Money Follows the Person
Rebalancing Demonstration

The Final Word: Connecticut MFP Participants' Qualitative Feedback on Program Experiences

February 2018

Prepared by
Kathy Kellett, PhD
Kaleigh Ligus, BS
Julie Robison, PhD

UConn Health | Center on Aging
263 Farmington Avenue
Farmington, CT 06030-5215

UCONN HEALTH

CENTER ON AGING

Table of Contents

Introduction

The Money Follows the Person Rebalancing Demonstration (MFP) is a federal initiative to help states transition people needing long-term services and supports (LTSS) from institutional settings to the community in an effort to enhance individual preferences and rebalance Medicaid expenditures. This program was implemented in 2008 by the state of Connecticut (CT). By December 31, 2016, 4,212 consumers had transitioned through the program. Previous research has shown the positive impact of MFP, demonstrating that for most respondents who remained in the community, quality of life significantly increased after transition and remained elevated; only a low percentage of participants were readmitted to an institution one year following transition (Robison et al., 2015). Data on outcomes for MFP participants comes from the Quality of Life (QOL) survey, an evaluative tool developed by Mathematica Policy Research and adapted by the state of Connecticut. This report presents data collected from 1,265 consumers in CT who answered an open-ended question in the MFP QOL survey conducted from 2009-2016 at 6, 12, and 24 months following transition.

Quality of life is a broad multidimensional concept that includes subjective evaluations of the beneficial and challenging aspects of life associated with physical, mental, and social domains, and has been defined as "individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (The World Health Organization Quality of Life Group, 1998). From a biopsychosocial perspective, as people age, progressive change occurs in the interactions between their genetic makeup (biology), mental health/personality (psychology), and sociocultural environment (social world), and these contribute to their experience of health or illness (e.g., quality of life) (Newman & Newman, 2017). According to Schalock (1996), quality of life can be viewed as an organizing concept to guide policy and practice and improve the conditions of people's lives. Measuring multiple domains and how they relate to one another in assessing QOL is a vital part of evaluating LTSS. Findings from such evaluations have the potential to strengthen social service agencies in their work with people who need a range of services and supports.

This study uses Maslow's Hierarchy of Needs as a theoretical framework. In the original depiction of Maslow's (1943) conceptual model, he proposed a step-wise pattern of movement from lower-level needs (e.g., physiological and safety-security) to higher-level needs (e.g., love and belonging, self-esteem, and self-actualization) that people strive to meet, and that the fulfillment of lower-level needs enables an individual to increasingly fulfill higher-level needs. Recent research, however, suggests that while the fulfilment of needs, as defined by Maslow, are important to individual happiness, the order in which lower and higher-level needs are met has little influence on how much they contribute to perceived quality of life (Tay & Diener, 2011).

Adaptations of Maslow's Hierarchy of Needs have permeated numerous disciplines beyond the field of psychology. In the healthcare literature, adaptations of Maslow's framework view human needs through the lens of intensive care in an effort to further culture change and better patient outcomes (Jackson et al., 2014). Others have adapted the framework as a means to assist in structuring partnerships between primary care settings and community practices (Henize, Beck, Klein, Adams, & Kahn, 2015). Here, we use Maslow's model to organize and prioritize themes associated with CT MFP consumers' self-reported needs and to better understand their quality of life. For the purpose of this study, we adapted Maslow's (1943; 1970) third tier, love and belonging needs, and describe it more broadly as social needs (Appendix A).

Prior research suggests that higher self-determination is associated with more positive outcomes including a better quality of life (Lachappelle, et al., 2005). In asking consumers if they had anything else to add at the end of the survey, MFP participants had the opportunity to describe any program benefits and/or challenges they experienced and comment on their

quality of life. While research suggests that asking open-ended questions may invite more negative than positive feedback (Friborg, 2013), asking this question helped us explore what program challenges still need to be addressed and what recommendations could be made to broaden reform and enrich consumers' quality of life.

Methods and Analysis

This qualitative study examined responses from an open-ended final question in the CT MFP Evaluation QOL survey which have not previously been explored. Data were collected as part of a larger study of Money Follows the Person program participants in Connecticut at six, twelve and twenty-four months after transition. Written informed consent was obtained at the time a participant enrolled in the program, before transition. QOL interviews were completed by phone or in person in one of three ways: with the individual receiving services alone; with the individual and assistance from another person (e.g., family member, friend, staff member); or completed by proxy (e.g., family member, legal representative, or close friend). For this study, proxy interviews (31%, n=1494) were excluded from the analysis.

Qualitative interviewing is a technique typically done by asking open-ended questions and allows a respondent to speak in his/her own words and share experiences or knowledge of a particular subject (Popping, 2015). While closed-ended questions tend to reflect the researcher's agenda and by nature can limit responses, open-ended questions provide an opportunity for respondents to share additional information that cannot be captured by other forms of research (O'Cathain & Thomas, 2004). In this study, the open-ended question provided an opportunity for survey participants to speak in their own words and express their thoughts and feelings about MFP and its implementation.

Analysis of data from open-ended questions allows researchers to find themes and concepts in aggregate data and report these as new or emerging ideas in a scientific field. One type of content analysis, directed content analysis, explores existing theories and increases the understanding of the subject matter (Glaser & Strauss, 1967; Hill, Knox, Thompson, Williams, & Hess, 2005; Hsieh & Shannon, 2005). This type of content analysis is important when evaluating programs because the researcher can collect a broader range of thoughts from a single question, and those opinions can be compared overall and used to improve a service or program (Hsieh & Shannon, 2005).

Interviews were conducted at three time points: six, twelve and twenty-four months after transition. On average, interviews lasted thirty minutes. The majority of survey questions were closed-ended, scaled questions. An open-ended question at the conclusion of the survey asked consumers, "Is there anything else you would like to add?" Interviewers transcribed responses by directly quoting interviewees as accurately as possible.

Data analysis of the open-ended question was conducted by two researchers at the UConn Health Center on Aging (COA) using ATLAS.ti software to systematically identify and organize themes. Primary documents with data from six, twelve and twenty-four months were imported to ATLAS.ti. Prior to coding, researchers created an extensive codebook as a guide using Maslow's Hierarchy of Needs for broad categories. Subthemes for broad categories were then identified through a visual inspection of the data. A cyclical, iterative approach to coding ensured intercoder agreement, and recoding was done when necessary to establish strong levels of intercoder reliability (O'Brien, Harris, Beckman, Reed, & Cook, 2014).

Results

By the end of 2016, 4,212 consumers had transitioned through the MFP program, and 7,759 QOL surveys had been completed. Between December 2008 and December 2016, 30%

(n=1,265) of transitioned consumers provided 2,274 responses to the open-ended question at the end of the QOL survey. Due to the nature of the longitudinal study, some consumers provided several unique comments at separate time points: 843 consumers responded to at least one QOL survey, 328 responded at two time points, and 94 responded at all three time points.

Demographics

Of the 1,265 consumers who responded to the open-ended question, 43% were between ages 50-64 and 39% were age 65 and older. The age of respondents ranged from 20 to 98, and there were nearly as many males as females (n=627 and 638, respectively). To be eligible for the program, participants had to be enrolled in Medicaid prior to transition. After transition, participants receive services through a Medicaid Home and Community-Based Services (HCBS) program: 38% (n=482) were CHCPE (Connecticut Home Care Program for Elders), 21% (n=271) were part of the Personal Care Assistance Waiver, and 20% (n=254) were served through the Medicaid State Plan. Other consumers participated in the Mental Health Waiver (12%, n=147), Acquired Brain Injury Waiver (6%, n=76), and other Medicaid HCBS programs, including various Developmental Disability Services Waivers (3%, n=35).

Themes within the Text

Physiological needs was the most frequently mentioned theme accounting for 53% (n=1,197) of all comments. Eleven percent (n=251) of all comments were categorized as safety-security needs, 23% (n=529) were social needs, and 7% (n=169) were self-esteem needs. The fifth tier, or self-actualization category, of Maslow's model comprised 6%, (n=128) of all comments (Figure 1).

Figure 1. Themes within the Text

Self-Actualization Needs
(6%, n=128)

Self-Esteem Needs
(7%, n=169)

Social Needs
(23%, n=529)

Safety-Security Needs
(11%, n=251)

Physiological Needs
(53%, n=1,197)
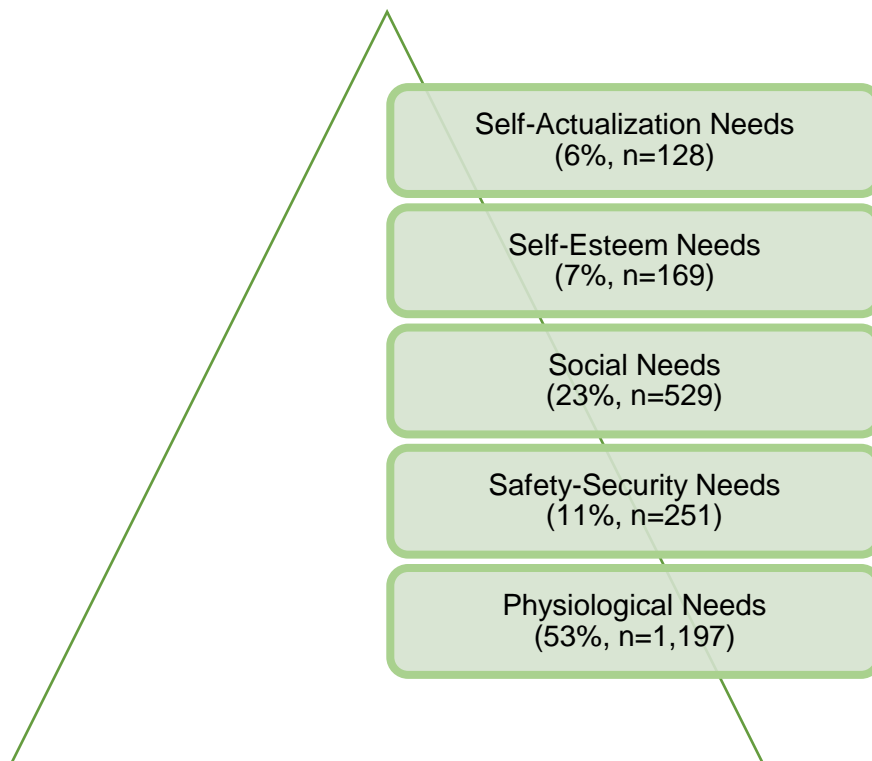
Subcategories of physiological needs included help (e.g., personal care assistance), housing, assistive technologies, and medical needs (e.g., physical health). Personal care assistance was differentiated from other kinds of support (i.e., social support) because its focus is to help meet the physical needs of the consumer. In the literature, housing is typically included in physiological needs because it provides shelter (Thielke et al., 2011). In our data, there was some overlap between physiological and safety-security needs where consumers mentioned safety and security issues specifically related to housing. Given that assistive technologies and physical health impact physical needs, they were also included in the physiological category. Safety-security needs included more abstract needs than those in the physiological needs category and included transportation and finances as subcategories. Safe and accessible rights-of-way are essential elements of community life. Because many people with disabilities experience insufficient access to modes of transportation, it disproportionately harms them and is a safety-security issue (Thielke et al., 2011). Similarly, financial security is crucial to people with disabilities and any threat to the stability of their finances can result in greater vulnerability (Batavia & Beaulaurier, 2001). Social needs included support from family, friends, social services, and programs (i.e., MFP) that enable a consumer to live in the community. Self-esteem needs included general well-being (i.e., confidence, achievement, and respect), and references to choice and control.

