

**Nine month interviews conducted between April and August 2006**

**Prepared for:**

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Center for Health Policy and Research (CHPR)  
and the Real Choice Collaborative Team**

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**Consumer Quality Initiatives, Inc.**

**Bringing the people's voice to behavioral health research...  
and from research to practice.**

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**APPENDIX A:** Participants' Self-Reported Quality of Life Additional Analyses: Comparing 'Before Real Choice' and 2-months/'Before Real Choice' and 9-months

### *Project Description*

***The “Real Choice” self-directed supports and services Pilot project is funded by the Centers for Medicare and Medicaid Services (CMS) under the 2001 Real Choice grant and coordinated by the University of Massachusetts Medical School Center for Health Policy and Research (CHPR). Consumer Quality Initiatives (CQI) was hired as an independent evaluator to conduct a qualitative assessment of consumers’ experiences and satisfaction with the Real Choice Pilot project.***

### *Methodology*

***The qualitative interview guide was developed with consumer input. All thirteen (13) participants were interviewed after they had been in the Pilot nine months. Data was analyzed using N’Vivo, a qualitative software package, to identify themes in the participants’ experiences.***

### *Summary of Findings*

#### Major Strengths of Real Choice Pilot

- At nine months, participants continued to report significant improvements in their independence and quality of life compared to their life before Real Choice.
- Participants achieved much needed control over their lives.
- Participants reported getting needed supports and services, such as workers, transportation, medical equipment, household items, community and educational activities, personal care items, and gap-filling/crisis services.

#### ***Participant Perspectives on Strengths of the Real Choice Pilot:***

[Real Choice] increased my independence. That was a very major thing for me. I cherish my independence and as I gradually improved my needs decreased and I was able to do more things. Before I couldn’t take a shower by myself. Now I couldn’t imagine having someone in the shower now. Being able to go out on my own. Being able to seek out different things, my own interests my own. There’s a lot of things, a lot of things. Opened up my world. When you’re in a situation like mine when you have a disability, when you are able to take care of yourself all by yourself, go out by out all by yourself, that’s a miracle and that’s because of Real Choice.

I’ve been able to go to parks, visit with family and friends, get to medical appointments without the need of an ambulance.

The independence, opportunity. It gives you something to look forward to day to day. You're able to experience and do things you'd never be able to do before. If you're fighting depression or ailments or anything.

They made it better having family, not a stranger, coming in to help out. I feel more comfortable.

### Most Challenging Aspects of Real Choice Pilot

- Some participants continue to struggle with paying for items out of pocket and waiting for reimbursement and with being able to purchase needed items quickly and efficiently.
- Training and information to community liaisons needs to be more comprehensive at the start of the program and then participants need better training and information during all phases of the Real Choice program, from intake through discharge.

### ***Participant Perspectives on Strengths of the Real Choice Pilot:***

The only issue is that I'm still paying out of pocket for medical supplies and then waiting to get reimbursed. That's difficult.

I think they need to be more informative if anybody else started the program. They should know what they could do or not do. That's what I'd like to see for someone else. Not coming in blind. Not knowing what to ask for.

### **Recommendations (\* if also appeared in two month report)**

#### **Ensure Consumer-Direction, Satisfaction, and Fulfillment of Needs**

- Use Consumer Friendly Language if Encouraging Representatives
- Periodically Confirm that the Community Liaison Relationship is Working, especially around Mental Health Needs and Cross-Disability Needs
- Provide Ongoing Participant and Community Liaison Training\*
- Conduct Case Review Consults as Needed
- Implement a Process for Communicating Policy Changes

#### ***Financial Considerations***

- Develop a Consistent Policy Regarding Workers' Rates of Pay\*
- Promote Consumer-Driven Communication with Fiscal Intermediary
- Develop Procedures to Eliminate Paying Out of Pocket\*
- Ensure Consistent Turnaround Time for Payment and Payroll

**2****INTRODUCTION**

The goal of the Real Choice Pilot program evaluation is to assess the effectiveness of flexible funding for people who have disabilities in increasing participants' quality of life and independence.

***Consumer Quality Initiatives (CQI) was chosen as the independent evaluator of consumer experiences for this project. CQI is a Massachusetts-based consumer-directed and staffed research and evaluation organization. Our mission is to establish a consumer/family voice that is integral to quality improvement and systems change activities.***

Qualitative evaluation is useful for gaining insights into how a program functions and how participants experience and relate to the program. The purpose of the consumer-directed qualitative component of this evaluation is to provide Real Choice stakeholders, including the University of Massachusetts Medical School's Center for Health Policy and Research (CHPR), state partners, the Real Choice Consumer Planning and Implementation Group, and the Real Choice Collaborative Team of state and consumer partners with in-depth, narrative and explanatory information about participants' experiences of the Pilot project.

**3****METHODOLOGY****Instrument Development**

CQI utilizes community-based participatory action research methodology, which involves community members, those impacted by an issue, program or policy, throughout the research process in order to enhance the relevance and reliability of research results.

Thus, before considering the topics its evaluation would cover, Jon Delman, CQI Executive Director, reviewed Real Choice planning documents prepared by the Real Choice/ Independence Plus Consumer Planning and Implementation Group (CPIG). He then met several times with Erin Barrett, CHPR Project Director, to better understand the complexities of the model. He also met with the CPIG to further refine the scope of the survey. Further review and recommendations were offered by Emma Quach, CHPR Project Associate.

