

Money Follows the Person Rebalancing Demonstration

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

2020 Survey Results

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I. Introduction, Methods, and Analysis

As part of its 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 using the Consumer Assessment of Healthcare Providers and Systems Home and Community-based Services (HCBS CAHPS®) survey. This report uses MFP HCBS CAHPS survey results as well as data from MyCommunityChoices.com to explore the experiences of various groups of MFP participants, including those with 1 month surveys completed in 2020 and the 1 and 12 month surveys for the cohort of consumers who transitioned in 2019.

A. Money Follows the Person HCBS CAHPS® Survey

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

B. Survey Administration

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

C. Analysis

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

This report displays the percentage of participants who gave the most positive or highest composite score, global rating, or recommendation. To produce the highest composite scores, responses are divided into two groups: the most positive and all other responses. Likewise, each global rating is categorized as either the highest score (a 9 or 10, or verbal rating of excellent), versus all other

responses. Highest recommendation is determined similarly – only “definitely yes” is given the highest score, while the other three responses are grouped together.

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

Table 1. Key Measures*

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

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

II. Results

Results are divided into five sections:

➤ Section 1: Survey and Respondent Characteristics for Surveys Completed in 2020

A total of 850 HCBS CAHPS surveys were completed with MFP participants in 2020: 483 1 month and 367 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 2020

This section presents select results from the 459 1 month surveys completed in 2020 with consumers residing in the community. HCBS CAHPS key results and areas of interest from the previous 2019 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 2019

The full set of both 1 month and 12 month MFP HCBS CAHPS surveys are available for consumers who transitioned in 2019. 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 HCBS paid supports early and later in their post-transition journey?

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

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

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

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

- Section 6. The Reinstitutionalization Effect

This section examines the history and effect of readmission to a facility by following consumers from transition through their 1 or 12 month survey. First, the cohort of the 535 consumers who transitioned in 2019 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 2020 and were reinstitutionalized, long-term or temporarily, by their 1 month survey. Health, mental health, and service use items compare consumers who were never reinstitutionalized with those who experienced even temporary reinstitutionalization by 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 2020

A total of 850 HCBS CAHPS surveys were completed with MFP participants in 2020: 483 one month and 367 12 month surveys. While overall the majority of participants (93%) resided in the community at the time of their survey, at 12 months, one out of ten participants who completed a survey was in a facility (Table 1.1).

Table 1.1. Surveys Completed in 2020 by Setting

| | Community n (%) | Institution n (%) |
|------------------|--------------------|----------------------|
| 1 Month | 459 (95.0) | 24 (5.0) |
| 12 Month | 330 (89.9) | 37 (10.1) |
| All 2020 Surveys | 789 (92.8) | 61 (7.2) |

One month surveys were timed to be completed between 30 and 45 days post-transition. On average, 1 month surveys were completed 43 days post-transition, and 12 month surveys were completed an average of 11 months post-transition (Table 1.2).

Table 1.2. Time From Transition to Survey Completion in 2020: 1 Month and 12 Month Surveys

| | Minimum | Maximum | Mean | Standard Deviation |
|--------------------------|---------|---------|-------|--------------------|
| 1 Month Survey (Days) | 21 | 168 | 43.25 | 13.89 |
| 12 Month Survey (Months) | 10 | 15 | 11.37 | 0.74 |

Table 1.3 shows survey participants' home and community-based program at transition. 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 state plan or residential care home (RCH) services.

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 | 17 (3.5) | 17 (3.7) | 0 (0) | 9 (2.7) | 0 (0) |
| CHCPE-AB | 159 (32.9) | 148 (32.2) | 11 (45.8) | 101 (30.6) | 21 (56.8) |
| CHCPE-SD | 17 (3.5) | 17 (3.7) | 0 (0) | 14 (4.2) | 4 (10.8) |
| DDS waivers | 11 (2.3) | 11 (2.4) | 0 (0) | 19 (5.8) | 0 (0) |
| MH waiver | 14 (2.9) | 14 (3.1) | 0 (0) | 12 (3.6) | 1 (2.7) |
| PCA-AB | 27 (5.6) | 24 (5.2) | 3 (12.5) | 4 (1.2) | 0 (0) |
| PCA-SD | 102 (21.1) | 95 (20.7) | 7 (29.2) | 80 (24.2) | 2 (5.4) |
| State Plan/RCH | 136 (28.2) | 133 (29.0) | 3 (12.5) | 91 (27.6) | 9 (24.3) |

*See Appendix D for a complete list of acronyms

Table 1.4 shows survey and respondent characteristics for surveys completed in 2020. The COVID 19 pandemic severely limited the number of in-person surveys completed in 2020. In 2020, only 2% of surveys were completed in-person, compared to 19% in 2019. This in turn increased the number of surveys completed by proxy, as in-person surveys are often done to accommodate consumers with a communication/hearing impairment, those completing the survey with assistance, or those who are in an institution. In 2020, 22% of all 1 month surveys were completed by proxy, compared to 15% in 2019.

Table 1.4. Respondent and Survey Characteristics – Completed in 2020 by Time Point and Setting

| | | 1 Month Community n (%) | 1 Month Institution n (%) | 12 Month Community n (%) | 12 Month Institution n (%) |
|------------------------|---|-------------------------------|---------------------------------|--------------------------------|----------------------------------|
| Survey Respondent | | | | | |
| | By self | 314 (68.4) | 20 (83.3) | 229 (69.4) | 25 (67.6) |
| | With assistance | 45 (9.8) | 0 (9.7) | 22 (6.7) | 1 (2.7) |
| | By proxy | 100 (21.8) | 4 (16.7) | 79 (23.9) | 11 (29.7) |
| Assistant Relationship | | | | | |
| | Spouse/partner | 8 (17.0) | 0 (0) | 6 (26.1) | 0 (0) |
| | Adult child | 16 (34.0) | 0 (0) | 6 (26.1) | 0 (0) |
| | Parent | 4 (8.5) | 0 (0) | 0 (0) | 0 (0) |
| | Attorney or legal representative | 2 (4.2) | 0 (0) | 1 (4.4) | 0 (0) |
| | Paid staff person | 3 (6.4) | 0 (0) | 5 (21.7) | 0 (0) |
| | Other | 14 (29.8) | 0 (0) | 5 (21.7) | 1 (100.0) |
| Proxy Relationship | | | | | |
| | Spouse/partner | 17 (17.0) | 0 (0) | 10 (12.7) | 1 (<1.0) |
| | Adult child | 47 (47.0) | 4 (100.0) | 38 (48.1) | 7 (63.6) |
| | Parent | 8 (8.0) | 0 (0) | 13 (16.5) | 0 (0) |
| | Attorney or legal representative | 11 (11.0) | 0 (0) | 4 (5.1) | 3 (27.3) |
| | Paid staff person | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| | Other | 17 (17.0) | 0 (0) | 14 (17.7) | 0 (0) |
| How Person Assisted* | | | | | |
| | Answered some questions | 41 (87.2) | 0 (0) | 21 (56.8) | 0 (0) |
| | Restated/reminded/prompted for questions | 16 (34.0) | 0 (0) | 14 (37.8) | 1 (100.0) |
| | Translated questions | 5 (10.6) | 0 (0) | 2 (5.4) | 0 (0) |
| | Helped with use of assistive or communication equipment | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| | Other help provided | 1 (2.13) | 0 (0) | 0 (0) | 0 (0) |
| Survey mode | | | | | |
| | Telephone | 453 (99.1) | 23 (95.8) | 322 (97.6) | 34 (91.9) |
| | In-person | 4 (<1.0) | 1 (4.3) | 8 (2.4) | 3 (8.1) |
| Survey used | | | | | |
| | English | 430 (93.7) | 24 (100.0) | 307 (93.0) | 36 (97.3) |
| | Spanish | 29 (6.3) | 0 (0.0) | 23 (7.0) | 1 (2.7) |

*Could assist in one or more ways

Demographics among the four groups showed some differences between survey setting and time point (Table 1.5). Most notably, fully half of participants (50%) in an institution at 1 month were age 45 to 64; by 12 months, those age 75 and older made up the largest percentage (41%) of institutionalized respondents. 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).

Travers, J., Naylor, M., Coe, N., Meng, C., Li, F., & Cohen, A. (2021). Demographic characteristics driving disparities in receipt of long-term services and supports in the community setting. *Medical Care*, 59. <https://doi:10.1097/MLR.0000000000001544>

Table 1.5. Demographics – Surveys Completed in 2020 by Time Point and Setting

| | | 1 Month | | 12 Month | |
|-----------------|--------------------|-----------|-------------|-----------|-------------|
| | | Community | Institution | Community | Institution |
| | | % | % | % | % |
| Age | | N=459 | N=24 | N=330 | N=37 |
| | <18 | <1.0 | 0.0 | <1.0 | 0.0 |
| | 18-44 | 9.8 | 0.0 | 9.4 | 8.1 |
| | 45-54 | 15.7 | 4.2 | 15.2 | 2.7 |
| | 55-64 | 34.4 | 45.8 | 31.8 | 13.5 |
| | 65-74 | 19.8 | 29.2 | 22.4 | 35.1 |
| | 75+ | 19.8 | 20.8 | 20.3 | 40.5 |
| Language | | N=456 | N=23 | N=330 | N=36 |
| | English | 78.9 | 78.3 | 75.5 | 63.9 |
| | Spanish | 4.4 | 0.0 | 4.5 | 2.8 |
| | Multilingual/Other | 16.7 | 21.7 | 20.0 | 33.3 |
| Race | | N=446 | N=23 | N=322 | N=36 |
| | White | 69.5 | 82.6 | 64.9 | 83.3 |
| | Black | 23.5 | 4.3 | 28.6 | 11.1 |
| | Other | 7.0 | 13.0 | 6.5 | 5.6 |
| Ethnicity | | N=454 | N=23 | N=327 | N=36 |
| | Non-Hispanic | 84.1 | 91.3 | 83.2 | 83.3 |
| | Hispanic | 15.9 | 8.7 | 16.8 | 16.7 |
| Education Level | | N=446 | N=21 | N=322 | N=36 |
| | < 8th Grade | 12.1 | 9.5 | 13.0 | 5.6 |
| | Some high school | 14.8 | 23.8 | 14.3 | 8.3 |
| | High school degree | 43.9 | 19.0 | 42.5 | 44.4 |
| | Some college | 21.1 | 42.9 | 20.8 | 22.2 |
| | 4 year college | 5.6 | 4.8 | 5.9 | 13.9 |
| | > 4 year degree | 2.5 | 0.0 | 3.4 | 5.6 |
| Gender | | N=459 | N=23 | N=330 | N=36 |
| | Male | 51.0 | 39.1 | 51.5 | 38.9 |
| | Female | 49.0 | 60.9 | 48.5 | 61.1 |

Section 2. 1 Month Community Surveys Completed in 2020

This section presents select results from the 459 1 month surveys completed in 2020 with consumers residing in the community. Results include areas of interest from the 2019 report, in particular HCBS CAHPS key results, and case manager, physical/mental health, assistive devices, and home modification items. Although not shown, similar data from the 24 1 month institutional surveys is available for any specific questions.

Consumers reported using a variety of program services in the 1 month after transition, especially care management services (69%) and personal care assistance (64%) (Table 2.1). While most service use is similar to that reported at 1 month in 2019, case management service use increased by 5% in 2020. “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).

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

| | Community n (%) |
|--|--------------------|
| Personal care assistant/attendant services | 295 (64.3) |
| Behavioral health services** | 6 (1.3) |
| Recovery assistance services (MHW) | 12 (2.6) |
| Homemaking services or Homemaker-Companion | 238 (51.9) |
| Community Service Provider (MHW) | 8 (1.7) |
| Care management services*** | 317 (69.1) |
| Job coach or vocational supports | 0 (0) |
| None of these services | 59 (12.9) |

* Consumers can use more than one service

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

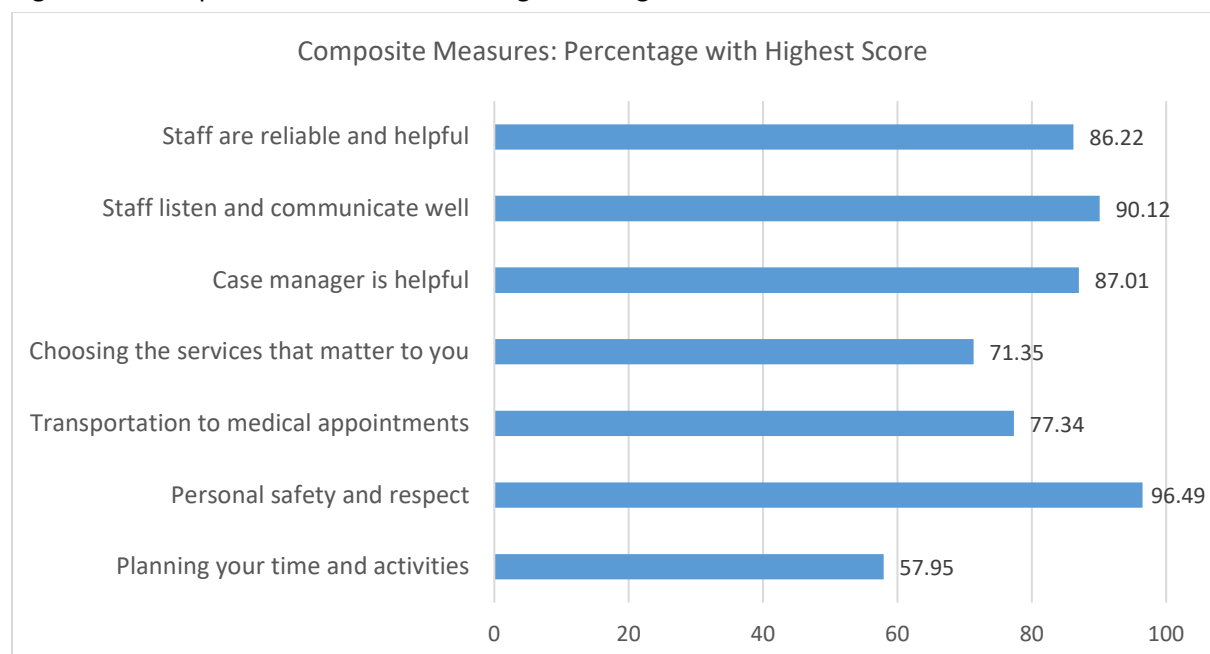
***Care management services can include TC, SCM, or other case management services

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. The composite measure “planning your time and activities” received a markedly lower score than the other composites – only 58% gave this the highest score, compared to 71% to 90% of the other composites (Figure 2.1). The planning your time and activities score is also noticeably lower than the 68% in 2019, which may be an effect of the COVID-19 pandemic as one consumer commented:

With COVID-19 I don't like the situation. We are stuck in our apartments, and we have been getting tested. I will like more time to go out into the community but I don't have a companion that can go out to the stores with me.

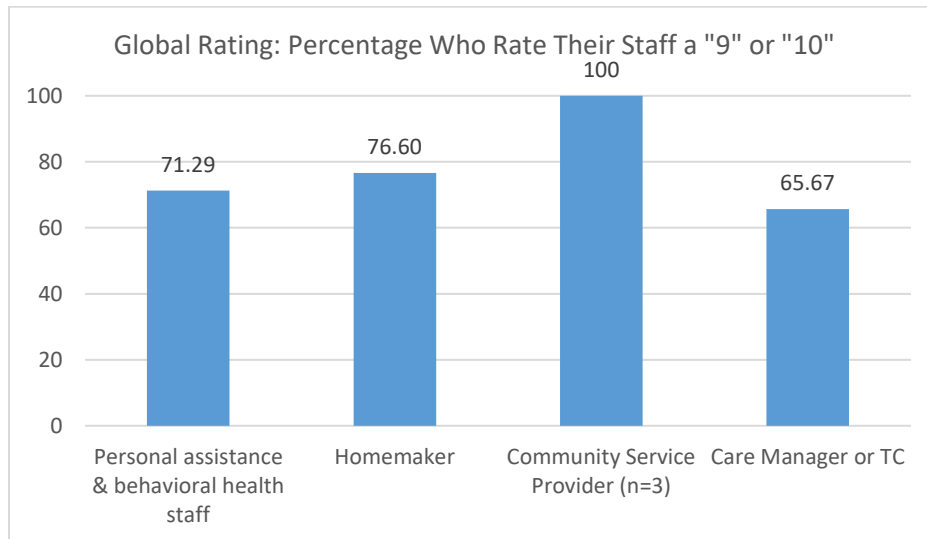
Figure 2.1. Composite Measures: Percentage with Highest Score



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

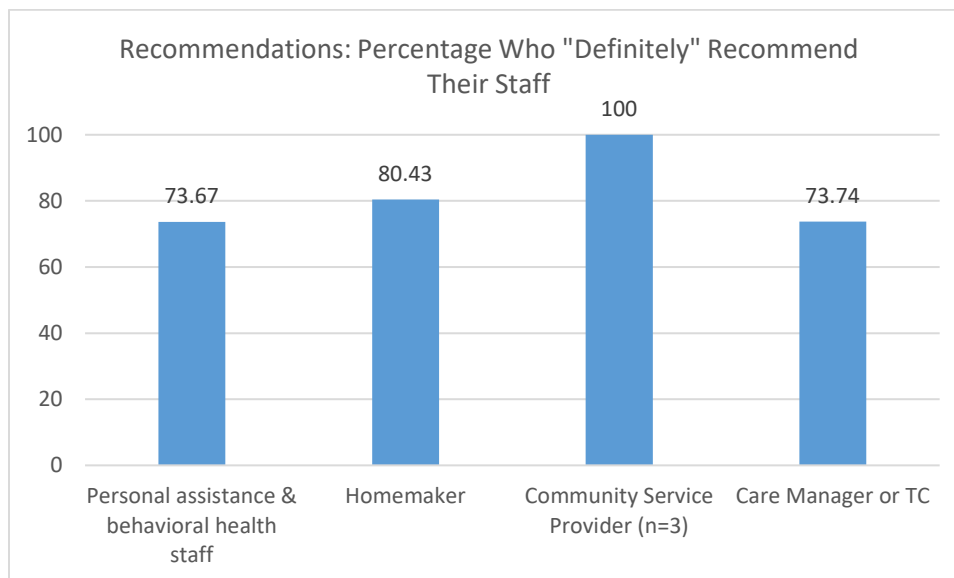
Figure 2.2 presents the percentage of consumers in the community who gave their staff the highest rating possible – a nine or ten, on a scale from zero to ten. More than three-quarters of participants rated their homemaking staff a nine or ten. Participants were more likely to give their personal assistant and behavioral health staff a 9 or 10 than their care manager/TC. However, when asked if they would recommend each type of service, consumers were as likely to “definitely” recommend their care manager/TC as their personal assistant and behavioral health staff (Figure 2.3)

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



Direct care staff

Although 74% of respondents would definitely recommend their PCA/behavioral health staff, and 80% would definitely recommend their homemaking staff, comments indicate that respondents do not always have good experiences with their PCAs and/or the home care agencies. Some consumers unexpectedly struggled to find assistance upon transition. For example, post-transition they found out that the agency did not staff their area or could not provide the PCAs, even after the agency told the SCM they would take the consumer as a client. In cases like these, family members often had to fill in as best they could. Others had issues such as PCAs not showing up or not completing their tasks, or had to change agencies until they found one who could provide quality caregivers.

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

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

MFP is a really great and important program. The care manager and TC have been great. My biggest issue comes from the agency that supplies the aides. The aides as well. The people from the agency are rude and always seem to act like things are my fault. The options for aides aren't great, and I've had far too many aides who just come in and sit on the couch. They always seem to have excuses as to why they can't come in or have to come late and leave early. I think these agencies need an overhaul.

Consumers completing their 1 month survey in 2020 often reflected on the influence of COVID-19 on their decisions and experiences in the month post-transition. The pandemic exacerbated the HCBS workforce shortage – more people chose to have services at home, but there were fewer professional staff to provide the care. PCAs and other paid caregivers did not want to potentially expose themselves or their families to COVID-19, and family members had similar concerns about being exposed to COVID-19 by paid staff. Comments indicated acquiring and using personal protective equipment (PPE) such as masks and gloves was also an issue, and PPE standards and guidelines among agencies varied.

The PCA is very attentive and has shown compassion, but is not properly trained on PPE or compliant with using PPE.

During COVID-19 there have been quite a few issues such as not having masks. Staff did not have training for working during COVID or for family visits. We finally received [Department of Developmental Services] guidelines. It took over a month for staff to wear masks. Today was the first day I have seen them wear masks. There is no thermometer to check each other or visitors. There is no due diligence. We are having a meeting with the case manager and supervisor this Friday.

Care manager

Most participants (81%) knew who their care manager was, and 91% could contact them when needed (Table 2.2).

Table 2.2. Care Manager Contact

| | Yes n(%) | No n(%) |
|---|-------------|------------|
| Know who care manager is | 322 (80.7) | 77 (19.3) |
| Able to contact care manager when need to | 279 (91.2) | 27 (8.8) |

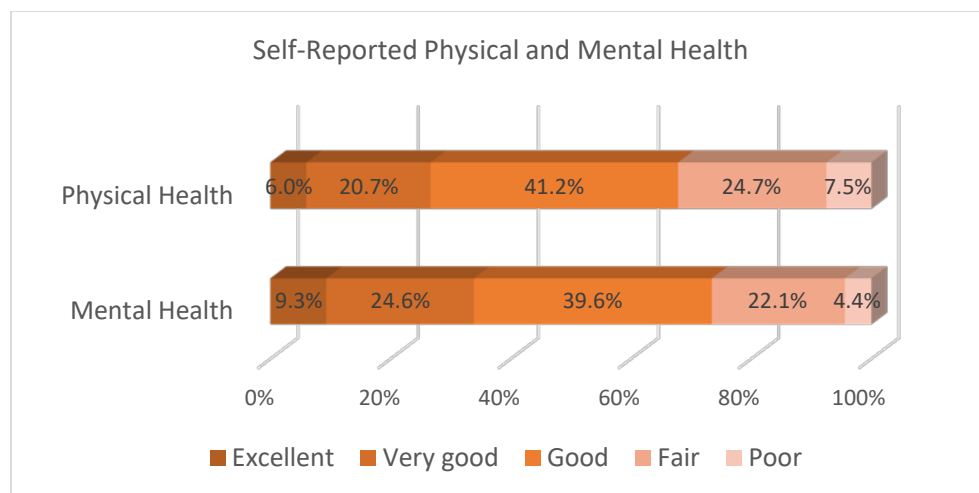
However, some respondents were confused about the care manager or TC role, such as the family member who commented, “We did not realize that the TC-Care Manager would be the person to go to for durable medical equipment or PCA changes.” The SCM is often responsible for securing agency-based PCA services, which for some did not always work out smoothly, while others found they needed more assistance than was planned for.

I cannot say that the program did not help, because it did. Because of COVID, I couldn't see how my husband was doing in person, what his room looked like, how he was improving – I only got information from phone. The PCA came here two times for a couple of hours, then stopped coming. I wish someone came here to reassess him, because he is declining mentally. He doesn't remember much, asks questions over and over. I have to work, I'm afraid when he is home alone. I tell him not to turn on stove. I feel like everything was left to me.

Physical and Mental Health

Figure 2.4 shows that about 40% of consumers rated their physical or mental health as good. One-third of consumers (32%) reported their physical health as fair or poor, and over one-quarter (27%) said their mental health was fair or poor. Further, 29 percent of consumers residing in the community at 1 month reported depressive symptoms, which is notably less than in 2019, when 35% of community consumers felt this way. It might have been especially uplifting for consumers to move out into the community in 2020, given the rapid facility spread of COVID and enforced social isolation from outside visitors. At 1 month post-transition, 15% of consumers reported falling since transition, and one-fifth of consumers had used the emergency room.

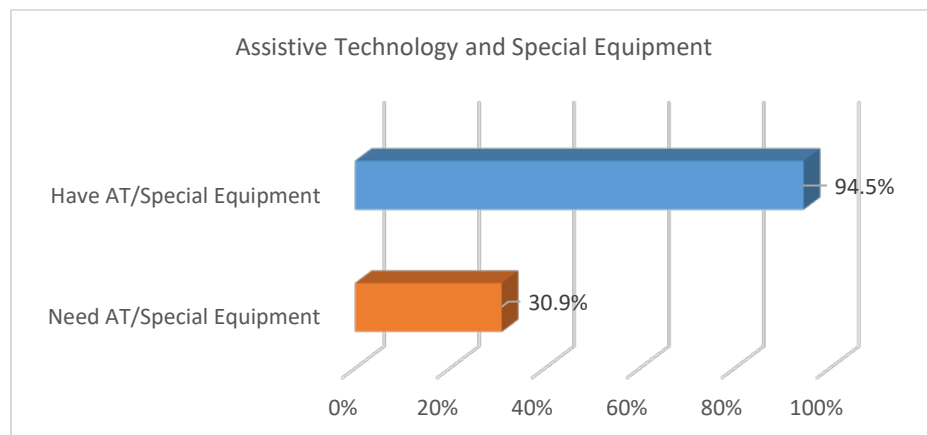
Figure 2.4. Self-Reported Physical and Mental Health



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 it is needed because of a disability or health condition and is allowable in the consumer’s 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 the vast majority of consumers reported having at least one type of assistive device or special equipment, nearly one-third 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).

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



Consumers most often reported having mobility equipment (85%), home modifications (69%), or special medical equipment, (69%) (Figure 2.6). When asked if they needed certain equipment, 14% of consumers still needed some type of home modification, 11% needed a PERS, and 7% needed some type of special equipment.

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

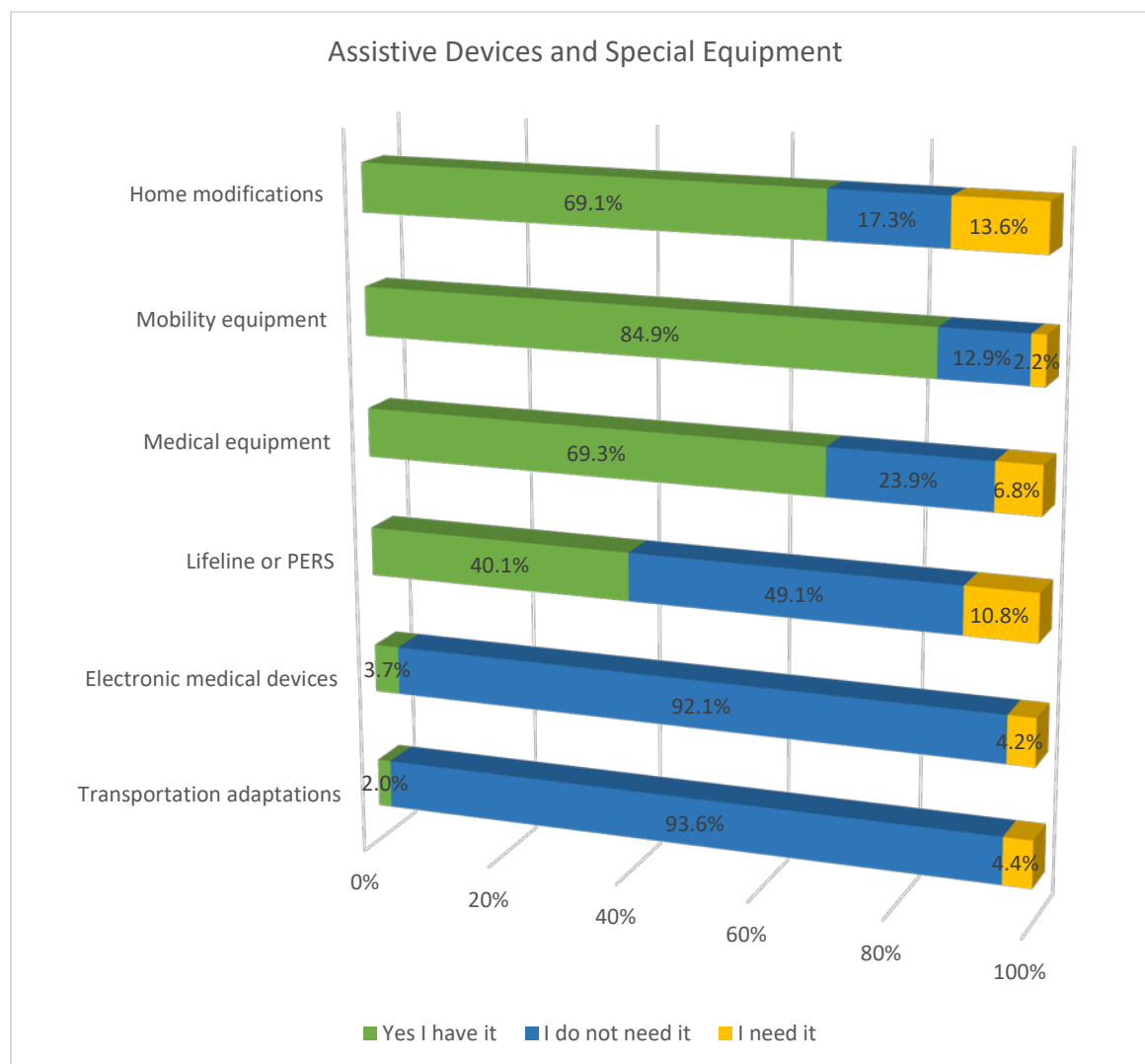
One of the biggest problems so far that wasn't addressed is medications. It was a nightmare getting all his meds he needed from the facility and getting his diabetes equipment. It was really scary for me because I had no way to check his blood sugar for a few days and that was simply not okay. There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

The shower chair and raised toilet arrived four weeks after transition. We used borrowed items before that. At six weeks post transition the ramp approved prior to transition has still not been built. The MFP budget did not cover things like the modified kitchen utensils [the consumer] needs, but we could not move money they were not using for one item to get the items [the consumer] needs because of her disabilities.