Word Frequencies

Words have been described as the "smallest meaningful unit of language" and therefore have great significance in social interactions (Holtgraves, 2010, p.1386). They also have a rich and distinct meaning for each person (Pennebaker & King, 1999). We explored the word frequency of consumer responses using ATLAS.ti to see how the vocabulary of consumers might add influence and confidence to the coding of responses.

There were 39,444 unique words used by respondents. Researchers removed articles and prepositions such as "to", "I", "the", "and", "a", etc. The top ten words were used 3,056 times. The most frequently used word was "need(s)" (15%, n=466). Since MFP is a social service program, it is not surprising that this word was so often used by participants. The second most frequently used word was "have" (14%, n=413). The word "have" is defined as: "to hold or maintain as a possession, privilege, or entitlement," and it is not surprising that this word was also used so often (Merriam-Webster's Collegiate Dictionary, 2014, p. 571).

The next most frequently used words included: "like" (12%, n=372), "get" (10%, n=319), "would" (10%, n=308), "help" (10%, n=292), "more" (9%, n=261), "home" (8%, 242), "out" (6%, n=194), and "apartment" (6%, n=189). These words either indicated areas of concerns or program benefits that consumers reflected on as they participated in the program (Figure 2).

Figure 2. Frequency of Individual Words
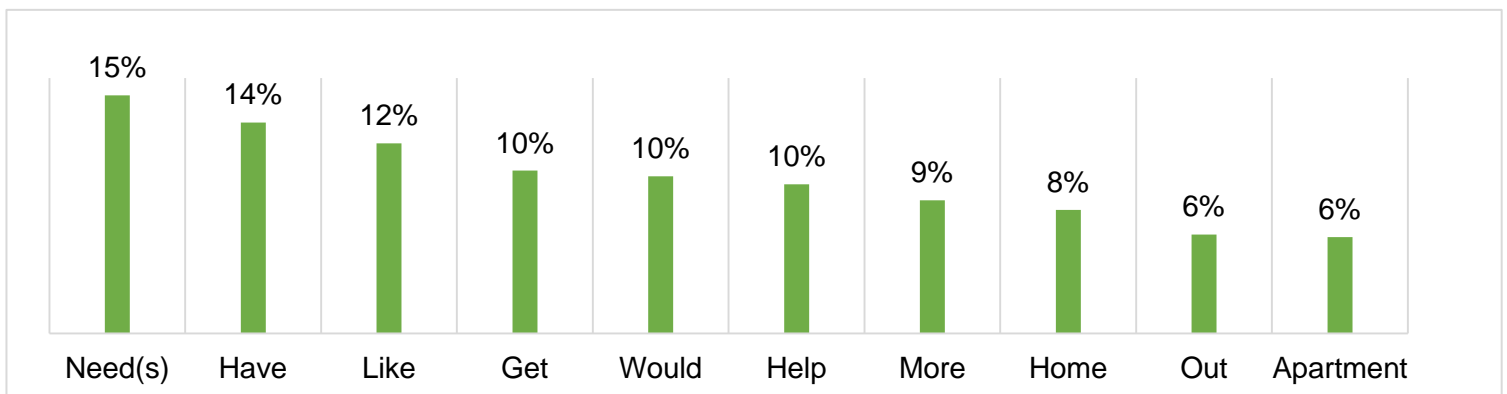
Physiological Needs

Fifty-three percent (n=1,197) of all comments were related to physiological needs and fit into the following subcategories: personal care assistance, housing, assistive technologies and medical needs (Table 1).

Table 1. Physiological Needs

	%	n
Personal Care Assistance	42	505
Housing	28	336
Assistive Technologies	16	193
Medical	14	163
Total	100	1197

Personal Care Assistance

The majority of comments (42%, n=505) under physiological needs were related to seeking and receiving assistance with basic physical needs. Of these comments, many fell into two broader categories of challenges involving community-based assistance (63%, n=318) and the positive aspects of help experienced (25%, n=124) (Table 2).

Table 2. Help

	%	n
Help-Challenges	63	318
Help-Positive Aspects	25	124
Help-Other	12	63
Total	100	505

Help – Challenges Involving Community-Based Assistance

Some consumers expressed dissatisfaction with the amount of community-based assistance, the quality of help, and/or specific aspects related to the provision of care. These challenges have the potential to impact a person's overall quality of life and optimal level of well-being.

Amount of Assistance

The majority of comments addressing community-based care focused on the amount of assistance and the need for additional assistance. Some comments in this category expressed concern about limits in daily care and stated a need for increased hours or asked for specific services, such as homemaker or physical therapy. Frequently, these unmet needs arose due to a change in the person's functional level or informal caregiver availability after moving to the community.

> *I would like to have paid services. When my plan was designed, my son and his fiancée were supposed come live with me but their plans changed. I would like to receive assistance because my son is moving out of the state.* [6 month]

> *Sometimes I need a little bit more help when family is not around. Sometimes I have an unscheduled appointment to go to that I need help with. Maybe if I had more hours that would help a great deal.* [24 month]

I need a person that can spend more time with me and to relieve my daughter of some work. [24 month]

Frustration with Home Health Care Agencies

Comments about community-based assistance sometimes emphasized frustration with the home health care agencies he/she was working with. Many of these consumers reported that agencies were not fulfilling their roles and as a result they felt an interruption in continuity of care. Some expressed wanting to change agencies due to these factors.

I can't do my own laundry. I can't do a lot of things with a wheelchair. The girl didn't come in yesterday and they didn't call to say that she wouldn't be here. When someone helped me call them, they said that they called, but my line was busy. [6 month]

Consumers also shared concerns about aides quitting without notice, difficulty in hiring aides quickly, and an agency switching aides without first notifying the consumer.

One of my personal care assistants quit on me this past week. I still have two personal care assistants, but need to have three. [12 month]

I had a really good staff of women working for me and we had a good schedule. They knew what I wanted and when and then all of a sudden the scheduler at [Agency] took away one of my regular aides, the one in the morning. [6 month]

I am very unhappy with the services that I am receiving from my home health care agency. It's very inconsistent and not reliable. Most days I don't know who's coming to stay with me and for how long. I would like more accountability on this for the agency. [24 month]

I am looking for another personal care assistant to replace one of the ones I now have; also I need to have a personal care assistant backup person and someone for weekends. [24 month]

Provision of Care

Some comments regarding community-based assistance addressed challenges associated with the provision of care by agencies and aides. These comments expressed displeasure with the quality of care provided by both the agencies and staff. They also mentioned lack of effective oversight by agencies in educating aides and the inattentiveness of aides in listening to the consumer regarding care preferences.

I had caregivers not trained in using a Hoyer lift or medical equipment. My current caregiver takes too much time off and I have too many replacements. I had one young caregiver, age 19, who stole from my charge account and another one who charged calls to my phone. [6 month]

My aides do not help me adequately. They spend a lot of time on their phones, don't do things that need to be done and try to leave early. [12 month]

Weekend and/or Night Care

Similar to requesting additional hours of assistance, some consumers expressed a need for weekend or night care due to lack of reliable providers during these time frames.

Weekend help doesn't always show up because weekday people used their hours. Everybody is very adequate except [Name]. They do not show up on weekends. [6 month]

I need an aide for night time so I can go to bed when I want and if I get up at night. I need some help on weekends also. [12 month]

Sometimes at night when I want to go to the bathroom, I can't, because there's nobody to help me. I'm alone from 12:30 - 7:00 am. During the day, I'm alone for three hours due to differences in shifts of personal care assistants. [24 month]

Help – Positive Aspects

Consumers made numerous comments regarding the positive aspects of help, whether paid or unpaid. Comments focused on the high quality of care and the involvement of family and/or friends. Some responses reflected on the services received while others focused on agency feedback. On a few occasions, consumers mentioned specific names of those providing the care. Consumer comments were consistent over the six, twelve, and twenty-four month survey periods.

High Quality of Care

The majority of comments related to positive aspects of help and focused on the quality of care received by consumers and their satisfaction with the level of care.

My current live-in help is competent, thorough, great cook and awesome good to me. [6 month]

I am happy with the aides I have. They do a good job taking care of me and I want to keep them. [12 month]

I was extremely pleased with the two personal care assistants I had. I have progressed to the point where I no longer need the personal care assistants. [12 month]

My nurses should be given an award for workers of the year! [24 month]

Family and Friends Involved in Care

Some comments in this category were related to the assistance received from family and friends. There were no comments for this theme at twenty four months.

Initially I received paid services, but now can do all things for myself with some help from friends and family. [6 month]

I'm lucky I have a family back-up. I can't imagine what I would do without it. [12 month]

I'm an A-plus patient for the care I have and family who spoils me. I couldn't be better situated with family around and a good house. [12 month]

Services Received

A smaller number of consumer comments focused on the receipt of various services, including the home care agencies. There were no comments for this theme at twenty four months.

The services have been adequate. The people have been polite. In that sense, it's been good. [6 month]

Help comes in during the day. They listen to needs very well and cut back when too many people came by to sit and talk for socialization. My social situation is better now because I get around better and see more people. [12 month]

Agency Feedback

A few consumers provided comments on the positive aspects of help and included feedback regarding some of the agencies/aides involved in providing care.