Based on the information collected, CQI drafted a qualitative interview guide that focused on two primary areas: program fidelity and outcomes. The program fidelity domains were: the spending plan, fiscal intermediary, community liaison, and choice of and flexibility in workers. The outcome domains were: quality of life, independence, and activities in and outside the home.

**Program Fidelity**

- Spending plan
- Fiscal intermediary
- Community liaison
- Choice of and flexibility in workers

**Outcomes**

- Quality of life
- Independence
- Activities in and outside the home

With the draft interview guide in hand, CQI held meetings with four groups of consumers in February and March of 2005. In each case, consumers represented a particular constituency: 1) people with developmental disabilities, 2) people with mental illness, 3) people with physical disabilities, and 4) elders. The groups contained two to five people, with a total of 12 people involved.

The primary purpose of the meetings was to determine whether the questions were valid and reliable. Some meeting participants had been involved in self-directed care previously, while some had not (i.e., individuals with mental illness). In addition, some of the terminology (e.g., community liaison, fiscal intermediary) was new to people, so those terms needed to be explained up front.

In general, the questions about the Pilot (spending, community liaison, workers) as posed were understandable. The questions pertaining to concepts and outcomes (e.g., quality of life, independence) were more difficult for people to understand, so those questions were modified after the input meetings.

Two month interviews were conducted between August 2005-January 2006, then a report on the results of the two month interviews was completed.<sup>1</sup>

### **9-month Interview Instrument Revision**

After the two-month interviews and analysis, revisions were made to the two-month instrument in order to capture the experiences of participants at nine months. The domains and structure of the interviews remained the same, though several questions were changed in order to reflect the participants' current point in the Real Choice Pilot (e.g., from experiences with hiring worker to experiences supervising and retaining workers). Also, more in-depth information was collected on representatives and the assessment process. CQI proposed changes, and input was received from CHPR staff before the instrument was finalized.

### **Interviewing**

CQI's consumer and/or family member interviewers conducted face-to-face interviews at each participant's home. All 13 Real Choice participants were interviewed between April and August 2006. The interviews were scheduled to take place after a person had been in the Pilot for nine months.<sup>2</sup> Most participants had purchased most, but not necessarily all, of the items in their spending plan at that time.

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<sup>1</sup> see Real Choice Pilot Participant Interviews: Consumer Quality Initiatives. May 2006.

<sup>2</sup> Most participants were interviewed within one month of the two-month timeframe depending on their availability for the interview. One participant (the 14<sup>th</sup> participant in the two-month study) had been interviewed at two months, but died before the nine-month follow-up. Otherwise, all participants stayed in the program between two and nine months.

## Analysis

Interview notes were taken by the CQI interviewer. Interviews were not transcribed verbatim because interview notes were complete and sufficient for analysis. All the interviews were coded in N'Vivo, a qualitative analysis software package. The coding helped identify themes that emerged for each area of inquiry, although most analysis was done by question because of the interview guide's structured nature.

## Demographics of Participants

We collected some limited background information on the participants at nine months, including whether the participant was involved in other programs besides the Real Choice Pilot as well as whether they had a primarily mental health or physical disability that qualified them for the Pilot. These questions were asked because of feedback received from various stakeholder groups while presenting the two-month results. We found that many participants had both physical and mental health disabilities. Also, about half were involved with another agency, such as the Department of Mental Health (DMH) or the Department of Mental Retardation (DMR), or they had a caseworker at another community agency.

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## FINDINGS

### I. New Themes at Nine Months

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#### Support Broker Agency Change in Southeast Area

A few months before the nine-month interviews, there was a change in vendors in one of the two regions where the Pilot program was implemented. Participants said that working with the new support broker agency felt more consumer-directed because the staff spent more time with them and had more information regarding Real Choice. They were also more encouraged to submit requests for desired items related to their identified needs. They felt that their new community liaisons were better informed and “knew what was going on”.

#### Fiscal Intermediary, Paperwork and Purchasing Items

Some participants felt they were getting the “run around” when trying to submit paperwork to get items purchased. The paperwork was time consuming, particularly when the fiscal intermediary found mistakes and sent the paperwork back to the participant to correct. Some felt the fiscal intermediary did not want to communicate directly with the participant, but instead preferred to go through the

community liaison. This made those participants feel like they had less control of their spending plan.

### **Anxiety Regarding Second Year Budget**

A few participants had not yet spent all the money in their first year budget. At nine months, these participants knew that they would soon be developing their second year budget and were concerned that their dollar amount would be reduced significantly from the first year, particularly if they had not spent all of their money. Participants felt it was the fiscal intermediary who was most responsible for the delays in spending, not them. A couple participants said they did not spend their entire budget amount because they did not need the particular items, whereas a few others said they did need the items in their spending plan but had barriers to spending the full amount.

