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?" Ninety-five percent of self-directed consumers chose their paid assistants at 1 month, compared to 8% of agency-based consumers. While the difference remains substantial, by 12 months, 80% of self-directed consumers reported picking the people paid to help them, compared to 15% of agency-based consumers.

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




### *Assistance with Everyday Activities*

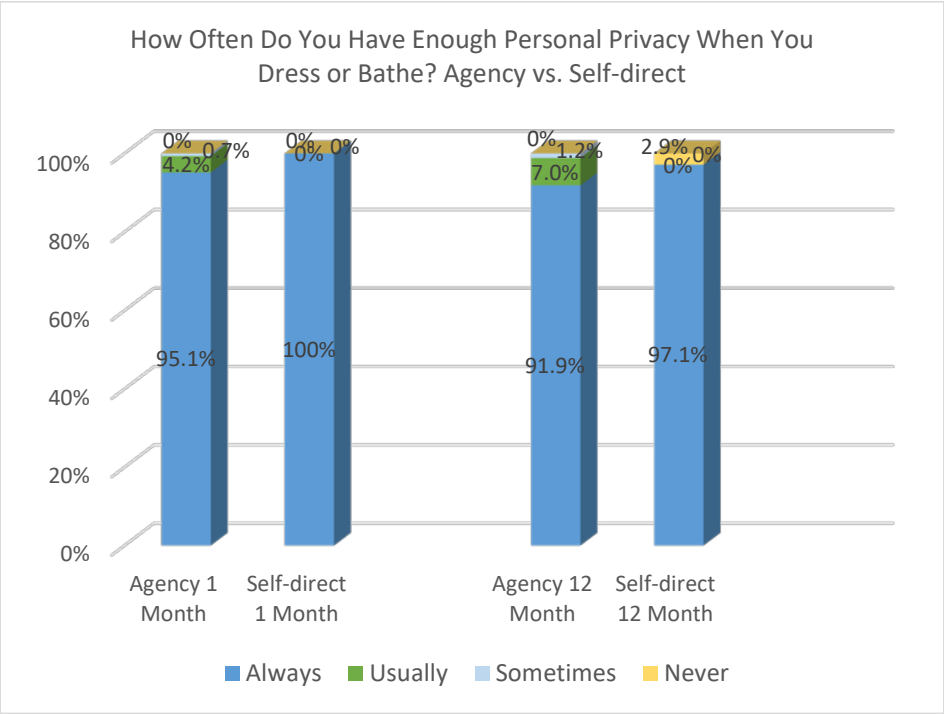
Consumers who received personal care assistance were asked what tasks they needed assistance with. As seen in Table 5.4, greater percentages of self-directed consumers reported needing assistance with each activity, aside from housekeeping at 1 month and personal care at 12 months.

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 | 145 (87.9) | 33 (97.1) | 90 (88.2) | 35 (87.5) |
| Meals or eating | 138 (83.6) | 33 (97.1) | 88 (86.3) | 38 (95.0) |
| Taking medications | 88 (53.3) | 26 (76.5) | 56 (54.9) | 26 (65.0) |
| Using the toilet | 97 (59.5) | 23 (67.7) | 57 (55.9) | 26 (65.0) |
| Housekeeping or laundry | 142 (76.8) | 30 (75.0) | 91 (77.1) | 37 (86.1) |

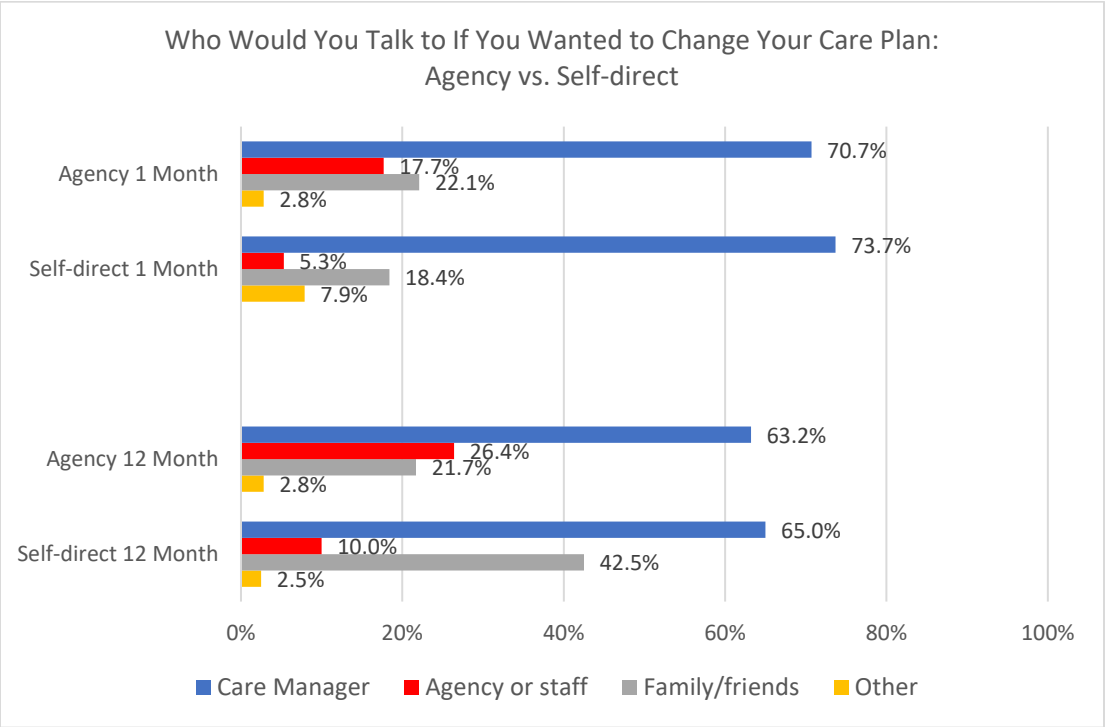
When asked how often they had enough personal privacy when bathing or dressing, fewer agency-based consumers said they always had enough privacy at 1 month and 12 months compared to self-directed consumers (Figure 5.5).

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




At both 1 and 12 months, both agency-based and self-directed consumers were most likely to contact their case managers to change their care plan (Figure 5.6). At both time points, more agency-based consumers would contact either the home care agency or a staff member to change their care plan, while at 12 months more self-directed consumers would turn to family or friends.

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



### *Living Situation and Social Support*

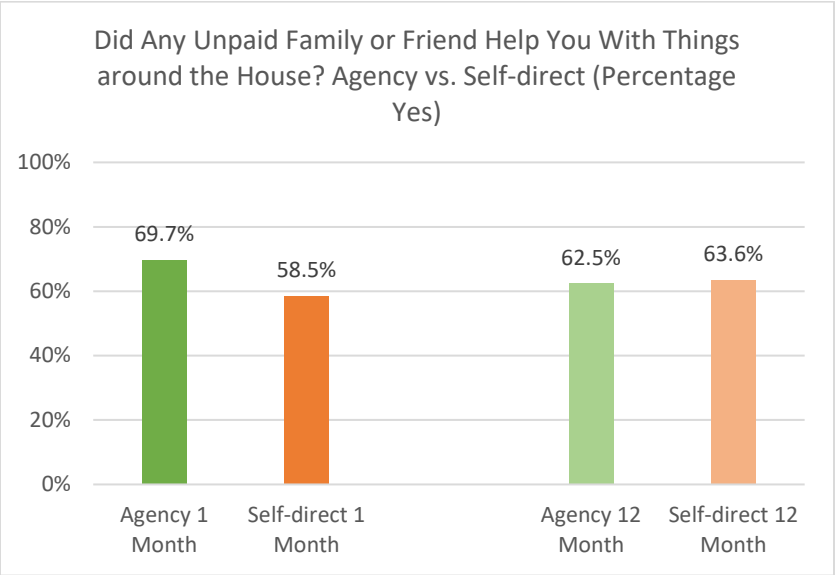
Household composition showed strong differences between the two groups of consumers (Table 5.5). The percentage of each group who live alone is most striking – at both time points, agency-based consumers were much more likely to live alone. For those consumers who lived with someone, at 1 month agency-based consumers were more likely to live with family, although by 12 months a greater percentage of self-directed consumers did so.