Current aide is from [Name] agency and they are good to work with. [6 month]

I am very happy with the aides, but sometimes I think I could use some extra time for them. Often, for example, they will not leave me alone in the emergency room and then they work extra without being paid. So we need to have more time for them. [12 month]

… Agency on Aging works on things right away. [12 month]

Be home, be well, is my motto … the home care agency is providing better care than the skilled nursing facility. [24 month]

Specific Name Mentioned

On occasion, consumers mentioned the name of a particular person that was especially helpful to them during the transition process and in the six months following transition.

[TC] has been very influential in my recovery, going above and beyond for me. [6 month]

[TC] is fantastic. Any time I have a problem, I can depend on her. She bends over backwards to it and return my calls the same day. [6 month]

Housing

Twenty-eight percent (n=336) of comments under the theme of Physiological Needs were related to shelter or housing needs. Of these, 50% (n=169) reported housing challenges. Twenty-four percent (n=79) expressed concerns related to housing modifications and 13% (n=43) had positive things to say about their housing (Table 3).

Table 3. Housing

	%	n
Housing-Challenges	50	169
Housing-Modifications	24	79
Housing-Positive Aspects	13	43
Housing-Other	9	29
Housing-Facility	4	16
Total	100	336

Housing – Challenges

Housing is an integral part of transitioning in the MFP program, and understanding the housing conditions that consumers are living in is an important piece of evaluating the program itself. Overall, issues with housing were location and management based, but consumers also voiced concern about the condition of the dwelling they lived in. Housing challenges shared by consumers ranged from discontent with the location of their new apartment, safety-security issues from neighbors or other residents, including dangerous living situations, and inaccessible housing for people with disabilities.

Transition Barriers

Transition challenges included the selection of housing, lack of resources when moving in to the new dwelling, and the transition during the first few months of living in the housing provided.

When I was set up in my apartment, it was essentially that I didn't get many options regarding any sort of equipment. It was basically, "This is what you're getting." [6 month]

There was so much wrong with this apartment. They gave me no furniture, filthy microwave and filthy carpet with urine stains. Vacuum cleaner broke when trying to clean carpet. I need a good bed, instead they brought me a filthy pad for on top of the bed. [6 month]

I hate my new apartment, but it was either this one or live in the street. I am very unhappy with my situation. [24 month]

Housing Management Challenges

Housing management challenges included difficulties communicating with landlords and/or maintenance workers and pertained primarily to concerns about the dwelling that were not being addressed (e.g., lack of response to complaints or repairs needed).

The maintenance people are very lax here. The door needs to be fixed and they have done repairs that did not last - hence I feel unsafe. Everything here keeps breaking and I have to continually call maintenance, but they do not respond fast. [6 month]

The water in the shower is broken. They haven't fixed it yet for couple weeks. [12 month]

There are problems with this building with parking for people that come to help me, and also with the building being cold and people having to wear jackets inside. [12 month]

Housing Conditions

Some consumers reported issues with the living situation. This included complaints about conditions, criticisms about apartment size, and issues with neighbors.

The apartment is really noisy. You can hear everyone walking, loud music, and kids running around. The elevators shut down for two weeks. They only have one that is my only way out of the apartment. [6 month]

I moved to another apartment in the same building which is identical to the one I left because of a mold issue in the first apartment. [12 month]

The location of my apartment is good, but there are roaches and ants. I need a new stove and refrigerator. The kitchen floor needs to be replaced and the bathroom is also very old and needs updating. [12 month]

My apartment is too small. The bedroom is in the living room - that's what makes it look so junky. I just feel closed in because I can't get out. [24 month]

Accessible Housing

Finding accessible housing was a significant issue for many consumers. Difficulty with housing access was often related to safety-security concerns and, as mentioned earlier, sometimes overlapped with the second tier of Maslow's hierarchy.

I like my apartment, but the bathroom is way too small so it's hard for me to get into the tub. The carpet pile is too high to maneuver my electric wheelchair. [6 month]

I am trying to move lower in the building to have easier access to the ramp. There was a fire and the elevators were turned off so I had to take the stairs and was stuck on the stairs until the fireman arrived and told me to sit down. [24 month]

Personal Safety-Security

Some consumers voiced concern about their housing and threats to personal safety or security while living there. Some have had break-ins in their apartment and items stolen. Others reported they did not feel safe because of crime or the potential for criminal activity in their neighborhood.

In some cases, consumers reported feeling unsafe because of a past experience of personal injury and feared repeated injury.

> *I feel safe when I am in my own apartment, but someone is stealing from me when I go to the doctor appointments. They stole my toaster, my phone, pots and pans and clothes ...* [6 month]

> *I was mugged in my neighborhood and therefore I do not feel safe in the neighborhood. I am trying to move.* [12 month]

> *Sometimes people leave the back door to building open a little so that sometimes make me feel unsafe because anyone can come in.* [24 month]

Housing Location

Housing location was reported to be problematic for numerous reasons including difficulty with transportation and isolation from friends and family.

> *I don't want to be in Manchester (I call it the "boon docks"). I would rather be in Hartford where I could take a bus to anywhere.* [6 month]

> *I do not like it here. I have no friends here. I cannot get the bus. It does not come down this street. I want to move back to Hartford where I can get around and see my friends.* [12 month]

> *I am very depressed. I do not like the apartment I live in, I cannot see anything outside. The apartment is facing trees. I am isolated by not participating in senior centers and activities in my building.* [24 month]

Cost of Living

Concerns about the high cost of living were most often associated with high rental costs and the price of utilities, such as heating and electricity.

> *Right now I'm looking to move because the heating and electricity here is too expensive. The building is old and it costs too much to pay for electricity.* [12 month]

> *I need to find another apartment because the rent is being raised where I am and Section 8 will not cover the increase.* [24 month]

Home – Modifications

Consumers mentioned home modifications and the need for specific changes to their new homes to accommodate injuries, disability or general need. Consumers sometimes mentioned if the modification was in the process of completion or if it was hindered by money, residence management or the MFP program. Many consumers mentioned needing widened doorways for easier mobility in a wheelchair or the addition of a ramp to enter and exit the home while the majority of comments were a need for bathroom modifications including grab bars.

Widening doorways

> *I wish that some of the doorways were bigger. I can't get my power chair into the bedroom so my bed and everything else is in the living room.* [6 month]

> *I need a handicapped accessible apartment. The kitchen is long and narrow and I can't get into the kitchen with my wheelchair.* [6 month]

> *I need to find a new apartment hopefully on the first floor - and with wide doorways. I need to have a way to let people in when the aide is not there.* [12 month]

Ramp access to front door

> *I am waiting for a ramp to the street. I am talking with the manager of the apartment building - but they are waiting for the weather to improve.* [6 month]

> *I need to find another place to move to because this place is being sold. They only put in a half of a ramp at this place so I cannot go out by myself. I cannot get my wheelchair onto the ramp.* [6 month]

> *I'm trying to get my ramp replaced. They built it too steep for my power wheelchair and I can't use it on the ramp.* [12 month]

> *I would like to be able to get outside more. But there is no ramp here so I cannot go out without help.* [24 month]

Bathroom modifications

> *I need to get a shower chair because it is difficult to get in and out of bathtub.* [6 month]

> *I need a roll-in shower. Now I only can get sponge baths from my aides because I cannot fit into tub using the Hoyer lift.* [12 month]

> *My shower was never made accessible and I have never been able to use my shower. I need grab bars. I also need a power chair. I currently only have a manual chair, and I have shoulder and other problems that limit me. I feel like a prisoner.* [12 month]

> *I'm working with the landlord to get the grab bars installed in the shower so I can take a shower.* [24 month]

Housing – Positive Aspects

Many consumers expressed relief at being discharged from a nursing home environment and transitioning to the community. Consumers shared some positive aspects of living in the community including contentment with living conditions (e.g., safe, clean) and an overall sense of well-being.

Transitioning to the community

Most positive comments about housing focused on being able to transition to the community after spending time in a nursing home.

> *I feel very fortunate to not be in the nursing home anymore.* [6 month]

> *I loved getting out of there [nursing home]. I was only supposed to be in there for six months, but I was there for two and a half years.* [6 month]

At twelve and twenty-four months, consumers continued to share their happiness in being out of a nursing home and living in the community.

> *I'm just happy to be out of the nursing home. I'm happy to be alive.* [12 month]

> *For now, just want to stay here and stay the same way … This is a good place and I feel lucky.* [24 month]

Contentment with living conditions

Consumers often reported contentment with the conditions of their home in the community, and there was continuity in their reporting at 6, 12, and 24 months.

> *Rooms are clean.* [6 month]

> *My apartment is very quiet.* [12 month]

11

Things are good and the neighborhood is healthy. [12 month]

I love this place. It's clean. [24 month]

Overall sense of well-being

Many consumers were grateful and expressed happiness at being able to live in the community again and reported doing well.

I am grateful to be here. I've come a long way. I had five mini strikes, but now I am doing much better. After what I've been through, I'm doing good now. [6 month]

I am happy to live where I reside. [12 month]

Everything is going great and I like where I live very much! [12 month]

Assistive Technologies

Assistive technology (AT) and services were initially defined in federal law in the Individuals with Disabilities Education Act of 1990 and include any item, piece of equipment, software program, or product that helps, maintains, or increases the functional abilities of people with disabilities. Of the physiological needs comments, 16% (n=193) focused specifically on AT. The QOL survey introduces the topic of AT earlier, with a set of questions asking whether consumers have or need a series of specific types of AT. More than three-quarters (80%, n=154) of the AT comments at the end of the survey reflected a specific need or want in the consumer's life. Fifteen percent (n=29) of comments addressed challenges related to AT and fewer (4%, n=7) were positive (Table 4). Home modifications were not considered assistive technologies for this study and were included in the housing section.

Table 4. Assistive Technologies

	%	n
AT-Needs and Wants	80	154
AT-Challenges	15	29
AT-Positive Aspects	4	7
AT-Other	1	3
Total	100	193

AT – Needs and Wants

There was a range of needs and wants associated with AT including: mobility equipment or other devices to assist consumers; medical alert systems; transportation aids; computer access and communication aids; devices for people who are deaf or have severe hearing loss, and devices for people who are blind, legally blind, or who have low vision.