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

I'm waiting on my medical raised toilet seat, shower chair, and gel pad for my bed. Also I need Depends.

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



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

Section 3. Community Experiences from 1 Month to 12 Months Post-transition of Consumers Who Transitioned in 2019

The full set of both 1 month and 12 month MFP HCBS CAHPS surveys are available for consumers who transitioned in 2019. This section looks at the experiences of these consumers who 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 questions such as, 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 service differ from those using self-directed supports?

Respondent sample

A total of 535 consumers transitioned in 2019. Altogether, they completed 754 HCBS CAHPS surveys: 393 1 month and 361 12 month surveys (Table 3.1). About 90 percent of surveys were completed with consumers residing in the community, resulting in 356 1 month and 324 12 month community surveys. This section reports data from the 680 1 and 12 month community surveys.

Table 3.1. Surveys Completed for 2019 Transitions by Time Point and Survey Setting

| | Community Surveys n (%) | Institution Surveys n (%) | Settings Combined n (%) |
|------------------|----------------------------|------------------------------|----------------------------|
| 1 Month | 356 (90.6) | 37 (9.4) | 393 (100.0) |
| 12 Month | 324 (89.8) | 37 (10.2) | 361 (100.0) |
| Both Time Points | 680 (100.0) | 74 (100.0) | 754 (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.” The participant then determines for themselves if they had a care manager or someone who helped them in this way. All MFP consumers receive TC services for 6 months following transition and may receive short-term Specialized Care Manager (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 for the HCBS CAHPS reports.

Two types of HCBS showed noticeable differences from 1 month to 12 months – use of homemaking services increased, while case management services decreased. Homemaking services, such as housecleaning and laundry, can be provided by different types of caregivers, most often by PCAs or homemaker-companions. MFP Consumers may not have much case management support at 12 months after transition. After six months, MFP “case management” services are reduced to monthly check in calls by the TC, and waiver services may not have begun for waiver consumers, especially if they have not completed the 365 days post-transition, due to a hospital or other facility stay, by the time they complete the 12 month survey.

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

| | 1 Month n (%) | 12 Month n (%) |
|---|------------------|-------------------|
| Personal care assistant/attendant services | 233 (65.4) | 211 (65.1) |
| Behavioral health services (ABI, Autism, DDS) | 6 (1.7) | 5 (1.5) |
| Recovery assistance services (MHW) | 7 (2.0) | 9 (2.8) |
| Homemaking services or Homemaker-Companion | 171 (48.0) | 188 (58.0) |
| Community Service Provider (MHW) | 9 (2.5) | 5 (1.5) |
| Care management services | 223 (62.6) | 177 (54.6) |
| Job coach or vocational supports | 0 (0) | 1 (<1) |
| None of these services | 47 (13.2) | 53 (16.4) |

* Consumers can use more than one service

A. HCBS CAHPS Key Results

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

Composite measures

Figure 3.1 shows the percentage of participants in each setting who gave the most positive answer for each composite item. Notable differences include the drop in case manager helpfulness score from 1 month (87%) to 12 months (80%).

The program is excellent. The TC, they all did a wonderful job.

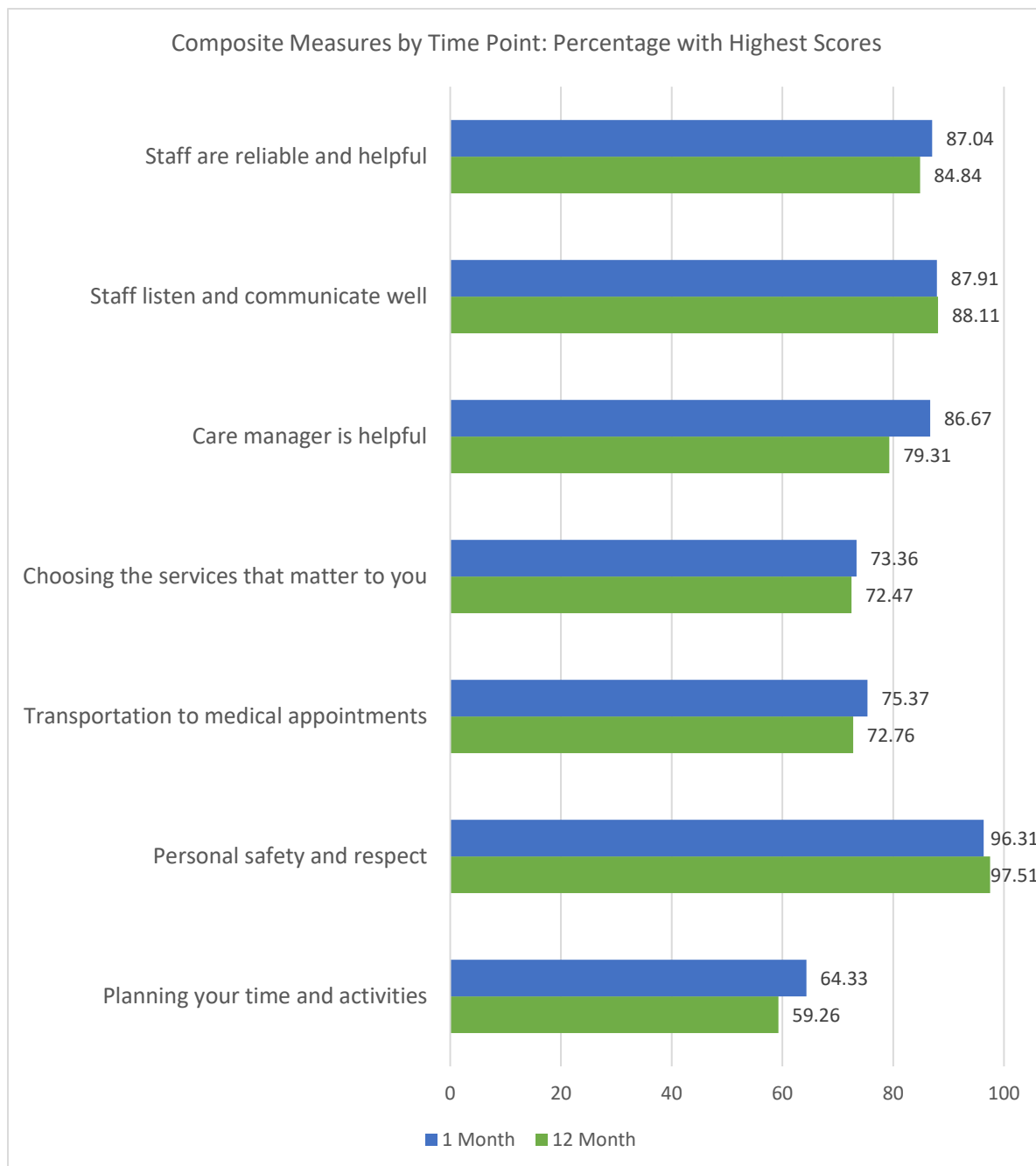
I have not gotten hold of my current case manager. My services have run out. I need to be re-evaluated.

Scores for the composite planning your time and activities also dropped. At 1 month, only 64% of consumers gave this composite the most positive score, and at 12 months this dropped to 59%. This latter composite includes community participation items such as seeing friends and family. COVID-19 was likely a factor for lower community participation in 2020; other comments indicated that community involvement did not happen automatically, and more support from the program would be helpful.

I feel like I was thrown in the community and was left to figure a lot out on my own. ... Even though I have an apartment now, I still can't get involved in my community and I feel like no one has or can help me with that part.

COVID has changed everything. I was hoping for social gatherings and to meet people in a new area where I did not know anyone. It is rough meeting any new people. Also due to COVID I have not had any routine medical appointments.

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



Global Ratings

Three-quarters of participants residing in the community rated their PCAs/RAs/ILSTs a nine or ten both at 1 and 12 months (Figure 3.2). As one community residing participant expressed, “I’m very happy with the services I have. My aide is great. He prays with me often.” Other consumers commented that they had had to change aides or agencies, that they needed more assistance, or better trained caregivers. Coordination between care providers was also an issue.

It took a good six to eight months to get competent help. Having all of these different people at the beginning was overwhelming.

I have a Hoyer lift, but it needs a two person assist and I just have the one live in aide. I haven't been able to get into my wheelchair.

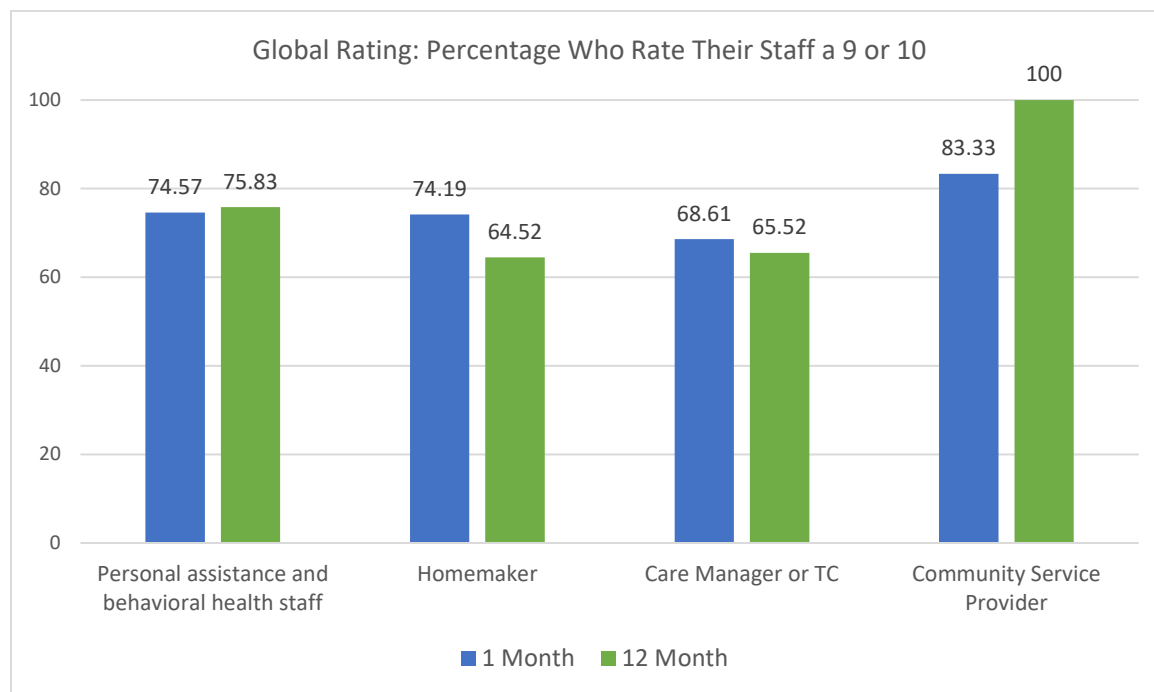
I had a lot of trouble with the first home care agency, but it's been a little better since switching to a new one. I still have a problem with them when one of my aides can't come in – they never have a replacement for me, and that's a big problem.

They are not training the PCA well – what dementia is, people with disabilities. The PCA does not give me concrete answers when I ask them what they cook for my father. My father has lost a lot of weight and I would like to know why. He just says he eats a little here and there. I'd also like to know why the nurse does not call me when she goes to see my father every time. I'd like to receive updates on his medical status.

I didn't know I could ask to have my hours increased. It'd be helpful if I could have more hours.

The percentage of consumers who rated their homemaking or homemaker/companion a 9 or 10 fell over the year post transition, from 74% at 1 month to 65% at 12 months. Approximately two-thirds of consumers would give their TC or case manager a 9 or 10 at both 1 and 12 months. Expressed one participant, “The TC is also very wonderful. I would give them a 10. We're lucky [participant] is home and not in a nursing home. Especially during COVID.” Meanwhile, 83% of MHW consumers rated their CSP a 9 or 10 at 1 month, which increased to 100% at 12 months (1 month n=6; 12 month n=2).

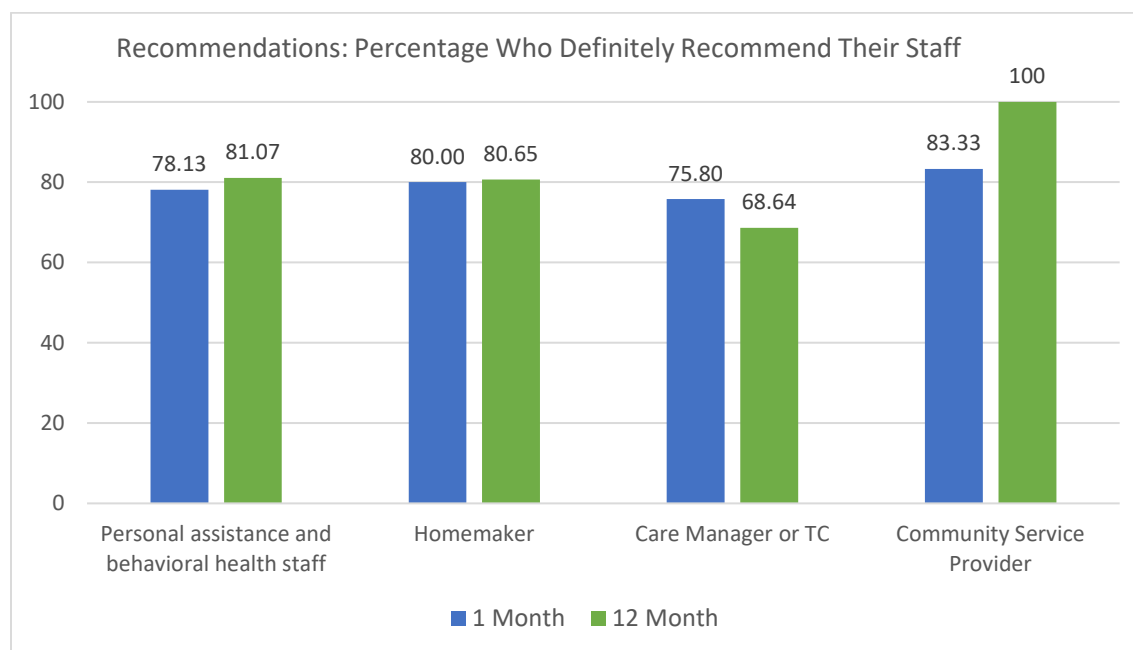
Figure 3.2. Global Rating by Time point: Percentage Who Rate Their Staff a “9” or “10” (Scale 0-10)



Recommendations

Although the homemaking staff top ratings went down over time, the percentage of consumers who would “definitely” recommend them stayed the same at about 80% (Figure 3.3). Most noticeably, the percentage of consumers who would definitely recommend their case manager fell from 1 month (76%) to 12 months (69%).

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 toileting (Table 3.3). Those who reported receiving homemaker services were considered to need help with housekeeping tasks such as cleaning or laundry. The greatest need for assistance for community consumers at both time periods was for personal care, which rose over the year from 83% at 1 month to 87% at 12 months. Use of housekeeping or laundry services rose over the year, 54% at 1 month to 62% at 12 months reported using these types of services.

Table 3.3. Self-reported Assistance with Everyday Activities

| Needs assistance with: | 1 Month n (%) | 12 Month n (%) 222 |
|-------------------------|------------------|-----------------------|
| Personal care | 200 (83.0) | 192 (86.5) |
| Meals or eating | 197 (81.7) | 188 (84.7) |
| Taking medications | 159 (66.0) | 146 (65.8) |
| Using the toilet | 145 (60.2) | 129 (58.1) |
| Housekeeping or laundry | 171 (54.3) | 193 (62.1) |

To determine unmet need in these areas, community consumers who had personal care staff were asked if they did not do the activity in the past three months specifically because of lack of staff to assist them. At 1 month, seven participants indicated one or more unmet need: 1 for personal care, 2 for

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

Participants not receiving personal assistance were asked if they always had the assistance they needed for bathing/dressing, meals, medications, and toileting. Four individuals at 1 month (6.9% of those asked) at 1 month and three participants at 12 months (5.2% of those asked) had an unmet need for one or more of these tasks.

Two 1 month and two 12 months participants reported that a staff person had hit them or hurt them. All four of these consumers said that the staff agency was working with them to resolve the problem.

C. Additional Staff and Care Manager Measures

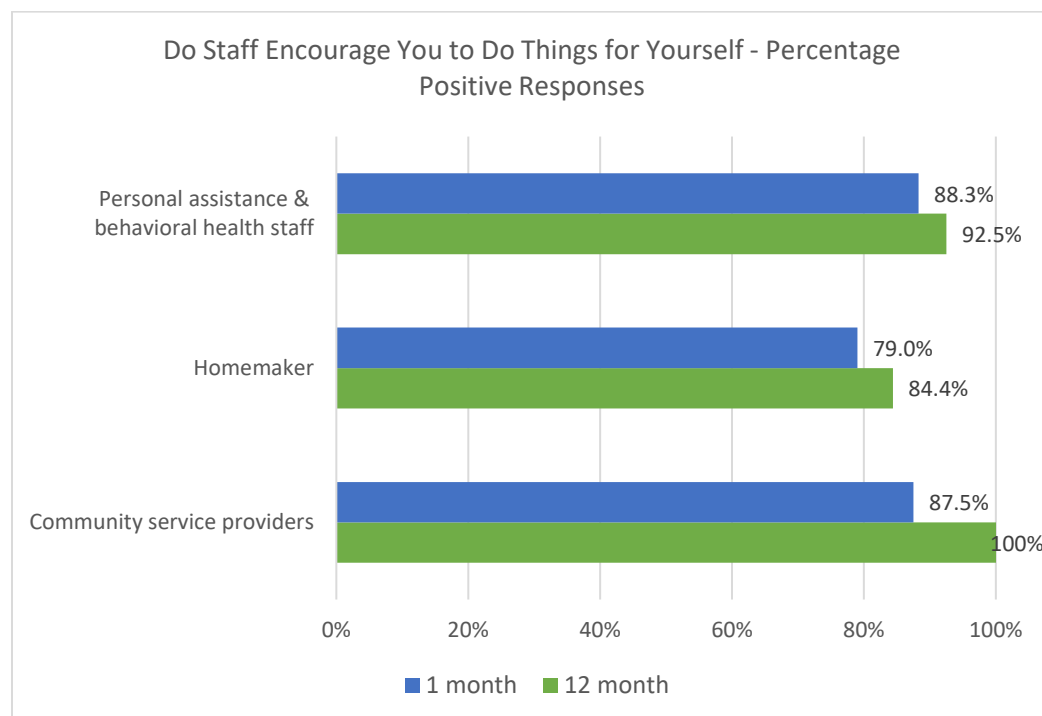
Personal Privacy and Encouragement

The majority of participants said their staff “always” provided them enough privacy for bathing or dressing (90% 1 month, 95% 12 month). A majority of participant also agreed that their staff encouraged them to do things for themselves, with percentages going up over time (Figure 3.4).

My aides and my sister are helping me be able to do things for myself. I can do more for myself than I did a year ago.

Since I've [been] here I have worked hard with my [physical therapy]. My PCAs had to use a Hoyer lift when I first got home and now I can walk. I was using a bed pan now I can go to the bathroom. I've made a lot of improvement. I didn't want to go back to the nursing home after being hospitalized from COVID. I need more PCA services and new PCA since I've been back from hospital. I'd like to know if I can receive Meals on Wheels and permanent mechanical wheelchair.

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

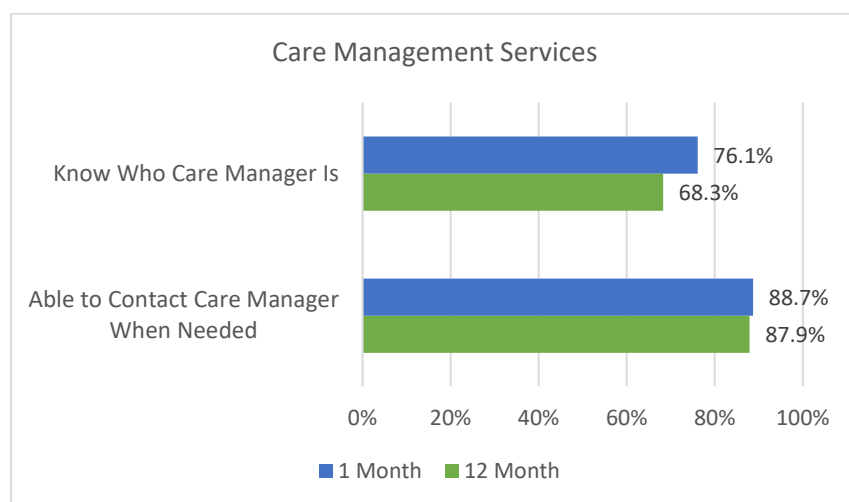


Care Managers and Care Plans

When asked if they knew who their care manager was, three-quarters of consumers at 1 month and two-thirds of consumers at 12 months said they did (Figure 3.5). A majority of these consumers at either time point were able to contact their care manager when they needed to.

Covid-19 does not allow home visits from the Case Manager from [agency], but they have frequent phone calls and answered questions based on this current arrangement.

Figure 3.5. Care Management Services - Percentage Positive Responses



At 1 month post-transition, 41% of consumer had asked their care manager for assistance with getting changes to their services, and at 12 months that percentage increased to 47% (Figure 3.6). Figure 3.7 shows that at either time point over half of consumers would contact their care manager for changes to their care plan. By 12 months, consumers were more likely to contact their family or friends than a home care agency to change their services (Figure 3.7).

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

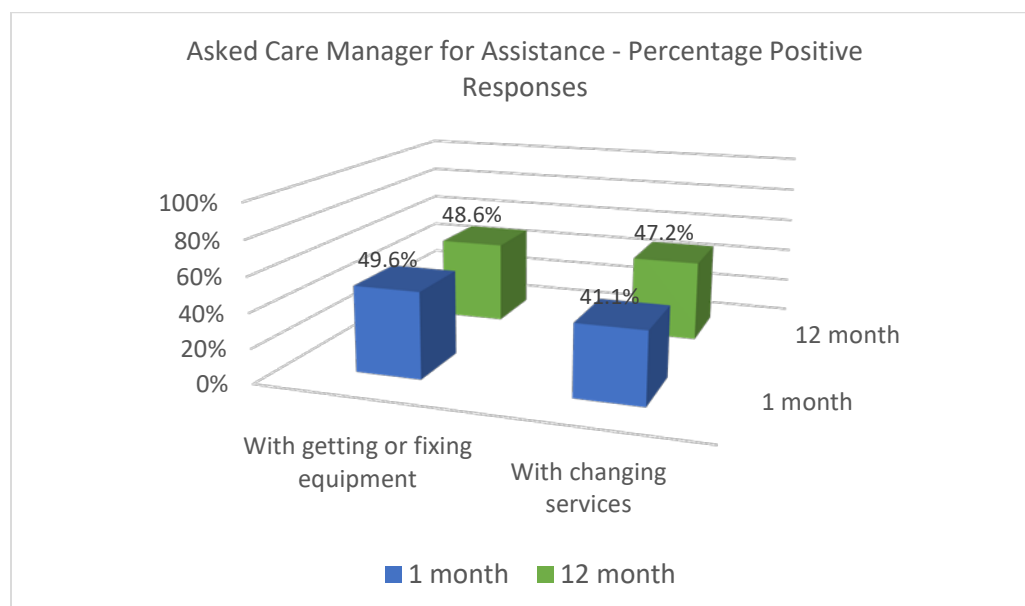
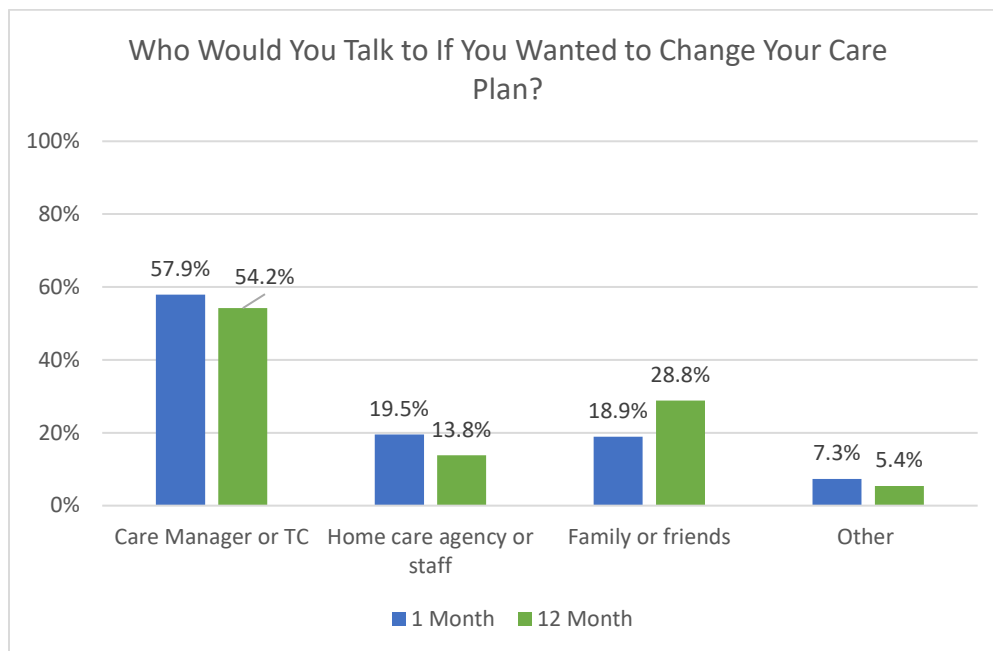


Figure 3.7. Who Would You Talk to if You Wanted to Change Your Care Plan?*

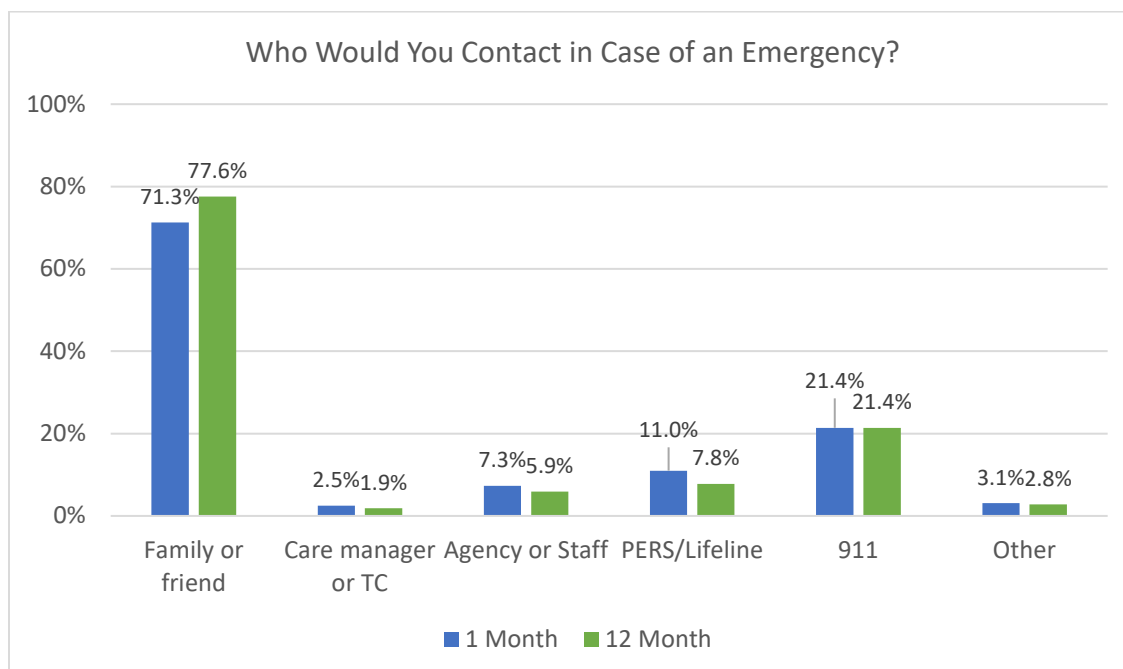


*Can name more than one

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, with that percentage going up over time (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 (Figures 3.9 and 3.10). Employment of family members by self-directing consumers increased substantially over time – from 40% to 59%. It is possible that this was influenced by the COVID-19 pandemic, as it was more difficult to find caregivers and people became hesitant to let non-family into their homes.