### **Hiring Family/Friends is a Positive Feature for Some**

For some participants, being able to hire family and/or friends as their workers was an important part of the Real Choice Pilot<sup>3</sup>. Real Choice gave all participants the option of having family members or friends as their hired workers. Only some choose this option. Real Choice provided an opportunity for people to strengthen their natural supports, as they had family members or friends who were interested in being more involved but had not been able to help to the full extent possible because they needed to earn a living. Those who used family and friends as their workers said it was helpful because they were people whom they trusted and looked forward to seeing. Real Choice gave participants the opportunity to expand the support they received from people they cared about.

Several participants mentioned that they preferred working with and hiring people they already knew, particularly family.

... I eventually went through people I knew and that's worked out great. I found them through word of mouth, some family. ... It's easier to change when they are people I know rather than with agencies. And it's easier to pay someone for transportation than to deal with cabs and pay up front.

They made it better having family, not a stranger, coming in to help out. I feel more comfortable. Like I had one girl when I was living in \_\_\_\_\_ tower. She was good and nice but she made me feel like I had to straighten things before she came in. It doesn't bother me when you come or my community liaison. But I don't like a stranger

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<sup>3</sup> Some participants chose to use agencies to hire workers, instead of family or friends, because they did not have family members or friends who they felt were appropriate for the work they needed done.

asking lots of questions about my illness. I don't want them to feel sorry for me because I don't feel sorry for me.

I want to hire more workers for transportation, but not someone I don't know. [So I haven't hired anyone, except my mom].

## II. Participant Experience of Pilot Operations at Nine Months

### A. Assessment

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#### The Assessment Process

Overall people were satisfied with the assessment process. Most said they remembered having their needs assessed, and said it was a positive experience.

Nonetheless, most participants did not differentiate between the one-time assessment at the very beginning of the Pilot and the ongoing spending plan development they did with their community liaison. Although participants did not clearly differentiate between the one-time needs assessment and the ongoing process of spending plan development with their community liaison, the important finding is that all said they were involved in the assessment process and felt they had control over identifying their needs.

The quotes below refer to both the assessment process and the spending plan process:

I don't remember a form. I remember her writing it down and she told me to go get the prices and I remember getting the items with the best warranties.

I believe it was on an intake form. They were writing everything down on a sheet. They did most of the writing but I signed some paperwork at the end.

My community liaison did all that. I just went over it and signed it. I had the option, but I wasn't able. My mental processes were not that great. I made suggestions for what I needed. I picked my own furniture, my own food. Most of the things I picked myself.

## **B. Representatives**

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### **Representatives**

At two months, participants were asked whether they had a “representative”, and only one participant identified such a person. CHPR staff was interested in further exploring participants’ ideas about the use of representatives, so questions were added to the nine-month interview guide to assess participants’ interest in having a representative to help them with the following:

- designing a spending plan;
- making decisions about daily supports;
- recruiting, hiring, training, and managing workers;
- authorizing payroll; and
- performing other activities as participants see fit.

First, participants were asked whether they understood the role of a representative. Some participants did not have a complete understanding of the role of a representative, even if they had someone helping them in this capacity. Then the interviewer read them a description of how a representative might help, in comparison to a community liaison. Based on the description provided, most participants were able either to identify how someone was helping them in this capacity or explain why they felt that they did not need someone to help them in this capacity.

At nine months, more than half of the participants said they had a representative (e.g. someone helping them in this capacity, even if not as a “legal” or formally appointed representative). The role of the representative varied for each person. This is interesting because at two months only one participant reported having a representative, but it seems that expanding on the definition of a representative made more than half of the participants identify someone that assisted them in these ways.

Most of those who said they had a representative at nine months said the representative was a close family member who had some, but not total, involvement in helping the participant with Real Choice. Most participants were clear that this person was involved only to provide assistance, but not to make decisions. Participants were wary of having someone too involved in their affairs, either because they felt they could handle issues on their own or because they felt that a representative was for someone who had serious cognitive impairments.

Only one person who did not have a representative said he wished he had one to work with him on his spending plan. The other four participants who did not have a representative were clear that they did not need a representative because they were capable of making their own decisions.

Yes, it would be someone to help me make decisions. Just help me make decisions about the whole program. I had the choice to get one, but I chose not to because I feel I am competent to make my own decisions.

If I get to the point where I can't make a decision, [my nephew] knows what my preferences are. I have my full wits about me so he doesn't help with decisions now.

## C. Spending Plan

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### Money Allotted

Participants said they were allotted between \$8,000 and \$27,000 for their first year budget. One participant said he/she was allotted \$1,000, which is either incorrect or refers to her monthly allotment, not yearly allotment, and one person did not know what his/her budget total was.

Some were worried that their allotment would be decreased in year two, particularly if they had not spent their entire budget. They felt this uncertainty was unfair because they needed the items they identified in their first year, but ran into difficulties purchasing all of their items due to emergencies or health concerns. These difficulties delayed the progress in the implementation of their spending plan. Some also reported having trouble coordinating the purchase of certain items, particularly at stores that would not take a Stavros check from them.

By not spending this money, these people will say, "Obviously she didn't need it."