Mobility Equipment

My wheelchair is too heavy for me to push around, but I can't get another one yet. I'll just have to wait. My hands get all bloody even if I put on gloves. It's just too heavy. [6 month]

Other devices or equipment

I would like a tray that goes over my bed. [6 month]

I'd like to have an electric lift, I have a manual one. [24 month]

Lifeline or a 24 Hour Life Alert System

> *I do not feel safe and need a Lifeline because when I fall, I cannot get up by myself.* [12 month]

> *I would like a Lifeline, but I can't afford to pay for it.* [24 month]

Transportation Aids

> *I need a custom van to put a wheelchair in so I can drive myself. That is, I would like my own private transportation to be able to go out and drive to many places and take rides.* [12 month]

> *Ideally, I would like my own adaptive van, to allow me to live: go for a boat ride, concert etc.* [24 month]

Computer Access and Communication Aids

> *I am paralyzed from the neck down. I really need the Dragon voice computer program and my own computer. Also, the phone activation so I can answer the phone by myself, and then when I stop talking the phone will shut off.* [6 month]

> *I was told I could have a computer, but a year later, I don't have one. I also need some devices to help me use the computer. I had previously called the appropriate person, and this person was surprised I didn't have the computer.* [12 month]

> *I would like an iPad for better communication with my family, son and daughter. The state phone given to me does not always work properly. I have trouble retrieving messages and getting reception.* [6 month]

Devices for People who are Deaf or have Severe Hearing Loss

> *I need new hearing aids, mine do not work well anymore. I need to hear better. There are too many noises around the building that I don't know what they are.* [6 month]

> *I was put in this apartment without it being ready for a deaf person nor was it handicapped accessible. I need a vibrating alert for connection to my fire alarm for when I sleep.* [12 month]

Devices for People who are Blind, Legally Blind, or have Low Vision

> *I would like to know more about getting a magnification device. I'm blind in one eye and could use it.* [6 month]

> *I am legally blind. I need to connect with Bureau of Education & Services for the Blind. I need a talking clock and other devices for the blind.* [12 month]

AT – Challenges

Challenges associated with AT included frustration with trying to get the appropriate equipment, difficulty getting equipment repaired, not receiving AT within a reasonable time, or lack of services to support AT.

> *I had to fight to get a proper commode. It was too small and I couldn't fit on it.* [6 month]

> *Wheelchair given me is not working and I'm getting no response from the company who gave it to me and no response from the case worker.* [6 month]

> *Went months without a bed … still waiting for the new toilet seat. Don't understand why it is taking so long.* [12 month]

They tried to install a Lifeline here, but said there is no tower in the area, but I would like it again … [6 month]

AT – Positive Aspects

Overall, consumers using AT had positive comments about the equipment and expressed appreciation for the benefits associated with the various technologies.

The assistive devices help me go places and go out because I'm paralyzed. [6 month]

I feel more confident going outside with my 24 hour Life Alert. [24 month]

<u>Medical</u>

As a group, people needing long-term services and supports and those with chronic conditions and disabilities encounter more medical and health challenges than their nondisabled counterparts (Krahn, Walker, Correa-De-Araujo, 2015). It is not surprising therefore that many consumers in this study reported challenges related to their health status, the environment that impacts their capacity to be as healthy as possible, and disparities that demonstrate inequalities above and beyond inherited qualities and personal choice (Table 5).

Table 5. Medical

	%	n
Medical-Challenges	45	74
Medical-Needs	33	53
Medical-Insurance	12	19
Medical-Other	5	8
Medical-Positive Aspects	5	9
Total	100	163

Medical – Challenges

Nearly half of consumers sharing comments about their medical situation reported concerns about health problems that affect their life.

I fell and broke my femur just two days after transition. I heard the snap of the bone when I fell. I did not have Life Alert. [6 month]

I am suffering a whole lot lately from migraines. I am sad and blue and irritable and grumpy because of my migraines. [12 month]

I have stage three lung cancer and have not decided whether to have more chemo. I have already had radiation therapy and it burned my esophagus so badly that it is hard for me to drink. I had half of my lung removed - that was my hospitalization. [12 month]

I fell and went to hospital, but they found low sodium levels and so I stayed in the hospital and went to nursing home for four days before returning home. [24 month]

Medical – Needs

A third (n=53) of those providing comments about their medical situation reported medical related needs. These included wanting to see a therapist, dentist, or needing help with prescriptions.

I feel lonely, maybe a therapist would help … [6 month]

I need to know who to contact to have oxygen tanks so I can go out for hours at a time versus taking several heavy tanks and changing them. [6 month]

My therapist left practice to work on her own, so I have not had a therapist in almost two months. I usually see a therapist every two weeks. I have talked to Department of Mental Health and Addiction Services about this. [12 month]

I keep requesting to see an eye doctor, but haven't been able to get a response to this. [12 month]

I think it would be nice if I had some kind of dental assistance. I would really like to go to the dentist but there is nothing available that I know about. [24 month]

Sometimes my whole prescription is not delivered and I miss days of it. [24 month]

Consumer comments regarding insurance mainly described lack of coverage with Medicare, Medicaid and private insurance.

I am frustrated with my medical condition and insurance practices not covering things. [6 month]

My wheelchair is too big to maneuver around. I want to get another smaller wheelchair but Medicare won't cover it. [12 month]

I need an electric bed but the insurance won't cover it. [12 month]

I am having trouble with dermatologist who won't take Medicaid. [12 month]

Medicare is not paying for some medications. [6 month]

I do not want physical therapy to end as quickly as it did on Medicare. I still need to get better. [12 month]

Medical – Other

Fewer respondents made comments about their current state of health including their medication management, doctor appointments, and future health plans.

Medications are currently being adjusted by doctor. [6 month]

I have so many doctor appointments there is no time for anything else. [12 month]

I am planning on gastric bypass surgery soon and hope to be able to walk a bit better after I lose weight. [12 month]

Medical – Positive Aspects

There were only a few comments about positive aspects in the medical theme, but those who shared underscored positive outcomes related to their health.

I am feeling very positive about the improvement of my health. [6 month]

I have OT and PT and am improving. [6 month]

It was a very good move from the nursing home because I lost weight at the nursing home, but then I reached a plateau. Since I left the nursing home, I lost an additional one hundred pounds on my own. So it is better than being at the nursing home. [24 month]

Safety-Security Needs

Of the total number of comments for the study, 11% (n=251) focused on safety-security issues. Of these, over half (58%, n=145) were about transportation and the remainder (42%, n=106) were associated with finances (Table 6).

Table 6. Safety-Security Needs

	%	n
Transportation	58	145
Finances	42	106
Total	100	251

Transportation

After transitioning from institutional care to the community, consumers must leave their homes to attend doctor's appointments, do various errands, and attend family or other social events. The majority of comments in this section were about transportation challenges in the community (88%, n=128). At all three survey time points, many consumers described difficulty with community-based transportation agencies. Few consumers had constructive criticisms and many shared examples of how the agencies are not fulfilling their role regarding transportation (Table 7).

Table 7. Transportation

	%	n
Transportation-Challenges	88	128
Transportation-Other Comments	6	9
Transportation-Positive Aspects	6	8
Total	100	145

Transportation – Challenges

Consumer comments underscored frustration with transportation availability and associated limitations in not being able to participate in community activities, problems with agencies providing transportation, and the need for additional transportation.

Limited Community Participation

> *Transportation is my biggest problem. I used to drive everywhere and see friends until I broke my hip, now people want to treat me like an invalid and don't want me to do anything. I want to go back to driving.* [6 month]

> *I would like to do more things for fun like go to movies and see car shows, but don't know how to find transportation for those things.* [12 month]

> *Transportation is a huge issue. I cannot go anywhere because the company that is approved only takes me to medical appointments. I never leave the house.* [12 month]

> *I have been asking for transportation to go to a senior center and meet new people, but they never get me a ride. I asked a long time ago, don't know why I can't get a ride.* [24 month]

Difficulties with Agencies Providing Transportation

> *I would like for the van service that I have to be more reliable, and I complain and it's like talking to a wall, no one takes responsibility.* [6 month]

> *I'm not happy about transportation services. There is a ten mile radius limit to transport assistance, and that's not enough, because I have doctors outside of ten miles that I've been unable to get to in the past.* [6 month]

> *[Agency] will not transport me in my power chair because they say it is too big for their lifts - this limits me to a large degree in being independent. So I have to go in a manual chair which I cannot operate …* [24 month]

Punctuality of Agency

> *[Agency] is inconsistent with how many days ahead to book. They come too late, like thirty minutes too late or one hour early for appointments or do not show at all.* [6 month]

> *I am anxious to get with this new Americans with Disabilities Act program so that I can get rides to go to stores. [Agency] is not too dependable - I had to miss doctor appointments because they were late.* [6 month]

> *[Agency] kept me waiting for four hours when I wanted to go shopping.* [12 month]

> *Only problem is [agency] for rides. I missed two doctors' appointments and some tests at [the hospital] because they did not come on time.* [24 month]

High Cost of Transportation

> *I would like free medical transportation. I have a lot of medical appointments and it costs me $2.60 each way. I don't have $5.20 for each appointment - I can't afford it.* [6 month]

Transportation – Other Comments

Other transportation comments related to wanting their own transportation or wanting choice and control regarding individual transportation.

> *I would like to have a car.* [6 month]

> *How can I get transportation to drive myself?* [6 month]

Transportation – Positive Aspects

A small percentage of consumers shared positive aspects of transportation including getting a ride to a medical appointment or to another event.

> *Transportation to doctors is great.* [12 month]

> *Just started receiving paratransit services for going places like shopping right now I need help until I get used to it.* [12 month]

> *Finally got a ride to church!* [24 month]

Finances

Of the total number of comments categorized under the safety-security needs theme, 42% (n=106) were related to finances. Of these 106 comments, 42% (n=45) concerned personal finances, 36% (n=38) focused on challenges, such as lack of funds, and 19% (n=20), were related to the government (Table 8).

Table 8. Finances

	%	n
Finances-Personal	42	45
Finances-Challenges	36	38
Finances-Government	19	20
Finances-Other	3	2
Finances-Positive	1	1
Total	100	106

Personal Finances

Many of the comments about personal finances focused on frustration with not being able to have or do certain things and feeling a lack of personal control over funds.