Figure 3.9. How Do You Hire Your Aides?

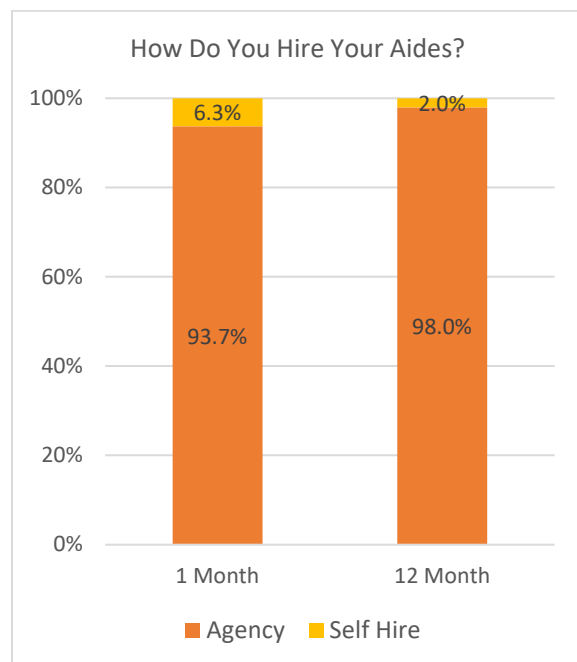
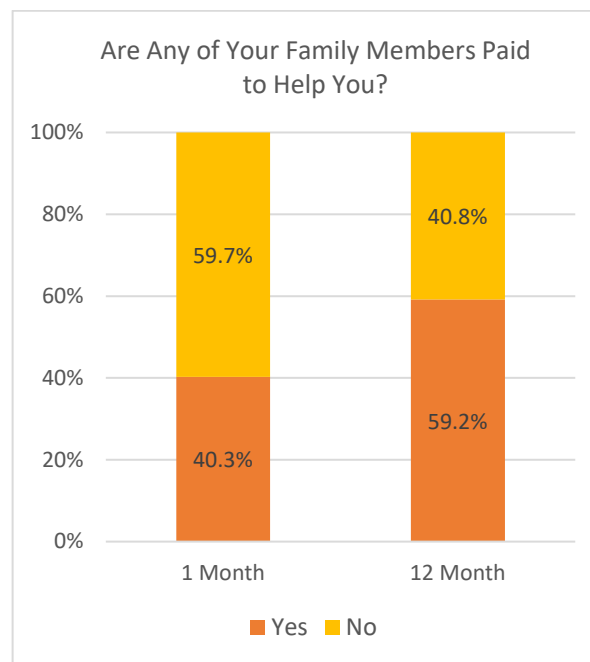


Figure 3.10. Employ Family Members



E. Living Situation and Social Support

Although 57% of consumers at 1 month and 58% at 12 months lived alone or without other adults, almost three-quarters of all consumers had a family member who lived nearby and about the same percentage were able to see family members as often as they liked at both 1 and 12 months (Table 3.4). This finding at 12 months is very positive given the COVID 19 pandemic, and contrasts sharply with the isolation from family for nursing home residents during 2020. Nearly half of the consumers at either 1 month or 12 months reported having a friend who lived nearby. Of these, more consumers at 1 month saw their nearby friends as often as they liked to (57% 1 month, 49% 12 month), which likely reflects the effect of COVID 19 in restricting seeing friends, but not family. Figure 3.11 shows that the percentage of participants who received assistance around the house from either family or friends decreased slightly at 12 months.

Table 3.4. Living Situation and Social Support*

| | | 1 Month % | 12 Month % |
|--------------------------------------|-----|--------------|---------------|
| Number of adults living in household | | N=348 | N=324 |
| | 1 | 56.9 | 57.7 |
| | 2-3 | 35.3 | 33.6 |
| | 4+ | 7.8 | 8.6 |
| Lives with family member/s | | N=150 | N=137 |
| | Yes | 66.7 | 65.7 |
| | No | 33.3 | 34.3 |
| Lives with non-family | | N=150 | N=137 |
| | Yes | 36.0 | 36.5 |
| | No | 64.0 | 63.5 |
| Family member/s live nearby | | N=356 | N=324 |
| | Yes | 71.6 | 74.1 |
| | No | 28.4 | 25.9 |
| Friend/s live nearby | | N=353 | N=323 |
| | Yes | 47.6 | 48.0 |
| | No | 52.4 | 52.0 |
| Can see nearby family | | N=254 | N=240 |
| | Yes | 72.0 | 70.5 |
| | No | 28.0 | 29.5 |
| Can see nearby friends | | N=167 | N=154 |
| | Yes | 56.9 | 48.7 |
| | No | 43.1 | 51.3 |

*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

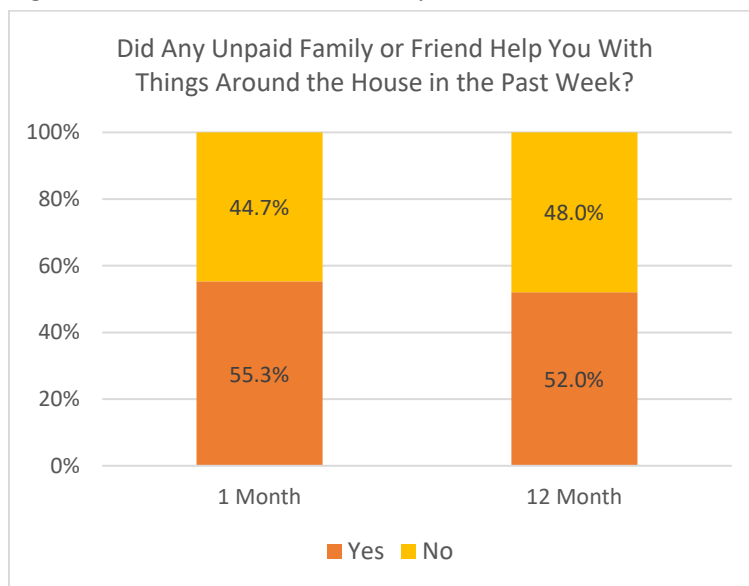


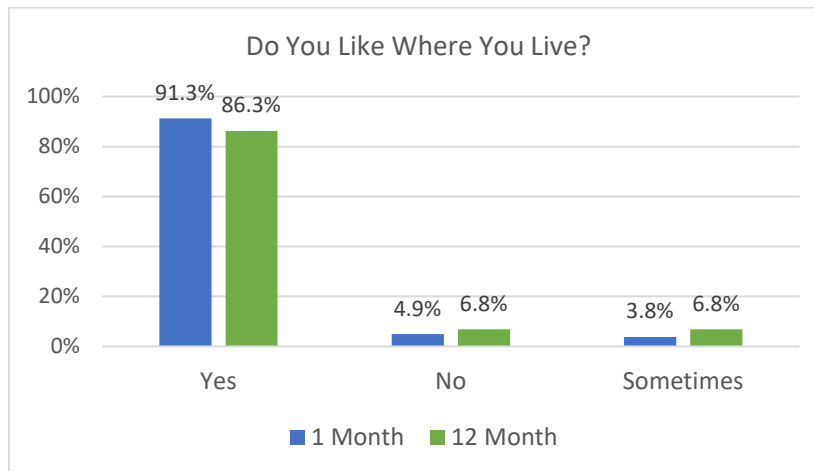
Figure 3.12 shows that most consumers at both time points said they liked where they live, although the number decreased somewhat from 1 to 12 months (91%, 86%). Almost all consumers at both 1 month (96%) and 12 months (94%) felt safe where they live.

I really like living at home and having my daughter here for me.

It has been a little challenging being home on your own, but it is a lot better than being in the nursing home. I am still too young to be living like that.

I feel safe in my apartment, but not as safe in the neighborhood.

Figure 3.12. Do You Like Where You Live?

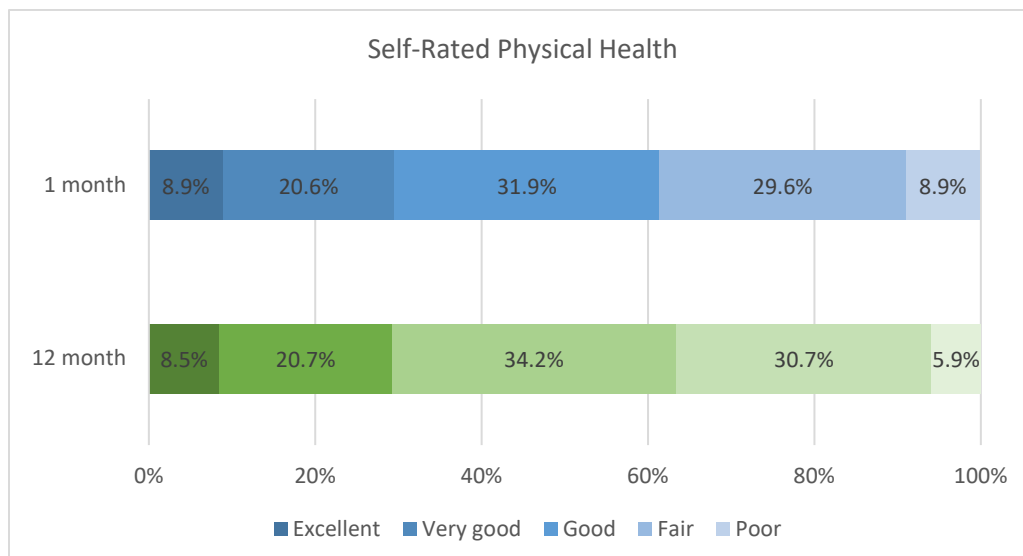


F. Physical Health

Physical Health, Falls

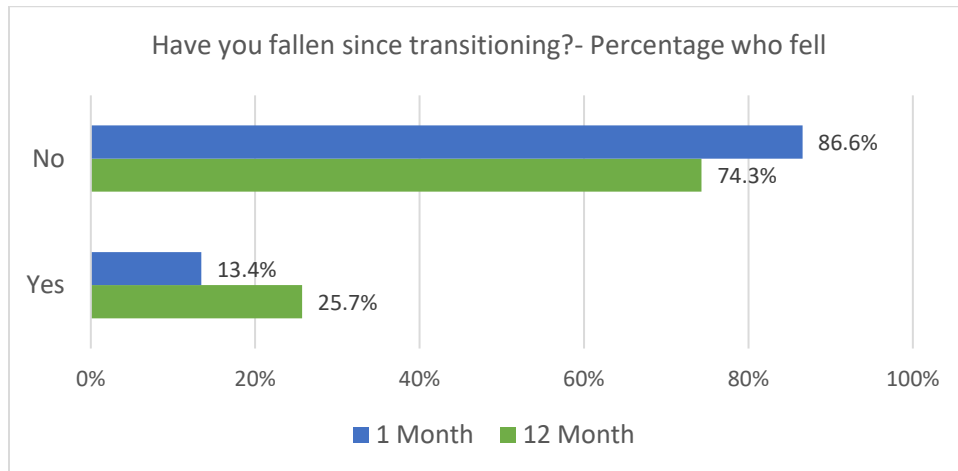
Consumers' self-reported physical health did not change much over the year. Figure 3.13 shows that at each time point, 37-39% of consumers rated their health as fair or poor, while another 29-30% of consumers rated their health as very good or excellent.

Figure 3.13. Self-Reported Physical Health



Thirteen percent of consumers reported falling by their 1 month survey. This percentage doubled between the 1 and 12 month survey, which is not surprising due to the longer amount of time (Figure 3.14).

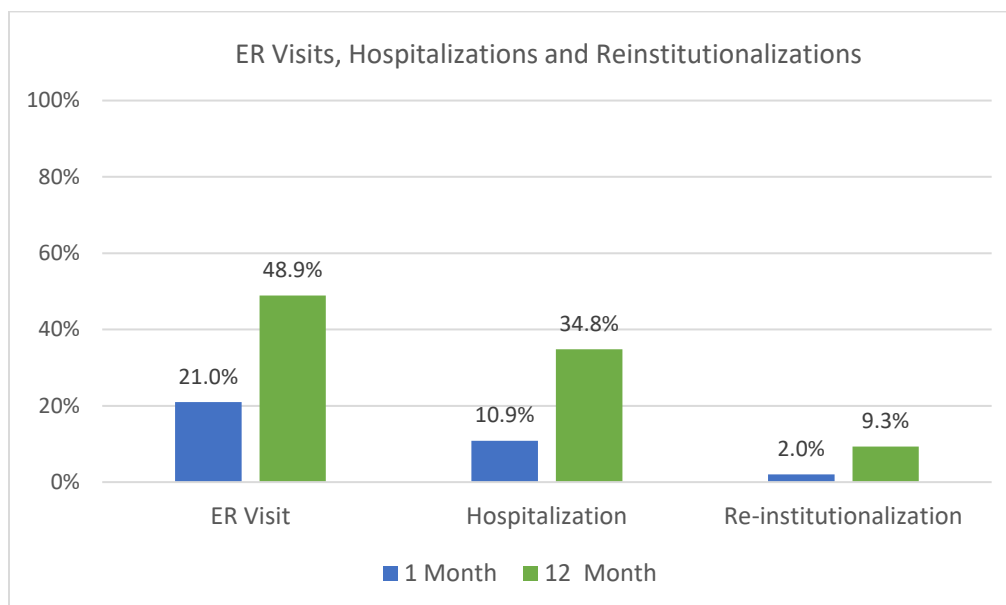
Figure 3.14. Falls



Emergency Room, Hospital and Facility Use

As can be expected, increased emergency room and hospital use were both positively associated with remaining in the community for a longer period of time (Figure 3.15). Participants interviewed at 12 months were more than three times as likely to have been hospitalized and more than twice as likely to have used an emergency room. Still, one-fifth of consumers residing in the community had been to the emergency room (ER) by their 1 month survey. By 12 months, 9 percent of consumers had been reinstitutionalized and subsequently discharged home sometime after their 1 month survey.

Figure 3.15. Emergency Room Visits, Hospitalizations, and Reinstitutionalizations



G. Mental Health

Mental Health

Self-rated mental health declined over time: at 1 month, 39% of consumers rated their mental or emotional health as very good or excellent, compared to 33% at 12 months (Figure 3.16).

Depressive symptoms remained high at both time points – 35-36% of participants reported depressive symptoms each time (Figure 3.17). These rates are notably higher than the larger population. In 2020, 24.2% of adults in Connecticut reported symptoms of depression (U.S. Census Bureau, 2021). These data indicate a need for better mental and emotional support post-transition.

Figure 3.16. Self-Reported Mental Health

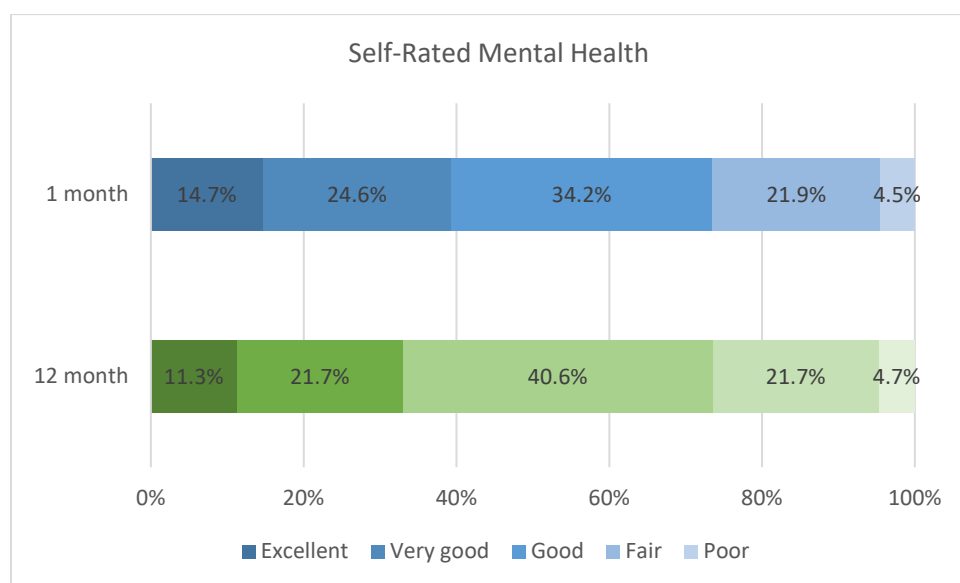
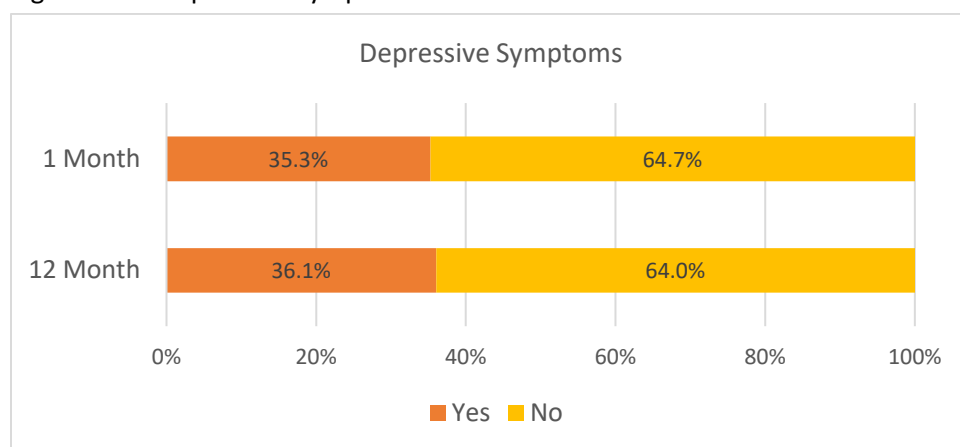


Figure 3.17. Depressive Symptoms*



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

National Center for Health Statistics (2020-2021). *Household Pulse Survey: Anxiety and Depression*. Center for Disease Control and Prevention. <https://www.cdc.gov/nchs/covid19/pulse/mental-health.htm>

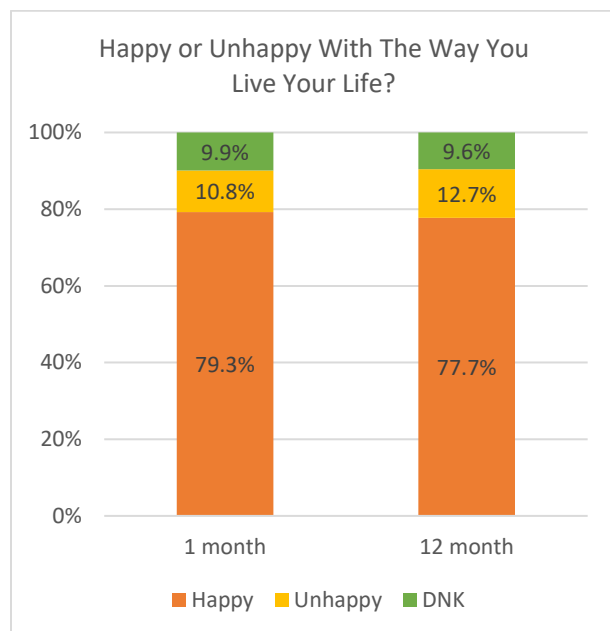
Whooley, M., Avins, A., Miranda, J., & Browner, W. (1997). Case-finding instruments for depression. Two questions are as good as many. *Journal of General Internal Medicine*, 12(7), 439–445. <https://doi.org/10.1046/j.1525-1497.1997.00076.x>

Overall Quality of Life

Global life satisfaction stayed stable once in the community. Between 78 to 79% of consumers reported feeling happy with the way they live their life at both 1 and 12 months (Figure 3.18).

MFP turned my life around. I was depressed and now I am happy. I have my struggles due to my medical conditions but I am happy now.

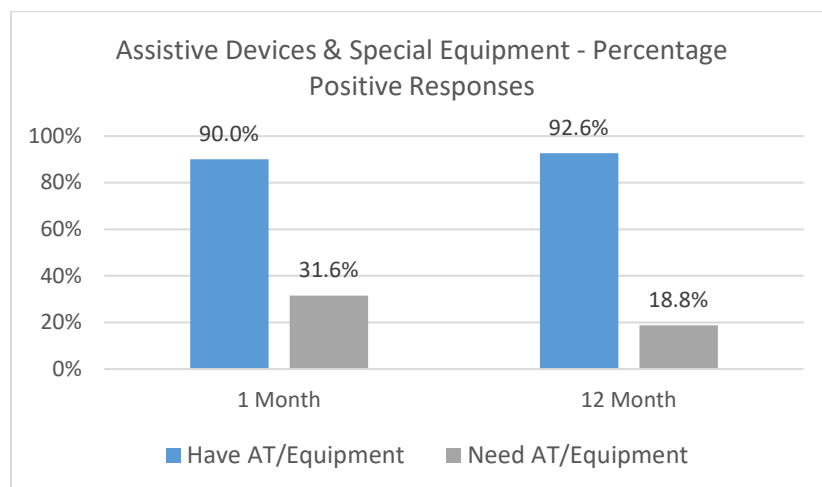
Figure 3.18. Happy or Unhappy with the Way You Live Your Life



H. Assistive Devices, Medical Equipment, Home Modifications

The vast majority (90% 1 month and 93% 12 months) of community consumers reported having at least one type of assistive device, special equipment, or home modification (Figure 3.19). At 1 month, 32% of consumers lacked some type of device or modification needed for community living. By 12 months, just under one-fifth (19%) still needed at least one assistive device.

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



At 1 and 12 months, consumers most often reported having mobility equipment (79%, 83%), home modifications (69%, 72%), or special medical equipment (64%, 64%) (Figures 3.20 and 3.21). Although a personal emergency response system (PERS) is allowed under most budgets, less than half of consumers reported having one. Not many consumers had their own lift van/adaptive driving controls or an electronic medical device.

At 1 month post-transition, consumers most commonly still needed home modifications (12%), a PERS (10%), or special medical equipment (7%). The lack of special equipment and/or devices in the community decreased from 1 month to 12 months for all categories. Still, at 12 months post-transition, 9% of consumers reported they still needed home modifications and 6% still needed a PERS. Not having necessary home modifications or equipment can jeopardize one's ability to live successfully in the community, and providing these before or soon after transition should continue to be a program goal.

There were a few things we never received such as an entrance ramp that was supposed to be installed and a series of other things. (12 month survey)

I have been out of the nursing home for a month now, and I have yet to receive my electric wheel chair, shower bench, or help to buy the adult diapers and bed pads. (1 month survey)

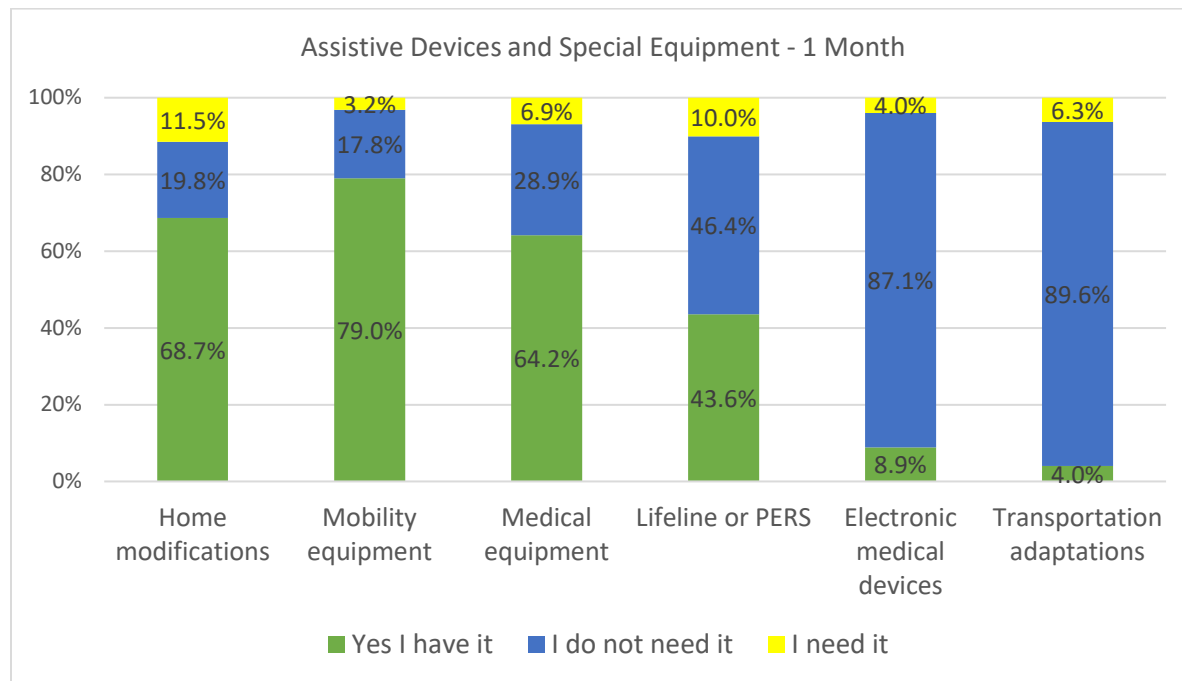
My wheelchair is broken and have not been able to get it fixed. I feel unsafe if I go outside. I still don't have the diabetic supplies. (12 month survey)

Never got shower grab bars and would like the entrance ramp fixed. (12 month survey)

I do need my girls to keep coming. I hope the bathroom modification to allow it easier for the aides [to help me] into the shower will still be approved. (12 month survey)

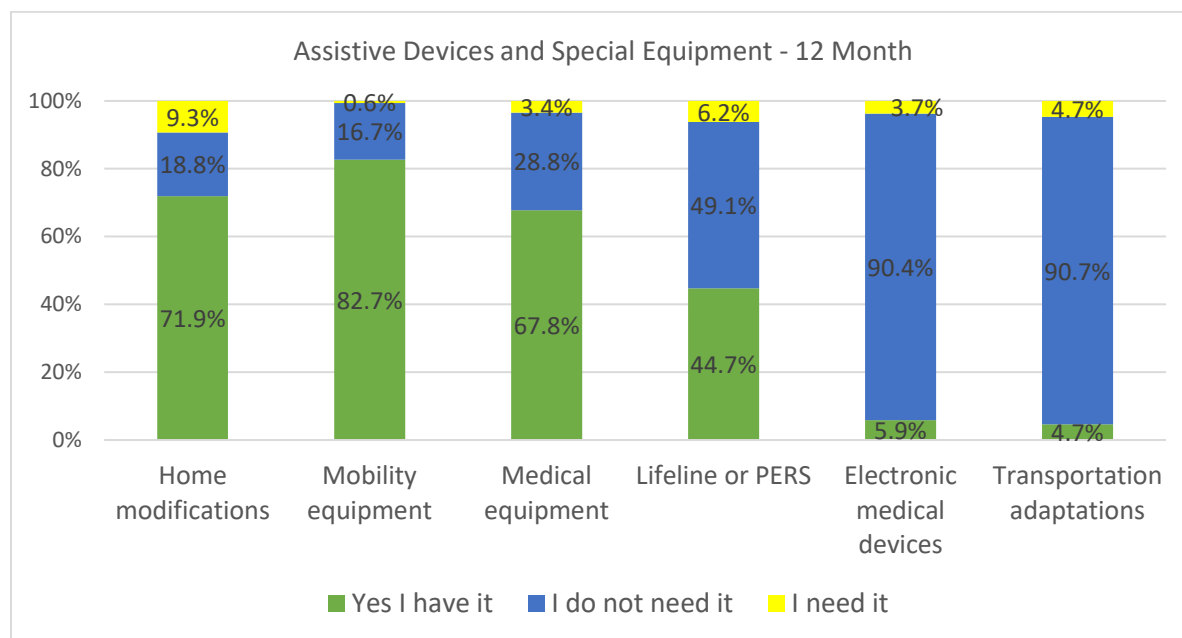
[Consumer] is still waiting on the specialized laptop. He's been waiting about a year to receive it. (12 month survey)

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



Seventy percent or more participants reported having internet access at their home, and over half (54% 1 month, 61% 12 months) of consumers owned a computer, tablet, or smart phone. Overall, less than 10% of consumers at 1 month or 12 months said they needed internet access or some type of internet capable device (Figures 3.22 and 3.23).