### Items in the Spending Plan

Participants purchased a variety of items with their budgets. The most common purchase was *workers for personal support and/or transportation*. Other items purchased, in descending order of frequency, included:

- 1) *Medical equipment or services* not covered by MassHealth, including dentures, dental work, electric scooters, wheelchairs, glasses, a walker, special shoes, vitamins, knee braces, home modifications, safety pads, hospital beds, etc.;
- 2) *Household items*, furniture, silverware, dishes, air conditioners, sheets;
- 3) *Electronics*, computers for purchasing items online, doing school assignments or communicating with others, and/or fax machine for sending in Real Choice related paperwork;
- 3) *Activities/education*, movies, trips, a glass blowing class, nursing classes;

- 4) For a few people, *personal care items*, like shampoo, shaving cream, etc., and
- 5) *Emergency needs*, including rent money for a new apartment after a fire.

### Developing a Spending Plan

Most people worked collaboratively with their community liaison to develop their spending plan, and most said their spending plan was developed in the way they wanted. Some said that they came up with the ideas, and their community liaison wrote them down and submitted the spending plan. Often, the community liaison did most of the paperwork related to developing and submitting the spending plan. Some participants very much appreciated that the community liaison dealt with the calculations that went into deciding how much to budget for each category.

Yes, me and my community liaison sat down and thought of what my needs would be for the year to come. A cleaning person, transportation, activities to get out. We made up that type of situation, as far as what we would put in for with the spending plan. As far as individual amounts, I don't know...He helped me make it up, in other words. Figure wise with the calculations. He was very good with that. I think you do really need a person to assist you because it's a lot of figures to go over for housekeeping activities, transportation to break down and figure out how much per month.

A couple participants said that they were discouraged from applying for "too much" in their initial spending plan. They were told by their community liaison not to ask for too much because they might not get it.

I just sat down and thought about what things I'd like to do and what I would need. My community liaison said not to ask for too much because they might not approve it. She didn't know and neither did I. So I didn't put down everything I could have needed.

Others were in fact encouraged to apply for things they might need. While amending their spending plan, some were told to include items they needed, but were not sure would get funded (e.g. air conditioner).

If I thought I needed something, or I wasn't sure, she would make definitive decisions. Like, "Well, I won't need it all the time so I won't put it in," and she'd say, "Well, will you need it at all?" or "What about in the next 6 months?" That kind of thing.

## Changes to the Spending Plan

Participants described a range of experiences with making changes to the spending plan. Some said they had not made changes to their spending plan, but a few of those participants were thinking about it.

When the New Year starts, maybe new glasses. I never talked to my community liaison about amending my plan. She could have mentioned it. I'm sure I could of, but I haven't. I wanted to talk to [my community liaison] and see what her recommendations were.

Some made a couple of changes over the nine months. And a few said they made changes as frequently as every month. Most participants went over their spending plan every month with their community liaison and talked about whether their needs were still being met by their spending plan.

Yes, each month it was something different. A one time basis. Every month a new spending plan was submitted. I needed things like brooms, mops, detergent, clothing. That's a one-time thing.

Yes, we needed to. We had to amend it twice. When I moved to my first apartment. Then when we had the fire. We had to amend for the emergency funds.

## Feeling in Charge of Spending Plan

Most participants felt in charge of their spending plan. For a couple participants, feeling in charge was actually not a top priority for them. Getting the items they needed was a bigger priority.

Yes, there's a team of people that I think are in charge. The community liaison and me work on a plan and we know how to make changes due to training from Elder Services.

Yeah, because I'm able to decide what it is I need and I address it. It's up to them to approve it, but you can ask. I have no problem advocating.

Yes, in a lot of ways. Well, I feel that I get to make the big decision and if it's a legitimate thing they usually back me. I have never felt not in charge.

Not totally, not until I started getting anything. Since Options took over, yes.

He's not ruling me, not "no this is the way it should be". I get the final say and final look over of the figure before he turns it in.

### **Challenges with the Spending Plan/Paying Out of Pocket**

Some participants continue to have issues with having to pay for items out of pocket and/or getting items purchased in a quick, efficient manner. Since the initial two month interviews, there has been a policy change stating that participants should not be paying out of pocket for spending plan items, but a few participants reported continued problems with this. No participants reported being informed of any policy change, and were not aware of any formal actions or committee to address purchasing issues participants were facing.

Some others also had difficulty working with the Fiscal Intermediary (FI) to purchase items. The FI was working to purchase items over the internet, but some were having difficulty completing the necessary paperwork in the correct manner so the purchase could be made.

The only issue is that I'm still paying out of pocket for medical supplies and then waiting to get reimbursed. That's difficult. I would make a \$3000 order [for medical supplies from a medical supply company] but I can't pay for it. I know Elder Services was going to look into it. I would rather see them have a structure and a plan. Try it with \$100 and see if it worked. Elder Services is open to ideas, which is nice in dealing with the FI, which is Stavros. I buy in bulk so it's a lot of money for supplies. If UMASS figured it out, they haven't communicated it to Elder Services.

Nothing was the way I wanted it, when SCIL was in charge. The issue now is [the FI]. It's the end of the period [first year of RC] and people still don't have what they want. She will say one thing, like, "Do things this way." I do it and she says, "This is great." Then she comes back and says, "I don't want to get involved." She'd rather talk to [my community liaison] at Options....Time ticks away...Months go by. Doing all the order forms...is not easy.