> *I want to go back to school and become a human service resource person. I was just thrown out there and here you go. I can't catch up. It's hard - it really is. I can't do it alone. I need help. Now I have no car and negative $400 in the bank.* [6 month]

> *Money is a problem. I can't pay my wife to be a personal care assistant because of the number of hours, but she helps out quite a bit and therefore cannot work at a job so money is tight.* [6 month]

> *My conservator takes too long to do things … would like to know about my finances because no one tells me. Don't know when I'll see conservator next.* [12 month]

> *I want to be in charge of my own money, at least have awareness of where my money goes and what it pays for.* [24 month]

Financial Challenges

Comments on challenges related to finances were primarily focused on not having enough money.

Lack of Funds

Some consumers focused on lack of funds. In expressing problems with income, many stated the need for money for doctor's visits, personal assistance, food stamps or utilities.

> *Sometimes I cannot afford to take the bus to doctor appointments.* [6 month]

> *I run out of funds and was turned down for food stamps so I have to go to the soup kitchen at the end of each month because there is not enough money for food.* [6 month]

> *After I pay my co-pays, I have nothing left.* [6 month]

> *I have gone without medications due to lack of money.* [24 month]

> *I'm experiencing trouble with money lately. I asked for an increase in money and was determined eligible for an increase, but then they raised the rent. After they raised the rent, the extra money never came through. I'm talking with the Department of Social Services about this.* [24 month]

> *I would like my telephone back, but right now can't afford it.* [24 month]

Assistance from the Government

Other comments about finances referred to a need for financial assistance from the state or federal government. There were comments only at six and twelve months.

> *Hoping I will get approved for my disability claim which will help my financial situation.* [6 month]

> *The only thing I am concerned about is my Social Security Insurance.* [6 month]

> *It's hard to see real doctors – specialists – because it's hard to get someone who takes state.* [6 month]

> *The only issue is with the Supplemental Nutrition Assistance Program. I only receive $16.00 to cover two people.* [24 month]

Social Needs

In this study, 23% (n=529) of the total number of comments fell into the social needs category. Social needs are often related to the conditions in which people live and age and include social determinants of health that have the potential to contribute to decreased functioning among people with disabilities and those needing long-term care. Themes in this category included services and supports related to the MFP Program, other supports, such as tangible services, and social services associated with Medicaid, the Supplemental Nutrition Assistance Program (SNAP), the Rental Assistance Program (RAP), or Energy Assistance program (Table 9).

Table 9. Social Needs

	%	n
Money Follows the Person	68	362
Support	20	105
Social Services	12	62
Total	100	529

Money Follows the Person

Of all the comments on social needs, 68% (n=362) specifically mentioned the MFP Program. Of these, over half (52%, n=189) were positive remarks about the program and how beneficial it is for the support it provides to those living in the community (Table 10).

Table 10. MFP Program

	%	n
MFP-Positive Perceptions	52	189
MFP-Challenges	18	64
MFP-QOL Survey	14	50
MFP-Transition	10	37
MFP-Other	6	22
Total	100	362

MFP – Positive Perceptions

Of the themes that emerged within positive perceptions of the MFP program, most reflected a high level of consumer satisfaction with the program overall. Another theme focused on the

importance of autonomy; a smaller number of comments expressed appreciation for specific aspects of the program, or underscored the value of staff involvement and support.

High Level of Consumer Satisfaction

Consumer satisfaction is the state of mind that consumers have about a program or a product when their expectations have been met. It is subjective and not an exact measurement because it is non-quantitative. However, satisfaction with quality of services over an extended period of time ensures that quality improvement efforts are properly focused on issues that matter most to the consumer and provide evidence that the program is meeting the needs of those who, in this case, choose to live in the community and receive the services and supports needed to do so.

Of the comments related to positive perceptions of the program, many consumers expressed a high level of satisfaction with the program. Consumers described the program with a range of adjectives including: "excellent," "great," "helpful," "wonderful," "beneficial, "fantastic," and "outstanding." Besides emphasizing program excellence, consumers expressed appreciation for the program. Comments were consistent over the six, twelve, and twenty-four month survey periods.

Program Excellence

Consumers' comments were typically succinct but expressive in communicating satisfaction with the MFP program.

> *This program is awesome. It allows people in nursing facilities to live outside in the community and it is way better!* [6 month]

> *It has been a God send, I really appreciated it more than words can describe. I hope this program continues helping others like me.* [6 month]

> *My experience with the program has been very positive. You guys have done an excellent job.* [24 month]

> *Fantastic program. It helped me a lot.* [24 month]

> *Outstanding program!* [24 month]

Appreciation for the Program

Enjoyment of current living situations and appreciation for the services and supports provided, demonstrate the value of the program in enabling eligible people to transition from an institutional setting to preferred community-based living.

> *I really enjoy it here. Money Follows the Person rocks! I love Money Follows the Person. You guys have done so much to help me.* [6 month]

> *I like the program very much now that I'm home.* [6 month]

> *… appreciative of everything that the program has done …* [12 month]

> *I'm really grateful for the program. It helped me out. It's a lot better than being in a nursing home.* [24 month]

Autonomy

Autonomy is the ability to make informed choices, free of coercion, based on an individual's personal beliefs and values. The concept of autonomy reinforces an individual's right to self-determination, or the freedom to make decisions for themselves in all areas of their lives. Autonomy is particularly salient for people who have lived in an institutional care facility and felt a loss of independence, but have been able to transition to community-based living and regain

the ability to live as independently as possible. Consumer comments expressed how the program has increased their happiness about being more independent and being able to have more control over their lives.

> *I am grateful for everything this program has done. It helped me become independent and I really work at that in spite of my medical issues.* [6 month]

> *Very helpful [program] … helped a lot when I first got home after nursing home. I'm more independent now.* [12 month]

> *This program saved my life. I had nowhere to go and was homeless and ready to commit suicide rather than stay at nursing home, but Money Follows the Person intervened and gave me a place to live and a way to be independent. Hope I will not be abandoned by Money Follows the Person.* [12 month]

> *It's been great. I went from being in the nursing home and completely bedridden to being on the outside and doing [things] for myself. The program has been a definite success for me - I've made good strides and accomplishments.* [24 month]

> *Money Follows the Person has been wonderful, and I appreciate everyone that's been involved and that I can now be independent. I am so much better off now than before because of the program.* [24 month]

> *Good program … got me started at my own home with services and now I am pretty independent.* [24 month]

Appreciation for Specific Aspects of the MFP Program

Consumers also shared comments that described specific aspects of the program that were helpful and enable them to live in the environment of their choosing. These comments primarily focused on different types of services and supports including help locating a suitable place to live, being able to access and utilize assistive technology, finding appropriate paid assistance, and the availability of general services and supports.

Housing

> *I am very happy with the program. We really needed a program like this one for people who have their homes and can return to them after being at the nursing home. [I] could not have returned without the 24-hour help.* [6 month]

> *The program is super-duper. I'm so glad to be in my apartment again.* [6 month]

> *Thank you for this program. I am very happy here in this apartment.* [6 month]

> *Money Follows the Person is a great program. The program helped me to get an apartment.* [12 month]

Assistive Technology and Home Modifications

> *It's gone a lot smoother than I thought. Money Follows the Person is on top of things like I got a wheelchair with a collapsible arm so I can get in a car easier from my chair. Money Follows the Person got the portable ramp I use at home and take with me to use other places.* [6 month]

> *Program has helped a lot especially like the special handicapped shower they put in.* [24 month]

Paid Assistance

> *The paid assistance through Money Follows the Person has helped me so much!*
> [6 month]

General Services and Supports

> *Pleased in the program. There is always follow-up with inquiries about how I'm doing. Services are good.* [6 month]

> *Program gave me all the help I need, I am blessed. I am taking a computer class.* [24 month]

> *Program helped get services and things needed, etc. Help works out ok. Behavioral specialist and day support option is good too.* [24 month]

Staff Involvement

> *I've had a great experience with Money Follows the Person. The girls that set up my apartment were terrific. I'm very happy.* [6 month]

> *The case workers from [agency] and Money Follows the Person did everything they could possibly do to make the transition work.* [6 month]

> *People I have met in the Money Follows the Person program have all been very courteous and helpful. They know their job and they're warm people. I feel like some of the ones I've worked with more closely are my friends. The program is a nice package altogether.* [6 month]

> *I'm so thankful for this and the people that work with me and are still helping me. They've done the most wonderful job. God blessed me to have such good people. They put their heart out for me. I wish I could thank them more and more.* [6 month]

> *Couldn't have asked for a better living [situation] … My social worker and case manager have helped me a lot and review every ninety days with me and my conservator.* [24 month]

MFP – Challenges

Challenges are an expected component of any Demonstration and those mentioned in this study by a small percentage of participants primarily focused on lack of follow-up and communication from MFP staff. Specific aspects included the challenges faced during transition and the lack of follow through from staff on the purchase of necessary equipment in the community. Consumers mentioned being promised items but not knowing who to contact to receive the items.

> *I am not happy with the program so far. I have not heard from anyone from Money Follows the Person in a long time.* [6 month]

> *I was told it was too late to apply for equipment I need. It's after sixty days and I really need security on my door. Seems like the program failed me. I believe that social workers felt I had to do my own research and they didn't help me with alternatives.* [12 month]

> *Money Follows the Person left me hanging. They made promises that I would get all the equipment and supplies that I needed and now I'm left with nothing. I don't have a transition coordinator and I am completely bed bound and can't go out of the house. I am very mad.* [12 month]

This program does not encourage friendships, my care manager does not allow friends in my house without being interviewed first. I have had trouble with aides and companions not treating me properly and taking items from my home. My care manager has been unresponsive. [12 month]

I wish I could get more personal help people calling or stop by to see how I am doing. After Money Follows the Person ended I feel like they forgot about me. [24 month]

MFP – Quality of Life Survey

A few respondents had comments regarding the MFP QOL survey itself.

This process needs to be better. Some of the questions are too vague. Need to allow for more explanation if the answer is not yes or no. [12 month]

Thankful for the questions and checking up on things. [12 month]

MFP – Transition

Consumers had specific comments about their transition experience from institutional care to the community. Comments stemmed from six month, twelve month and twenty-four month surveys equally. Many comments specifically mentioned an MFP staff member or a specific community-based agency. Some responses were positive and others focused on challenges experienced during the transition itself, such as the time the transition took or lack of services to support community living.