Figure 3.22. Internet Devices

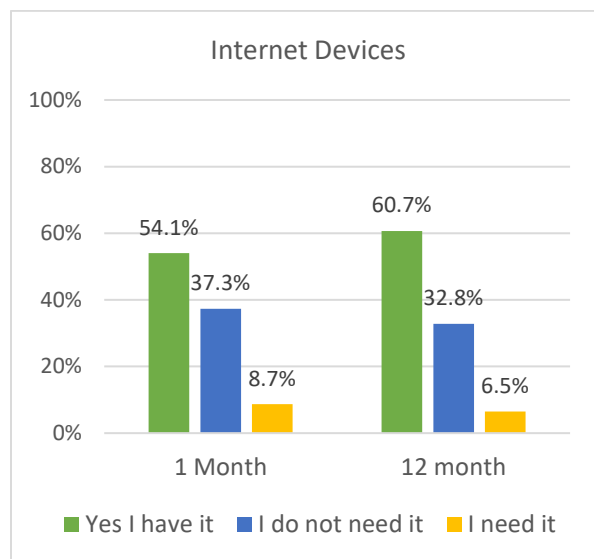
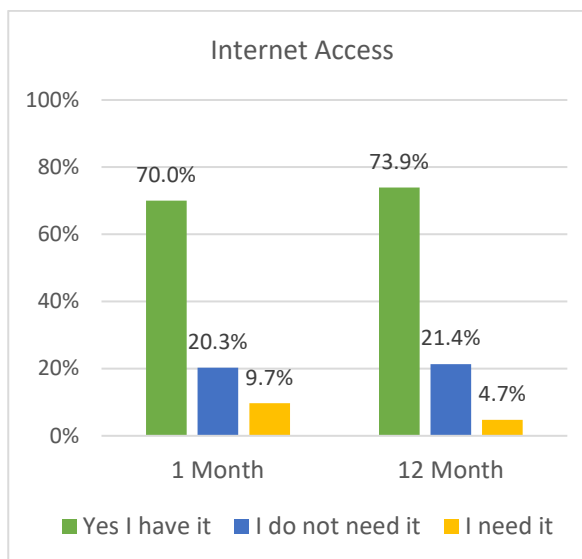


Figure 3.23. Internet Access



I. Other Services

A small number of participants at either 1 month (n=25) or 12 months (n=29) received a home delivered meal service, and even fewer used a day program (Tables 3.5 and 3.6).

Table 3.5. Home Delivered Meal Service Rating

| | 1 Month | 12 Month |
|-----------|----------|----------|
| | n (%) | n (%) |
| Excellent | 5 (20.0) | 6 (20.7) |
| Very Good | 8 (32.0) | 9 (31.0) |
| Good | 8 (32.0) | 8 (27.6) |
| Fair | 1 (4.0) | 5 (17.2) |
| Poor | 3 (12.0) | 1 (3.5) |

Table 3.6. Day Program Rating

| | 1 Month | 12 Month |
|-----------|----------|----------|
| | n (%) | n (%) |
| Excellent | 4 (30.8) | 3 (50.0) |
| Very good | 4 (30.8) | 2 (33.3) |
| Good | 5 (38.5) | 1 (16.7) |
| Fair | 0 (0.0) | 0 (0.0) |
| Poor | 0 (0.0) | 0 (0.0) |

Half of participants at either 1 month (49%) or 12 month (48%) reported using a van or transportation service for medical and/or nonmedical services. Although about three-quarters of participants rated the medical transportation composite with the highest scores at both 1 and 12 months (Figure 3.1), participant comments indicated that transportation is a real challenge to living in the community in Connecticut. Most low cost or Medicaid transportation is limited to medical appointments, and reliable low cost and accessible nonmedical transportation is hard to find. Comments from participants indicated transportation service issues such as not showing up at all, not coming on time to take them to an appointment, being left outside waiting for a return ride for extended periods of time, and missed appointments because they could not find a ride. Participants who did not use a van service often depended on family or friends for their rides. This can become an issue especially for patients with multiple appointments, such as dialysis patients who need reliable transportation to and from their treatments three times a week. One husband related how he was continually taking time off from work because the transportation service was not showing up to pick up his wife after dialysis. Other comments included:

The transportation services will sometimes miss in picking us up, saying that we have not called when I had called and gotten a confirmation already.

I had a very bad medical transportation company... they left me over an hour after dialysis and I got pneumonia.

Transportation services like Dial-a-ride and VEYO are terrible. Veyo would pick us up late, or forget to pick us up. Dial-a-ride is a shared drive service and the travel times are too long.

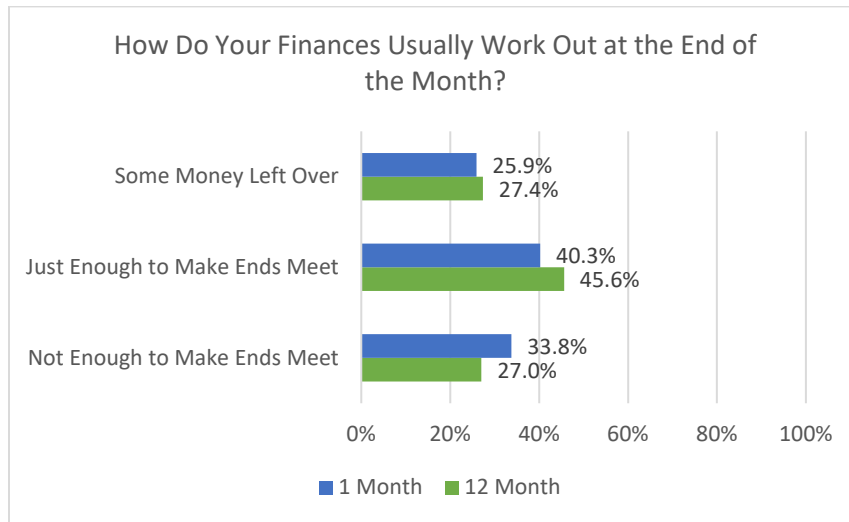
The medical rides are coming in regular size cars not a van and I have a walker and it's hard for me to get into a regular car.

J. Finances, Employment and Volunteering

Over a third of consumers did not have enough money to make ends meet at 1 month after transition, as did 27% at 12 months (Figure 2.24). Comments indicated that family members sometimes step in to fill the gap, such as paying for medical supplies or equipment, and that delayed access to food stamps or social security can also contribute to not enough money.

They've [MFP staff] been great, but I've been waiting on food stamps for two months now, that's why I don't have enough money. 1 Month survey

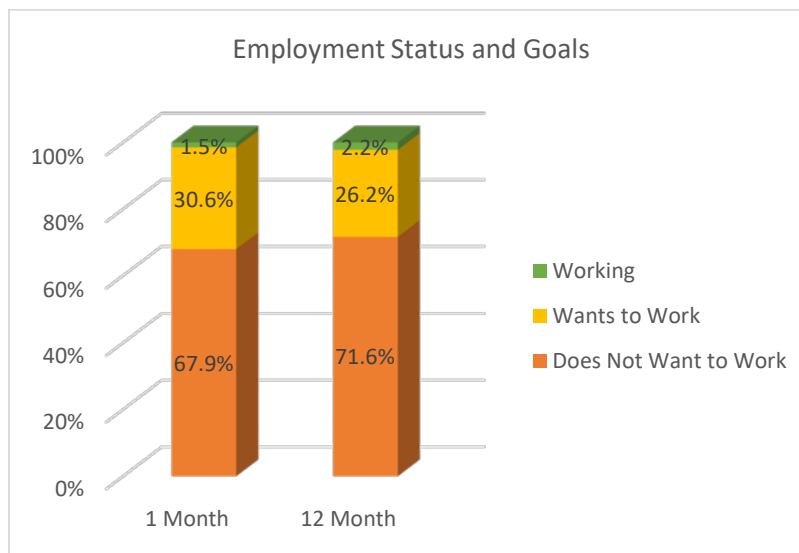
Figure 3.24. How Do Your Finances Usually Work Out at the End of the Month?



Employment and Volunteering

All community residing consumers age 18 and older were asked questions regarding work status and employment goals (Figure 3.25). Although approximately 2 percent of consumers at both 1 month and 12 months were currently employed, it is notable that nearly one-third of unemployed participants at 1 month (31%) and one-fourth at 12 months (26%) wanted to work. Providing employment supports for these consumers would be an area to explore, especially as having a job often increases independence and community involvement.

Figure 3.25. Employment Status and Goals



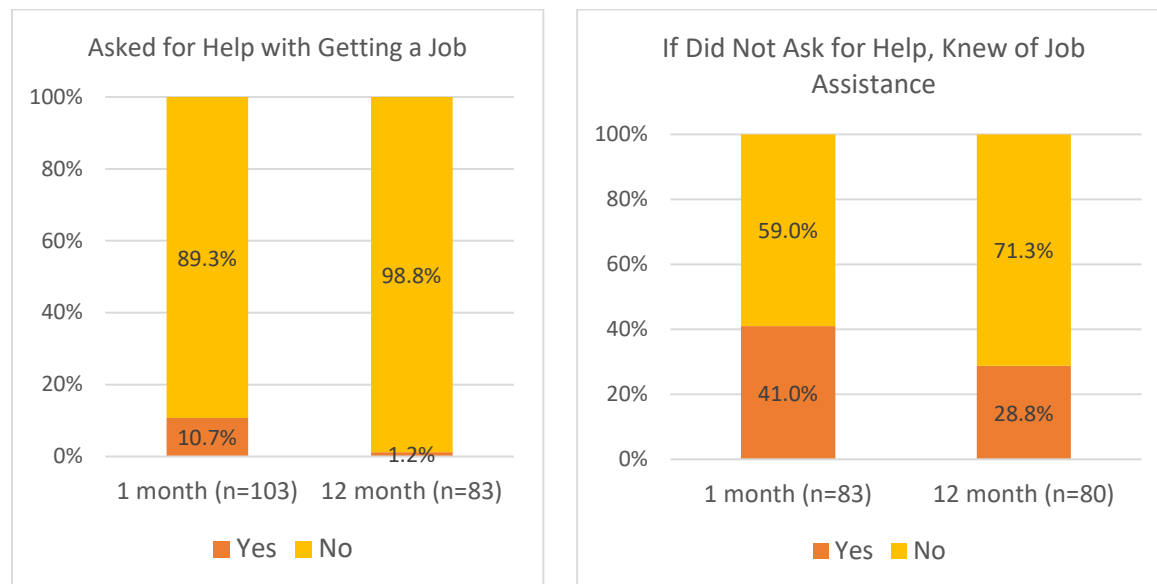
Not surprisingly, when asked what was holding them back from working, health and disability related concerns were the most frequently reported reason for not working for both participants who wanted to work and for those who did not (Table 3.7). Few participants who wanted to work reported that training/education, looking but can't find work, potential loss of benefits, or employment resources were challenges to employment. Compared to unemployed participants who wanted to work, participants who did not want a job were much more likely to give retirement or "nothing is holding me back" as the reason for not working.

Table 3.7. Most Common Reasons for Not Working

| Most Common Reasons for Not Working | 1 Month Would like to work N= 104 n (%) | 12 Month Would like to work N= 83 n (%) | 1 Month Does not want to work N= 231 n (%) | 12 Month Does not want to work N= 227 n (%) |
|-------------------------------------|---|---|--|---|
| Health Concerns | 79 (76.0) | 69 (83.1) | 129 (55.8) | 122 (53.7) |
| Transportation | 11 (10.6) | 3 (3.6) | 1 (0.4) | 4 (1.8) |
| Retired | 1 (1.0) | 0 (0) | 11 (4.8) | 31 (13.7) |
| Nothing/Do not want to work | 5 (4.8) | 4 (4.8) | 83 (35.9) | 90 (39.6) |

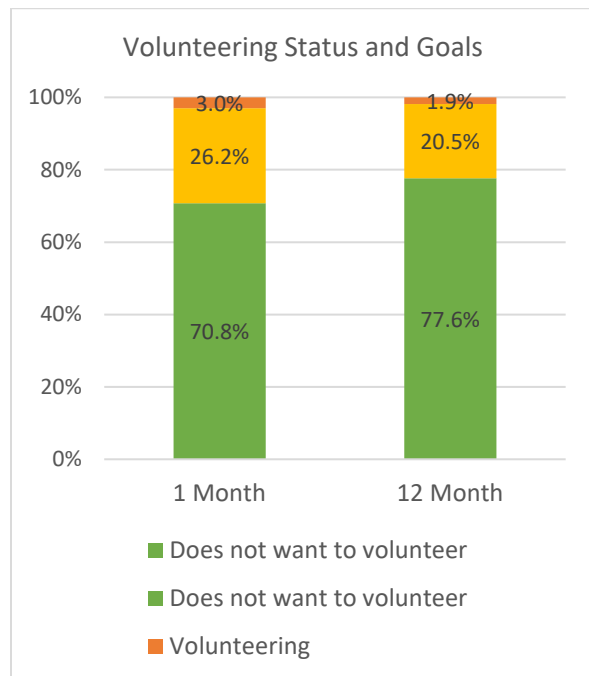
Just 11% of unemployed participants at 1 month had asked for assistance with finding a job, and this dropped to only 1% by 12 months (Figure 3.26). Meanwhile, over half of unemployed participants at both 1 month (59%) and 12 months (71%) did not know of job assistance (Figure 3.27). Providing outreach to increase awareness of job assistance and encouragement to use these resources might help people who want a job to become employed.

Figure 3.26. Sought Out Employment Assistance Figure 3.27. Aware of Employment Assistance



While few participants were currently volunteering, 26% of participants at 1 month, and 21% at 12 months, said they were interested in doing so (Figure 3.28). Connecting participants with volunteering opportunities would potentially be beneficial for community engagement and mental health.

Figure 3.28. Volunteering Status and Goals



Section 4. 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 2019 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 composed 73% of both the 1 month and 12 month sample (Table 4.1). Consumers not accepted to a waiver transitioned using state plan or other community Medicaid services. Referred to here as state plan consumers, they composed the remaining 27-28% 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 (%) |
|--------------|------------------|-----------------|
| Waiver | 258 (72.5) | 236 (72.8) |
| State Plan | 98 (27.5) | 88 (27.2) |
| All programs | 356 (100.0) | 324 (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. At 1 month, 86% of waiver consumers report using some type of personal care assistance, compared to only 19% of state plan consumers. Waiver consumers use of homemaking services in particular increases over time.

What is most striking is the use of case management services. A waiver case manager is not assigned to waiver consumers until three to 12 months post-transition. All MFP TCs provide case management services to both types of consumers for several months. However, state plan consumers are much less likely to report using case management services even at just 1 month post transition – 74% of waiver consumers reported using case management at 1 month post transition, compared to 34% of state plan consumers. It is not clear why TCs are apparently less involved with non-waiver consumers just a few weeks after transition. It may also be that state plan consumers do not consider TCs to be case managers.

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

| | 1 Month | | 12 Month | |
|---|-----------------|---------------------|-----------------|---------------------|
| | Waiver n (%) | State Plan n (%) | Waiver n (%) | State Plan n (%) |
| Personal care assistant/attendant services | 221 (85.7) | 19 (19.4) | 203 (86.0) | 17 (19.3) |
| Behavioral health services (ABI, Autism, DDS) | 9 (3.5) | 0 (0) | 5 (2.1) | 0 (0) |
| Recovery assistance services (MHW) | 7 (2.7) | 0 (0) | 9 (3.8) | 0 (0) |
| Homemaking services or Homemaker-Companion | 149 (57.8) | 22 (22.4) | 166 (70.3) | 22 (25.0) |
| Community Service Provider (MHW) | 9 (3.5) | 0 (0) | 5 (2.1) | 0 (0) |
| Care management services | 190 (73.6) | 33 (33.7) | 157 (66.5) | 20 (22.7) |
| Job coach or vocational supports | 1 (<1.0) | 0 (0) | 2 (<1.0) | 0 (0) |
| None of these services | 7 (2.7) | 40 (40.8) | 8 (3.4) | 45 (51.1) |

* Consumers can use more than one service

Overall, waiver consumers are more likely to be age 65 or older, while state plan consumers are more likely to be age 45 to 64. State plan consumers are also more likely to be male (Table 4.3).

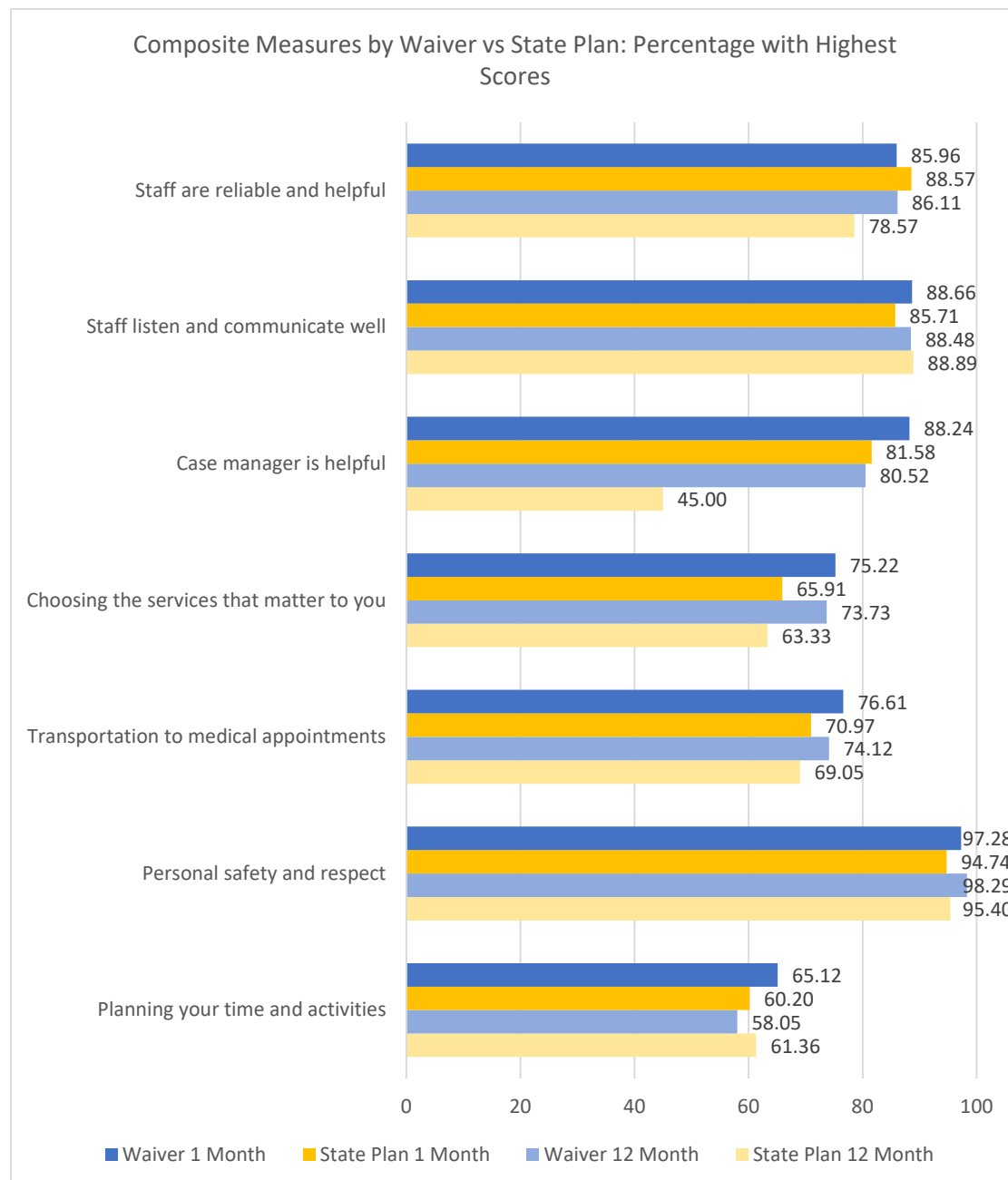
Table 4.3. Demographics – Waiver/State Plan by Time Point

| | | 1 Month | | 12 Month | |
|---------------|--------|--------------|-----------------|--------------|-----------------|
| | | Waiver % | State Plan % | Waiver % | State Plan % |
| Age | | N=258 | N=98 | N=236 | N=88 |
| | <18 | 1.2 | 0.0 | 0.0 | <1.0 |
| | 18-24 | 1.2 | 2.0 | <1.0 | 1.1 |
| | 25-34 | 3.1 | 1.0 | 3.4 | 2.3 |
| | 35-44 | 4.7 | 9.2 | 4.2 | 5.7 |
| | 45-54 | 10.5 | 26.5 | 12.3 | 23.9 |
| | 55-64 | 24.0 | 43.9 | 23.7 | 52.3 |
| | 65-74 | 23.6 | 14.3 | 26.7 | 12.5 |
| | 75+ | 31.8 | 3.1 | 27.5 | 2.6 |
| Gender | | N=258 | N=98 | N=236 | N=88 |
| | Male | 42.6 | 65.3 | 44.9 | 68.2 |
| | Female | 57.4 | 34.7 | 55.1 | 31.8 |

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

Striking differences in the composite measures between waiver and state plan consumers included choosing the services that matter to you, case manager is helpful, and transportation to medical appointments (Figure 4.1). At 1 month, noticeably fewer state plan than waiver consumers gave the highest score to the care manager is helpful items, and by 12 months this fell to 45% compared to 81% of waiver consumers. Although transportation to medical appointments is not a separate waiver-only service, a smaller percentage of state plan consumers rated their medical transportation as highly as waiver consumers did, even just one month post transition. One state plan consumer specifically expressed that the issue was living more than ten miles away from his medical providers.

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



Waiver consumers were much more likely to give their PCA staff and especially their case managers the highest rating compared to state plan consumers (Figure 4.2). Staff recommendations follow a similar pattern – more waiver consumers would definitely recommend every type of their staff compared to state plan consumers (Figure 4.3). The case manager ratings and recommendations show this stark contrast even at 1 month post transition.

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

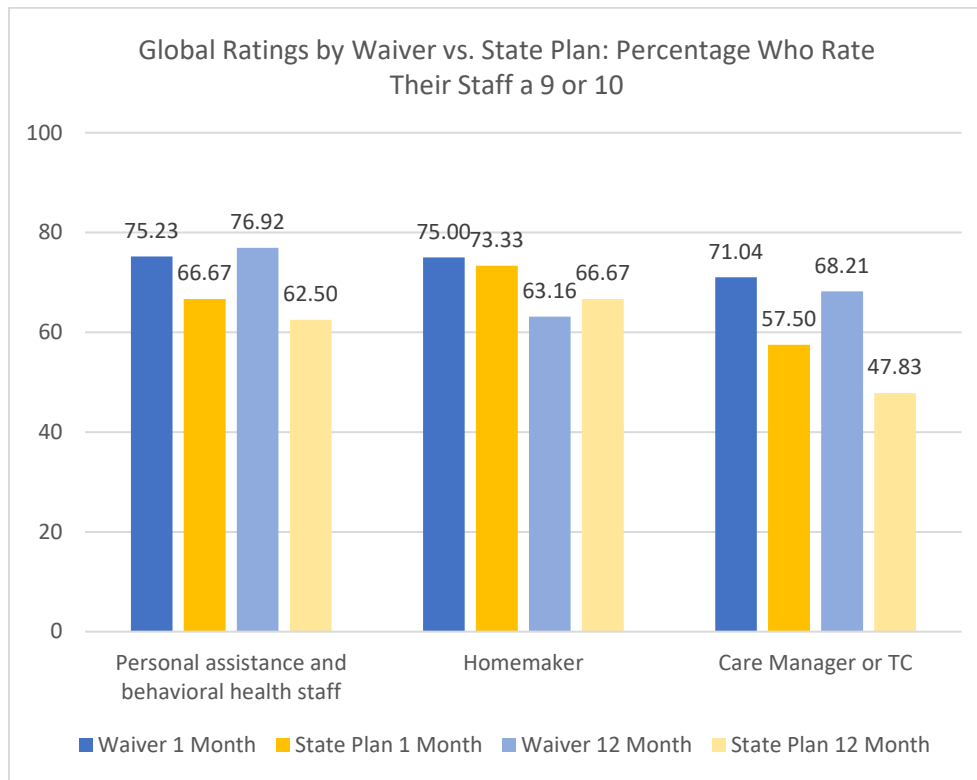
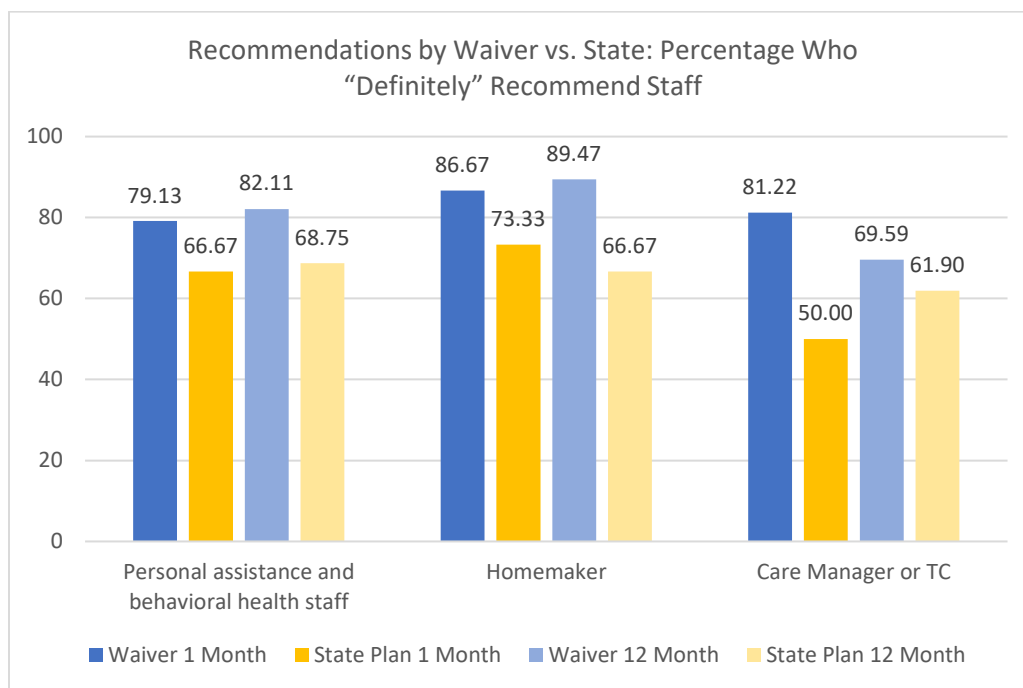


Figure 4.3. Recommendations by Waiver vs. State Plan: Percentage Who “Definitely” Recommend Staff



Case Manager Items

Although at 12 months fewer state plan consumers reported having a case manager or services coordinator, those who did were equally likely as waiver consumers to be able to contact that person when they needed to (Figures 4.4 and 4.5). Although at 1 month both waiver and state plan consumers received TC services and waiver services have not started, waiver consumers were more likely to talk to their TC or SCM if they wanted to change their care plan (Figure 4.6). Overall, waiver consumers reported having more resources to use if they wanted changes to their services.