## **D. Community Liaison**

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### **Changes to Community Liaison**

Due to a change in the support broker agency in one region, five participants (more than a third) changed community liaison between the two-month interview and nine-month interview. Four of those who made a change said they were having a better experience with Real Choice after the change. They said they were getting better information about the Pilot from the new community liaison than their initial community liaison. The other participant who made a change had

just gotten a new community liaison a few weeks prior to the interview and had not been able to contact or have a meeting with his new community liaison; he felt he should be given a new community liaison who had the time to work with him.

Participants who had a new community liaison appreciated that the new support broker agency gave them several potential community liaison to choose from, and that they were able to interview the community liaison as they would any other worker. Those who needed a community liaison who spoke a language other than English had less choice, but were not dissatisfied with the community liaison they received.

### **Role of Community Liaison**

The role of the community liaison was described primarily as someone who would go over the spending plan and budget with the participant on a regular basis. The community liaison would give suggestions, telling them what the Pilot might or might not pay for. In general, the role of the community liaison was to act as a teacher, to explain and to give useful information.

Community liaisons also checked in regularly with the participant, assessed if new needs emerged, and listened to the participant about how they were doing and how the Pilot was going. Several participants also felt that the community liaison's role was to help them problem solve, particularly as a go between when disputes or questions arose with the vendor agencies and/or fiscal intermediary.

She's like a go-between between me and Stavros. She's there to listen if I need to talk. She makes suggestions. She's there when I need her.

She will say her role is to instruct me to do paperwork and fend for myself with Stavros. I have no complaints. She sees herself as a teacher.

I believe the role is to help you create a budget that will work and will be responsive to your long-term goals and needs. Individual short term as well. Your budget is like your bank account. You have to manage emergencies like if your car breaks down. That's what I believe she's supposed to do.

### **Level of Support**

Participants were asked if their community liaison was providing more help than they needed, just enough help, or not enough help. As shown in Table 1, the majority of participants said they were getting enough help from their community liaison.

	<b>2-month Percentage</b>	<b>N</b>	<b>9-month Percentage</b>	<b>N</b>
More help than you need	21%	3	0%	0
Just enough help	57%	8	77%	10
Not enough help	21%	3	23%	3

At both two months and nine months, three participants reported that they were not getting enough support from their community liaison. Only one participant reported not getting enough help at both interviews. Overall, five different participants (five individuals) felt that, at some point during the Pilot, they were not getting enough support from their community liaison.

The sub-sections below examine the sources of the participants' dissatisfaction and explain why participants' levels of satisfaction changed (or did not change) between two-months and nine-months.

*What happened to the participants who were dissatisfied at two months?*

Two of the participants not receiving enough help at two months changed their community liaison between the two-month and nine-month interviews. With the change came increased satisfaction with the level of support at nine months. One participant was dissatisfied with the Pilot at two months because he was not fully trained by his community liaison on what the Pilot would fund (e.g. food). By nine months, he had a new community liaison who retrained him so he better understood what the Pilot would and would not fund. He said:

At 2-months

I would like to make some changes because my cable is too expensive. It's \$57 a month. I wish they would cover the cable, help me get some clothes, and special food for my diet. My diet is expensive. I know the money is not enough. My community liaison told me what the program would cover. They budgeted \$11,000 but I don't see it. My community liaison asked the big boss if I could buy a TV for my bedroom, pay for my cable, get medication and they wouldn't cover it. [...] Sometimes I shop and spend \$200 and it only buys six bags of food. It's not enough, especially with my special diet. I have to eat fish, shrimp and salad.<sup>4</sup>

<sup>4</sup> Although the participant says his community liaison explained what the program would cover, it seems this information was either incorrect or misunderstood because cable TV and groceries are not covered by Real Choice. This misunderstanding was a major source of dissatisfaction for this participant at 2 months.

At 9-months

Sometimes my first community liaison would come and I would not be able to understand. My community liaison didn't explain things and it was hard because I don't understand what people say about the program in English. My new community liaison explains. [...] My first community liaison just came to teach me how to use the wheelchair in case I needed to take public transportation. He was like a teacher. Teaches about how to get along with my condition. Not too much about the program. [...] My new community liaison comes and sits down and talks to me and filled out paperwork I have and talks to me about any problems. What the program provides and doesn't provide.

*Why have two participants become dissatisfied at nine months?*

Two of the three participants who were not getting enough help from the community liaison at nine months had been satisfied with their level of support at two months. At the time of the nine month interview, these participants were living in an institution or congregate living situation<sup>5</sup>, and therefore had not been able to meet a sustained goal of community living. Therefore, they did not feel they were getting enough support from the community liaison.

*Why did one participant remain dissatisfied at two and nine months?*

One participant said that she was not receiving enough help from her community liaison at two and nine months. Unlike the two other participants who were dissatisfied at two months, she had not changed her community liaison. By nine-months, after some trial and error, the participant was able to have most of her needs met with the implementation of her spending plan but she did not attribute this to help she received from her community liaison. She said she minimized her community liaison's involvement in supporting her with her spending plan because she had not found her to be helpful and preferred instead to go directly to the fiscal intermediary or support brokerage supervisor. She said:

2-months

To be honest, I don't even know what her role is or what she is supposed to be doing. I don't want to criticize. ... Yes, she told me if I wanted somebody else, but who am I going to get. I don't know anybody who has the qualifications, the energy, or the time.