I am extremely pleased with transition coordinator [name] and with Traumatic Brain Injury / Homecare Agency [name]. Very pleased overall with program and with transition back into the community. [6 month]

Tell [TC] I still love her. And I'll never run out of kitchen supplies. All the people that helped me were such good-hearted people. [24 month]

It could be faster in the beginning when I was waiting to go home from [institutional care]. I was waiting too long for things. [6 month]

As far as the transition program, it failed to have enough services available for me in the community - lack of planning, lack of being able to contact people for support when issues did arise. I get no response from [TC] for several months. [6 month]

I was told I would be receiving things of use to me, but that hasn't materialized. And I am disappointed in that. My main issue though, is with my transition coordinator, [Name]. [TC] has been rude to me. [6 month]

When I moved here, the furniture they got was not adequate and too small, sofa had bedbugs and bed was too small, transition coordinator never followed up on this. [12 month]

I would have liked for my transition coordinator to have told me about [name], a home care agency that takes personal care assistant waiver. I had a lot of issues hiring my own personal care assistant and handling all that stuff. The only services my transition coordinator told me about were [another agency]. [12 month]

Support

Consumer comments related to the overall category of support accounted for 20% (n=105) of comments under the social needs category. Of all comments associated with support, half (46%, n=48) were focused on tangible supports (e.g., services, goods, or education). Thirty-one percent (n=33) were associated with needs for belonging, emotional support, love, and

relationships (e.g., spouse, significant others). Seventeen percent (n=18) of comments focused on informational support (e.g., legal advice or services). Six percent (n=6) of responses addressed other types of support (Table 11).

Table 11. Support

	%	n
Support-Tangible	46	48
Support-Companion	31	33
Support-Information	17	18
Support-Other	6	6
Total	100	105

Support – Tangible

Many consumers requested computers or other items, such as a first aid kit. Some asked for help in getting furniture or home accessories, such as drapes. A few consumers asked for educational support or access to training.

> *If you could get me a computer, I would really like that.* [6 month]

> *When I moved here, they told me they were going to give me a fire extinguisher and a first aid kit. They gave me the extinguisher but not the first aid kit.* [6 month]

> *I want to go to school online for counseling, but need help to fix my laptop.* [12 month]

> *I love chess, but have no one to play with. Some sort of computerized or video chess game would go a long way in helping me.* [12 month]

> *Need a new mattress.* [12 month]

> *I would like to go to the program in West Haven and would like to go to classes like math to learn something to prepare me for a job other than mail.* [24 month]

Support – Companionship

Most of the comments under the theme of companionship were associated with missing family or a loved one and wanting to see them more often. Other comments mentioned having found people who provide them with companionship and a sense of belonging.

> *I would like to see my family more often.* [6 month]

> *I miss my husband because he is not allowed to stay here with me.* [6 month]

> *I feel lonely because my family lives far away.* [6 month]

> *My brother is my best friend and we help each other.* [6 month]

> *Met a new friend who drives and takes me to the senior center where I take a photography class. My schedule is full and I feel very happy.* [24 month]

Support – Information

Consumers wanted information on a broad range of topics including: how to get more community-based services; access to transportation; a list of doctors that take Medicare/Medicaid, and how to open a bank account. There were no comments on this theme for the 24 month survey.

They worked so fast to get me home, so I need to know more about the services that are available and how to get them. [6 month]

I would like a list of doctors that take Medicare/Medicaid and more information on assisted living options. [12 month]

I would like more information on how to solve my financial problems and how to open a bank account so I can get my Social Security check. [12 month]

I would like to find a number to call to learn what programs or activities are available in my area. [12 month]

I would like to know more about voice activated boards. [12 month]

Social Services

Social service programs are typically government initiatives at the federal, state or local level to help maintain and support citizens in need. MFP is a Medicaid program and many consumers participating in the program rely on social service programs including Social Security, Supplemental Nutrition Assistance Program, and Rental Assistance Program. Of all the responses in the social needs category, 12% (n=62) were related to social services. Comments included some of the challenges consumers experienced with these programs, some of the benefits that were valued, and fewer reported their need for help from these programs (Table 12).

Table 12. Social Services

	%	n
Social Services-Challenges	58	36
Social Services-Positive Aspects	18	11
Social Services-Needs	14	9
Social Services-Other	10	6
Total	100	62

Social Services – Challenges

In the social services theme, most comments (58%, n=36) were associated with social services challenges including the lack of food stamps or help from the Supplemental Nutrition Assistance Program (SNAP). Other responses expressed frustration with insufficient information about programs that could offer support.

Why if they raised my rent, then why can't I get more money for food stamps? [6 month]

I am a celiac and can't have gluten in my diet plus I'm a diabetic and I don't receive enough in food stamps to pay for the food needed for my special diet. As a result, I've been charging the food and my credit cards are maxed out. [12 month]

I want to know more about Working for Integration, Support & Empowerment program from Middletown, I was interviewed but they never came back; I want to live in a group home for mental patients. [24 month]

I think there are people who need aides like I have and do not know the programs are available to them. Is there a way of letting people know these services are available? Because I see the value of the need of help. [24 month]

Social Services – Positive Aspects

Some consumers were positive about the social services programs they qualified for and received. Others mentioned a community-based agency that was helpful in assisting the transition and supportive of life in the community.

> *Food stamp issue — the transition coordinator followed through.* [6 month]

> *Services are great.* [6 month]

Social Services – Needs

A smaller percentage of consumers mentioned needing a specific type of social service, such as a case manager or social worker with whom he/she could discuss the range of available services he/she might be eligible for.

> *I started out receiving some services, like home health aide, but then I am no longer on Title 19 and therefore they took away those services that I had been receiving.* [6 month]

> *I am needing assistance from a case manager or transition coordinator regarding access to medical care, assistance paying utilities.* [6 month]

> *I need to see a social worker - have asked doctor and agency, but I have not seen a social worker yet.* [12 month]

Self-Esteem Needs

Seven percent (n=169) of all comments expressed aspects of self-esteem. Although causation has not been established in the literature, there is a strong association that exists between self-esteem, happiness, and a general sense of well-being (Baumeister, Campbell, Krueger, & Vohs, 2003). In this study, comments about general well-being were therefore categorized under self-esteem needs.

<u>General Well-Being</u>

Comments related to general well-being expressed general satisfaction with life. Words, such as "happy," "contented," "great," "fine," "ok" were frequently used. These comments were general compared to those that specifically mentioned the MFP program or an aspect of community living.

> *I'm very contented.* [6 month]

> *Happy where I am, no noise like where I came from and I can have my little dog here.* [6 month]

> *I'm very happy with how things are working out – being in the community.* [12 month]

> *I'm happy regarding how it's going. No complaints.* [12 month]

> *I'm very happy with my life now that I've gotten out of the nursing home. I am mostly independent and very happy about that.* [24 month]

> *I am doing well on my own.* [24 month]

> *I'm satisfied. I like where I am living. It's nice – everything is convenient.* [24 month]

Self-Actualization Needs

According to Maslow (1943), self-actualization is becoming increasingly more what one wants to be and can be achieved through different pathways, such as engaging in activities and/or

interactions which are personally fulfilling. In this study, choice and control emerged as a theme and was categorized as a self-actualizing activity.

<u>Choice and Control</u>

Six percent (n=128) of all comments were about choice and control. There were nearly as many comments about the limitations experienced with choice and control as there were comments about the positive aspects of choice and control and what people would like to do with their lives in the future. Fewer comments related to choice and control and a desire to have more privacy in their life (Table 13).

<div align="center">Table 13. Choice and Control</div>

	%	n
Choice and Control-Limitations	32	41
Choice and Control-Positive Aspects	30	38
Choice and Control-Future Plans	29	37
Choice and Control-Privacy	9	11
Total	100	128

Choice and Control – Limitations

Some consumers expressed frustration at not being able to make the choices or have the control they wanted or not having enough choices and control over their life.

> *The residential care home is like a boot camp. I don't like it here because there is no freedom and too many rules.* [6 month]

> *I am discouraged and depressed because I have staff people with me all the time. It's constant supervision that I don't need.* [12 month]

> *I feel isolated because my conservator and neuropsychologist are dictating where and what I can do. They run my life. It is very upsetting! They treat me like an adolescent. I want to be part of a team.* [12 month]

> *People need to stop treating me like a child. In other words, they need to stop acting like they're the boss.* [24 month]

> *I feel that I was given choices except that there were not enough options to choose from.* [6 month]

Choice and Control – Positive Aspects

Consumers also expressed positive comments associated with choice and control and about the way they were living their lives when the completed the QOL survey.

> *I am happy living on my own and making some of my own decisions.* [6 month]

> *Now I can go out when I want, go shopping. It's so much better than before.* [6 month]

> *Wonderful program! No Complaints! I would not be able to be here on my own if not for this program. I am happy living this way on my own. I have control.* [12 month]

> *Very helpful [program] … I'm more independent now.* [12 month]

> *I'm doing ok now on my own now – doing everything for myself.* [24 month]

> *I am very happy and have all the freedom I want.* [24 month]

Choice and Control – Future Plans

Consumers sometimes spoke about the future and of having different experiences from what they currently were experiencing. Sometimes it was associated with where they might like to live or what they might like to be doing. In some cases, consumers expressed a desire to be employed or to volunteer, and others wanted the choice and control to be able to drive again.

> *I am working to get myself back into my art and self-employment.* [6 month]

> *I would like to have a job and earn my own money.* [12 month]

> *I want to work. I went to Easter Seals. As soon as I have enough money to get my photo ID, they are going to give me a job for 17 hours a week.* [12 month]

> *I would like to get outside and do more fun things, such as attend a concert or go to a sporting game. I would also love to volunteer and become a teacher.* [24 month]

> *I would like to volunteer at the nursing home down the street, but transportation is a problem.* [6 month]

Choice and Control – Privacy

A small percentage of consumers shared their desire to have more privacy in their homes.

> *I need more privacy.* [6 month]

> *I am so unhappy – more than words can say. I just want some privacy.* [12 month]

Discussion

Data analysis for this project began with the word frequency count tool in ATLAS.ti to generate a list of individual words used in the text. While the analysis of word frequency does not provide a deep investigation of text, it is an initial step in identifying basic themes or ideas for further exploration. Pennebaker and King (1999) suggest that while the use of computer aided word frequency counts are void of emotion and context, they highlight the greatest frequencies of word usage and as such are an important component in qualitative analysis. Interestingly, the data show "need(s)" as the most frequently used word. This word expresses a necessity, a course of action that's essential or important, or it could suggest that something necessary is lacking.