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=195 | N=41 | N=121 | N=44 |
| | 1 | 51.8 | 36.6 | 54.6 | 38.6 |
| | 2-3 | 40.0 | 48.8 | 41.3 | 50.0 |
| | 4+ | 8.2 | 14.6 | 4.1 | 11.4 |
| Lives with family member/s | | N=94 | N=26 | N=55 | N=27 |
| | Yes | 81.9 | 76.9 | 74.5 | 85.2 |
| | No | 18.1 | 23.1 | 25.5 | 14.8 |
| Lives with non-family | | N=94 | N=26 | N=55 | N=27 |
| | Yes | 27.7 | 34.6 | 32.7 | 18.5 |
| | No | 72.3 | 65.4 | 67.3 | 81.5 |
| Family member/s live nearby | | N=195 | N=41 | N=121 | N=44 |
| | Yes | 71.8 | 73.2 | 78.5 | 77.3 |
| | No | 28.2 | 26.8 | 21.5 | 22.7 |
| Friend/s live nearby | | N=196 | N=41 | N=121 | N=44 |
| | Yes | 47.4 | 53.7 | 49.6 | 45.5 |
| | No | 52.6 | 46.3 | 50.4 | 54.5 |

Figure 5.7 shows that at 1 month post-transition, agency-based consumers reported receiving more informal support from family and friends for household tasks, although by 12 months rates of household informal support were nearly equal.

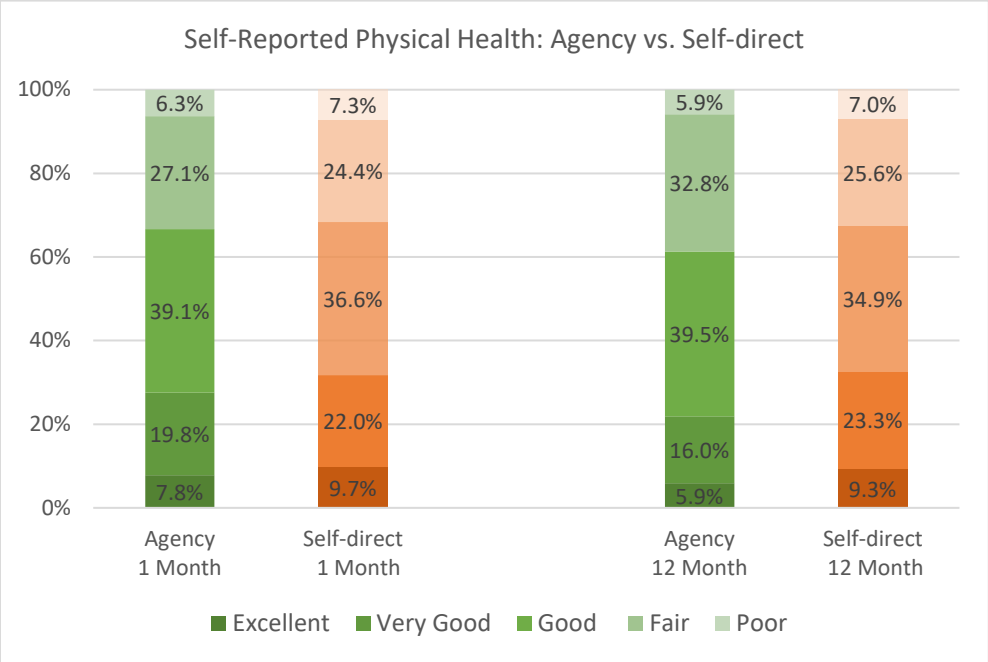
Figure 5.7. Assistance from Unpaid Family or Friends with Things around the House: Agency vs. Self-direct (Percentage Yes)




## *Physical Health*

At both 1 month and 12 months, self-directed consumers were more likely to report very good or excellent physical health (Figure 5.8).

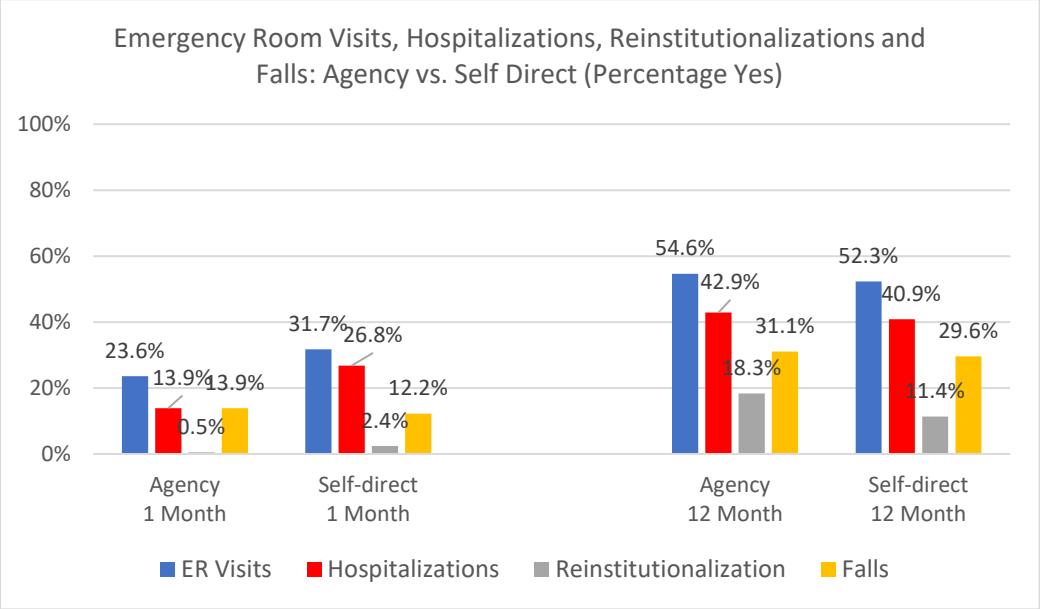
Figure 5.8. Self-Reported Physical Health: Agency vs. Self-direct




There were also some differences in emergency room visits, hospitalizations, and reinstitutionalizations between agency-based and self-directed consumers (Figure 5.9). Most notably, at 1 month, self-directed consumers used the emergency room and were hospitalized more often than agency-based consumers. However, at 12 months, agency-based consumers had higher utilization rates of all three types of health

services, with a notably higher likelihood of reinstitutionalization. This is not surprising given the overall poorer health of agency-based consumers at 12 months.