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

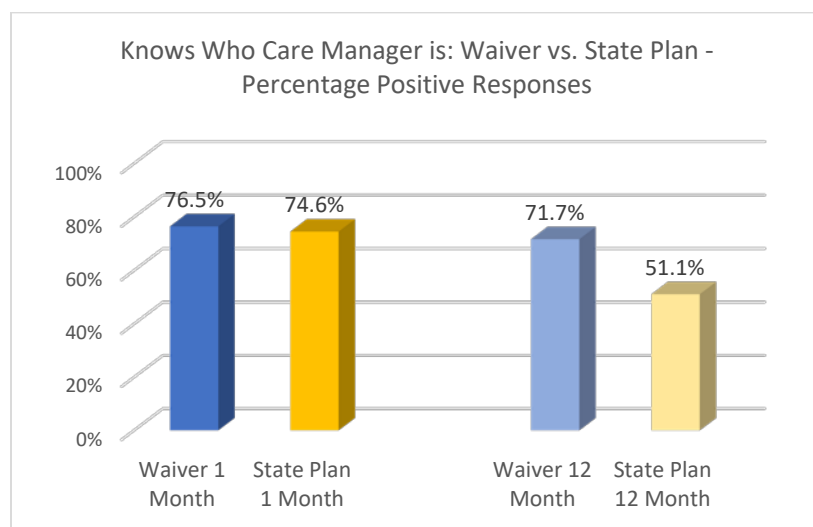


Figure 4.5. Able to Contact Case Manager, Waiver vs. State Plan

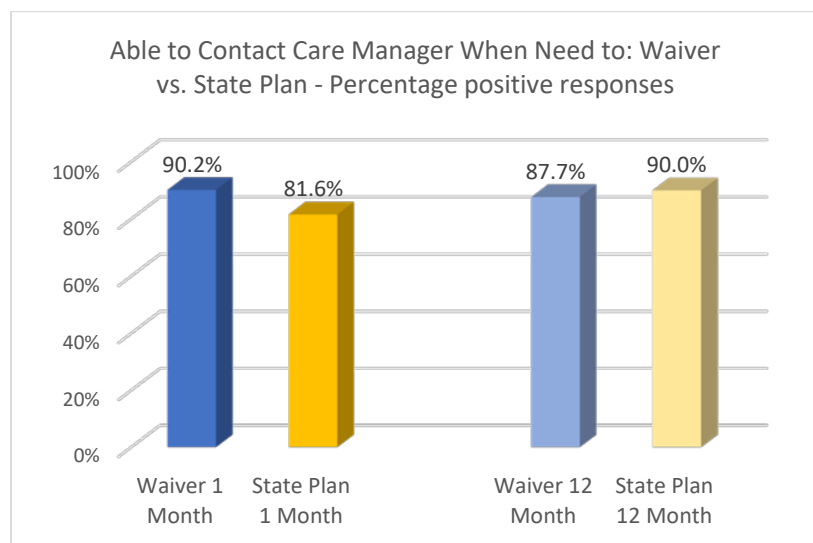
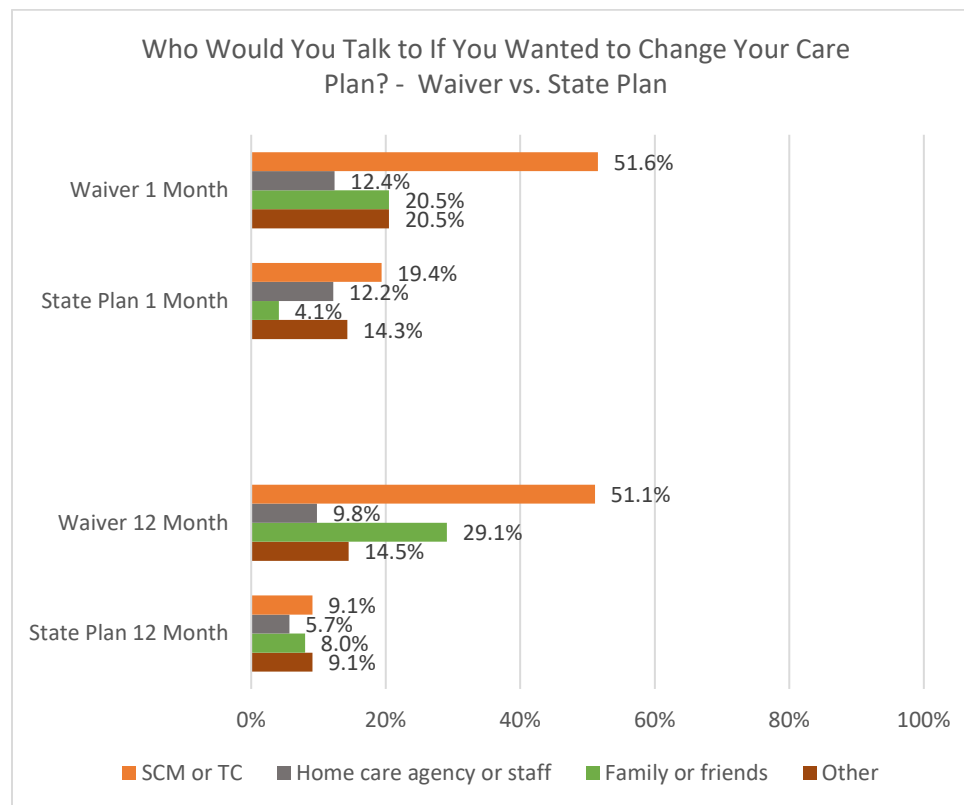


Figure 4.6. Who Would You Talk to if You Wanted to Change Your Care Plan? – Waiver vs. State Plan



Living Situation and Social Support

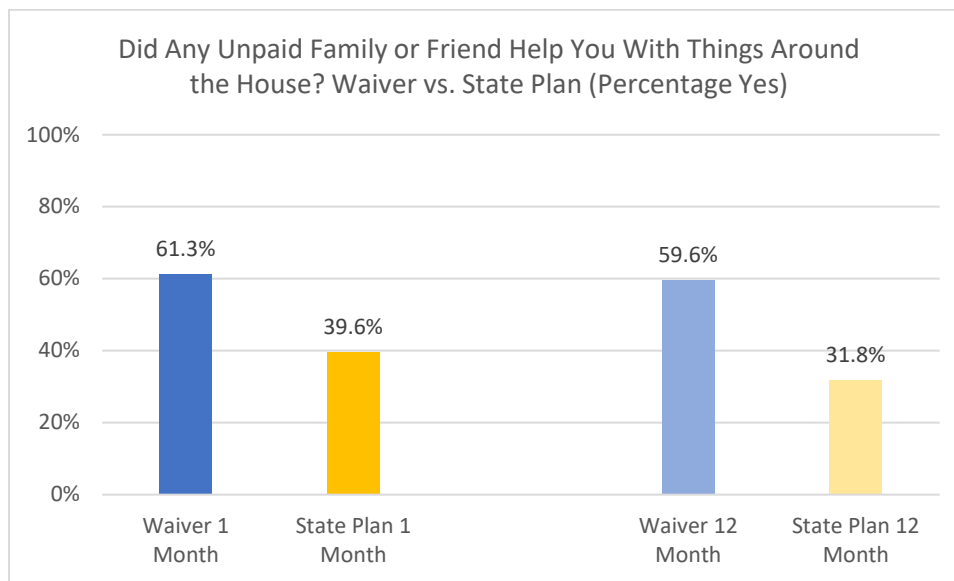
Consumers with state plan services reported less social support overall than consumers who receive services through a waiver. Consumers with state plan services are much more likely to live alone – nearly three-quarters of consumers with state plan services lived alone at either time point, compared to just over half of waiver consumers (Table 4.4). In addition, state plan consumers were less likely to have family or friends living 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=253 | N=95 | N=236 | N=88 |
| | 1 | 50.6 | 73.7 | 52.1 | 72.7 |
| | 2-3 | 43.5 | 13.7 | 41.5 | 12.5 |
| | 4+ | 5.9 | 12.6 | 6.4 | 14.8 |
| Lives with family member/s | | N=125 | N=25 | N=113 | N=24 |
| | Yes | 73.6 | 32.0 | 71.7 | 37.5 |
| | No | 26.4 | 68.0 | 28.3 | 62.5 |
| Lives with non-family | | N=125 | N=25 | N=113 | N=24 |
| | Yes | 29.6 | 68.0 | 31.0 | 62.5 |
| | No | 70.4 | 32.0 | 69.0 | 37.5 |
| Family member/s live nearby | | N=258 | N=98 | N=236 | N=88 |
| | Yes | 79.5 | 51.0 | 79.7 | 59.1 |
| | No | 20.5 | 49.0 | 20.3 | 40.9 |
| Friend/s live nearby | | N=256 | N=97 | N=235 | N=88 |
| | Yes | 52.7 | 34.0 | 49.4 | 44.3 |
| | No | 47.3 | 66.0 | 50.6 | 55.7 |

Waiver recipients report getting more assistance from family or friends around the house (Figure 4.7). This is not surprising given waiver consumers are more likely to live with other people and/or have either family or friends living nearby. While the percentage of waiver consumers with unpaid assistance from family or friends stays stable over time, for state plan consumers, presence of this support drops noticeably from 1 month to 12 months (40% 1 month, 32% at 12 months have family/friend support).

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



Compared to state plan consumers, waiver consumers were much more likely to like where they live (Figure 4.8). Over 90% of waiver participants liked where they lived at either time point, compared to about three quarters of state plan participants. Waiver consumers were also more likely to feel safe where they live, especially at 1 month post transition (Figure 4.9). Approximately 15% of state plan participants lived at residential care homes at either time point, and all of them said they did not like where they live, pointing to issues such as medication delivery, food, and treatment by employees.

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

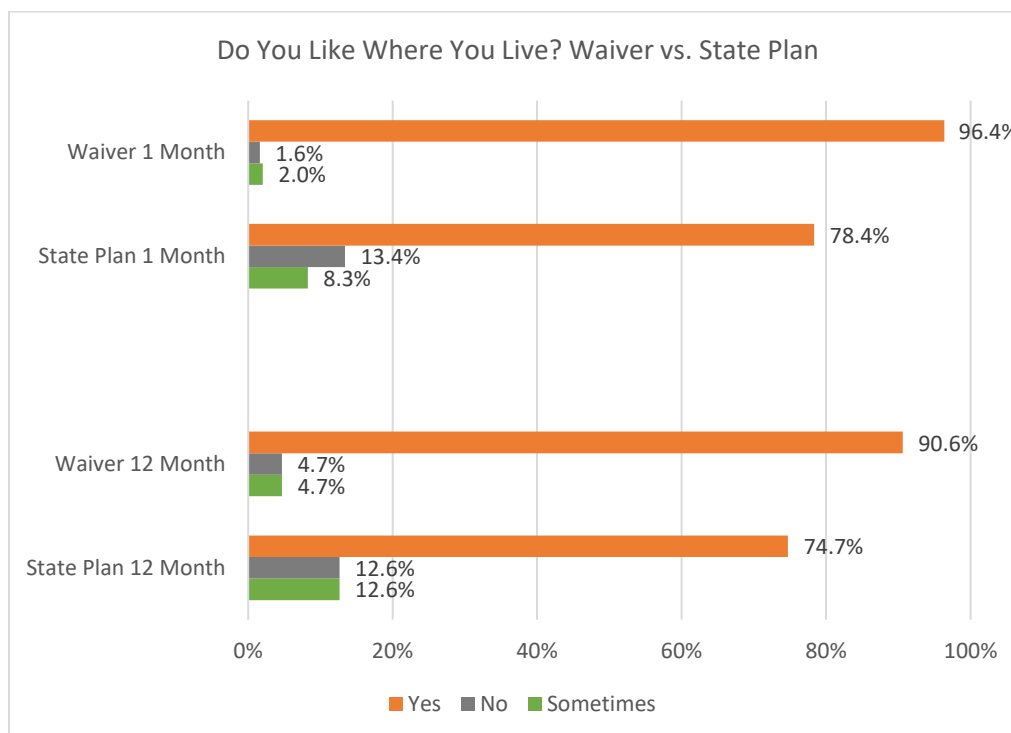
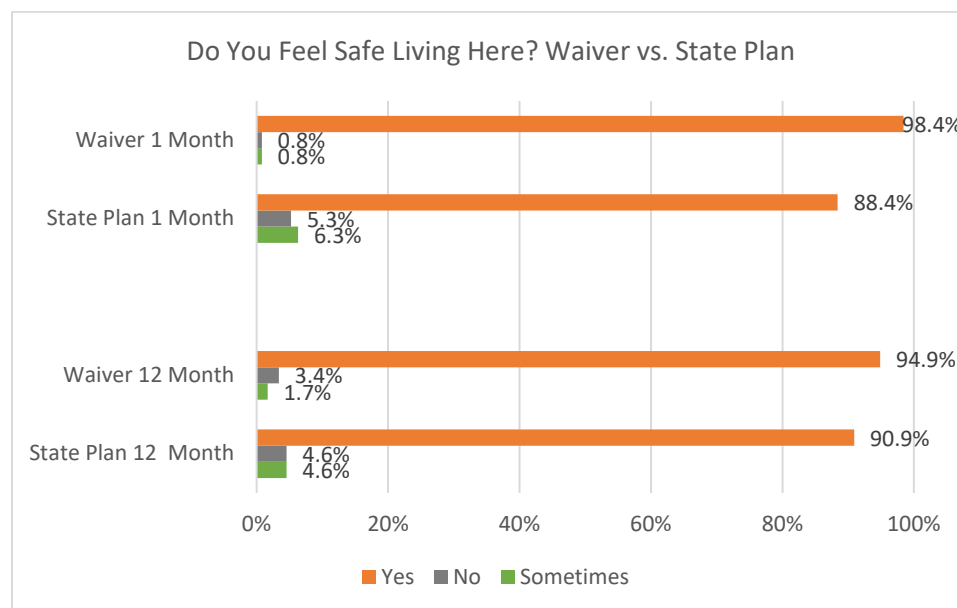


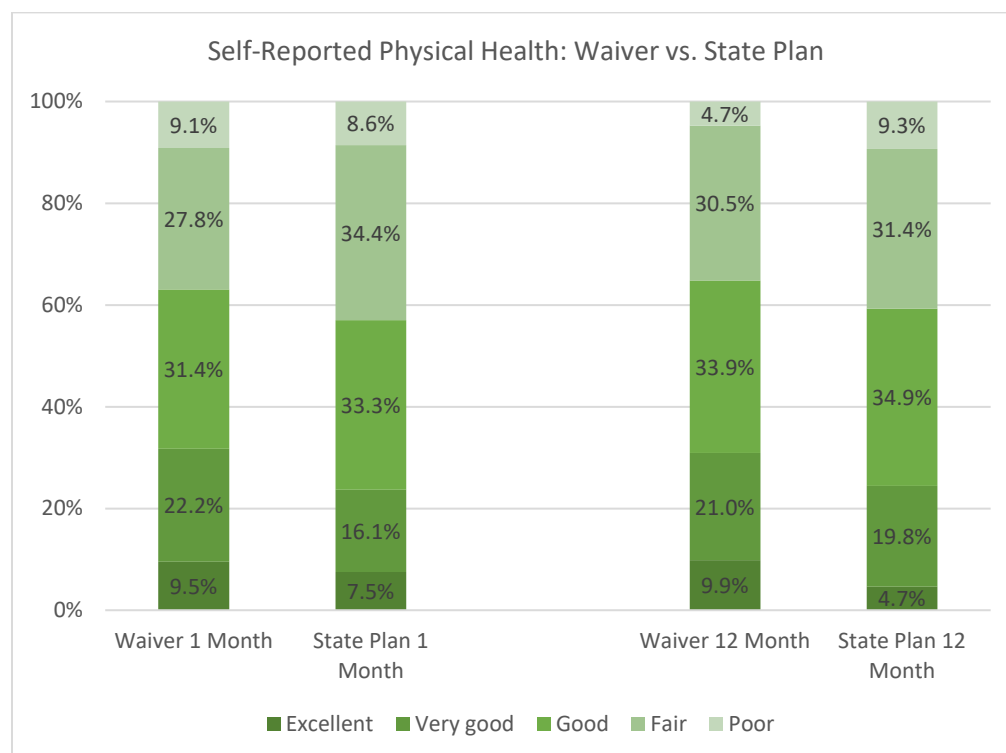
Figure 4.9. Do You Feel Safe Living Here? Waiver vs. State Plan



Physical Health

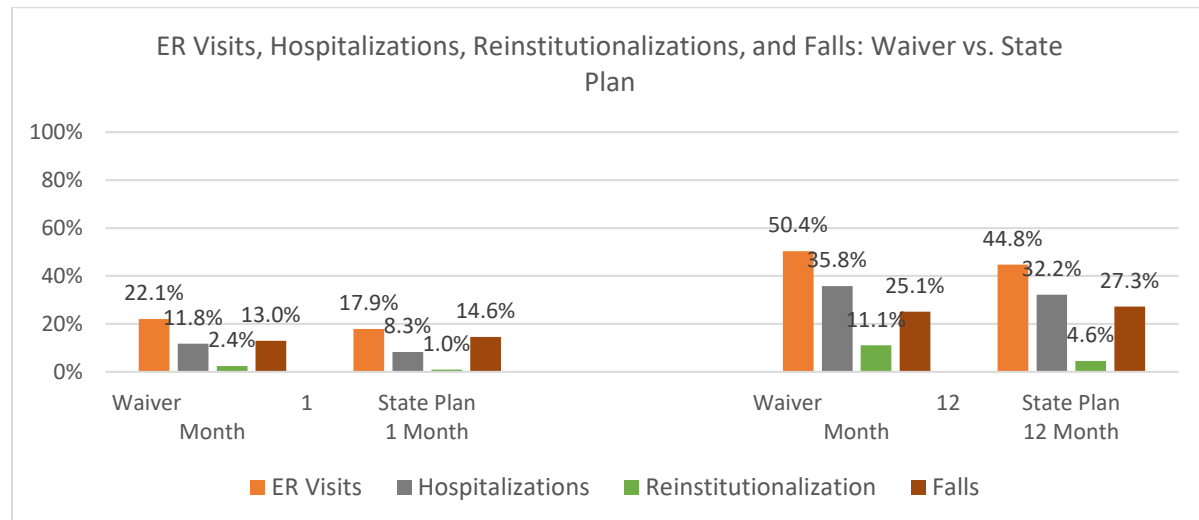
While substantial percentages of either group gave low ratings for their physical health, this was especially true for state plan consumers (Figure 4.10). At 1 month, 43% of state plan and 37% of waiver consumers said their physical health was fair or poor, and these between group differences stayed pretty constant over the year.

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



While the likelihood of falling was slightly more prevalent among state plan consumers, waiver participants were more likely to experience an ER visit, hospitalization, or reinstitutionalization at both 1 month and 12 month (Figure 4.11). The age difference between the two groups may explain this finding.

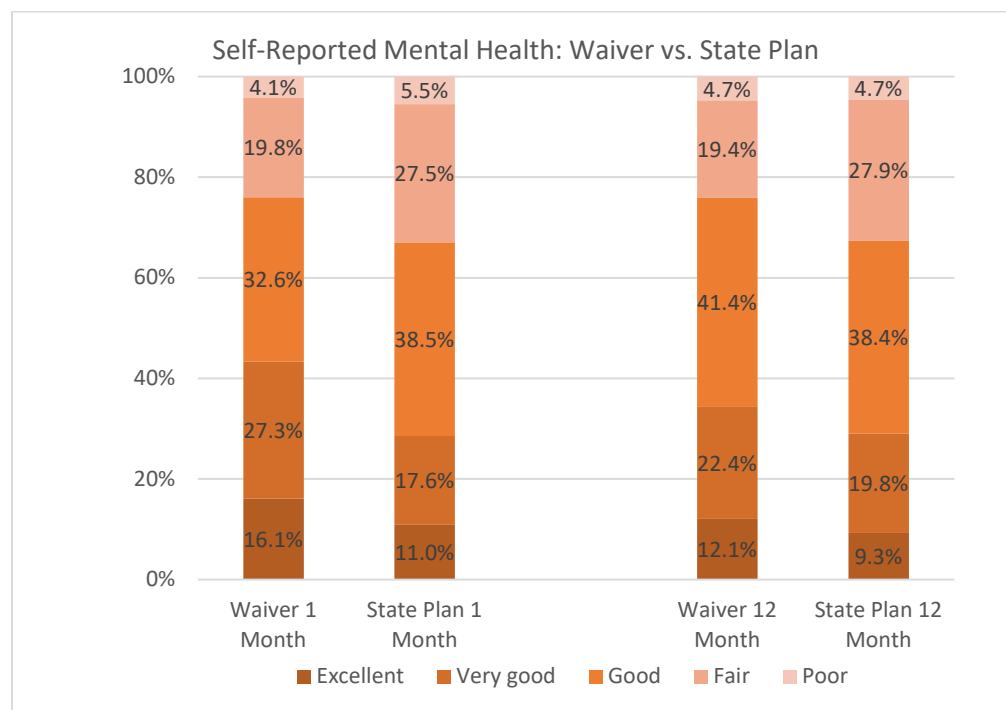
Figure 4.11. ER Visits, Hospitalizations, Reinstitutionalizations, and Falls: Waiver vs. State Plan



Mental Health

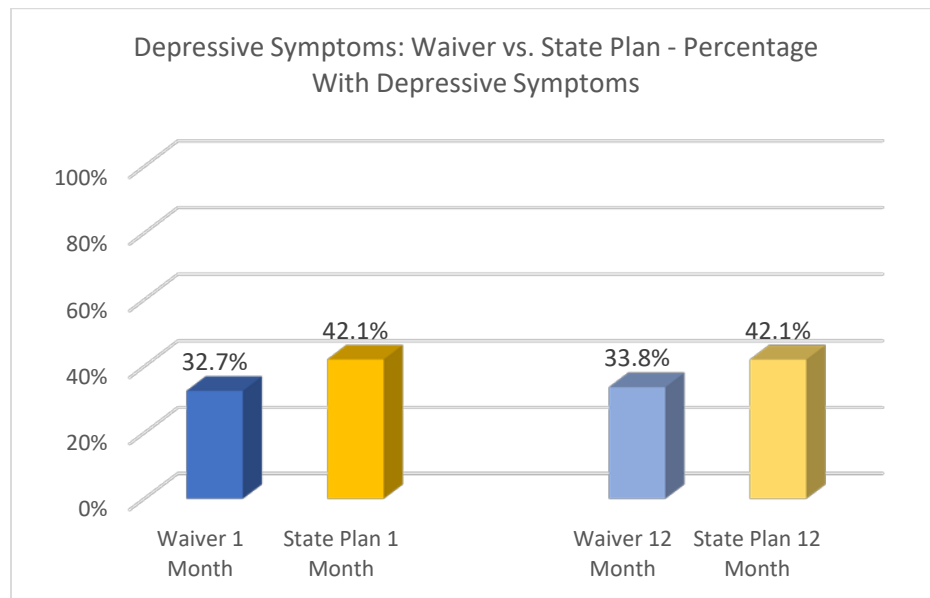
There were striking differences in mental health between waiver and state plan consumers. Waiver consumers reported noticeably better mental or emotional health than state plan consumers at both 1 and 12 months (Figure 4.12). At 1 month, 43% of waiver consumers reported very good or excellent mental health, compared to just 29% of state plan consumers. At 12 months, the percentage of waiver consumers with very good or excellent mental health dropped to 35%, but this was still more than the 29% of state plan consumers who reported very good or excellent mental health.

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



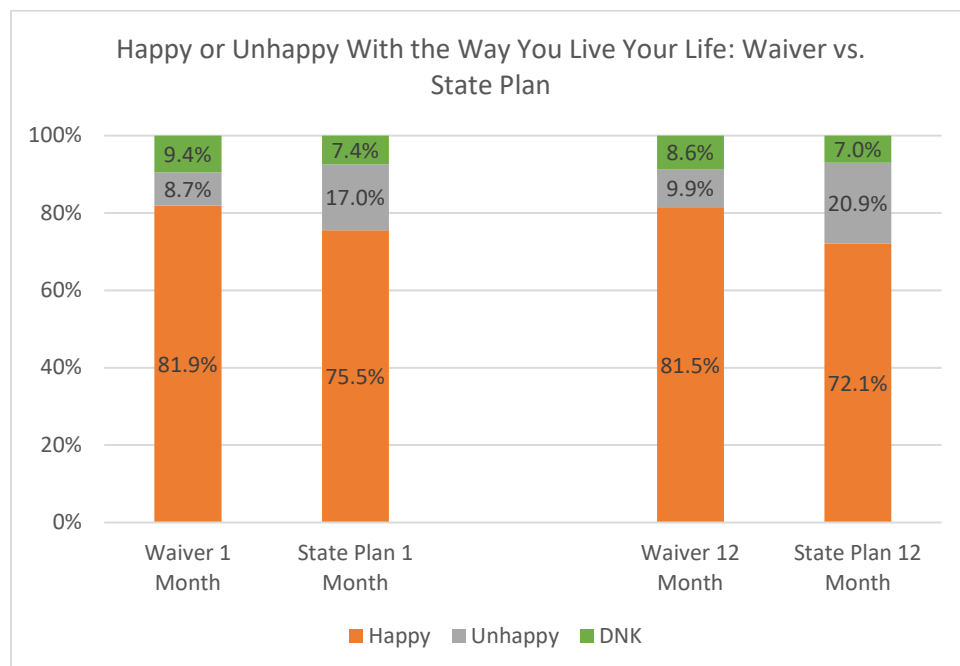
While the rate of depression for waiver consumers was close to that of all community consumers, state plan consumers reported much higher rates of depressive symptoms (Figure 4.13). Four of every ten state plan consumers reported depressive symptoms at either 1 or 12 months.

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



Although the majority of waiver and state plan consumers reported being happy with the way they live their life, state plan consumers were more than twice as likely to report feeling unhappy (Figure 4.14).

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 devices, medical equipment, or a PERS unit at both 1 and 12 months. This again may be an effect of the greater physical needs of waiver consumers. However, state plan consumers often reported a greater unmet need for these devices than did waiver consumers. This is especially true for home modifications – 14% of state plan consumers lacked necessary home modifications even at 12 months. State plan consumers also reported a noticeably higher unmet need for a PERS unit at both 1 and 12 months. At 1 month, need for medical equipment for state plan consumers was double that of waiver consumers (12% state plan vs. 5% waiver), although by 12 months, this difference no longer existed.

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=252 | N=96 | N=236 | N=88 |
| | I have it | 76.6 | 47.9 | 79.2 | 52.3 |
| | I do not need it | 13.1 | 37.5 | 37.5 | 34.1 |
| | I need it | 10.3 | 14.6 | 14.6 | 13.6 |
| Mobility equipment | | N=253 | N=95 | N=236 | N=87 |
| | I have it | 87.0 | 58.0 | 89.1 | 64.4 |
| | I do not need it | 9.1 | 41.1 | 10.2 | 34.5 |
| | I need it | 4.0 | 1.1 | 0.4 | 1.2 |
| Medical equipment | | N=253 | N=96 | N=236 | N=87 |
| | I have it | 76.0 | 33.3 | 78.4 | 39.1 |
| | I do not need it | 19.0 | 55.2 | 17.8 | 58.6 |
| | I need it | 5.1 | 11.5 | 3.8 | 2.3 |
| Lifeline or PERS | | N=253 | N=96 | N=235 | N=87 |
| | I have it | 55.7 | 11.5 | 56.2 | 13.8 |
| | I do not need it | 36.4 | 72.9 | 38.7 | 77.0 |
| | I need it | 7.9 | 15.6 | 5.1 | 9.2 |
| Internet capable devices | | N=250 | N=96 | N=236 | N=87 |
| | I have it | 49.6 | 65.6 | 58.9 | 65.5 |
| | I do not need it | 41.6 | 26.0 | 32.6 | 33.3 |
| | I need it | 8.8 | 8.3 | 8.5 | 1.2 |
| Internet access | | N=248 | N=92 | N=234 | N=84 |
| | I have it | 72.2 | 64.1 | 73.9 | 73.8 |
| | I do not need it | 21.0 | 18.5 | 20.5 | 23.8 |
| | I need it | 6.9 | 17.4 | 5.6 | 2.4 |

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

Community living consumers who transitioned in 2019 were next separated 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 which category to put them into for this section – agency-based consumers or self-directed consumers. Only participants who answered this question are included in this section. As shown in Table 5.1, consumers using agency-based services composed 69% of the 1 month and 68% of the 12 month sample.

Services and Select Demographics

Table 5.1. Service Type by Survey Time Point

| | 1 Month n (%) | 12 Month (%) |
|---------------|------------------|-----------------|
| Agency-based | 174 (69.0) | 160 (67.8) |
| Self-directed | 78 (31.0) | 76 (32.2) |
| Total | 252 (100.0) | 236 (100.0) |

Compared to agency-based consumers, self-directed consumers reported noticeably greater use of personal care services at 1 and 12 months and use of homemaking services at 12 months (Table 5.2). Most self-directed consumers do not employ separate homemaking staff; instead their PCAs also provide their homemaking services. Unexpectedly, more self-directed consumers reported using case management services, especially at 1 month post-transition, than those with agency-based services.

Table 5.2. Self-reported Home and Community-Based Services Use*

| | 1 Month | | 12 Month | |
|---|-----------------|----------------------|-----------------|----------------------|
| | Agency n (%) | Self-direct n (%) | Agency n (%) | Self-direct n (%) |
| Personal care assistant/attendant services | 144 (82.8) | 74 (94.9) | 133 (83.1) | 71 (93.4) |
| Behavioral health services (ABI, Autism, DDS) | 3 (1.7) | 1 (1.3) | 4 (2.5) | 0 (0) |
| Recovery assistance services (MHW) | 5 (2.9) | 1 (1.3) | 9 (5.6) | 0 (0) |
| Homemaking services or Homemaker-Companion | 100 (57.5) | 51 (65.4) | 102 (63.8) | 70 (92.1) |
| Community Service Provider (MHW) | 6 (3.4) | 1 (1.3) | 5 (3.1) | 0 (0) |
| Care management services | 119 (68.4) | 61 (78.2) | 102 (63.8) | 53 (69.7) |
| Job coach or vocational supports | 1 (<1.0) | 0 (0) | 1 (<1.0) | 0 (0) |
| None of these services | 2 (1.1) | 2 (2.6) | 1 (<1.0) | 0 (0) |

* Consumers can use more than one service

Consumers whose staff were hired through an agency were more than three times as likely as self-direct consumers to be 65 years and older. Agency-based consumers are also more likely to be female (Table 5.3).