By the end of 2016, 4,212 consumers had transitioned through the MFP program, and 7,759 QOL surveys had been completed. Between December 2008 and December 2016, 30% (n=1,265) of consumers provided 2,274 responses to the open-ended question at the end of the QOL survey. Due to the nature of the longitudinal study, some consumers provided several unique comments at separate time points: 843 consumers responded to at least one QOL survey, 328 responded to at least two time points, and 94 responded at all three time points. The absence of comments from 70% of consumers is noteworthy in that when asked the final question, they had nothing else they wanted to say about the program.

Outcomes from an earlier study of CT's MFP program participants shed light on the 70% in our research who did not offer any comments at the end of the surveys and suggest that overall the program has been successful in addressing participants' concerns (Robison et al., 2015). According to Robison et al. (2015), the majority of more than 2,000 people who transitioned to the community have flourished. Responses to participant surveys in the study completed before and at six, twelve, and twenty-four months after transition demonstrate that, for most respondents who remained in the community, satisfaction with services, satisfaction with living

arrangements, and global life satisfaction (e.g., feeling overall happiness with all areas of life at a specific time) improved significantly and remained high (Robison et al., 2015) (Table 14).

Table 14: Selected Quality of Life Indicators (Robison et al., 2015)

| | Before Transition (n = 2,262) | | Months After Transition | | | | | |
| | | | 6 (n = 1,605) | | 12 (n = 1,328) | | 24 (n = 770) | |
Quality of life measures	%	n	%	n	%	n	%	n
Satisfied with services	76.3	1,103	90.9*	1,314	91.6*	1,096	92.9*	645
Like where you live	58.3	914	95.3*	1,494	94.1*	1,226	92.9*	697
Global life satisfaction	63	921	83.9*	1,227	82.8*	1,001	83.3*	589

*p < 0.001

Respondents in our study more frequently made comments about physiological needs than other needs (e.g., safety-security, social, self-esteem needs). Maslow (1943; 1970) stated that people are motivated to attain certain needs and that some take precedence over others, such as the physiological needs, and we found this to be true in our study. These included comments about help to support physiological needs, and those associated with housing, assistive technologies, and medical needs. The greatest physiological challenges were inadequate help and need for additional help with basic needs. Some consumers expressed frustration in not being able to find appropriate housing and getting housing modifications completed, while others noted their satisfaction with their living arrangements. Many consumers also expressed the need for assistive technologies including the challenges involved in not having this kind of support readily available. Overall, medical challenges included dealing with illness and complications of disability while comments on medical needs were associated more with the need for a physician, specialist, therapist, or help with prescriptions.

Maslow (1943; 1970) suggested that once basic needs are met, higher needs emerge, such as the need for safety-security. Of the total percentage and number of comments, the fewest (11%; n=251) were associated with safety-security and referred to challenges with transportation or finances. Again, some comments about safety and security overlapped and were included under the housing theme in the physiological category because they specifically related to problems with housing. While the transportation subtheme of safety-security is not mentioned as frequently as other themes in our study, it is not less important. People with disabilities have consistently described how transportation challenges impact their lives in important ways (Bezyak, Sabella, & Gattis, 2017; Institute of Medicine, 2007). Several decades after the passage of the Americans with Disabilities Act of 1990, persistent gaps in compliance continue to create major barriers for people with disabilities and hinder them from participating in health care, educational opportunities, employment, and in community life. Isolation from health care providers, in particular, can profoundly impact quality of life, health, and safety-security. For those living in rural communities, the challenges are magnified. Having access to adequate, affordable transportation for consumers who have transitioned to the community is crucial in contributing to their quality of life and in making the difference between health care access and

isolation. Now and in the future, it is essential to support people with disabilities in their communities by expanding policy discussions to address the transportation and mobility needs.

Although consumers mentioned finances less frequently than transportation, they expressed valid concerns about economic self-sufficiency and the ability to be financially secure. People with disabilities have historically been financially vulnerable and have higher poverty rates than those without disabilities (Stapleton, O'Day, Livermore, & Imparato, 2006; U. S. Census Bureau, 2012). Financial instability hinders access to housing, nutrition, health care, and other important resources. It is important that consumers be able to maintain financial stability, balance their budgets, and be equipped to cope with situations that threaten their financial security, such as unexpected illnesses or other emergencies.

In this study, 23% of the comments (n=529) were related to social needs. Social needs have been described by Maslow (1943, 1970) as belonging needs. These needs are associated with psychological and emotional needs rather than basic needs and are vital for maintaining good physical and mental health (Ozbay et al., 2007; Moore et al., 2015). We adapted this category of Maslow's Hierarchy and describe it more broadly so that it includes comments about social ties to individuals, groups, and the larger community (e.g., MFP Program). Although theoretical models underscore the value of both the structural (e.g., network size and frequency of interactions) and functional (e.g., emotional - receiving support - and instrumental - receiving practical help) dimensions of social support, the functional aspect is a greater predictor of good health (Ozbay et al., 2007). The level of need expressed by consumers in multiple categories of our study demonstrates the importance participants place on receiving both emotional and instrumental support to enable them to remain in the community.

Of the comments on social needs, most were related to the MFP program and offered positive feedback about the value of the program in terms of the support it provides so that people who have transitioned can remain in the community. Of the comments on social needs, 20% (n=105) focused on the value of tangible support, support from a companion, or informational support. Fewer comments in this category were associated with social services in general. It should be noted that functional abilities are crucial for well-being and quality of life. In light of the established relationship between declines in functional ability and depression, it is of the utmost importance to address social support and the functional needs people have when transitioning to the community (Muramatsu, Yin, & Hedeker, 2010). Given that people are increasingly seeking HCBS services, consumer concerns about insufficient social services should not be minimized (Ng, Stone, & Harrington, 2015). The importance of social support and its impact on psychological well-being and quality of life, suggest that state and federal efforts should continue to sustain and expand funding for HCBS (Muramatsu et al., 2010).

The self-esteem needs of consumers were mentioned less frequently than physiological and social needs but more often than safety-security needs and were reflected in the comments that expressed general well-being. Of the total number of comments (n=2,274) in this study, 7% (n=169) were associated with self-esteem and general well-being. Self-esteem has been described as an overall opinion of oneself and one's worth (Wagner, Hoppmann, Ram, & Gerstorf, 2015). It is influenced by an individual's thoughts/perceptions, how a person feels about his/her abilities and limitations, the reactions of other people, experiences at home and in the community, culture, role, and media messages.

Six percent (n=128) of comments were categorized as self-actualization and involved choice and control. About a third of the comments related to positive perceptions of the MFP program focused on autonomy and the value placed on it by consumers. It should be noted that these comments could also have been categorized under self-actualization. Studies demonstrate that perceiving autonomy or control regarding choices in one's life is associated with lower disability

risks and mortality and therefore may contribute to greater quality of life (Wagner et al., 2015). The ability to live independently, practice self-direction, make choices, and enjoy inclusion all contribute to autonomy (Wehmeyer, 2004). Our data underscore an important strength of the MFP program and demonstrate how successful it is in helping people transition to a less restrictive and much better environment in which they can enjoy community living and the ability to experience greater autonomy and choice and control. Self-regulatory capacities should continue to be viewed and promoted as important resources for people with disabilities because they fuel motivation and have the potential to enable people to experience healthy psychological development and a sense of well-being (Ryan & Deci, 2000).

In our study, physiological, safety-security, social, self-esteem and self-actualization needs were clearly areas of importance to consumers and their quality of life. While our study did not aim to identify or differentiate between the roles of intrinsic and types of extrinsic motivation in individuals, consumers' comments support individual experiences that either enhance or thwart their needs within various social contexts and have the potential to positively or negatively impact their lives in those areas including quality of life (Ryan & Deci, 2000). For example, in addition to physiological needs, consumers expressed a need for more social supports. Because functional declines pose a threat for independent living for people with disabilities and can be associated with depression and/or anxiety about living in the community, it is important to ensure that people transitioning to the community have adequate social support and that there are enough providers or other community connections to offer that support. Creating a more conducive environment in which the health and well-being of people with disabilities can flourish will help them remain in the community successfully. Despite mentioning a range of needs and challenges in multiple domains, the numerous positive comments about CT's MFP program demonstrate its vitality and significance in enabling people with disabilities to realize their goal to live in the community and experience an enhanced quality of life.

Methodological Limitations

While sample size is less relevant in qualitative research, it should be noted that the sample in this study is not representative and applicable to all of those participating in the CT MFP program because responding to the final open-ended question was voluntary. Comments reported by interviewers originated with consumers and as such may have contained potential sources of bias, such as: recalling or not recalling events or situations as they occurred in the past; an individual's response tendency to consistently respond more negatively or positively, and/or concerns about how their response will impact others' opinions of them (Baumgartner & Steenkamp, 2006).

Limitations associated with researchers could potentially include the manner in which data were collected, such as not actively listening to the consumer, incorrect transcribing, or taking comments out of context. MFP interviewers all go through a rigorous training program and continuous quality assurance process, in order to limit these pitfalls. Additionally, like all people, researchers have biases and there is a potential when interpreting the outcomes for the connotation of statements to be subject to the researcher's own views and opinions.

Conclusions and Recommendations

The MFP program is an opportunity for Medicaid recipients to live in the community rather than in nursing facilities and other institutional care settings. In evaluating the program, feedback from the open-ended question at the end of the survey is highly valuable because it demonstrates how effectively MFP has enabled many consumers to live and remain in the place of their choice – the community. Consumers expressed great satisfaction with the impact on personal life and preservation of autonomy. They also showed appreciation for specific aspects

of the program, such as the provision of housing and assistive technology, the commitment of caring staff and the provision of supports and services to ensure they remain in the community.

While consumers underscored multiple positive aspects of the program and overwhelming appreciation for its benefits, they also expressed concerns and frustrations about program and system challenges. The majority of concerns focused on meeting physiological needs so consumers could avoid being reinstitutionalized and experience living safely in the community. As a result, some consumers underscored the need for more supports and services in the community, greater access to durable medical equipment, and better housing and transportation. Working together to identify and resolve some of these challenges will improve and strengthen the program and contribute to the well-being of program participants.