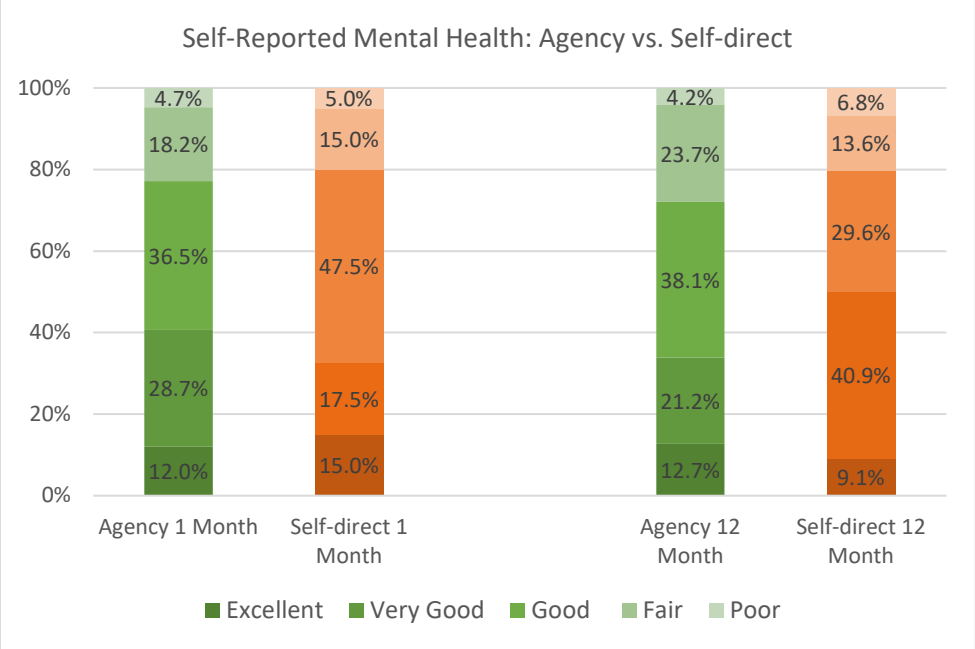
Figure 5.9. Emergency Room Visits, Hospitalizations, Reinstitutionalizations, and Falls: Agency vs. Self-direct (Percentage Yes)




## *Mental Health*

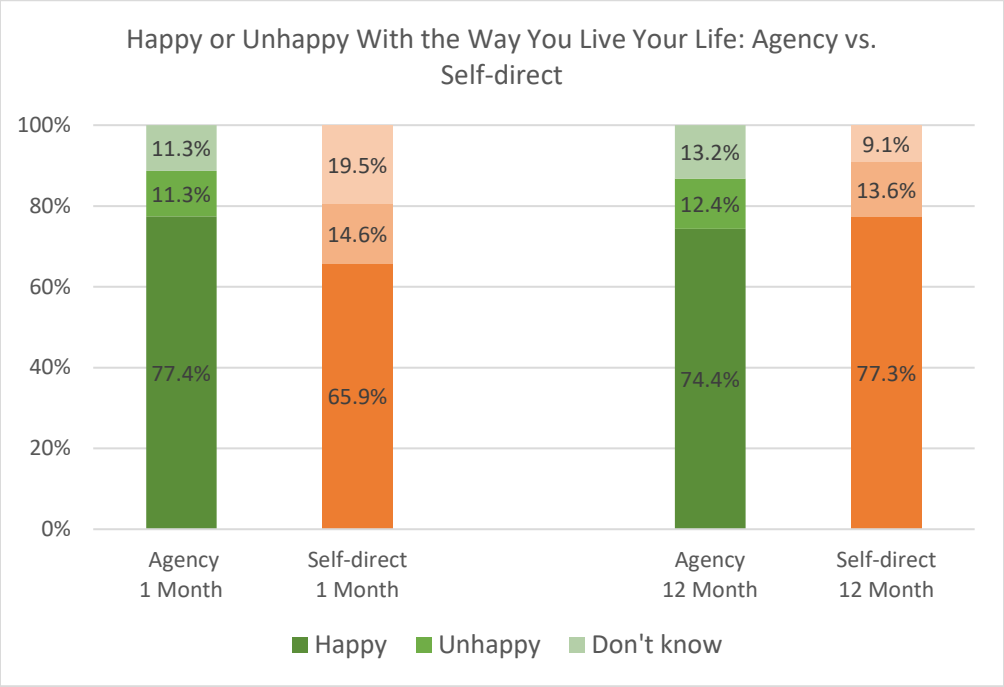
While at 1 month, agency-based consumers reported higher rates of very good or excellent mental or emotional health, by 12 months considerably more self-directed consumers reported their mental health as very good to excellent (Figure 5.10). At 12 months, half (50%) of self-directed consumers reported very good to excellent mental health, compared to 34% of agency-based consumers.

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



Agency-based consumers were much more likely to report feeling happy with the way they live their life at 1 month (77% agency-based, 66% self-directed), although this difference is not seen at 12 months (Figure 5.11).

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




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

Both agency-based and self-directed consumers reported having various assistive devices, special equipment, and home modifications (Table 5.6). The difference between these groups was greatest for internet devices and internet access. At 12 months, 100% of self-directed consumers had internet access, compared to 81% of agency-based consumers. Both agency-based and self-directed consumers reported an unmet need for various types of these items. However, other than self-directed consumers' greater need for home modifications at both time points, and their greater need for a PERS at 1 month, other unmet need differences were slight, with no noticeable 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=194 | N=41 | N=120 | N=43 |
| | I have it | 76.80 | 58.54 | 77.50 | 74.42 |
| | I do not need it | 13.92 | 21.95 | 12.50 | 9.30 |
| | I need it | 9.28 | 19.51 | 10.00 | 16.28 |
| Mobility equipment | | N=194 | N=41 | N=120 | N=44 |
| | I have it | 89.18 | 90.24 | 90.00 | 95.45 |
| | I do not need it | 9.28 | 7.32 | 7.50 | 4.55 |
| | I need it | 1.55 | 2.44 | 2.50 | 0.00 |
| Medical equipment | | N=194 | N=41 | N=120 | N=44 |
| | I have it | 80.93 | 87.80 | 89.17 | 88.64 |
| | I do not need it | 13.40 | 7.32 | 7.50 | 6.82 |
| | I need it | 5.67 | 4.88 | 3.33 | 4.55 |
| Lifeline or PERS | | N=195 | N=41 | N=119 | N=44 |
| | I have it | 53.85 | 53.66 | 66.39 | 59.09 |
| | I do not need it | 36.41 | 31.71 | 29.41 | 36.36 |
| | I need it | 9.74 | 14.63 | 4.20 | 4.55 |
| Internet capable devices | | N=195 | N=41 | N=120 | N=44 |
| | I have it | 69.74 | 75.61 | 67.50 | 81.82 |
| | I do not need it | 26.15 | 19.51 | 26.67 | 15.91 |
| | I need it | 4.10 | 4.88 | 5.83 | 2.27 |
| Internet access | | N=193 | N=41 | N=116 | N=44 |
| | I have it | 82.90 | 92.68 | 81.03 | 100.0 |
| | I do not need it | 12.95 | 7.32 | 12.93 | 0.00 |
| | I need it | 4.15 | 0.00 | 6.03 | 0.00 |

## 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 2021 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 experience a fall or hospitalization, have increased choice and control, and are more active in the community (Porter et al., 2022). Even short-term reinstitutionalization can negatively affect the consumer and their family emotionally and physically, causing stress and interrupting the adjustment to community living. Paid caregivers are also affected as they unexpectedly find themselves without work. Long-term reinstitutionalization in particular incurs higher program and personal costs.

## A. Reinstitutionalization Pattern in the Year Post Transition

The cohort of the 459 consumers who transitioned in 2021 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=459 n (%) | Transition to 1 Month N=448 n (%) | 1 Month Setting N=448 n (%) | 1 Month to 12 Month N=393 n (%) | 12 Month Setting N=392 n (%) |
|---|---|---|---|---|---|
| Community | 459 (100) | 407 (90.8) | 410 (91.5) | 269 (68.4) | 315 (80.4) |
| Facility | 0 (0) | 41 (9.2) | 38 (8.5) | 124 (31.6) | 77 (19.6) |