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<sup>5</sup> One of these participants continuously lived in a rest home during the program; the other participant started in a nursing home, moved out into an independent apartment in elder housing, then moved back to nursing home.

9-months

There have not been significant improvements with my community liaison but I have learned to work with the fiscal intermediary. If something is in my budget, I work with the supervisor from the vendor agency. If I need something done right away, I can't count on my community liaison. So I'll let the supervisor and the fiscal intermediary know. So we'll all know we are waiting on the community liaison. [...] I know I can't rely on my community liaison, so I go around her to others. [...] She's not helping me at all.

**Support to Oversee Workers and Spending Plan**

The majority of participants said their community liaison was supporting them in overseeing their spending plan. A couple participants were mixed about the support they received, and one said they received no support. Most said their community liaison helped by looking up prices and troubleshooting purchasing or payment for items. Some also said their community liaison explained the spending plan in "laymen's terms". A couple participants said their community liaison helped them with their spending plan by identifying needs and/or supporting their decisions. Some noted that the community liaison would encourage them to submit for an item they were not sure about. Some also said that even though the community liaison did not agree with a particular item, they would include it in the spending plan per the participants' wishes.

Well, she supports whatever I put down. Even if she doesn't agree with what I want, she puts it down, which is a support.

My old community liaison would do nothing, but my new community liaison sits down and asks me about my needs.

Yeah, when we need to work on the spending plan we'll get together.

In contrast, only about half of the participants said they were supported by their community liaison in employing workers. Most said they did this themselves, including finding the workers, hiring them, and dealing with their paychecks and timesheets. Two said they got some support, but they mainly oversaw their workers. Most participants seemed satisfied with this level of independence in hiring and employing workers, although a few could have used additional support from time to time.

She didn't have to. I did that on my own. But she supported my decision.

She told me what I needed. She told me to get information and how much I wanted to pay [my workers], but [the supervisor at Elder

Services] did more to help with that than she did. I never fired anyone. All were good. I don't think the community liaison helped with hiring or firing. I worked with these agencies and that was a good decision on my part. All the nurses and home health aides were good.

When I had one bad [worker], my community liaison said, "No, if she doesn't want to come to work, then you have to fire her." So I did that. Now I'm looking for a new person. He says he'll look around for a cleaning service. So he's helping in that area.

## Training and Education

No standard training protocol seems to exist for overseeing a spending plan or employing workers. Seven out of thirteen participants said they got some training to oversee their spending plan, yet only four said they were completely satisfied with the training they received. Almost half of the participants said they got no training to oversee their spending plan. They said they were given a handbook, but no explanation of it was given by the community liaison. This was the case even for one participant who was legally blind and could not read the handbook.

There was an improvement in satisfaction with training and education for the participants who got a new community liaison. Most participants who did not change community liaison did not see much improvement in the training and education they have gotten since the beginning of the Pilot.

### *Training on Spending Plan*

The comments below indicate the variety of experiences people had with training and education on overseeing their spending plan.

I think they need to be more informative if anybody else started the program. They should know what they could do or not do. That's what I'd like to see for someone else. Not coming in blind. Not knowing what to ask for. It's a learning experience. A costly learning experience because now you can't have your budget amount increased [in the second year, based on the first year budget].

No, as a matter of fact, I was going to talk to [the supervisor from Elder Services] when she comes. It's my fault because I didn't ask her [for training]. I only have an eighth grade education so a lot of it I don't understand when it comes [in the mail]. My past community liaison didn't explain it to me.

It was a packet of info that told me what they were all about. That kind of thing. I read through it on my own. My community liaison didn't go through it with me. I felt fine about that because she didn't know more than I knew, so I read through it on my own and figured it out. I was one of the very first people.

As she's been learning, she's been training me. We both started off not knowing much so as she gets new information, she shares it with me.

### *Training on Employing and Supervising Workers*

The quotes below illustrate the variety of experiences people had with the training and education they received on employing workers.

Yes, she just told me to look in the yellow pages. That wasn't helpful because I didn't find anybody. I wish she would have sat down and helped me look through the book to find somebody but she didn't do that.

She didn't really give me any training, but before my illness I ran two businesses so I know about hiring and checking references.

No, the one person who gave me training on employing workers was [the supervisor at Elder Services]. I know nothing about taxes and hours and keeping records, so she said it was a good idea to go with an agency who would do all that.

Yes. She's actually given me the packet for hiring and time sheets and explained how to use them. She only deals with timesheets when dealing with the spending plan. She reviews them.

### **Information on Community Resources**

There is not a lot of consistency with the provision of information on community resources. Half said they did get information, and several said their community liaison presented them with specific information about community resources that might meet their needs. Others said they received no information, or only a list of resources with their manual. Only a few participants said they took advantage of available community resources. Those who did were very pleased. Resources utilized addressed medical, recreational, basic needs, and/or emergency needs.

Participants stated that it was most effective when their community liaison mentioned programs that were available and relevant to the participant, and presented the information to the participant, rather than only giving them a list of organizations and numbers to call. Some participants decided not to take

advantage of such resources, and some did. One participant who relied solely on the list in the manual to access services was frustrated because, for instance, multiple calls to various nursing agencies were unsuccessful in meeting her needs.