MFP encourages consumers to live independent and autonomous lives with support from community-based services and supports. Given the reliance on such supports, many consumers expressed opinions on how to better serve program participants. These recommendations have the potential to increase program effectiveness as well as consumer satisfaction with the program. The following recommendations are based on cumulative consumer feedback and suggest the need for improvement in five areas: community-based supports, assistive technologies, housing, transportation, and finances.

Community-Based Supports:

- Increase consumer awareness and education to assist them in seeking the services and supports they need
    - o Encourage and equip consumers to become their own advocates, particularly in seeking additional information outside of assigned community-based services
- Monitor the quality of consumer experiences in a standardized, systematic way and hold care provider agencies accountable for delivering quality services

Assistive Technologies:

- Provide information on how to obtain more devices through insurance or outside agencies like non-profits, etc.
    - o Include how to replace broken equipment
- Conduct additional evaluation on consumer needs pre-transition to ensure consumers have all necessary equipment

Housing:

- Provide more education on housing for transition and housing coordinators to strengthen care coordination and diminish stress for consumers during the process of locating housing
- Provide better information pre-transition about location, housing structure, landlord, etc.
- Provide education for tenants on how to communicate with landlords and on resources for tenancy supports
- Provide a clear process for making and resolving housing problems at the state level when landlords are not responsive

Transportation:

- Increase access to transportation services in the community
    - o Expand policy discussions on transportation to address the needs of travelers with disabilities and explore interrelated policy areas and service delivery models including from where medical services are provided to the locations where people with disabilities are able to live

- o Initiate conversations with agencies about transportation challenges and explore possible solutions to resolve the issues
- o Address rural and suburban communities as areas of need

Finances:

- Provide increased opportunities for benefits counseling and work incentive services for those with employment goals who are striving for greater financial independence
- Develop and deliver increased opportunities for people with disabilities to earn an income and maintain financial assets

Future Research:

- Complete an analysis of comments from MFP proxy informants and compare them with the consumer outcomes of this study
  - o Proxy comments (31%) were excluded in the current study but have the potential to show the perspective of family and friends of program participants

References

Batavia, A. I., & Beaulaurier, R. (2001, March). The financial vulnerability of people with disabilities: Assessing poverty risks. *The Journal of Sociology & Social Welfare*, *28*, 139-162.
Retrieved from: http://scholarworks.wmich.edu/jssw/vol28/iss1/10

Baumeister, R. F., Campbell, J. D., Krueger, J. I., & Vohs, K. D. (2003). Does high self-esteem cause better performance, interpersonal success, happiness, or healthier lifestyles? *Psychological Science in the Public Interest, 4,* 1-44.

Baumgartner, H., & Steenkamp, J. (2006). Response bias in marketing research. In R. Grover & M. Vriens (Eds.), *The handbook of marketing research – Uses, misuses and future advances* (pp. 95-109). Thousand Oaks, CA: Sage Publications.

Bezyak, J. L., Sabella, S. A., & Gattis, R. H. (2017). Public transportation: An investigation of barriers for peoples with disabilities. *Journal of Disability Policy Studies*, 28, 52-60. doi: 10.1177/1044207317702070

Friborg, O., & Rosenvinge, J. H. (2013). A comparison of open-ended and closed questions in the prediction of mental health. *Quality and Quantity 47,* 1397-1411.

Glaser, B., & Strauss, A. (1967). The discovery of Grounded Theory: Strategies for qualitative research. Chicago: Aldine Publishing Company.

Henize, A. W., Beck, A. F., Kelin, M. D., Adams, M., & Kahn, R. S. (2015). A road map to address the social determinants of health through community collaboration. *Pediatrics*, 136, 994-1001.

Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., & Hess, S. A. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology*, 52, 196-205. Retrieved from http://dx.doi.org/10.1037/0022-0167.52.2.196

Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277-1288. Retrieved from http://qhr.sagepub.com/content/15/9/1277

Holtgraves, T. (2010). Social psychology and language: Words, utterances, and conversation. In S. Fiske, D. Gilbert & G. Lindzey (Eds.), The handbook of social psychology (pp. 1386-1422). Hoboken, New Jersey: John Wiley & Sons, Inc.

Individuals with Disabilities Education Act, Pub. L. No. 101-476, 104 Stat. 1142 (1990).

Institute of Medicine (2007, April). The Future of Disability in America. Washington, DC: The National Academies Press. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK11434/

Jackson, J. C., Santoro, M. J., Ely, M. E., Boehm, L., Kiehl, A. L., Anderson, L. S., & Ely, W. E. (2014). Improving patient care through the prism of psychology: Application of Maslow's hierarchy to sedation, delirium, and early mobility in the intensive care unit. *Journal of Critical Care*, 29, 438-444.

Lachappelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbis, Y., Keith, K. D, Schalock, R.,… Walsh, P. N. (2005). The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research*, 49, 740-744.

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, 50, 370-398.

Maslow, A. H. (1970). Motivation and personality (3rd ed.). New York, NY: Addison, Wesley, Longman, Inc.

Merriam-Webster's Collegiate Dictionary (11th ed.). (2014). Springfield, MA: Merriam-Webster, Inc.

Moore, R. C., Eyler, L. T., Mausbach, B. T., Zvinka, Z., Zlater, Z. Z., Thompson, W. K., … Jeste, D. V. (2015). Complex interplay between health and successful aging: Role of perceived stress, resilience, and social support. *American Journal of Geriatric Psychiatry*, 6, 622-32. doi: 10.1016/j/jagp.2014.08.004

Muramatsu, N., Yin, H., & Hedeker, D. (2010). Functional declines, social support, and mental health in the elderly: Does living in a state supportive of home and community-based services make a difference? *Social Science & Medicine*, 70, 1050-1058. doi: 10.1016/j.socscimed.2009.12.005

Newman B. M., & Newman, P. R. (2017). Development through life: A psychosocial approach. (13th ed). Boston, MA: Cengage Learning.

Ng, T., Stone, J., & Harrington, C. (2015). Medicaid and community-based services: How consumer access is restricted by state policies. *Journal of Aging and Social Policy*, 27, 21-46. doi: 10.1080/08959420.2015.969078

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine, 89,* 1245-1251.doi: 10.1097/ACM.000000000000388

O'Cathain, A., & Thomas, K. (2004). "Any other comments?" Open questions on questionnaires—a bane or a bonus to research? *BioMed Central Medical Research Methodology*, 4.

Ozbay, F., Johnson, D., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: From neurobiology to clinical practice. *Psychiatry*, 4, 35-40.

Pennebaker, J. & King, L. (1999). Linguistic styles: Language use as an individual difference. *Journal of Personality and Social Psychology*, 77(6), 1296-1312.

Popping, R. (2015). Analyzing open-ended questions by means of text analysis procedures. *Bulletin de Methodologie Sociolgique*, 128, 23-39.

Robison J., Porter, M., Shugrue, N., Kleppinger, A., & Lambert, D. (2015). Connecticut's 'Money Follows The Person' yields positive results for transitioning people out of institutions. *Health Affairs,* 34(10),1628-1636. doi: 10.1377/hlthaff.2015.0244

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55, 66-78.

Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. Schalock (Ed.), Quality of life: Conceptualization and measurement (Vol. 1; pp. 123-139). Washington, DC: American Association on Mental Retardation.

Stapleton, D. C., O'Day, B. L., Livermore, G. A., & Imparato, J. (2006). Dismantling the poverty trap: Disability policy for the twenty-first century. *The Milbank Quarterly*, 84, 701-732.

Thielke, S., Harniss, M., Thompson, H., Patel, S., Demiris, G., & Johnson, K. (2011). Maslow/s hierarchy of human needs and the adoption of health-related technologies for older adults. *Ageing International, 37,* 470-488. doi: 10.1007/s12126-011-912-4

Wagner, J., Hoppmann, C., Ram, N., & Gerstorf, D. (2015). Self-esteem is relatively stable late in life: The role of resources in the health, self-regulation, and social domains. *Developmental Psychology*, 51, 136-149. doi: 10.1037/a0038338

Wehmeyer, M. L. (2004). Self-determination and the empowerment of people with disabilities. *American Rehabilitation*, 28, 22-29.

Tay, L., & Diener, E. (2011). Needs and subjective well-being around the world. *Personality and Social Psychology, 101,* 354-365. doi: 10.1037/a0023779

The World Health Organization Quality of Life Group (1998). The World Health Organization Quality of Life Assessment (WHOQOL). Development and psychometric properties. *Social Science & Medicine*, 46, 1569-1585.

Appendix A: QOL Final Word Code Frequencies Table

Maslow's Hierarchy of Needs (n=2,274)

	% (n)	% (n)
Physiological Needs		53 (1,197)
Help	42 (505)	
Help-challenges		63 (318)
Help-positive aspects		25 (124)
Help-other		12 (63)
Housing	28 (336)	
Housing-challenges		50 (169)
Housing-modifications		24 (79)
Housing-positive aspects		13 (43)
Housing-other		9 (29)
Housing-facility		4 (16)
Assistive technologies	16 (193)	
AT-needs		80 (154)
AT-challenges		15 (29)
AT-positive aspects		4 (7)
AT-other		1 (3)
Medical	14 (163)	
Medical-challenges		45 (74)
Medical-needs		33 (53)
Medical-insurance		12 (19)
Medical-other		5 (8)
Medical-positive aspects		5 (9)
Safety-Security Needs		11 (252)
Transportation	58 (145)	
Transportation-challenges		88 (128)
Transportation-other		6 (9)
Transportation-positive aspects		6 (8)

Finances	42 (106)	
Finances-personal		42 (45)
Finances-challenges		36 (38)
Finances-government		19 (20)
Finances-other		3 (2)
Finances-positive		1 (1)

Social Needs		23 (529)
Money Follows the Person	68 (362)	
MFP-positive perceptions		52 (189)
MFP-challenges		18 (64)
MFP-QOL survey		14 (50)
MFP-transition		10 (37)
MFP-other		6 (22)
Support	20 (105)	
Support-tangible		46 (48)
Support- companion		31 (33)
Support- information		17 (18)
Support-other		6 (6)
Social Services	12 (62)	
Social services-challenges		58 (36)
Social services-needs		18 (11)
Social services-positive aspects		14 (9)
Social services-other		10 (6)

Self-Esteem Needs		7 (169)
General well-being	100 (169)	

Self-Actualization		6 (128)
Choice and Control (CC)	100 (128)	
CC-limitations		32 (41)
CC-future plans		29 (37)
CC-positive aspects		30 (38)
CC-privacy		9 (11)