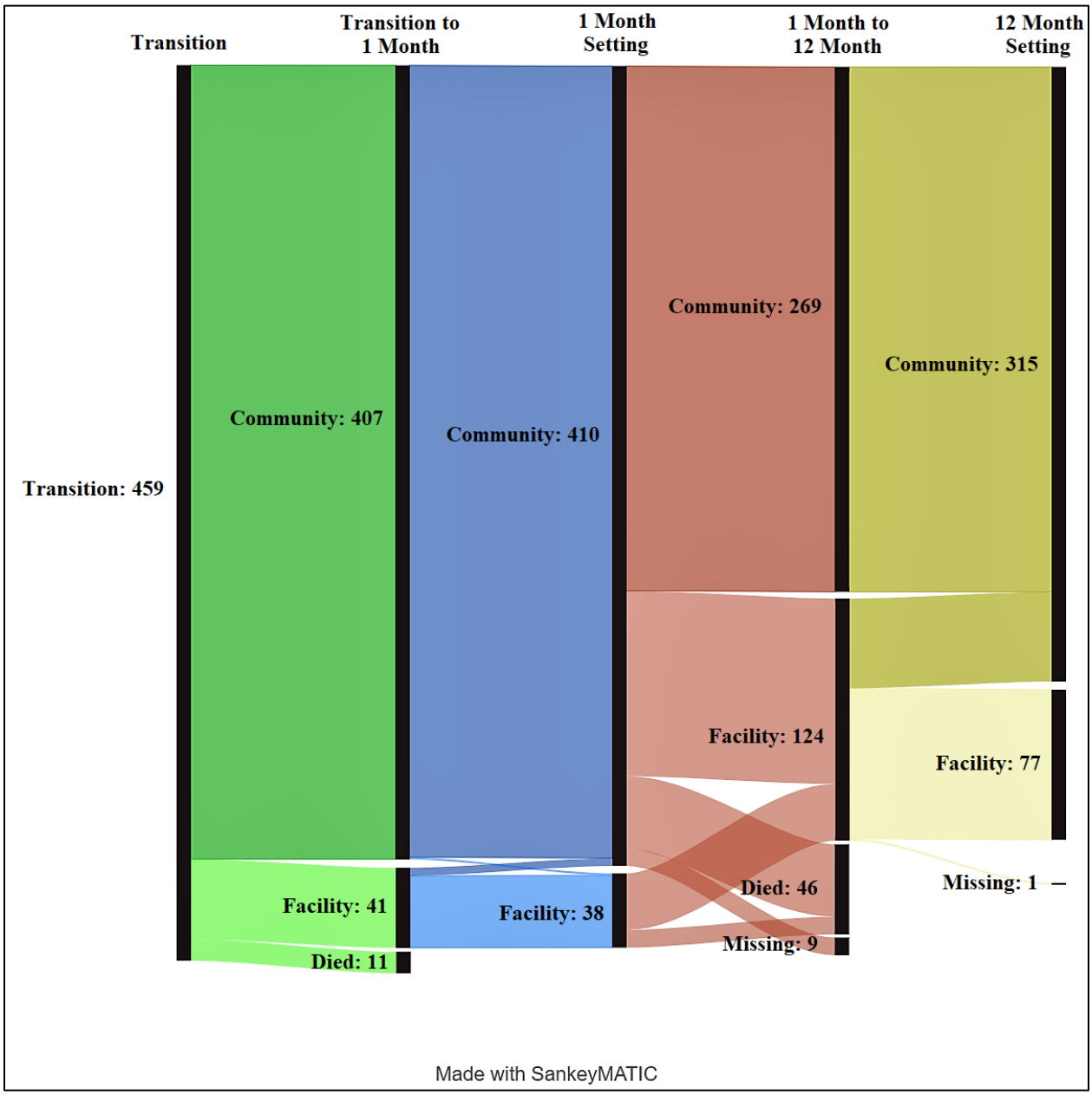
Sankey diagrams illustrate the flow and quantity of cases from one point to the next, or from one point through several different points of time. The proportion of cases determines the size of each flow relative to the total sample. In health policy research, Sankey diagrams often provide a visual aid 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 2021 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, 9% of participants returned to a facility for either a short-term or long-term stay within a month after their transition. With only a small number of (n=3) discharges by 1 month post transition, 8.5% 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 (32%) 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 20%.

Overall, the setting, reinstitutionalization, and death rates are very similar to those in the 2021 report, with a few of exceptions. This year there was a noticeable increase in consumers who experienced a reinstitutionalization from 1 month to 12 months (25% 2021, 32% 2022). There was also an increase in the percentage of consumers residing in a facility at 12 months (15% 2021, 20% 2022). The percentage of consumers who died over the span of their transition to 12 month time point decreased slightly at both the 1 month post transition (3% 2021, 2% 2022) and 1 to 12 months (11% 2021, 10% 2022).

Figure 6.1. Diagram of Participant Setting and Facility Use from Transition to 12 Months for 2021 Transitions

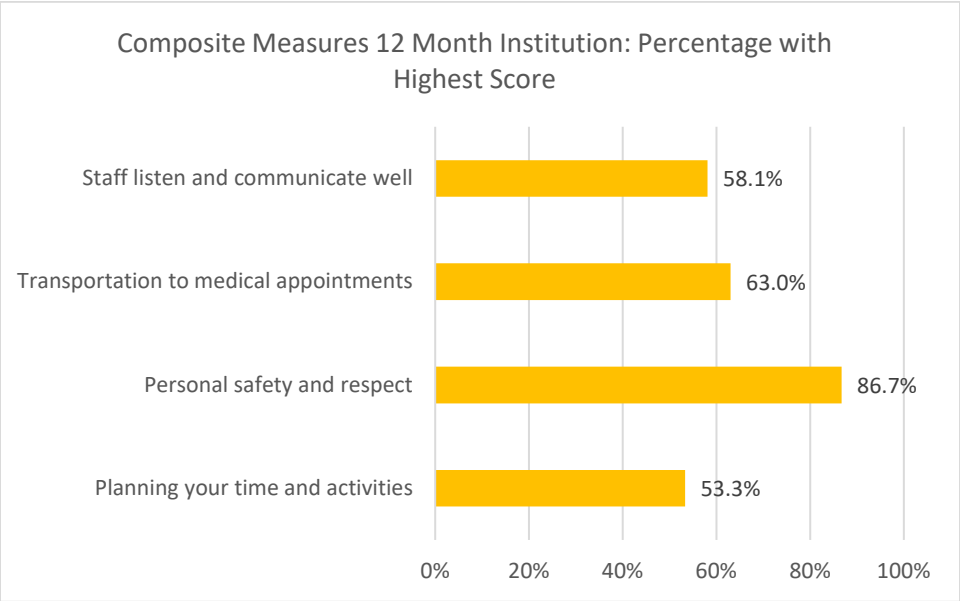



SankeyMATIC: A Sankey Diagram Builder for Everyone. http://sankeymatic.com

### *2021 12 Month Institution: Select Results*

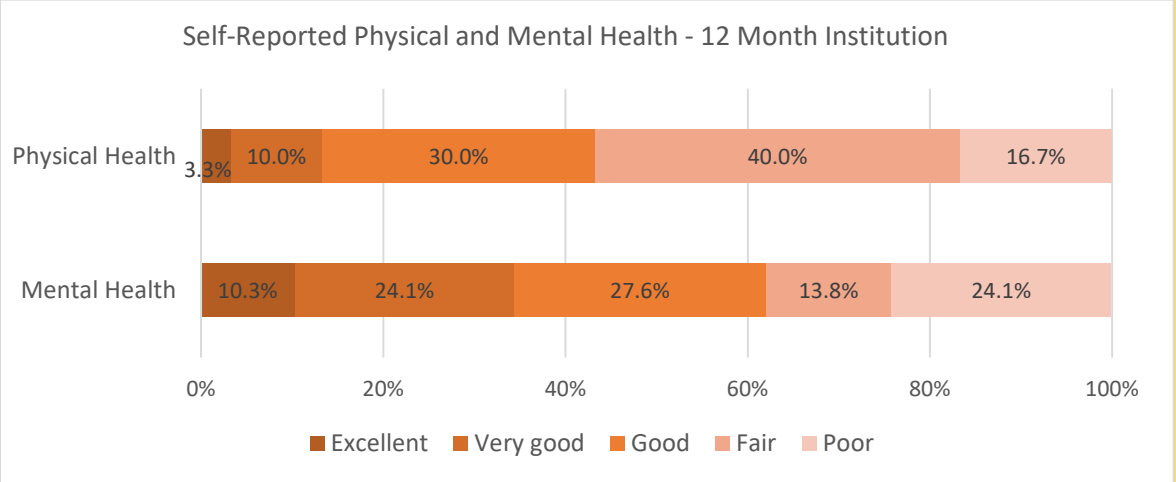
The following figures present 2022 survey data for the 31 consumers who transitioned in 2021 and were in a facility at 12 months. See Section 3 for comparative results for consumers in the community at 12 months. Compared to last year, the percentage of consumers in a facility at 12 months giving the highest score for medical transportation decreased significantly this year (88% 2021, 63% 2022).