We noticed that a few participants were interested in recreational and physical fitness activities at two months, but later decided not to pursue those activities (e.g. joining a gym, taking riding lessons). This might be attributed to the participants' shift in priorities. Nonetheless, there seemed to be barriers other than having these activities paid for that prevent participants from taking advantage of these activities. Those with physical disabilities who indicate a need or desire to participate in physical activities, but later do not take advantage of those opportunities with their budget, may need extra support.

The comments below show the variety of experiences people had with getting information about available community resources.

The list wasn't very helpful because you couldn't use them. I called, but they wanted you to pay up front. But what they did help with was the food pantries. That was excellent. ADA transportation was great and getting discounts on utilities. It was very aggravating because some days they would be like, "We'll call you back," or would take your information but not call you back. It was aggravating, what you'd have to go through I guess.

No, I don't know about any of this stuff. She's never talked to me about it. I don't remember if she went over it in the binder with me.

I got a big huge binder but I'm legally blind so it was pretty useless. It was not made available in another format. Given the amount of the budget, you'd think the community liaison should have sat down and gone through the binder with me. It would have been nice if I was a little more prepared. Maybe she figures I didn't need it.

Yes, she told me I can go to the swimming pool or to the beach in the community. I just go to the beach in my chair to go on the sidewalk. I haven't used any other resources.

### **Other Help Provided**

Participants said they were given general support from their community liaison, including talking about how things were going and being available by phone when issues or needs emerged.

She helps a lot by just sitting and talking to me. She doesn't rush through anything.

She's ready to talk on the phone if there is a problem. Good communicator. She deals with the forms. I was really upset that I spent all this time on the order forms and it wasn't good enough [needed changes for the FI]. She was very calm and came over and showed it to me.

Continuing communication with all the agencies and she's just pretty much been a big support in researching needs.

## **Changes to Community Liaison Role and Other Help Needed**

In spite of any concerns they may have raised, seven out of thirteen participants said they wanted no changes to the role of the community liaison. They said their community liaison was responsive and informative, and possessed good communication and management skills. Often participants had one or more complaints about the information or support their community liaison had provided over the last nine months, but in general, they felt their role was appropriate.

Those who said they needed either more training or help with purchasing items so they did not have to wait for reimbursement were looking for more support and/or responsiveness from their community liaison.

[I want my community liaison to] help me find somebody to take me out shopping, out looking. Like a one-on-one person to go bowling with. I don't know what she could do to help me with that.

If I get a new community liaison, I just want them to do what they're trained to do. Be more honest and responsible. Not be so aggressive with their behavior, strong demanding, strong suggestions.

## **E. Supervising and Retaining Workers**

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### **Supervising Workers**

Most said they had no problems supervising their workers.

I didn't have any problems. They knew what their role was. So I made sure what was done.

### **Difficulties Retaining Workers**

The majority of participants ran into some trouble retaining workers over the initial nine months of the Pilot, yet most were able to replace their workers with who they felt were better candidates. Workers were not retained either because

the worker was not suitable for the job and the participant fired them, or because the worker was dissatisfied with some aspect of the job and chose to quit.

Some participants fired workers who were not responsive or reliable, or were not available when needed. Some participants had workers who were dissatisfied with their rate of pay or were not being paid on time. Some workers were not able to keep the job because it did not provide enough hours, or enough reliability in scheduling. There seems to be some difficulty in hiring and retaining quality workers when the work requires very flexible scheduling and is part-time. Being able to pay workers a good rate was stressed by a few participants as essential to finding quality workers.

I tried to have a semi-schedule, but I don't need errands every week and my family is not always home for me to go visit with them. And it's hard because [my workers] do not sit around and wait for me to need to go somewhere.

Some get tired of waiting to get paid. They usually waited a month, sometimes longer. It's ridiculous. Ideally it'd be twice a month or sooner...[Elder Services] said they could pay up to \$20 an hour. \$23 for an agency. So, I would pay \$17 or \$20 for both transportation and cleaning. I was paying them \$17 an hour for awhile and then my community liaison said they cut it back to \$15 an hour. So they quit. I didn't blame them. I would quit too...They didn't explain why. They just said it had to be done.<sup>6</sup>

A few participants had no problem retaining workers. Although this sample is small and it is difficult to draw strong correlations, there seems to be less turnover when the workers are family members or friends.

### **Changes to Day or Time of Support from Workers**

Because most participants are hiring workers for needs as they arise throughout the week (e.g. transportation, shopping trips), having a worker who is flexible about scheduling is key. Also, participants need to be flexible, because most only employ workers on a very part-time basis so the workers have to balance other jobs and their own family responsibilities. It was hard for participants to find the right fit, so for some it took one or two tries before they found an appropriate worker. Eventually, most are able to find workers who were flexible yet responsive.

Yes, I just call them and say I had a cancellation of the appointment and they'll pick me up. With my housekeeper, if I have to go somewhere, she just comes anyway because I trust her.

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<sup>6</sup> It is not clear how this experience occurred, since it is not consistent with policy about consumer direction in worker pay rates.

They would make their own schedule. They'd tell me if they needed another day, and I'd tell them it was fine. It was fine with me. If it could fit into my schedule, it was fine. As long as it's within reasonable hours. But, if it was a PCA, it would have to be later. I wouldn't care about when.