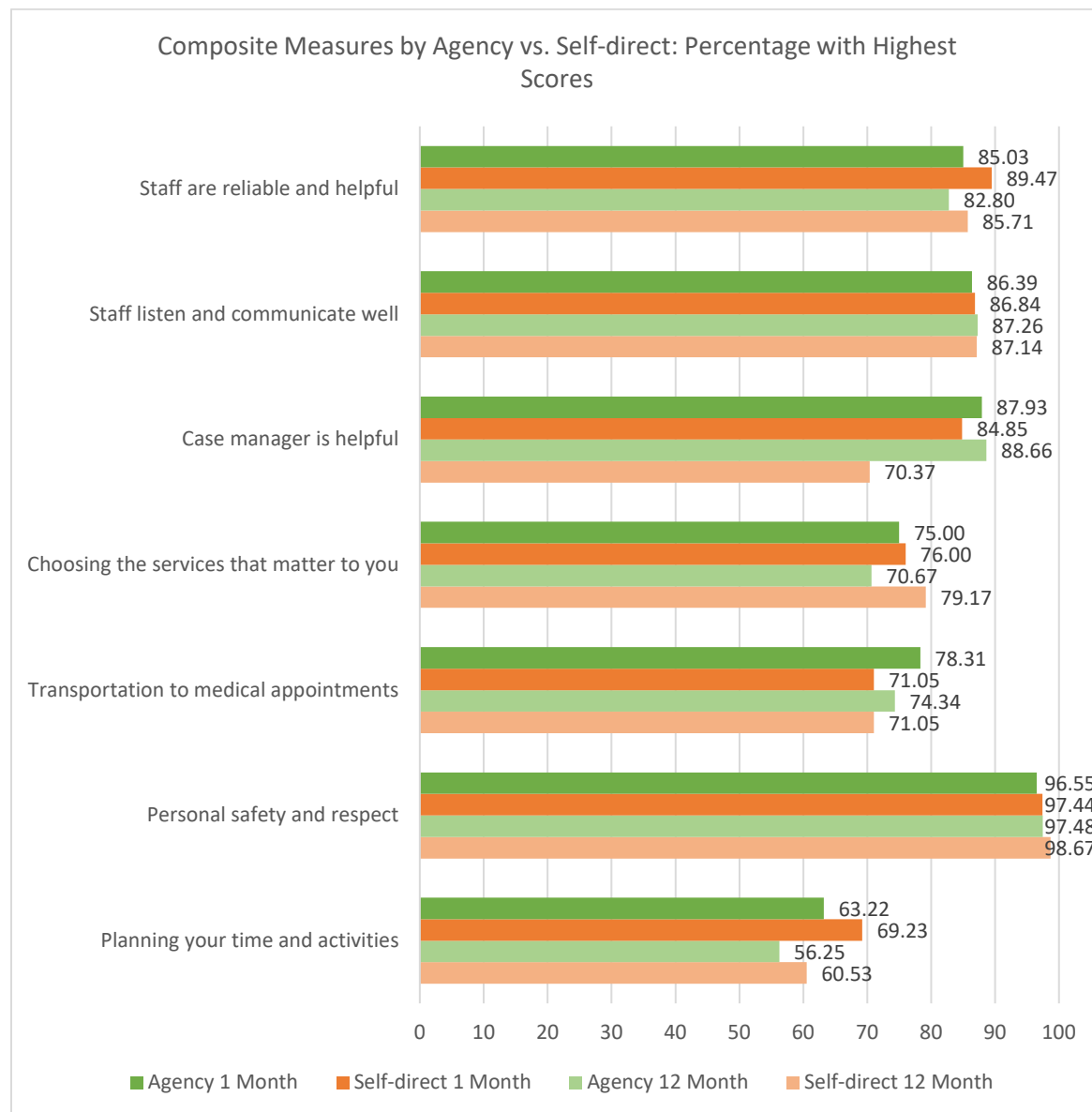
Table 5.3. Demographics – Agency/Self-direct by Time Point

| | | 1 Month | | 12 Month | |
|---------------|--------|--------------|------------------|--------------|------------------|
| | | Agency % | Self-direct % | Agency % | Self-direct % |
| Age | | N=174 | N=78 | N=160 | N=76 |
| | <18 | 1.1 | 1.3 | <1.0 | 1.3 |
| | 18-24 | <1.0 | 1.3 | 0.0 | 1.3 |
| | 25-34 | 1.1 | 7.7 | 3.1 | 5.3 |
| | 35-44 | 2.3 | 7.7 | 3.1 | 6.6 |
| | 45-54 | 12.6 | 17.9 | 9.4 | 21.1 |
| | 55-64 | 17.8 | 44.9 | 21.9 | 38.2 |
| | 65-74 | 26.4 | 6.4 | 30.0 | 11.8 |
| | 75+ | 37.9 | 12.8 | 31.9 | 14.5 |
| Gender | | N=174 | N=78 | N=160 | N=76 |
| | Male | 43.7 | 51.3 | 40.0 | 55.3 |
| | Female | 56.3 | 48.7 | 60.0 | 44.7 |

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

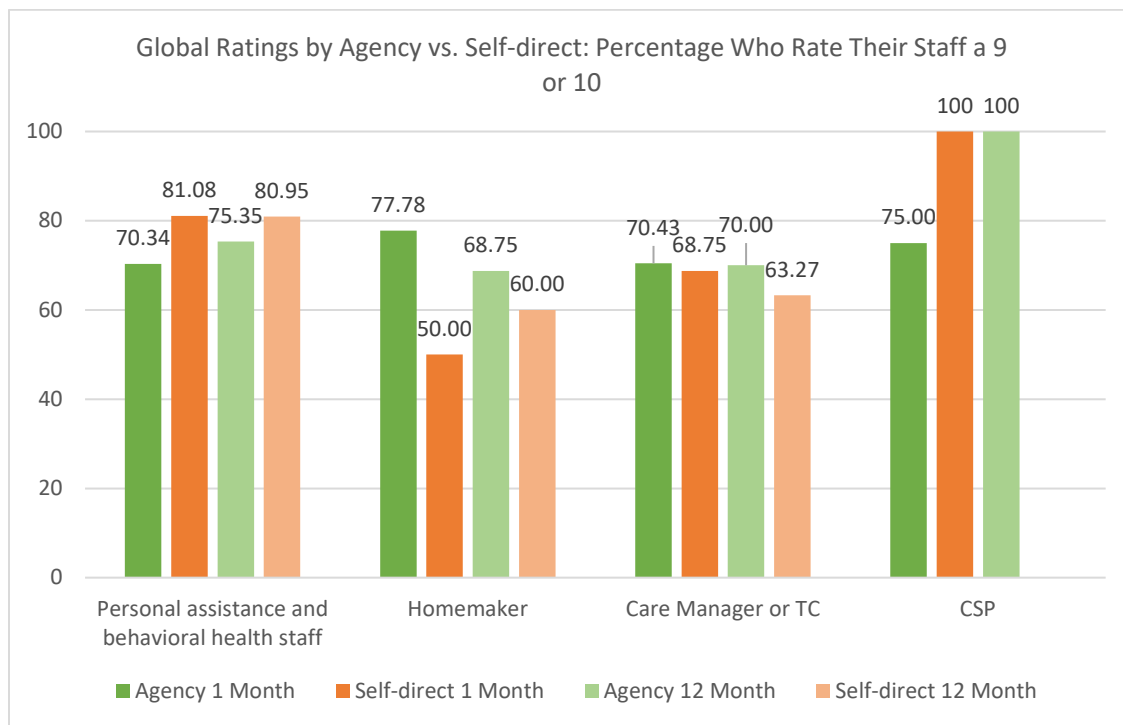
Several differences in the composite measures existed between agency-based and self-directed consumers (Figure 5.1). The most marked differences were case manager is helpful at 12 months and choosing your services at 12 months. While many agency and self-direct consumers gave the highest score for case manager is helpful at 1 month, significantly fewer self-directed consumers did so by 12 months. Self-directed consumers were much more likely than agency-based consumers to say they could choose the services that matter to them at 12 months. While more self-directed consumers gave the highest score for planning your time and activities than agency-based consumers, both groups experienced a sharp drop in this composite at 12 months.

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



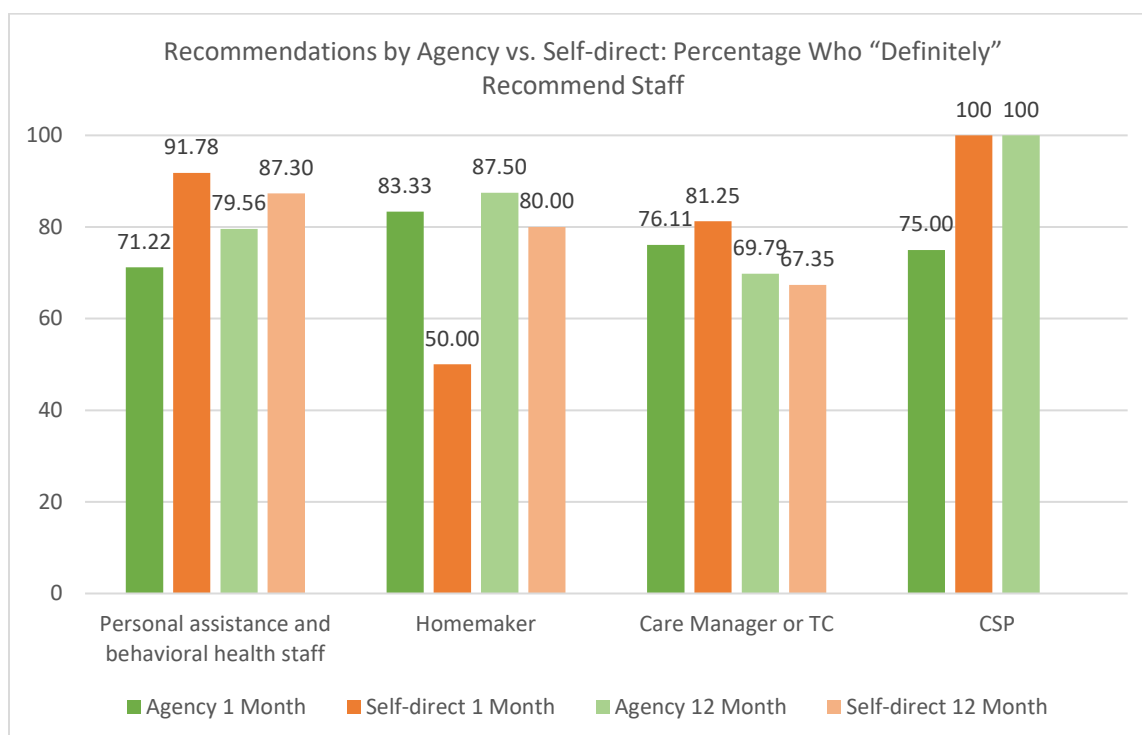
Staff ratings and recommendations also showed some marked differences between the two groups of consumers (Figure 5.2). In particular, at 1 month after transition, self-directed consumers rated their personal care staff noticeably higher than agency based consumers. Meanwhile, agency-based consumers were much more likely to rate their homemaker staff a 9 or 10, especially at 1 month post-transition. The homemaker staff sample size for self-directed consumers was very small (n=2 1 month, n=5 12 month), because most self-directed consumers used their PCAs for homemaker tasks as well as personal care. Case manager ratings for self-directed consumers dropped at 12 months, but remained stable for agency consumers.

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



At 1 month, self-directed consumers were much more likely to “definitely” recommend their personal assistance staff, while markedly more agency-based consumers would definitely recommend their homemaking staff (Figure 5.3). Case manager recommendations fell in particular for self-directed consumers by 12 months.

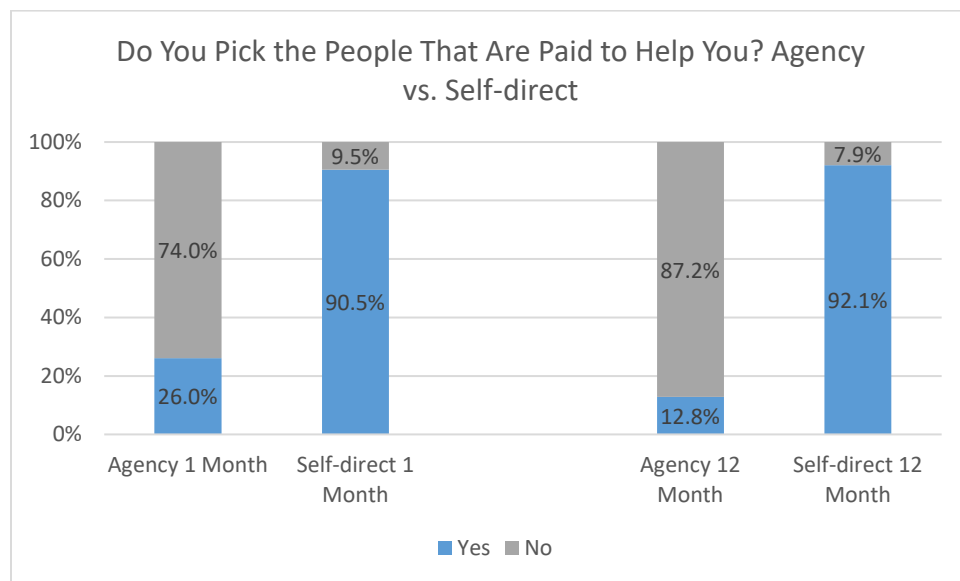
Figure 5.3. Recommendations by Agency vs. Self-direct: Percentage Who “Definitely” Recommend Staff



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?” Not surprisingly, over 90% of self-directed consumers chose their paid assistants at either time point, which was much higher than agency-based consumers (26% 1 month, 13% 12 month). As noted in section 3, at 1 month 40% of self-directed consumers employed family members as paid assistants, and this increased to 59% by 12 months.

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



Assistance with Everyday Activities

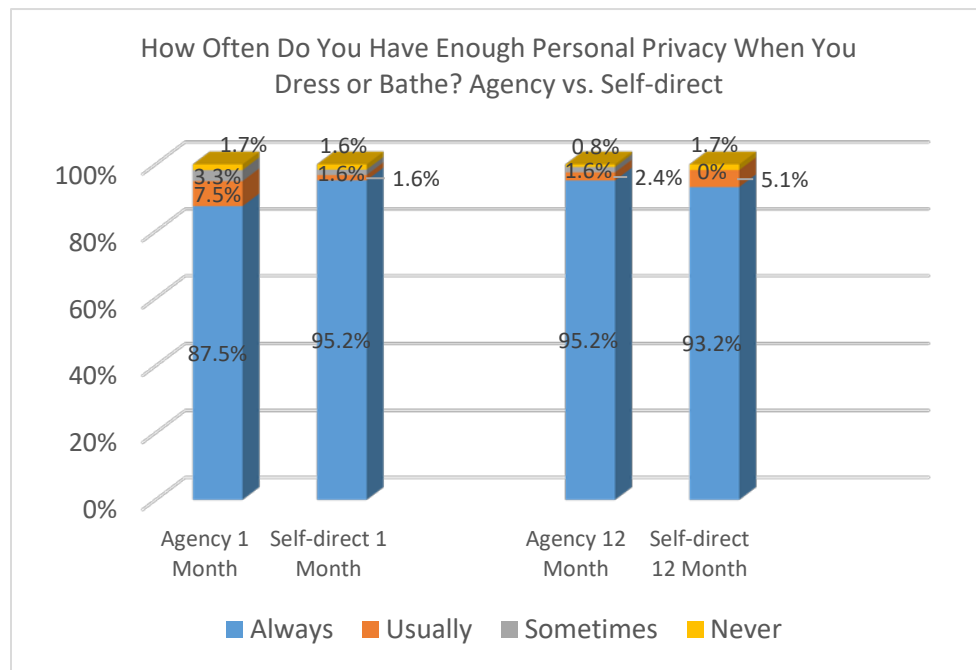
Consumers who received personal care assistance were asked what tasks they needed assistance with. As seen in Table 5.4, numerous differences existed in the type of PCA assistance provided to each group of consumers. Most noticeably, self-directed consumer were much more likely to need PCA assistance for toileting at 1 month and for meals/eating at 12 months compared to agency-based consumers. Self-directed consumers also used housecleaning and laundry assistance more often, especially at 12 months post-transition.

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 | 125 (83.3) | 63 (86.3) | 125 (86.8) | 61 (91.0) |
| Meals or eating | 119 (80.4) | 65 (87.8) | 118 (81.9) | 63 (95.5) |
| Taking medications | 101 (68.2) | 44 (60.3) | 93 (64.6) | 48 (71.6) |
| Using the toilet | 89 (59.7) | 50 (68.5) | 85 (59.0) | 42 (62.7) |
| Housekeeping or laundry | 100 (61.4) | 51 (72.9) | 102 (68.5) | 70 (94.6) |

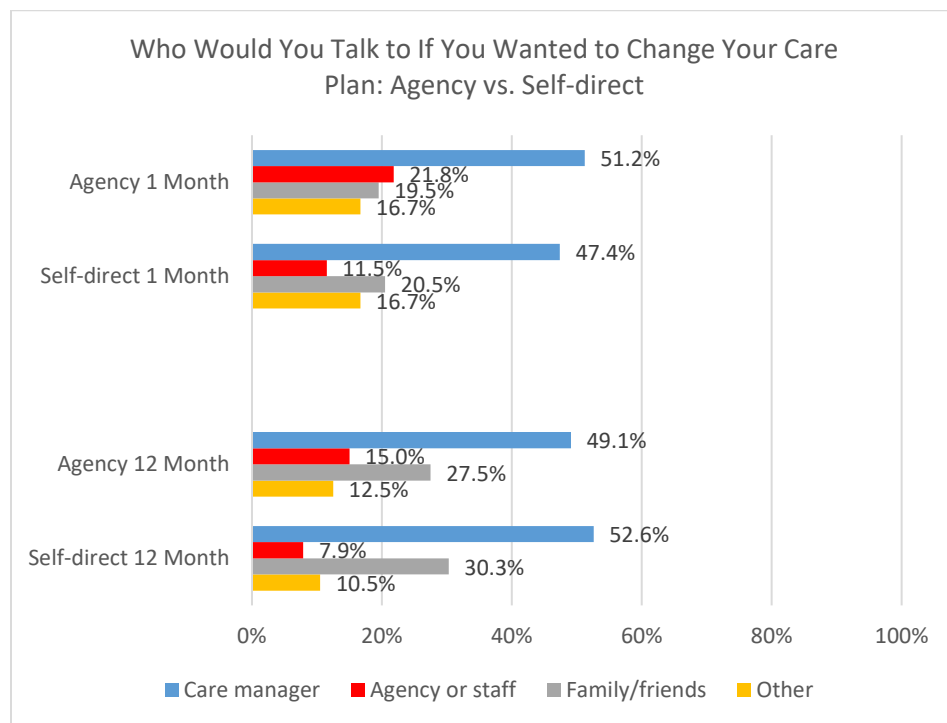
When asked how often they had enough personal privacy when bathing or dressing, fewer agency-based consumers always had enough privacy at 1 month compared to self-directed consumers (Figure 5.5).

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



Both agency-based and self-directed consumers were most likely to call their care manager to change their care plan (Figure 5.6). Not surprisingly, at both time points, more agency-based consumers named either the home care agency or a staff member than self-directed consumers.

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



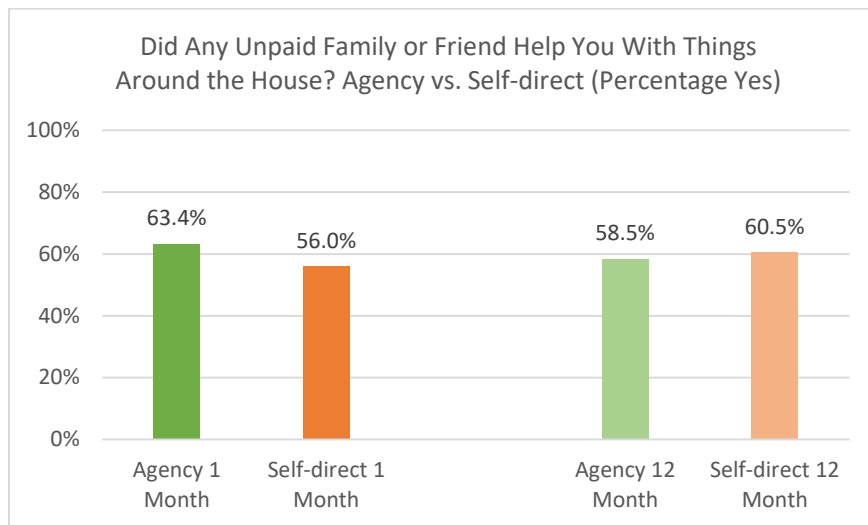
Living Situation and Social Support

Household composition showed strong differences between the two groups of consumers (Table 5.5). Although a majority of consumers in either group lived with family member/s, self-directed consumers were much more likely to do so – at 1 month 88% of self-directed consumers lived with family compared to 67% of agency-based consumers. On the other hand, agency-based consumers lived with non-family more often than self-directed consumers. At one year post-transition, 38% of agency-based consumers lived with non-family, while just 14% of self-directed consumers did so. Significantly more self-directed consumers said they had friends who lived nearby. At 1 month, agency-based consumers reported receiving more informal support from family and friends for household tasks, although this difference evened out by 12 months (Figure 5.7).

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

| | | 1 Month Agency | 1 Month Self-Direct | 12 Month Agency | 12 Month Self-Direct |
|---|-----|-------------------|------------------------|--------------------|-------------------------|
| | | % | % | % | % |
| Number of adults living in household | | N=171 | N=76 | N=160 | N=76 |
| | 1 | 52.1 | 55.3 | 54.4 | 52.6 |
| | 2-3 | 40.4 | 43.4 | 40.0 | 42.1 |
| | 4+ | 7.6 | 1.3 | 5.6 | 5.3 |
| | | | | | |
| Lives with family member/s | | N=82 | N=34 | N=73 | N=36 |
| | Yes | 67.1 | 88.2 | 65.8 | 86.1 |
| | No | 32.9 | 11.8 | 34.3 | 13.9 |
| Lives with non-family | | N=82 | N=34 | N=73 | N=36 |
| | Yes | 32.9 | 20.6 | 38.4 | 13.9 |
| | No | 67.1 | 79.4 | 61.6 | 86.1 |
| Family member/s live nearby | | N=174 | N=78 | N=160 | N=76 |
| | Yes | 78.7 | 79.5 | 79.4 | 79.0 |
| | No | 21.3 | 20.5 | 20.6 | 21.1 |
| Friend/s live nearby | | N=172 | N=78 | N=160 | N=76 |
| | Yes | 43.6 | 62.8 | 43.8 | 55.3 |
| | No | 56.4 | 37.2 | 56.3 | 44.7 |

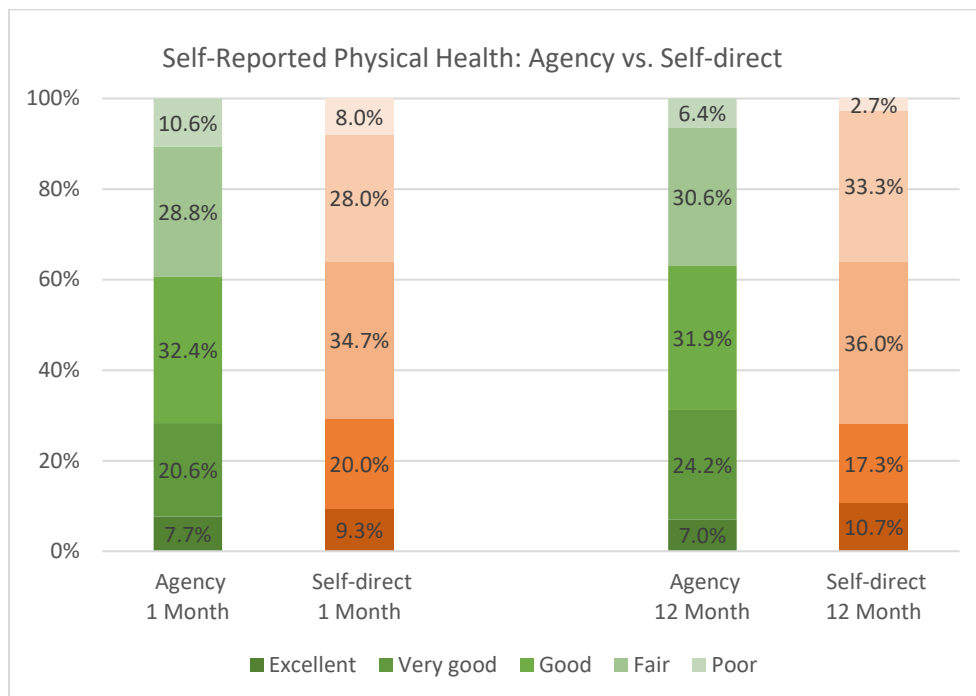
Figure 5.7. Assistance from Unpaid Family or Friends with Things Around the House: Agency vs. Self-direct (Percentage Yes)



Physical Health

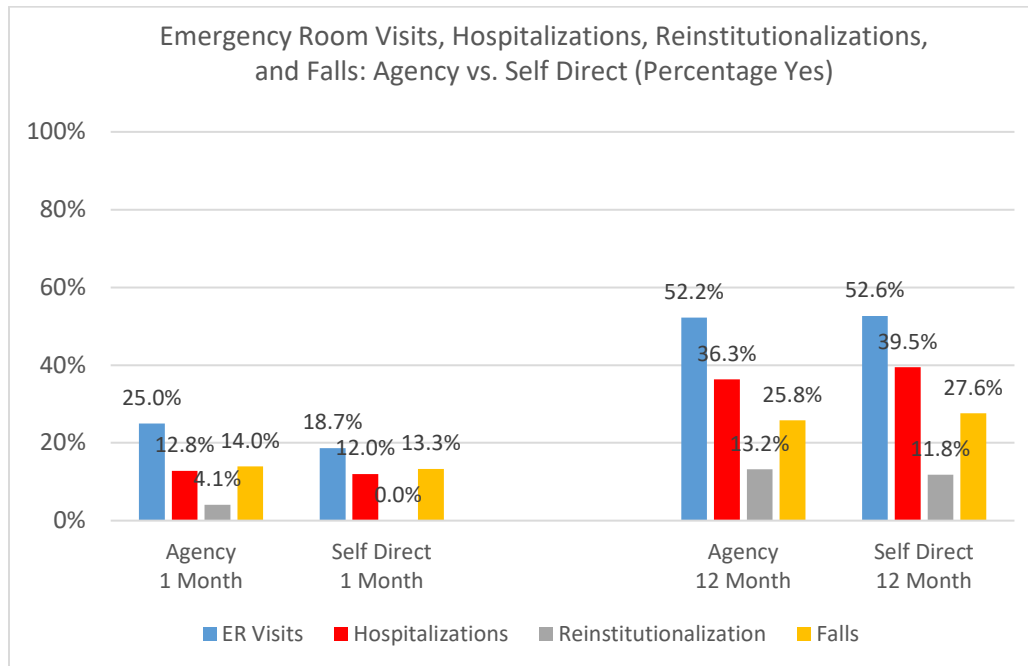
Self-reported physical health showed no marked differences between groups or time points (Figure 5.8). For example, 28-31% of consumers reported very good or excellent health, no matter if agency or self-directed services and at either 1 or 12 months.

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



There were few apparent differences in falls, ER visits, hospitalizations, and reinstitutionalizations between agency-based and self-directed consumers (Figure 5.9). Most notably, agency-based consumers used the ER more often in the first month – one out of four agency-based consumers went to the ER at least once by their 1 month survey – and no self-directed consumers were reinstitutionalized by their 1 month survey.

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



Mental Health

More self-directed consumers reported very good to excellent mental or emotional health at either time point compared to consumers using agency-based services (Figure 5.10). Most strikingly, while 30% of agency-based consumers reported fair or poor mental health at 12 months, only 17% of self-directed consumers reported this. When asked if they were happy or unhappy with the way they lived their life, more self-directed consumers said they were happy at 12 months compared to agency-based consumers (88% self-directed, 78% agency-based) (Figure 5.11).