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



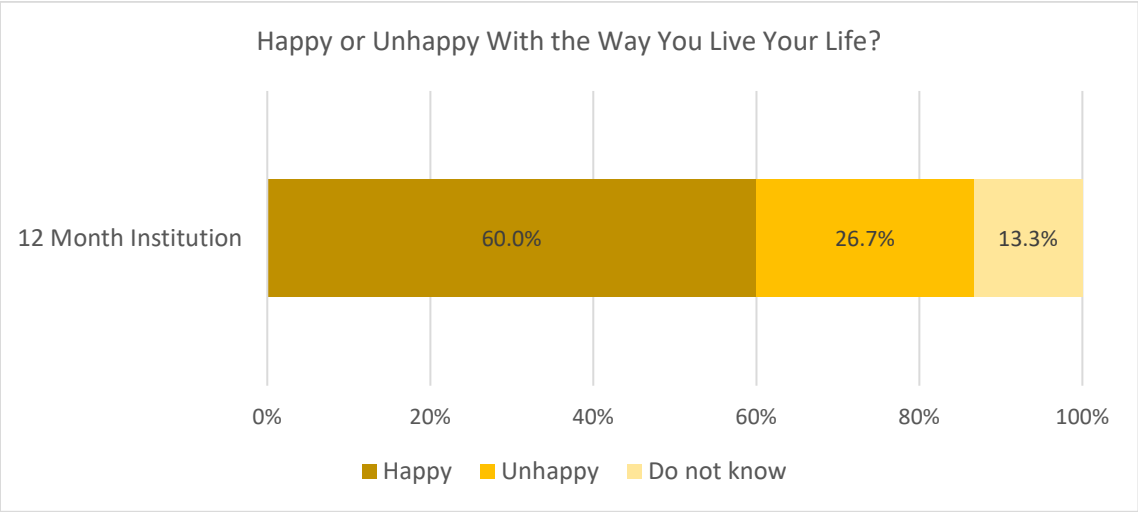

As expected, consumers in an institution at 12 months were much more likely to report fair or poor physical health than those in the community (57% institution, 34% community) (Figure 6.3). Institutionalized consumers were also more likely to report fair or poor mental health (38% institution, 26% community).

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




Half (50%) of consumers institutionalized at 12 months reported depressive symptoms, as did 35% of community consumers. In addition, 60% of reinstitutionalized consumers said they were happy with the way they live their life, compared to 73% of community residing consumers (Figure 6.4).

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




## B. Experiences Leading to Reinstitutionalization by the One Month Survey – Consumers Who Transitioned in 2022

This section provides an overview of the experience of reinstitutionalization at one month post-transition for consumers who transitioned in 2022. 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 422 consumers transitioned in 2022. Of these, 264 consumers completed a 1 month survey before the end of the year. Almost all consumers (94.3%, n=249) who completed a 1 month survey were living in a community setting at the time of their interview. Four of these consumers had been reinstitutionalized temporarily after transition, resulting in an overall readmission rate of 7.2% (n=19) by the 1 month survey (Table 6.2). This re-institutionalization rate for 2022 transitions is equivalent to the rate for 2021 transitions.

Table 6.2. Transitioned in 2022 – Experienced Reinstitutionalization by 1 Month Survey

| | n (%) |
|---|---|
| Total 1 month surveys | 264 (100.0) |
| | |
| Experienced readmission by one month survey | |
| No – Always in the community | 245 (92.8) |
| Yes – Reinstitutionalized either short or long-term | 19 (7.2) |

### *Consumer Characteristics*

Consumers who experienced reinstitutionalization by their 1 month survey did not differ from those always in the community by service type (Table 6.3).

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

| Service Type | Always Community N=245 n (%) | Ever Reinstitutionalized N=19 n (%) |
|---|---|---|
| Waiver | 194 (79.2) | 15 (78.9) |
| State plan | 51 (20.8) | 4 (21.1) |

This population was 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 | 73 (29.8) | 3 (15.8) |
| | 55-64 | 76 (31.0) | 7 (36.8) |
| | 65-74 | 56 (22.9) | 5 (26.3) |
| | 75+ | 40 (16.3) | 4 (21.1) |
| Race | | | |
| | White | 155 (63.5) | 15 (78.9) |
| | Black | 64 (26.2) | 4 (21.1) |
| | Other | 25 (10.3) | 0 (0) |
| Gender | | | |
| | Male | 117 (48.0) | 6 (31.6) |
| | Female | 127 (52.0) | 13 (68.4) |
| Education | | | |
| | < High School | 40 (16.7) | 5 (26.3) |
| | High school degree | 100 (41.7) | 6 (31.6) |
| | > High school | 100 (41.7) | 8 (42.1) |

### *Physical and Mental Health at One Month*

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

Figure 6.5. Self-Reported Physical Health


Figure 6.6. Self-Reported Mental Health

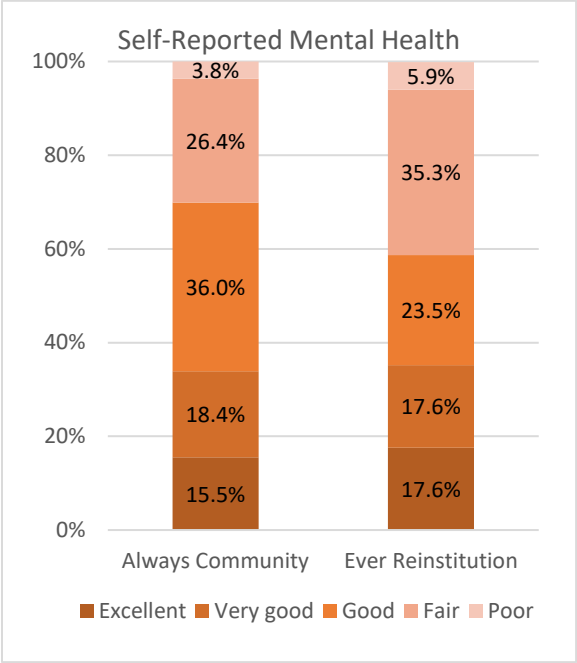
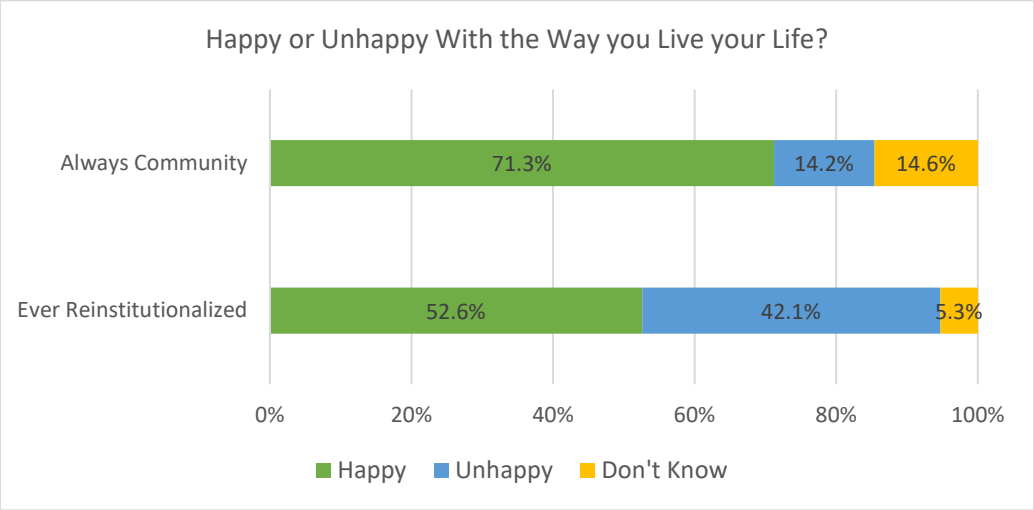



Table 6.5. Depressive Symptoms: Always Community vs. Ever Reinstitutionalized

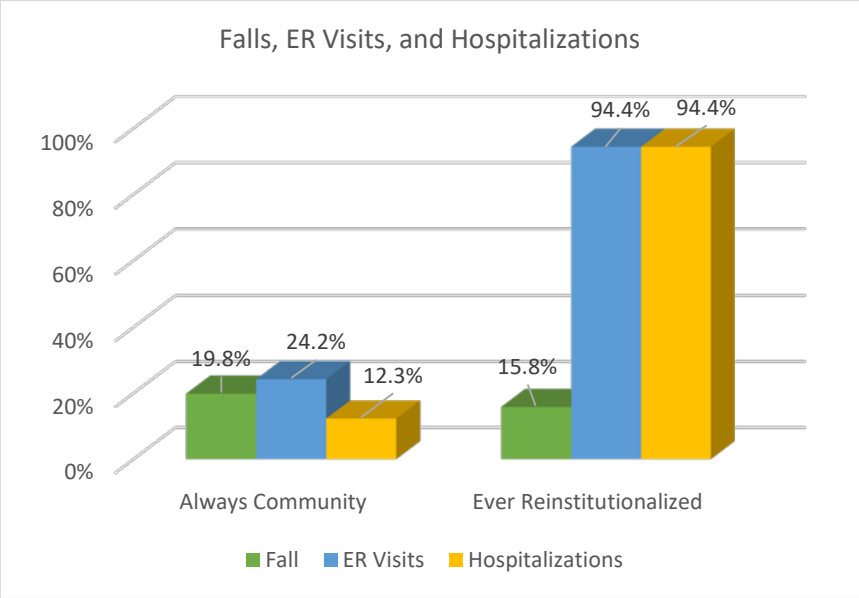
| Depressive Symptoms | Always Community n (%) | Ever Reinstitutionalized n (%) |
|---|---|---|
| Yes | 83 (34.4) | 11 (57.9) |
| No | 158 (65.6) | 8 (42.1) |

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



Consumers who experienced reinstitutionalization had very high rates of emergency room and hospital use, which likely led to their subsequent returns to a nursing facility (Figure 6.8). However, unlike last year, consumers who were always in the community were more likely to report a fall.

Figure 6.8. Falls, ER Visits, and Hospitalizations




## *The Consumer Experience*

Case histories for each of the 19 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. Composite vignettes provide more insight into the consumer's and family member's experiences, as well as the often-overlapping issues contributing to reinstitutionalization.

### Physical health decline post-transition

As in 2021, 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 developing pneumonia, 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, or even started using a wheelchair. Likewise, consumers who could transfer on their own with a little informal assistance in the facility, once home needed assistance from 2 people or even a lift device to get in and out of bed. Many of these consumers already had existing serious chronic and progressive conditions such as congestive heart failure or kidney disease. Other factors in health decline included

lack of professional medical care, relying on family members to provide complex care, falls with injury, and consumer mental health challenges. Other times it was not known why a consumer's physical health declined so rapidly after transition.

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

Lack of special medical equipment, such as a hospital bed or assistive devices, was another reoccurring issue leading to facility readmission. Sometimes this happened within the context of other circumstances, such as the unanticipated need for equipment due to consumer physical function decline post transition or insufficient support once in the community. Other times the equipment or modifications were approved and in process but were not in place at the time of transition. One consumer with multiple medical issues, including stroke with partial paralysis and insulin dependent diabetes, had to find an apartment quickly after the facility gave him a 30 day discharge notice. The apartment found fit his walker which he ambulated with when inside, but not his wheelchair which he used when out in the community. The consumer decided to take the apartment before the interior doors were widened. Immediately after transition, he began to use his wheelchair full time, which would not fit through the doors. This led to falls, the development of a deep vein thrombosis as well as other medical complications, and a reinstitutionalization.

### Lack of family or informal support

Family or other informal supports can play a critical role in the consumer's community supports, providing various assistance such as personal or medical care, medication management, supervision, or household tasks, or transportation (Reinhard et al., 2019). Informal support is especially important for consumers who live alone with no or limited paid supports. Regular check-ins or visits by friends or family can identify unanticipated issues and help resolve them before it becomes too much for the consumer or paid caregiver to handle. In addition, family are often the identified back-up in the care plan. At times consumers transition with ongoing health conditions which require more medical care than can be provided by paid supports, and family members agree to provide this care so their loved one can come home.

While family or friends can often fill in occasionally or in the short term, providing daily informal support can be too hard for some. One family found that caring for their loved one with dementia and physical impairments was too difficult, even using the adult family living (AFL) program. Notes indicate that the family might not have understood the full extent of care needed. The AFL family PCA found it difficult to successfully assist with hands on care and behavioral situations; meanwhile other family members found it too much to provide the necessary daily respite as the consumer could not be left alone. Once the family member being paid as the live in caregiver decided he could no longer do so, the family asked that their loved one be readmitted long-term to a facility.

### Physical health care and medication issues

Inadequate post-transition medical care, such as medications, nursing, or doctor visits, also played a role in readmissions within the first few weeks. Medication issues included incorrect medications, no refills, wrong dosage, lack of needles, and consumers refusing to take prescribed medications. There were nursing home errors, such as when the facility did not order the consumer's pre-filled diabetic needles. Another consumer did not go to their scheduled post-transition doctor appointment, which meant they ran out of pain medication. In another instance, the community provider increased a consumer's insulin dosage, despite logs showing blood sugar control with current prescription. The consumer became unresponsive, was hospitalized, and readmitted to a facility for stabilization and to treat unhealed diabetic wounds.

### Mental or behavioral health issues

A worsening or exacerbation of mental or behavioral health issues lead to the 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. In addition to poor adjustment to community living, other behavioral health issues which contributed to reinstitutionalization included consumer non-compliance with medical or self-care and not accepting the supports and services needed for stability in the community. Refusing to take medications or accept medical care was a factor in several of these situations. These issues also led to other challenges to community living, such as a decline in an otherwise stable physical condition or inability of family or friends to continue to provide informal assistance.

### 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." These consumers often use a combination of medical or behavioral supports, PCA, and informal care. Their health care regimens can include a complex combination of medications, nursing and doctor visits, wound care, injections, and weekly special treatments, and entails daily coordination and management. For these consumers, living in the community requires that everything go according to plan – an issue with one support or condition can cause others to fail, leading to reinstitutionalization. With comorbidity, the worsening of one medical condition can have a negative effect on another.

For example, one PCA waiver client's medical conditions included sliding scale insulin dependent diabetes, congestive heart failure, end stage renal disease with dialysis three times weekly, open wounds, leg amputation, and human immunodeficiency virus. Behavioral health issues included poor self-care, poor insight, and history of gambling. Prior to transition, his health care, including wound treatment, insulin, complex medication regime, and dialysis, was managed by the facility. Upon transition the facility did not provide the right medication dosages or diabetic needles. The facility also changed his dialysis days upon transition, which caused him to miss his scheduled doctor's appointment. This meant nursing for wound care was not ordered. Although the facility reported the consumer had insulin injection training, once in the community he could not administer his insulin. Unfortunately, he did not take his other medications regularly and refused PCA services. His wheelchair was stolen, and to get around he sometimes crawled, creating more wounds. His body could not effectively fight off new infections in his foot and dialysis port, and he subsequently developed sepsis, was hospitalized, and re-institutionalized.