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

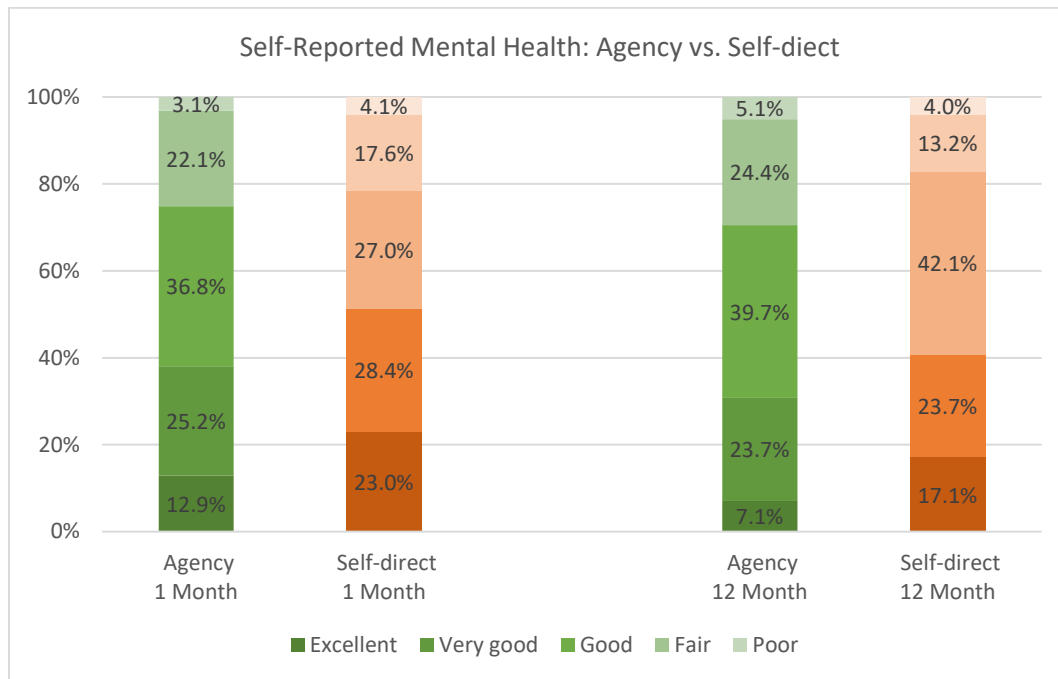
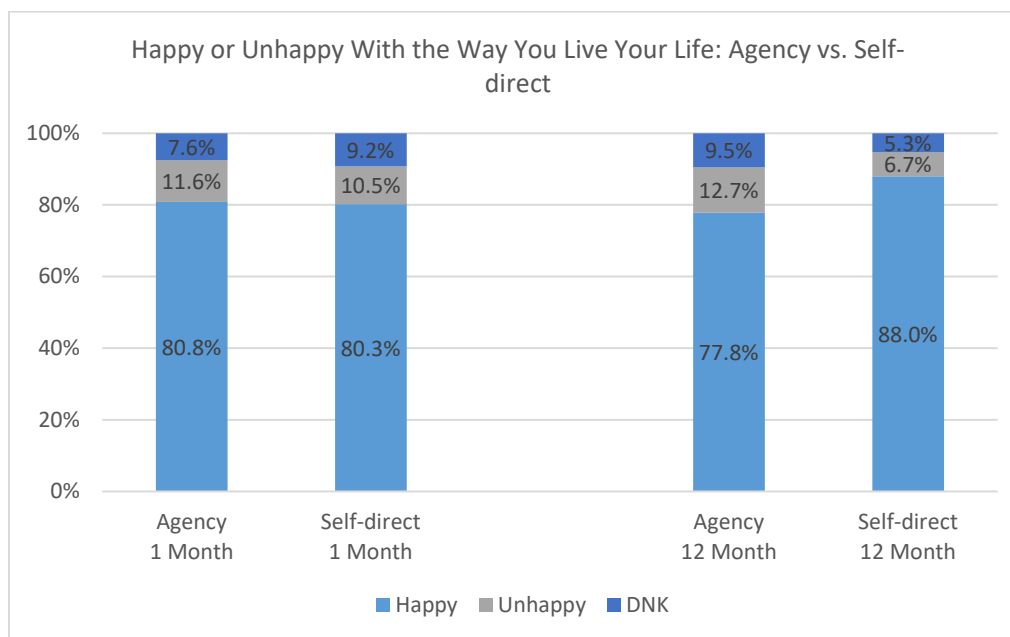


Figure 5.11. Happy or Unhappy With the Way You Live Your Life: Agency vs. Self-direct



Assistive Device, Special Medical Equipment, Home Modifications

As shown in Table 5.6, self-directed consumers were more likely to have any assistive devices, home modifications, special equipment, PERS, or even internet access than agency-based consumers. This was especially true for special equipment, mobility devices, and internet access. At 1 month, 84% of self-directed consumers reported having mobility equipment, compared to 70% of self-directed consumers.

By 12 months each of those percentages had increased, but the group differences remained. In most cases, agency-based consumers were more likely to say they needed a type of assistive equipment or home modification.

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=171 | N=75 | N=160 | N=76 |
| | I have it | 76.0 | 80.0 | 77.5 | 80.3 |
| | I do not need it | 14.6 | 9. | 13.1 | 13.2 |
| | I need it | 9.4 | 10.8 | 9.4 | 6.6 |
| Mobility equipment | | N=171 | N=76 | N=160 | N=76 |
| | I have it | 84.2 | 93.4 | 88.1 | 97.4 |
| | I do not need it | 11.1 | 4.0 | 11.3 | 2.6 |
| | I need it | 4.7 | 2.6 | 0.6 | 0.0 |
| Medical equipment | | N=171 | N=76 | N=160 | N=76 |
| | I have it | 70.2 | 84.2 | 75.6 | 92.1 |
| | I do not need it | 22.2 | 13.2 | 19.4 | 5.3 |
| | I need it | 7.6 | 2.6 | 5.0 | 2.6 |
| Lifeline or PERS | | N=171 | N=76 | N=159 | N=76 |
| | I have it | 52.1 | 57.9 | 54.7 | 59.2 |
| | I do not need it | 40.9 | 34.2 | 37.1 | 36.8 |
| | I need it | 7.0 | 7.9 | 8.2 | 4.0 |
| Internet capable devices | | N=170 | N=74 | N=160 | N=76 |
| | I have it | 48.8 | 59.5 | 56.3 | 68.4 |
| | I do not need it | 43.5 | 29.7 | 37.5 | 19.7 |
| | I need it | 7.7 | 10.8 | 6.3 | 11.8 |
| Internet access | | N=168 | N=74 | N=158 | N=76 |
| | I have it | 63.1 | 86.5 | 66.5 | 88.2 |
| | I do not need it | 27.4 | 8.1 | 27.9 | 7.9 |
| | I need it | 9.5 | 5.4 | 5.7 | 4.0 |

Section 6. The Reinstitutionalization Effect

This section explores the history and effect of readmission to a facility by following consumers from transition through their 1 or 12 month survey. The 2019 MFP HCBS CAHPS report clearly showed that overall people do better in the community – they are happier, less depressed, are more likely to like where they live, have increased choice and control, have better experiences with their paid staff, and are more active in the community (Porter et al., 2020). 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 535 consumers who transitioned in 2019 was used to look at any history of reinstitutionalization up to one year post-transition. Data came from the MFP HCBS CAHPS surveys and the CT DSS MyCommunityChoices website. In Table 6.1, the 1 month survey setting and 12 month survey setting represent the participant’s location at the time of their 1 month and 12 month survey. The columns between transition to one month, and between 1 month to 12 month, indicate any reinstitutionalization between the settings. If the participant was reinstitutionalized for any amount of time between transition and 1 month, or between the 1 month to 12 month timeframe, then “facility” is listed. “Community” indicates the participant was always in the community during that time and had not gone back to a facility even temporarily.

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

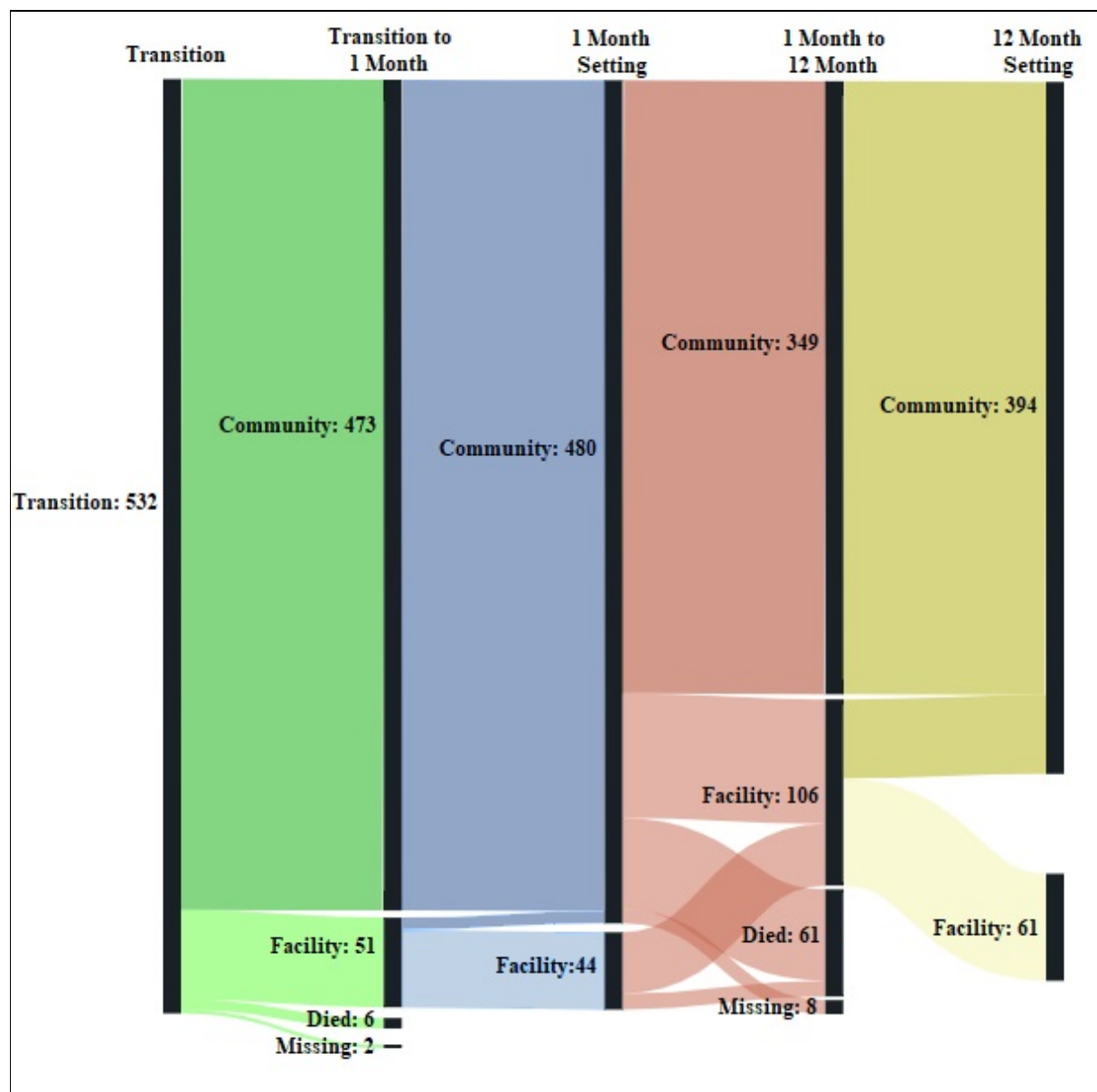
| | Transition N=532 n (%) | Transition to 1 Month N=524 n (%) | 1 Month Survey Setting N=524 n (%) | 1 Month to 12 Month N=455 n (%) | 12 Month Survey Setting N=455 n (%) |
|------------------|------------------------------|--|---|--|--|
| Community | 532 (100) | 473 (90.3) | 480 (91.6) | 349 (76.7) | 394 (86.6) |
| Facility | 0 (0) | 51 (9.7) | 44 (8.4) | 106 (23.3) | 61 (13.4) |

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 2019 at five points in time: transition, transition to 1 month, 1 month setting, 1 month to 12 month, and 12 month setting. Four main categories summarize the participant outcomes at each time point: community, facility, died, or missing. After excluding the cases of participants who were either missing or deceased, 10% of participants had returned to a facility for either a short-term or long-term stay within a month after their transition. By the time of their 1 month survey, slightly fewer consumers were still in a facility (8%). Unsurprisingly given the longer length of time between the 1 month and 12 month survey, nearly a quarter (23%) of consumers had been in a facility either temporarily or long-term. However, by the time of their 12 month survey, the percentage of participants who were still reinstitutionalized at that time dropped to 13%.

Porter M., James T., Bailey C., DePalma A., Wakefield D., & Robison, J. (2020). *Money Follows the Person: Consumer Assessment of Health Provider Systems Home and Community-Based Services (HCBS CAHPS) Survey Results: 2019 One Month Post Transition*. UConn Health Center on Aging. Prepared for the Connecticut Department of Social Services.

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

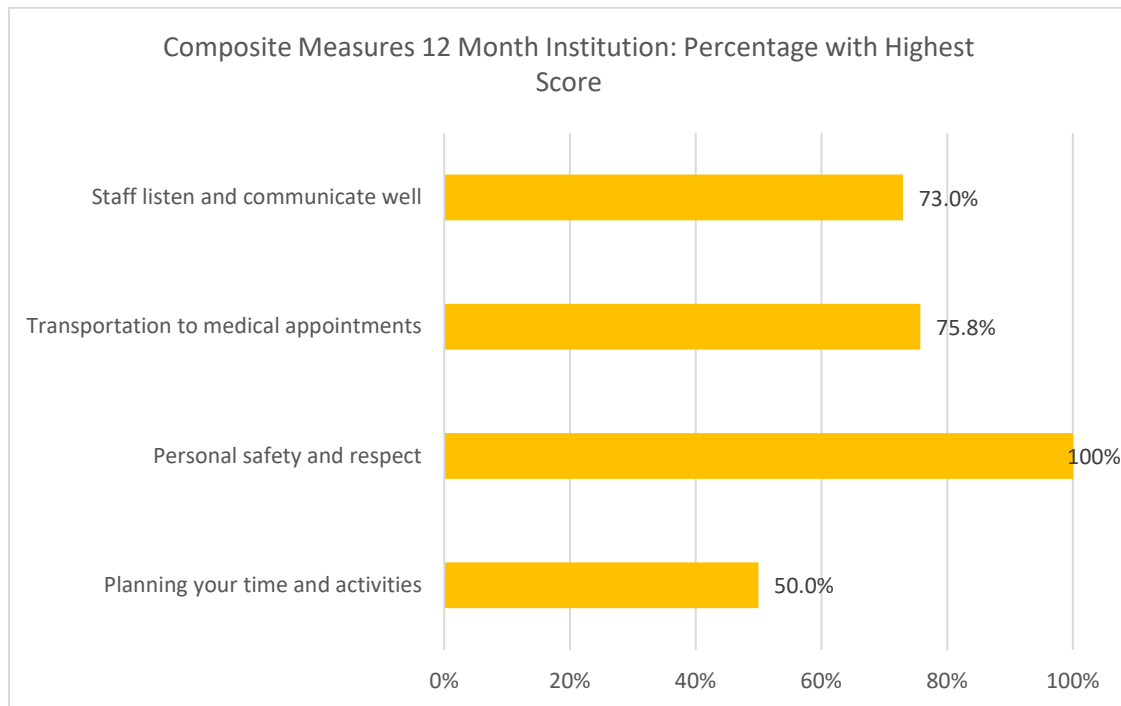


SankeyMATIC: A Sankey Diagram Builder for Everyone. <http://sankeymatic.com>

2020 12 Month Institution: Select Results

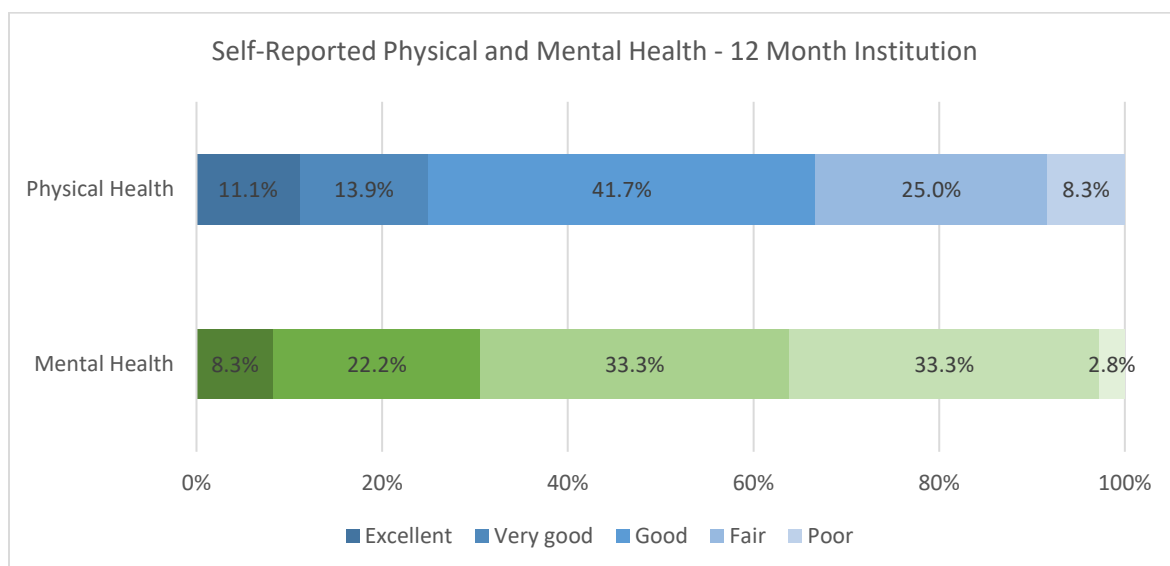
The following figures present survey data completed in 2020 for 37 of the consumers who transitioned in 2019 and were in a facility at 12 months. See report Section 3 for comparative results from consumers in the community at 12 months. As shown in Figure 6.2, at 12 months, more institutionalized consumers gave the highest score to the personal safety and respect composite than to the other three composites.

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



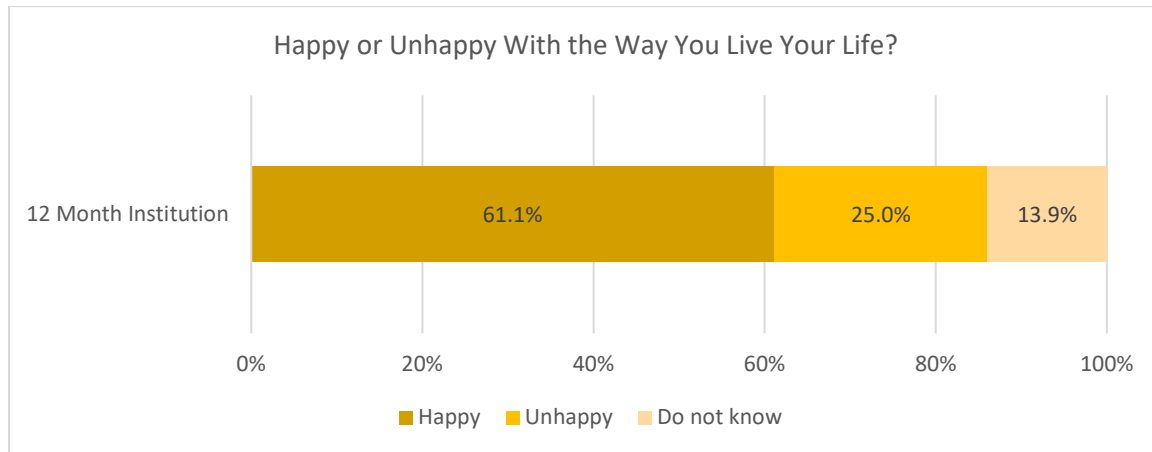
Unexpectedly, consumers in an institution at 12 months were less likely to report fair or poor physical health than those in the community (33% institution, 37% community) (Figure 6.3). However, institutionalized consumers were much more likely to report only fair or poor mental health (36% institution, 26% community).

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



Although a slightly lower percentage of consumers institutionalized at 12 months had depressive symptoms (33% institution, 36% community), only 61% of those institutionalized said they were happy with the way they live their life, compared to 78% 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 2020

This section looks at the experience of reinstitutionalization at one month post-transition for consumers who transitioned in 2020. 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 610 consumers transitioned in 2020. Of these, 499 consumers completed a 1 month survey. One month surveys are timed to be completed between 30 and 45 days post-transition. On average, these 1 month surveys were completed 43 days post-transition, with a range from 21 to 94 days.

Almost all consumers (95.4%, n=476) who completed a 1 month survey were living in a community setting at the time of their interview. Eight consumers had been reinstitutionalized temporarily after transition, resulting in an overall readmission rate of 6.2% (n=31) by the 1 month survey (Table 6.2).

Table 6.2. Transitioned in 2020 – Experienced Reinstitutionalization by 1 Month Survey

| | n (%) |
|---|------------|
| Total 1 month surveys | 499 (100) |
| Experienced readmission by one month survey | |
| No – Always in the community | 468 (93.8) |
| Yes – Reinstitutionalized either short or long-term | 31 (6.2) |

Consumer Characteristics

Consumers who experienced reinstitutionalization by 1 month were more likely to be getting waiver services (Table 6.3). Waiver clients have a baseline of a higher level of care, as they must meet nursing facility level of care, while state plan consumers do not.

Table 6.3. Waiver or State Plan Status by Reinstitutionalization

| Service Type | | Always Community n (%) | Ever Reinstitutionalized n (%) |
|--------------|---------|------------------------------|--------------------------------------|
| Waiver | (N=360) | 334 (92.8) | 26 (7.2) |
| State Plan | (N=139) | 134 (96.4) | 5 (3.6) |

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

Table 6.4. Demographics: Always Community vs. Ever Reinstitutionalized

| | | Always Community n (%) | Ever Reinstitutionalized n (%) |
|--------|---------------------------|------------------------------|--------------------------------------|
| Age | < 55 years | 127 (27.1) | 2 (6.5) |
| | 55 to 64 years | 152 (32.5) | 16 (51.6) |
| | 65 to 74 years | 96 (20.5) | 7 (22.6) |
| | 75 years or older | 93 (19.9) | 6 (19.4) |
| Race | White | 321 (70.1) | 24 (80.0) |
| | Black or African American | 104 (22.7) | 4 (13.3) |
| | Asian | 4 (0.9) | 1 (3.3) |
| | Native Hawaiian | 1 (0.2) | 0 (0) |
| | American Indian | 6 (1.3) | 0 (0) |
| | Other | 22 (4.8) | 1 (3.3) |
| Gender | Male | 239 (51.3) | 14 (46.7) |
| | Female | 227 (48.7) | 16 (53.3) |

Physical and Mental Health at One Month

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

Figure 6.5. Self-Reported Physical Health

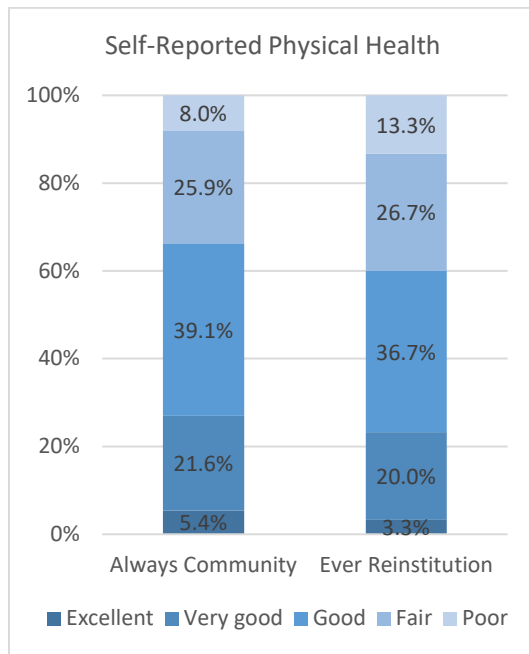


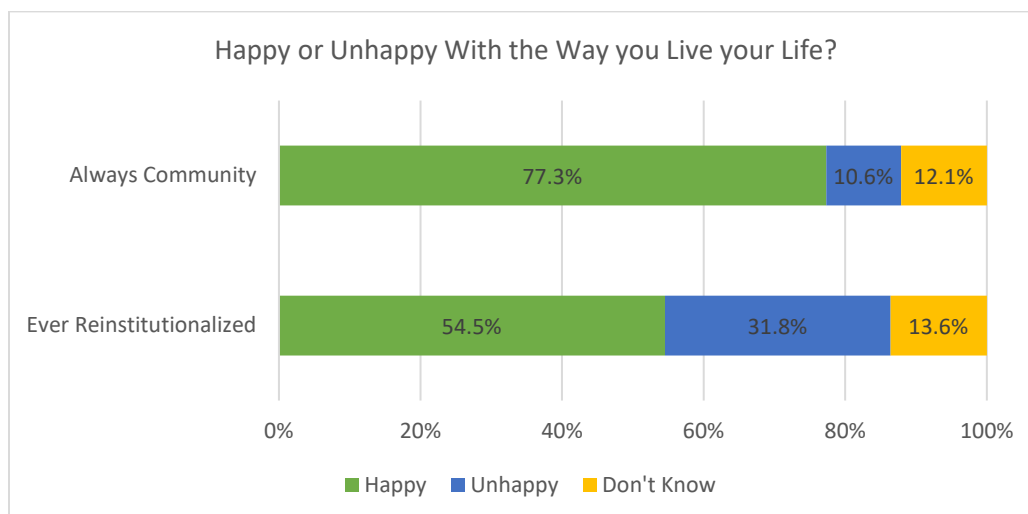
Figure 6.6. Self-Reported Mental Health



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

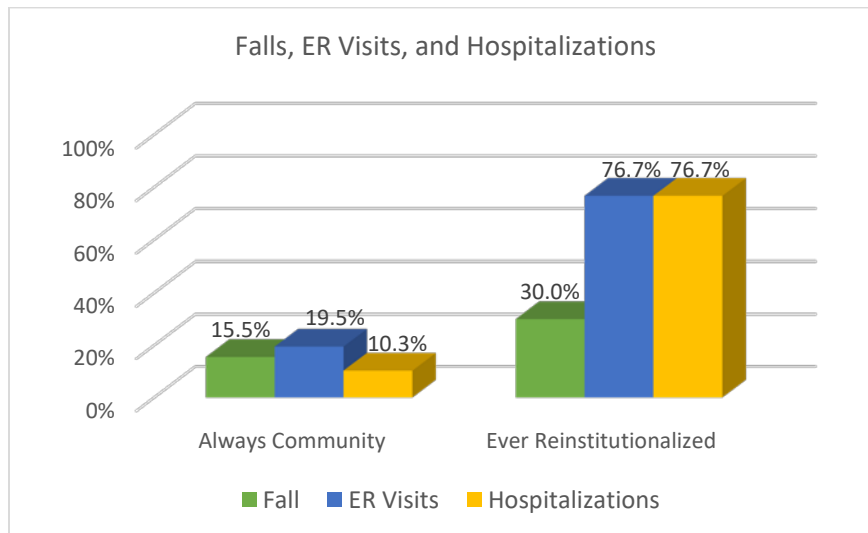
| Depressive Symptoms | Always Community n (%) | Ever Reinstitutionalized n (%) |
|---------------------|---------------------------|-----------------------------------|
| Yes | 131 (28.9) | 13 (43.3) |
| No | 323 (71.1) | 17 (56.7) |

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



Those who had been reinstitutionalized experienced a fall rate of almost double those who were always in a community and had very high rates of emergency room and hospital use (Figure 6.8).

Figure 6.8. Falls, ER Visits, and Hospitalizations



The Consumer Experience

Case histories for each of the 31 consumers who experienced reinstitutionalization 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.

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

Consumer physical decline post-transition

Physical health decline post transition was a leading cause of reinstitutionalization within four to six weeks post-transition. Health conditions which were stable in the facility became worse once in the community. Consumers who could transfer or walk independently at the facility began to need more and more assistance to do so in the community. Many consumer already have serious conditions such as end stage renal disease or insulin dependent diabetes. Other factors in health decline included lack of professional medical care or relying on the consumer or family members to provide complex medical care. COVID was a factor in five of the cases. Other times it is not known why a consumer's physical health declined so rapidly after transition.

Strauss A. & Corbin J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. SAGE Publications.

One consumer in his nineties transitioned home on the CHCPE waiver. He lived alone with no informal support. The consumer had multiple diagnoses, including cardiovascular conditions and diabetes with neuropathy. At assessment he could transfer independently and walk short distances with a walker; however, at the facility he often sat in a manual wheelchair which he could not move by himself. Soon after transition, he lost the ability to transfer independently. One evening, after the PCA left, he could not get out of his wheelchair by himself and spent the night and into the next day in his wheelchair. When the PCA came in the next day, he went to the hospital and was discharged to a facility. In addition to decline in physical health post-transition, other overlapping themes here include no informal care and multiple medical conditions which affected his ability to stand and walk.

Lack of PCA or other homecare services

Another reoccurring theme was lack of approved PCA, personal care, or non-medical homecare services. For example, sometimes PCAs did not show up, did not come on time, or did not do their assigned tasks once there. Other times agencies agreed to staff the case, but later found they did not serve that area, did not have enough PCAs due to the workforce shortage, or otherwise neglected to staff the case. The consumers found themselves without assistance until a new PCA could be hired. Self-directed consumers also found it difficult to find and hire enough reliable PCAs. Miscommunication compounded the issue in some cases – the PCA did not realize the extent of assistance needed, the date of transition changed, or the PCA services hours got changed by one member of the care team without notifying the others.

Issues with lack of staffing is illustrated by one PCA waiver consumer in her sixties. She was in a wheelchair, could not transfer independently, and needed extensive hands-on assistance. Diagnoses included cerebral palsy, diabetes, heart disease, open wound, and incontinence. The PCAs scheduled at transition did not show up, and she had no care for 24 hours. The next day, the consumer went to the emergency room for physical care and was reinstitutionalized until the agency could provide staffing. In a similar case, the PCAs showed up initially, but then just stopped coming and could not be quickly replaced. Both of these consumers had no informal supports to turn to for back-up assistance when agency services failed, and without needed hands on assistance, ended up going to the ER and back to a facility.

Lack of family or informal support

As mentioned above, family or other informal supports are often a critical component of the care plan, providing various assistance such as personal or medical care, medication management, supervision, or household tasks. Consumers sometimes transition with ongoing health conditions which require more medical care than can be provided by weekly nursing, and the family members agree to provide this care so their loved one can come home. Unfortunately, sometimes the family member subsequently finds that they cannot keep up this level of support or becomes overwhelmed. This was the case with one consumer with dementia and mental health conditions who transitioned to Adult Family Living; one other family member agreed to live there and provide unpaid assistance. Within a day of transition, the consumer had wandered off in the night and needed more supervision to keep her safe during the day. This situation was also complicated by the lack of door alarms which were part of the care plan but were not installed prior to transition. Both family members then decided that it was too much work and responsibility to continue with this care.