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

Another reoccurring theme was lack of PCA, homemaker, or other non-medical homecare services. For example, sometimes PCAs did not show up, come on time, or left early. Consumers who self-directed their PCAs found it difficult to find and hire enough PCAs, leading to instability in care. One consumer lost their self-hired PCAs because of COVID concerns. Personality differences or poor quality care also contributed to staff turnover. In some cases, consumers found themselves without assistance or necessary personal care until their next scheduled PCA arrived. Sometimes HCBS were not started due to a delay in nursing coming out to open the case. The lack of enough services was especially difficult for consumers without readily available family members or friends to fill in the gaps. At times it was not clear if the lack of HCBS was because of these workforce related issues, or if the care plan just did not support enough assistance.

Consumer physical and mental health decline could exacerbate this challenge. For example, one consumer transitioned with a live-in PCA, but soon began to refuse to get out of bed and became a two person transfer. Ambulation required two people to hold her up. The PCA could not do this on her own, and the family member back-up was unable to provide this daily assistance.

### 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 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 this year was that of consumers leaving the nursing home under might be considered unstable or unsafe circumstances. Different factors played a role in this situation. For example, one consumer was approved for more than 40 hours of self-directed PCA hours but decided to use only 40 hours so they could transition more quickly with just one hired PCA. Unfortunately, their PCA quit shortly after transition, and without any PCA assistance, the consumer was re-admitted to a facility. Other consumers decided to leave without approved durable medical equipment or completed home modifications. Living alone, without any informal supports or emergency back-up, was a factor in other sudden reinstitutionalizations.

Another example is a consumer whose medical conditions included history of seizures, falls resulting in broken bones, unsteady gait, bipolar disorder, hypertension, and COPD. While in the facility, the consumer accessed mental health services at a community clinic; they were also known to DMHAS. Able to do all ADLs independently and with stable mental health, the consumer was approved for state plan services only. The day after transition a referral was made to the Mental Health Waiver, but waiver services did not start until two and a half weeks later. With limited non-specialized services, the consumer's mental and physical health deteriorated markedly during this time. The consumer had been managing their own medications, and no nursing services were in place at transition. However, the consumer stopped going to their regular mental health provider and began to not take their medications regularly. They experienced physical health decline, fell, and began to use a walker. After going to the ER due to inability to stand, it was determined that two of their medications were apparently prescribed at too high a dose. The consumer was re-admitted to a facility for physical and mental health stabilization.

### Falls with injury

Falls with injury also led to readmissions soon after transition. Most often falling did not happen in isolation of other issues but resulted from a combination of factors such as functional decline, not enough assistance, or missing DME or other equipment. Medication mismanagement also contributed to falls, especially falls without reported injuries, such as a consumer who slide down the wall apparently due to low blood sugar.

Overall, consumers who had experienced reinstitutionalization by the time of their 1 month survey reported worse physical and mental health, and greater emergency room and hospital service use. For example, 47% rated their help as fair or poor, compared to 39% of consumers who were always in the community since transition. Qualitative themes most commonly associated with either a short or long-term reinstitutionalization for these consumers included physical health decline post-transition, lack of necessary home modifications or assistive devices, lack of or limited family or informal support, medication and health care issues, consumer mental or behavioral health issues, medical complexity, lack of PCA and other nonmedical HCBS, unstable transitions, and falls with injury.

## III. Conclusions and Recommendations

### *Surveys completed in 2022*

A total of 569 HCBS CAHPS surveys were completed with MFP participants in 2022: 300 1 month and 269 12 month surveys. Proxies completed 22% of surveys in 2022, which is 5% lower than in 2021 but not back to the pre-pandemic proxy rate of 15%. This is likely still driven by the low percentage of in-person surveys relative to pre-pandemic ratios (in-person surveys: 19% 2019, 1% 2022).

### *1 Month Community Surveys Completed in 2022*

This section examined data from the 281 1 month surveys completed in 2022 with community residing consumers. The percentage of consumers who gave high scores to the composite "planning your time and activities" which includes community involvement, increased this year, from 53% in 2021 to 60% in 2022. Still, planning your time and activities continues to be the lowest performing composite, which indicates an area for program improvement. The composite "choosing the services which matter to you" increased somewhat, from 65% in 2021 to 69% in 2022. Despite these gains, over one-third (36%) of consumers reported depressive symptoms, compared to 29% in 2021. Although 77% of consumers gave the medical transportation composite the highest score, there were still multiple comments about poor transportation service to both medical and nonmedical appointments. Another notable finding was the unmet need for assistive devices, equipment, and home modifications. At 1 month post-transition, one-third of consumers said they still needed at least one or more of these items, compared to one-quarter of consumers in 2021. 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 2021*

A total of 459 consumers transitioned in 2021. Altogether, they completed 598 HCBS CAHPS surveys: 340 1 month and 258 12 month surveys. This section reported on the 1 or 12 month surveys completed with consumers residing in the community at the time of their survey (n=544), looking in particular for notable differences by survey time point. Consumers at the 1 month survey reflected on their experiences since transition; at the 12 month survey, consumers considered their experiences in the last 3 months.

When asked about service use, self-reported use of PCA or homemaking services did not show significant changes from 1 to 12 months, while use of case management services decreased over time. This is not unexpected, as after 3 months any MFP "case management" is reduced to monthly check in calls by the TC.

Similar to 2021, community residing participants gave three composites comparatively low scores at both 1 and 12 months: choosing your services, medical transportation, and most notably, planning your time and activities. However, the percentage who gave planning your time and activities the highest score at 12 months increased notably over the previous year from 48% in 2021 to 58% in 2022. Choosing the services that matter to you fell from 2021 to 2022, continuing a downward trend: in 2020 73% gave this composite the highest score, compared to 69% in 2021, and 67% in 2022. 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. In addition, some consumers expressed struggles with loneliness and lack of social connection, especially those living alone. Connecting to one's community does not automatically happen upon transition, and this is one area where MFP might consider providing more support. For example,

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.

While about 70% of community participants rated their current PCAs/RAs/ILSTs a nine or ten, consumers at both 1 and 12 months post-transition commented on the difficulties they had finding reliable and well-trained staff. Staff turnover, and lack of consistent, quality staff were most frequently mentioned in 2022. The different PCAs often did not know what assistance the consumer needed or how to best provide that support, which sometimes meant consumers and family members had to continually train new staff. Consumers also remarked on communication difficulties with the home care agencies. Consumer and staff expectations regarding tasks and responsibilities did not always match. Historically Connecticut has faced challenges recruiting and retaining people to work as PCAs or in other home care positions. Exacerbated by the pandemic, the workforce shortage continues to be a major challenge to home and community-based care (MACPAC, 2022). There is a critical need in Connecticut for high quality, consistent HCBS staff. Without an influx of trained workers, consumers who rely on paid staff for their independence may find it increasingly difficult to stay in the community.

Just over half (52%-55%) of consumers lived alone, and between 56-62% of 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.

Although physical health remained fairly stable over the year, consumer mental health worsened slightly. By 12 months post-transition 26% of community consumers rated their mental or emotional health as fair or poor, and 35% reported depressive symptoms. When asked if they were happy or unhappy with the way they live their life, 78% at 1 month and 73% at 12 months said they were happy. Comments indicated that becoming part of one's new community can be challenging. Socialization and connection to others are essential to one's mental and emotional health, and connecting consumers with community resources should continue to be a priority of the MFP program.

Assistive devices, special equipment, and home modifications are common among MFP consumers – 94% at either time point reported having at least one of these. Still, 24% of consumers at either time point lacked some type of device or modification needed to live in the community. At 1 month post-transition, consumers most commonly still needed a PERS (11%), home modifications (10%), or special medical equipment (7%). By 12 months, 11% still needed home modifications. Many participants do not have the financial resources to purchase these items on their own, and comments indicated that sometimes friends or family paid for items that were essential instead of waiting for doctor's prescription, Medicaid approval, or for home modifications to be completed through MFP. Obtaining needed home modifications, special medical equipment, and assistive devices by transition or within a week of being home should continue to be a priority. Better communication and more careful tracking of what participants still need may help meet this goal.

When asked about finances, over one-quarter of participants said they did not have enough money to make ends meet (28% 1 month, 26% 12 months). Comments indicated that food insecurity in particular continued to be a great concern in 2022, as it was in 2021.

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

This same cohort of community living consumers who transitioned in 2021 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). Over three-quarters of community consumers (78%) received waiver services at either 1 or 12 months post-transition. The percentage of waiver consumers at 1 month increased appreciably over last year when 71% of 1 month consumers met waiver requirements. Waiver consumers must meet facility level of care and are eligible for waiver HCBS at transition, while state plan consumers are not eligible for ongoing HCBS personal care or homemaking services. HCBS service use shows this contrast, as 81 to 82% of waiver consumers used personal care assistance at either time point, compared to 12% of state plan consumers. By 12 months post-transition, 61% of state plan consumers reported using no services, compared to just 5% of waiver consumers.

The difference in use of and experience with case management services between the two groups is 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. However, even at this time state plan consumers are much less likely to report having case management services – 82% of waiver consumers said they had case management services at 1 month post-transition, compared to just 54% of state plan consumers. It may be that state plan consumers do not see their TCs as case managers, given they get fewer services overall. Helping consumers better understand the different roles and responsibilities of their MFP team may clarify for all consumers whom the consumer should turn to after transition.

Although state plan consumers were less likely to have a case manager and/or paid staff, at one month state plan consumers gave the staff and care manager composites noticeably higher scores than waiver consumers. However, at 12 months this had reversed for the case management composite, as 86% of waiver consumers gave the highest score compared to only 69% of state plan consumers. State plan consumers were more likely to definitely recommend their case managers at both 1 and 12 months.

Consistent with last year's report, despite being a younger cohort, state plan consumers reported less social support overall. Consumers with state plan services were much more likely to live alone, were less likely to have family living nearby, and were much less likely to get unpaid help from family or friends. State plan consumers were also less satisfied with their living arrangements at 1 month and less likely to feel safe where they live at 12 months post-transition. While both populations reported high rates of depressive symptoms especially at 12 months (34-35%), by 12 months waiver consumer were more likely to rate their mental or emotional health as fair or poor. On the other hand, at 12 months post-transition, waiver consumers were more likely to report being happy overall (74% waiver, 67% state plan).

As might be expected, waiver consumers reported poorer physical health at 12 months, as well as higher rates of both hospitalizations and re-institutionalizations. Noticeably more waiver consumers reported having home modifications, mobility or medical equipment, or a PERS unit at both 1 and 12 months. This again may be an effect of the greater physical needs of waiver consumers. However, state plan consumers reported a greater unmet need for a PERS unit at both time points, and medical equipment at 12 months. Fewer state plan consumer had internet access 1 year after transition.

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

Community living consumers who transitioned in 2021 were stratified by service type into those using agency-based services versus self-directed consumers who hired their own staff. Although the majority of consumers used agency-based services at either time point (83% 1 month, 74% 12 month), use of

self-direction increased over the year from 17% at 1 month to 27% at 12 months. Similar to 2021, there were marked differences in age, with agency-based consumers twice as likely to be age 65 or older. Self-directed consumers were more likely to use PCA services, but less likely to use case management services despite having equal access to TC and SCM services post-transition. Consumers using self-direction must be able to manage their own services, or have a family member or friend do it for them, which might factor into self-reported use of case management services.

Self-directed consumers rated their personal care staff higher than agency-based consumers on almost all staff metrics at both time points. A greater percentage of self-directed consumers rated their PCAs a 9 or 10 and reported the highest scores for the two staff composites covering staff reliability, helpfulness, and communication. It is likely that being the employer, with increased opportunity to choose, train, and manage one's PCAs, allows for a better match and greater consumer satisfaction. However, unlike the previous year, self-directed consumers reported lower scores for choosing the services that matter to them.

Similar to years past, agency-based consumers were much more likely to live alone. Age differed as well, with agency-based consumers twice as likely to be age 65 or older. Not surprisingly given this age difference, agency-based consumers were less likely to report very good or excellent physical health and more likely to experience reinstitutionalization within a year of living in the community (18% agency-based vs. 11% self-directed). One the other hand, self-directed consumers were much more likely to need home modifications at both 1 and 12 months post-transition. For example, at 1 month 20% of self-directed consumers needed some type of home modification, compared to 9% of agency-based consumers. Differences in mental or emotional health between the two groups were also evident. Agency-based consumer reported better mental health at 1 month compared to self-directed consumers, but by 12 months the opposite was true. At 1 month, 41% of agency-based and 33% of self-directed consumers reported very good or excellent mental health, while at 12 months, 33% of agency-based consumers and 50% of self-directed consumers reported this. Self-directed consumers were also much less likely to say they were happy overall at 1 month post-transition (77% agency-based, 66% self-directed), although these differences decreased over time.

### *The Reinstitutionalization Effect*

#### Consumers who transitioned in 2021

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 2021 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, 9% of participants had returned to a facility for either a short-term or long-term stay. Unsurprisingly given the longer length of time, nearly one-third (32%) of consumers had been in a facility between the 1 month and 12 months survey. However, at 12 months post-transition, 20% of participants remained reinstitutionalized.

Select results showed that consumers reinstitutionalized at 12 months rated all staff, safety, medical transportation, and planning time and activities composites lower than consumers residing in the community at 12 months. Not surprisingly, consumers reinstitutionalized at 12 months also reported worse physical and mental health than community consumers.

#### Consumers who transitioned in 2022

Next, reinstitutionalization for consumers who transitioned in 2022 and completed a 1 month survey (n=264) was explored. Seven percent (n=19) of these consumers were either in a facility at the time of their 1 month survey or were in the community at 1 month but had been in and out of a facility since transition (short-term reinstitutionalization). Those who were reinstitutionalized even short-term by 1

month were more likely to be older, female, less educated, and White compared to those who were never reinstitutionalized. Consumers who were never readmitted to a facility by 1 month expressed better health outcomes on all but one metric. Consumers reinstitutionalized even short-term reported worse physical and mental health, more depressive symptoms, and increased unhappiness. Falls was the one exception this year, as consumers always residing in the community were slightly more likely to fall by their 1 month survey.

Consumers who had transitioned in 2022 and had experienced a reinstitutionalization by their 1 month survey were examined in more detail. Qualitative analysis identified common circumstances or issues associated with facility readmission. 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. Qualitative themes most commonly associated with either a short or long-term reinstitutionalization included physical health decline post-transition, lack of special equipment or assistive devices, lack of family support, physical health care and medication issues, mental health or behavioral issues, multiple serious comorbidities, unstable transitions, and falls with injury.

### *Final Thoughts*

Although faced with a variety  of challenges, from insufficient staff to health challenges and missing 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:

> *We are really appreciative of the program, which has allowed our son to make progress at home, which he did not in the inpatient setting.*
>
> *I appreciate [that] it's given me another chance. The PCA situation is unfortunate, but I am thankful I have been given another chance.*
>
> *Money Follows the Person program works. They bailed me out of rehab. I lost my apartment while I was in there, so they got me an apartment, phone, hooked me up with [town], food stamps, and money. Everything went through me. I thought I didn't deserve it. I can't say anything bad at all – can only say good things about MFP.*
>
> *I really am thankful for the program for getting me out of the rehab facility I was in. I think it is an excellent program.*
>
> *I am good with everything, I am happy, I am happy with the services and everything. I am blessed with the complete package. I do very well.*

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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),<br><br>AND<br><br>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),<br><br>AND<br><br>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.

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## *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 Services 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 |