Informal support is especially important for consumers who live alone with no or limited paid supports. One medically complex consumer who lived alone and did not have any informal supports, transitioned on State Plan without any paid services. She was discharged without diabetic supplies but could not leave the house. The pharmacy would not deliver the supplies and would only allow a family member to pick them up. The consumer ended up missing her insulin for several days, caught COVID, became very ill, and was only found after the consumer missed several medical appointments.

Insufficient approved home and community-based services

Sometimes the HCBS approved for the consumer were insufficient for the consumer to continue to live in the community. Some common reasons included consumer ineligibility for services, services not provided by the waiver, or services could not fit within allowed budget. The consumer ended up needing more supports than provided. Some examples of this which lead to reinstitutionalization included no overnight care and/or no live-in, not enough PCA hours, could not transfer independently but not enough PCA hours in care plan, behaviors such as wandering due to cognition but not enough hours of care for supervision, and medication management needed but no daily family member or nurse to provide it. The lack of enough services was especially difficult for consumers without readily available family members or friends to fill in the gaps.

Medically complex, multiple-morbidities

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

With comorbidity, one medical condition or its treatment can have a negative effect on another. Such was the case for one consumer in her eighties with dementia, multiple heart conditions, and a wound. She lived alone, transitioned with live-in PCA services, and had involved family members in the next town. The consumer continuously rubbed and opened the wound, which would then bleed profusely due to the blood thinner medication for the heart condition. Because of her dementia, she could not understand the consequences of her actions or stop them. The PCA could not tend to an open wound, and the family could not always come on the spot to bandage the wound. Blood loss resulted in hospitalization and subsequent facility readmission. Comorbidity was one factor here, as the treatment for one diagnosis, along with behavior caused by another diagnosis, acutely aggravated another condition. Case notes also do not indicate that options were explored to address the behavior.

Consumer cognitive impairment

Poor consumer judgement due to dementia with formal diagnosis or altered mental status also factored into some reinstitutionalizations. This can mean the need for a higher level of care than originally planned for or the need for 24-hour supervision, which may not be possible to provide in the community. Spouses or family members providing supervision still have to sleep, go to their own doctor’s appointments or run errands, and it is not always possible to cover this time with either paid or other informal supports.

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

Lack of special medical equipment, such as hospital bed or medication lock box, home modifications, and assistive devices was also a reoccurring factor leading to facility readmission. In some instances the equipment was provided, but lack of training on using or maintaining meant it was not used. Examples include the consumer without any informal assistance who did not know how to charge or use her PERS unit, or the consumer who could not change his own oxygen tanks.

Ploeg, J., Garnett, A., Fraser, K., Baird, L., Kaasalainen, S., McAiney, C., Markle-Reid, M., & Dufour, S. (2020). The complexity of caregiving for community-living older adults with multiple chronic conditions: A qualitative study. *Journal of Comorbidity*, 10. <https://doi.org/10.1177/2235042X20981190>

One case illustrates how durable medical equipment was vital for successful community living. Two different oxygen machines did not work properly, the consumer could not tolerate a tilt wheelchair for the amount of time needed so that insurance no longer covered it, and they did not get a bariatric bed approved because they were not quite heavy enough. Other issues included lack of daily wound care due to a nursing shortage. The consumer was hospitalized more than once, and was only home briefly before being readmitted to the nursing facility.

Falls with injury

Falls with injury also lead to readmissions. As with many of the cases, these falls did not happen in isolation of other issues. For example, one widowed consumer, who was identified pre-transition as a very high fall risk, fell within minutes after arriving home. A key part of her fall prevention plan was to just stay in her wheelchair unless someone was there to assist her; but this was not a viable community-living plan given she lived alone and had hourly PCA services. Contributing reasons in addition to the fall included not having a safe discharge plan, inability to give herself insulin, neuropathy, cognition issues, heart failure, and a glucose meter that was not working correctly.

Lack of physical health medical care

This encompasses lack of post-transition medical care of any kind, including: nursing, wound care, medical supplies (e.g., insulin, needles for diabetes), medications, medical and dialysis appointments, or medical transportation. This theme wove through several cases, contributing to reinstitutionalization. Complications from infections due to poor wound care is one example. Causes of poor wound care included limited approved nursing in the care plan, agency nursing shortage, family members unable to do this medical care, and lack of transportation to wound appointments.

Often lack of medical care was just one of several issues leading a reinstitutionalization. For example, one consumer with a leg amputation, limited mobility, multiple comorbidities, and a wound could not get to his wound care appointment due to lack of transportation – the medical transportation he needed was not authorized, his PCAs did not show up, and he lived alone with no family or friends to drive him. He also missed in-home medical care due to nursing no shows. Infection in the wound lead to sepsis, further amputations, and facility readmission. Additional contributing issues beyond lack of medical care included physical health decline, increased need for personal care which his budget could not cover, lack of informal supports, missing approved home modifications, lack of special equipment to allow PCAs to enter the building, and lack of assistive devices training.

Consumer behavioral health

Consumer behavioral health issues which contributed to reinstitutionalization included poor adjustment to community living, consumer anxiety, worsening of mental health conditions, and consumer non-compliance due to behavioral health issues. This issue also led to other complications, such as worsening of a pre-existing physical health condition or negatively impacting the ability of other family members to continue to provide informal assistance.

Overall, consumers who had experienced reinstitutionalization by the time of their 1 month survey reported worse physical and mental health. Three out of ten had fallen at least once, a rate double that of consumers who had not been back to an institution since transition. Qualitative themes most commonly associated with either a short or long-term reinstitutionalization for these consumers included physical health decline post-transition, lack of PCA and other nonmedical HCBS, lack of or limited family or informal support, insufficient approved HCBS in the care plan, multiple serious comorbidities, consumer cognition, lack of special equipment or devices, falls, lack of post-transition medical care, and behavioral health issues.

III. Conclusions and Recommendations

Surveys completed in 2020

A total of 850 HCBS CAHPS surveys were completed with MFP participants in 2020: 483 one month and 367 12 month surveys. The COVID-19 pandemic severely limited the number of in-person surveys completed – in 2020, only 2% of surveys were completed in-person, compared to 19% in 2019. This in turn increased the number of surveys completed by proxy.

1 Month Community Surveys Completed in 2020

Data from the 459 1 month community surveys completed in 2020 with community residing consumers indicated an impact of the COVID-19 pandemic on their lives. The percentage of consumers who gave high scores to the composite planning your time and activities, which includes community involvement, fell from 68% in 2019 to 59% in 2020. Consumers in the community also expressed concerns regarding staff and community nursing shortages, potential COVID exposure, and inconsistent PPE guidance and use. On the other hand, the rate of depressive symptoms reported by community consumers at 1 month post-transition fell dramatically from 35% in 2019 to 29% in 2020. It might have been especially uplifting for consumers to move out into the community in 2020, given the rapid facility spread of COVID and enforced social isolation from outside visitors. Another notable finding was the unmet need for assistive devices, equipment and home modifications. At 1 month post-transition, 31% said they still needed at least one or more of these. 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 2019

The full set of both 1 month and 12 month MFP HCBS CAHPS surveys (n=754) were available for consumers who transitioned in 2019. This section reported on the 1 or 12 month surveys completed with consumers residing in the community at the time of their survey (n=680), 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 homemaking services increased substantially from 1 to 12 months, while case management services decreased. Unlike the intense TC and/or SCM involvement before and early on after transition, by 12 months, any MFP “case management” is reduced to monthly TC calls, and case management for waiver consumers may not have begun. This sharp reduction in the frequency and type of MFP case management services may also be reflected in the “case manager is helpful” composite measure, as the percentage of consumers giving the highest score for this composite dropped from 87% at 1 month to 79% at 12 months.

Community residing participants gave three composites comparatively low scores at both 1 and 12 months: choosing your services, medical transportation, and most notably, planning your time and activities. The percentage who gave planning your time and activities the highest score was just 64% at 1 month and fell to 59% at 12 months. These three composites speak to participant choice, control, health self-efficacy, and community involvement, which are all vital to thriving in the community and represent areas that the program could work to improve. While COVID-19 was likely one factor for lower community participation in 2020, other comments indicated that community involvement did not happen automatically, and more support from the program would be helpful. The majority of consumers said they were interested in volunteering (71% 1 month, 78% 12 month); connecting consumers with these opportunities would be one way to increase community engagement and social connection.

While three-quarters of community participants rated their current PCAs/RAs/ILSTs a nine or ten, consumers at both 1 and 12 months post-transition also remarked on the difficulties they had finding available, reliable, and well-trained staff or a high quality HCBS agency to work with. Connecticut and the MFP program must address this statewide shortage of high quality, consistent HCBS staff, which jeopardizes living in the community for people who need such assistance. Comments also indicated that unpaid family members often stepped in the best they could or provided other informal assistance such as transportation, medical or overnight care. Many consumers rely on family members and informal caregivers to fill in any gaps and provide services not covered by the consumer's HCBS program. The HCBS system depends in part on these caregivers, and increased support for them to continue in this role is needed.

The percentage of consumers able to see their nearby friends fell from 1 month (57%) to 12 months (49%). This likely reflects the impact of COVID 19 in restricting seeing friends, but not family. Another possible effect of social distancing during the pandemic was the large increase in self-directing consumers who employed family members as PCAs, from 40% at 1 month to 59% at 12 months.

Unlike physical health, which remained fairly stable over the year, self-rated mental health decreased over time. At 1 month, 39% of community consumers rated their mental or emotional health as very good or excellent, which fell to 33% at 12 months. While post-transition 78 to 79% said they were happy with the way they live their life, 35 to 36% of consumers at either time point reported depressive symptoms. Connecting consumers to emotional and behavioral health resources should continue to be a priority of the MFP program.

The vast majority of community consumers at either time point reported having at least one type of assistive device, special equipment, or home modification. Still, at 1 month post-transition, 32% of consumers lacked some type of device or modification; by 12 months 19% still needed home modifications or some type of equipment such as a PERS to help them live in the community. Unless a family member helps pay for it, many participants do not have the financial resources to purchase these items on their own. Obtaining needed home modifications and special medical equipment by transition or within a week of being home should continue to be a priority. Better communication and more careful tracking of what participants still need may help meet this goal.

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 2019 were separated into those who met the requirements for a waiver at transition (waiver consumers) and those who were not eligible for a waiver (state plan consumers). Waiver consumers composed 73% of both the 1 month and 12 month sample, while 27% of consumers received state plan services only.

Waiver consumers must meet facility level of care and are eligible for waiver HCBS at transition, while state plan consumers are not eligible for ongoing HCBS personal care or homemaking services. HCBS service use shows this contrast, as over 85% of waiver consumers used personal care assistance at either time point, compared to 19% of state plan consumers.

The difference in use and experience of case management services between the two groups is striking. When the 1 month surveys are completed, all consumers have access to the same MFP case management services, given everyone has a TC and many still have an SCM. However, even at just 1 month post-transition, state plan consumers are much less likely to report having case management services – 34% of state plan consumers and 74% of waiver consumers said they had case management services at 1 month post transition. Similar differences between the groups were shown across most other case management items. State plan consumers with care managers gave their care managers lower ratings and recommendations. For example, at 1 month, 71% of waiver consumers rated their case manager a 9 or 10, compared to 60% of state plan consumers. State plan consumers with case managers

also gave lower scores for the care manager is helpful composite, and were also much less likely to turn to their case managers for changes in their services, even just a few weeks after transition. It is not clear why TCs are apparently less engaged with non-waiver consumers just a few weeks after transition. State plan consumers get fewer services, so perhaps they do not see their TCs as case managers. Helping consumers better understand the roles of their care management team may help to reduce any confusion around who is responsible for their specific care needs.

State plan consumers were also consistently more likely to rate the composites covering choice and services and transportation to medical appointments lower than waiver consumers for 1 and 12 months. While service choice is linked to waiver or state plan status, medical transportation is not a waiver only service, and both types of consumers should have similar access. This could be linked to where one lives, and state plan consumers were less satisfied with their living arrangements. Transportation to medical appointments is essential for all consumers, and perhaps TCs and HCs could more proactively work with their state plan consumers on this, even when choosing where to live. State plan consumers also reported greater unmet need at 1 month for home modifications, medical equipment, or a PERS.

Although state plan consumers were a younger cohort, they reported less social support overall. Consumers with state plan services were much more likely to live alone, were less likely to have family or friends living nearby, and were less likely to get unpaid help. State plan consumers were also much more likely to be in fair or poor physical health at both 1 and 12 months. The differences in mental health were especially striking – state plan consumers reported worse mental health, were less happy overall, and were significantly more likely to have depressive symptoms. While mental health supports are a priority for all consumers, this population seems to have a greater need for these community resources.

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

Community living consumers who transitioned in 2019 were separated into those using agency-based versus self-directed services. Approximately two-thirds of consumers (68-69%) self-identified as using agency-based services, while the remaining 31 to 32% said they hired their own staff. Self-directed consumers used noticeably more personal care services, as well as more homemaking and case management services.

At 1 month and 12 months after transition, self-directed consumers were more likely to rate their personal care staff higher than agency-based consumers on almost all metrics. A greater percentage rated their PCAs a 9 or 10, would definitely recommend their PCAs, and reported higher scores for the composite staff are reliable and helpful. It is likely that being the employer, with increased opportunity to choose, train, and manage one's PCAs, allows for a better match and greater consumer satisfaction. Self-directed consumers also gave their case managers lower scores, especially at 12 months, on global rating and the composite care manager is helpful.

Consumers using self-direction must be able to manage their own services, or have a family member or friend do it for them. A greater sense of autonomy might also be a factor in why self-directed consumers reported greater choice over their services at 12 months and higher scores for planning your time and activities at both time points.

There were notable differences in living situation as well: Self-directed consumers were more likely to live with family members and were more likely to have friends living nearby. There were marked differences in mental or emotional health between the two groups at 12 months. One year after transition, 41% of self-directed consumers, but only 31% of agency-based consumers, reported very good or excellent mental health, and at 12 months, self-directed consumers were much more likely to say they were happy compared to agency-based consumers. At 1 month, agency-based consumers were

more likely to say they needed some type of mobility or medical equipment, and at 12 months, more agency-based consumers still needed home modifications, a PERS, or medical equipment.

The Reinstitutionalization Effect

Consumers who transitioned in 2019

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, consumers who transitioned in 2019 were followed from transition through 1 year post-transition to determine the reinstitutionalization at four time points after transition. Within 1 month after transition, 10% of participants had returned to a facility for either a short-term or long-term stay. By the time of their 1 month survey, slightly fewer consumers were still in a facility (8%). Unsurprisingly given the longer length of time, nearly a quarter (23%) of consumers had been in a facility between the 1 month to the 12 month survey. However, at 12 months post-transition, only 13% of participants were reinstitutionalized.

Select results showed that consumers reinstitutionalized at 12 months rated staff communication, medical transportation, and planning your time and activities lower than consumers in the community at 12 months. Consumers reinstitutionalized at 12 months reported slightly better physical health, but poorer mental health than community consumers.

Consumers who transitioned in 2020

Next, reinstitutionalization for consumers who transitioned in 2020 and who had completed a 1 month survey (n=499) were considered. Six percent (n=31) of these consumers were either in a facility at the time of their 1 month survey or were in the community at 1 month but had been in and out of a facility since transition. Compared to consumers who were never readmitted to a facility by 1 month, consumers reinstitutionalized even temporarily reported worse physical and mental health. They also reported a high rate of falls and emergency room and hospital use.

Consumers who had transitioned in 2020 and had experienced reinstitutionalization by their 1 month survey were looked at in more detail. Qualitative analysis identified common circumstances or issues associated with facility readmission. Eleven main themes emerged from this analysis. These themes did not occur in isolation of each other – all consumers had multiple factors which lead to their reinstitutionalization. Qualitative themes most commonly associated with either a short or long-term reinstitutionalization for these consumers included physical health decline post-transition, lack of PCA and other nonmedical HCBS, lack of or limited family or informal support, insufficient approved HCBS in the care plan, multiple serious comorbidities, consumer cognition, lack of special equipment or devices, falls, lack of post-transition medical care, and behavioral health issues.

Final Thoughts

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

I was in a skilled nursing facility for two years and asking to leave. The staff finally got me in touch with MFP. Now I feel like I am a member of the community. Everyone needs a chance to get into an assisted living if they are able.

We are really grateful for MFP. [Consumer] is so much happier than she ever could have been in a nursing home.

I'm feeling better than I have ever felt. I am in a new place, mentally, physically and spiritually.

This is a wonderful program. It gets people out of nursing homes, and without it I would have been there forever. This program probably saved my life because I got out right before COVID hit, and it was really bad at my facility.

I thank MFP because it has been a wonderful program. We suffered a lot seeing him in the nursing home and so did he. It was a blessing to have this program.

V. Appendices

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

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

Appendix C. MFP HCBS CAHPS® Composite Measures Items

Appendix D. Acronyms

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

HCBS CAHPS® survey

MFP Community survey

English

Instructions for Vendor

- The interview is intended as an interviewer-administered survey; thus all text that appears in initial uppercase and lowercase letters should be read aloud. Text that appears in **bold, lowercase letters** should be emphasized.
- Text in *{italics and in braces}* will be provided by the HCBS program's administrative data. However, if the interviewee provides another term, that term should be used in place of the program-specific term wherever indicated. For example, some interviewees may refer to their case manager by another title, which should be used instead throughout the survey.
- For response options of "never," "sometimes," "usually," and "always," if the respondent cannot use that scale, the alternate version of the survey with response options of "mostly yes" and "mostly no" should be used. These alternate response options are reserved for respondents who find the "never," "sometimes," "usually," "always" response scale cognitively challenging.
- For response options of 0 to 10, if the respondent cannot use that scale, the alternate version of the survey with response options of "excellent," "very good," "good," "fair," or "poor" should be used. These alternate response options are reserved for respondents who find the numeric scale cognitively challenging.
- All questions include a "REFUSED" response option. In this case, "refused" means the respondent did not provide any answer to the question.
 - All questions include a "DON'T KNOW" response option. This is used when the respondent indicates that he or she does not know the answer and cannot provide a response to the question.
 - All questions include an "UNCLEAR" response option. This should be used when a respondent answers, but the interviewer cannot clarify the meaning of the response even after minor probing or the response is completely unrelated to the question, (e.g., the response to "In the last 3 months, how often did your homemakers listen carefully to what you say?" is "I like to sit by Mary").
 - Some responses have skip patterns, which are expressed as "→ GO TO Q#." The interviewer should be advanced to the next appropriate item to ask the respondent.
 - Not all respondents receive all home and community-based services asked about in this instrument. Items Q4 through Q12 help to confirm which services a respondent receives. The table after it summarizes the logic of which items should be used.
 - Survey users may add questions to this survey before the "About You" section. A separate supplemental employment module can be added.
- Use singular/plural as needed. In most cases, questions are written assuming there is more than one staff person supporting a respondent or it is written without an indication of whether there is more than one staff person. Based on information collected from Q4 through Q12, it is possible to modify questions to be singular or plural as they relate to staff.

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

COGNITIVE SCREENING QUESTIONS

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

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

¹ ☐ YES

² ☐ NO → GO TO [Interviewer - Screening Failed]

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

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

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

2. How do they help you?

[EXAMPLES OF CORRECT RESPONSES INCLUDE]

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

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

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

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

3. What do you call them?

[EXAMPLES OF SUFFICIENT RESPONSES INCLUDE]

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

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

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

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

[Interviewer - Screening Failed]

¹ ☐ Continue anyhow

² ☐ End Survey

IDENTIFICATION QUESTIONS

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

GETTING NEEDED SERVICES FROM PERSONAL ASSISTANT AND BEHAVIORAL HEALTH STAFF

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

22. In the last 3 months, was this because there were no {*personal assistance/behavioral health staff*} to help you?
- 1 ☐ YES
- 2 ☐ NO
- 1 ☐ DON'T KNOW
- 2 ☐ REFUSED
- 3 ☐ UNCLEAR RESPONSE
23. Sometimes people need help taking their medicines, such as reminders to take a medicine, help pouring them, or setting up their pills. In the last 3 months, did you need help from {*personal assistance/behavioral health staff*} to take your medicines?
- 1 ☐ YES
- 2 ☐ NO → GO TO Q26
- 1 ☐ DON'T KNOW → GO TO Q26
- 2 ☐ REFUSED → GO TO Q26
- 3 ☐ UNCLEAR RESPONSE → GO TO Q26
24. In the last 3 months, did you **always** take your medicine when you were supposed to?
- 1 ☐ YES → GO TO Q26
- 2 ☐ NO
- 1 ☐ DON'T KNOW → GO TO Q26
- 2 ☐ REFUSED → GO TO Q26
- 3 ☐ UNCLEAR RESPONSE → GO TO Q26
25. In the last 3 months, was this because there were no {*personal assistance/behavioral health staff*} to help you?
- 1 ☐ YES
- 2 ☐ NO
- 1 ☐ DON'T KNOW
- 2 ☐ REFUSED
- 3 ☐ UNCLEAR RESPONSE
26. Help with toileting includes helping someone get on and off the toilet or help changing disposable briefs or pads. In the last 3 months, did you need help from {*personal assistance/behavioral health staff*} with toileting?
- 1 ☐ YES
- 2 ☐ NO → GO TO Q28
- 1 ☐ DON'T KNOW → GO TO Q28
- 2 ☐ REFUSED → GO TO Q28
- 3 ☐ UNCLEAR RESPONSE → GO TO Q28

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

⁻³ ☐ UNCLEAR RESPONSE

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

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

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

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

GETTING NEEDED SERVICES FROM HOME MAKERS

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

HOW WELL HOME MAKERS COMMUNICATE WITH AND TREAT YOU

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

YOUR CASE MANAGER

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

-3 ☐ UNCLEAR RESPONSE

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

Would you say . . .

1 ☐ Excellent,

2 ☐ Very good,

3 ☐ Good,

4 ☐ Fair, or

5 ☐ Poor?

-1 ☐ DON'T KNOW

-2 ☐ REFUSED

-3 ☐ UNCLEAR RESPONSE

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

1 ☐ Definitely no,

2 ☐ Probably no,

3 ☐ Probably yes, or

4 ☐ Definitely yes?

-1 ☐ DON'T KNOW

-2 ☐ REFUSED

-3 ☐ UNCLEAR RESPONSE

HOME-DELIVERED MEALS, ADULT DAY PROGRAM

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

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

1 ☐ Excellent,

2 ☐ Very good,

3 ☐ Good,

4 ☐ Fair, or

5 ☐ Poor?

-1 ☐ DON'T KNOW

-2 ☐ REFUSED

-3 ☐ UNCLEAR RESPONSE or DID NOT USE HOME-DELIVERED MEAL SERVICE

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

1 ☐ Excellent,

2 ☐ Very good,

3 ☐ Good,

4 ☐ Fair, or

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

CHOOSING YOUR SERVICES

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

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

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

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

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

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

How do you hire and pay your aides or caregivers?

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

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

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

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

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

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

TRANSPORTATION

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

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

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

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

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

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

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

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

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

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

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

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

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

PERSONAL SAFETY

The next few questions ask about your personal safety.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

COMMUNITY INCLUSION AND EMPOWERMENT

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ YES

² ☐ NO

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ YES

² ☐ NO

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

EMPLOYMENT MODULE

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

¹ ☐ YES → GO TO EM9

² ☐ NO

⁻¹ ☐ DON'T KNOW → GO TO THE ABOUT YOU SECTION

⁻² ☐ REFUSED → GO TO THE ABOUT YOU SECTION

⁻³ ☐ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

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

¹ ☐ YES

² ☐ NO → GO TO EM4

⁻¹ ☐ DON'T KNOW → GO TO THE ABOUT YOU SECTION

⁻² ☐ REFUSED → GO TO THE ABOUT YOU SECTION

⁻³ ☐ UNCLEAR RESPONSE → GO TO THE ABOUT YOU SECTION

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

¹ ☐ BENEFITS → GO TO EM5

² ☐ HEALTH CONCERNS → GO TO EM5

³ ☐ DON'T KNOW ABOUT JOB RESOURCES → GO TO EM5

⁴ ☐ ADVICE FROM OTHERS → GO TO EM5

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ Never,

² ☐ Sometimes,

³ ☐ Usually, or

⁴ ☐ Always?

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ Mostly yes or

² ☐ Mostly no?

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ YES

² ☐ NO

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

__ 0 TO 10

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ Excellent,

² ☐ Very good,

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

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

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

MFP QOL MODULE

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

In the community:

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

Community to community moves

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

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

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

Satisfaction with where you live

QOL_3. Do you like where you live?

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

QOL_4. Do you feel safe living here?

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

Falls

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

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

Either to be used as an alternative at interviewer discretion:

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

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

ER visits, hospitalizations, re-institutionalizations

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

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

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

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

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

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

Depression symptoms

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

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

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

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

Informal assistance

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

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

Global life satisfaction

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

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

Choice of providers

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

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

☐ Refused

Financial adequacy

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

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

Volunteering

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

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

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

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

Assistive technology, Devices, Special equipment

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

DMHAS QUESTIONS

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

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

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

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

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

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

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

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

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

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

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

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

ABOUT YOU

Now I just have a few more questions about you.

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

- ¹☐ Excellent,
- ²☐ Very good,

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

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

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

84. What is your age?

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

ALTERNATE VERSION: In what year were you born?

_____ (YEAR)

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

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

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

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

- ¹ ☐ 8th grade or less

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

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

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

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

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

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

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

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

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

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

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

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

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

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

93. What is the language you speak at home?

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

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

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

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

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

⁻³ ☐ UNCLEAR RESPONSE

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

¹ ☐ YES

² ☐ NO

⁻¹ ☐ DON'T KNOW

⁻² ☐ REFUSED

⁻³ ☐ UNCLEAR RESPONSE

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

Question 98 is not in MFP Follow-Up 2:

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

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

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

Name, address, and phone of person to contact:

First and last name: _____

Relationship to consumer: _____

Street: _____

Apt. _____

City: _____ State: _____ Zip: _____

Telephone: _____

Email address: _____

Best way to contact: _____

Contact notes: _____

END OF QUESTIONS

Thank you for completing this interview with me.

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

Alternative contact information:

Name: _____

Relationship: _____

Street Address: _____

Apt. or Unit: _____

City: _____

State: _____ ZIP: _____

Contact Phone: _____

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

AASCC: 203-752-3040

CCCI Eastern region: 860-885-2960

CCCI North Central region: 860-257-1503

CCCI Northwest region: 203-596-4800

SWCAA: 203-333-9288

WCAAA: 203-465-1000

Autism waiver: 860-424-5865

Katie Beckett waiver: 860-424-5582

DMHAS: 866-548-0265

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

INTERVIEWER QUESTIONS

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

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

☐ Participant by his/herself

Participant telephone numbers: _____ → Go to F1

- ☐ Participant with assistance from another person.

If Assisted

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

First name: _____

Last name: _____

Telephone numbers: _____ → Go to F1

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

If Proxy:

Proxy Contact Information:

Proxy First name: _____

Proxy Last name: _____

Proxy Telephone numbers: _____ → Go to P1

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

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

P2. Is the proxy also a legal representative?

- ☐ Yes
☐ No

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

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

F1. WAS THE RESPONDENT ABLE TO GIVE VALID RESPONSES?

¹ ☐ YES

² ☐ NO

F2. WAS ANY ONE ELSE PRESENT DURING THE INTERVIEW?

¹ ☐ YES

² ☐ NO → GO TO END OF SURVEY

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

¹ ☐ SOMEONE **NOT** PAID TO PROVIDE SUPPORT TO THE RESPONDENT

² ☐ STAFF OR SOMEONE PAID TO PROVIDE SUPPORT TO THE RESPONDENT

F4. DID SOMEONE HELP THE RESPONDENT COMPLETE THIS SURVEY?

¹ ☐ YES

² ☐ NO → GO TO END OF SURVEY

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

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

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

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

F7. Relationship to participant:

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

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

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

END OF SURVEY

Interview done by:

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

Participant Information:

First name: _____

Middle name: _____

Last name: _____

Medicaid ID: _____ (Please verify)

Date of Birth: _____ (MM/DD/YYYY)

Town of residence: _____

ZIP code of residence: _____

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

- ☐ Yes
- ☐ No
- ☐ Do not know

Program:

- ☐ MFP

Community First Choice?

- ☐ Yes
- ☐ No
- ☐ Do not know

Name of interviewer: _____

Date Interview Complete: _____

Appendix B. HCBS CAHPS Institutional Survey Description

HCBS CAHPS Institutional Survey – UConn

2-13-2019

Overall changes from the HCBS CAHPS Community survey:

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

Appendix C. CT MFP HCBS CAHPS® Composite Measures Items

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

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

* Question added by Connecticut

Appendix D. Acronyms

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