Oh yeah, definitely. They have to be very flexible because I have appointments. I have to see my doctor in Boston. They have to be flexible.

### **Knowing How to Make Changes to Worker Support and Making Needed Changes**

About half of participants said they would first tell their community liaison they needed a change in the type of support. A couple participants said they would make a change in their spending plan to allow for the needed changes. A couple others said they would fire the worker and/or call the support broker agency before discussing the needed changes with their community liaison. Others commented:

I would talk to my liaison. She would help me.

I put it on the thing for the spending plan and see if they'll accept the change. And we fax it off to [Elder Services]. I tell my community liaison I need a change. She says come into the office, so I do. We write it up and send it off.

Yes, I called the agency and I told them. And then they made the changes.

I would fire them.

### **Choosing Workers**

All participants said they were able to choose who their workers would be. One participant in the Southeast region said the first support broker agency sent her workers she did not like, but Options gave her two choices and one worked out very well. Having multiple choices is necessary for consumer direction.

I have a choice if I wanted them or not. They were sent to me. Then I decided whether to keep them. I had choices.

Yes, I met each one. I knew them actually from other places. I knew their parents and that their daughter was working in a nursing

home. The other was a friend and I knew she took care of someone who was elderly.

Yes, because I could afford to pay them. I know what I needed and expected and through this program I could set up the hours and times. I could coax them to come work for me. It's hard to get good help. I'm fortunate because I knew I was really sick, needed help bathing, and the people I have working for me would do it and be good at it.

### **Workers' Rates of Pay**

A few participants mentioned how important adequate rates of pay were for finding and retaining quality workers. A couple participants noted some disagreements between their support broker agency and themselves about appropriate rates of pay, and this troubled them because they felt they could not retain quality workers without the rate of pay they requested.

I can work with my needs through Real Choice if my needs increase or decrease, with these same workers. You can't get good quality workers if you can't pay them a competitive fee, and for someone to come into my house and take care of me I would like to know they not only know what to do ... When you go through the Center for Independent Living and you can only pay \$10 an hour, or only \$7.50, you're getting the bottom of the barrel.

It should be noted that a policy was not set by CHPR regarding a ceiling to workers' rates of pay. It seems from participant comments that a few people were told by their community liaison that workers' rates of pay should not exceed a certain amount, so there may have been an informal policy or preference at the support broker level that was communicated to participants. It may also be that community liaisons were trying help participants balance workers' rates of pay with other needed items in their budgets.

## **III. Participant Outcomes at Nine Months**

### **A. Independence**

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Participants were asked about their independence, including what independence feels like, how Real Choice has helped them have more independence, if it has changed their activities inside and outside the home, and what they need in place to have independence. These findings are consistent with participant comments at two months, which also showed that participants experienced an increase in their independence as a result of the supports and services they were able to purchase through Real Choice.

## What Independence Feels Like

About half of the participants described independence as the ability to do things for themselves and/or being able to do what they wanted without being dependent on others.

It means not having to depend on anyone for anything.

[Independence means] being able to do things that I want to do on my own.

It means not having to rely upon and depend upon people to do every little thing for me.

Sometimes [my workers who are family members] will say we'll cook for you, but I say no, I want to do it. To be independent. They won't let me do a lot like picking up things around the house. I do my own sponge baths, make my bed by myself.

Some of the participants described independence as being able to make decisions for themselves.

It means to make my own decisions to do for myself, to not depend on others, even for personal things like cooking. I used to be a cook so I'm able to cook. I'm used to doing things I depended on others to do due to laziness.

I manage my own affairs. I take a lot of pride in my independence, particularly because a lot has been taken away by the disease.

Survival. Well, like I say, in the nursing home they tried to make me bed-ridden. They had very negative decision making about my life.

A few participants described independence as something that was essential and fundamental to living life.

It means everything. If you're not...not to be independent is not very good. There is no chance for growth. I don't know. It's just awful.

It means a lot. I don't know how to explain it but it means a lot. That's one part of my illness that I resent because I lost that.

I mean, being able to live life like a normal person. I don't think there's a big difference between you and me. Like the difference is you with a car and you without a car.

A couple of participants said that independence meant having an independent living situation.

It means living on your own. Own apartment. Shopping, laundry, cooking.

To live independent for me and the way I live now, I just have my friend and my grandson comes sometimes, but that is independent for me because I'm not living with more family.

### **Real Choice Helped Increase Independence**

All but one of the participants felt that the Real Choice Pilot was helping them to become more independent. There were a variety of ways participants said Real Choice was increasing their independence, including: transportation, access to activities in the community such as shopping, and hiring workers to help with daily activities.

Below are representative responses from participants who said Real Choice had helped them increase their independence.

Yes, he takes me shopping. I would have to take a bus. Takes me to my friend's house, drops me off and comes back to pick me up. Takes me to the mall and drops me off, or often stays with me because I can't see the prices. He's wonderful.

Of course. In every way. Before I got [my worker] I couldn't get anything accomplished. The post office doesn't have a ramp. I don't know [location and worker's name deleted] cabs cost \$25-30 a ride. I have \$100 in my budget for transportation in case of emergencies.

I think it has. Just knowing that if I want to go do something, I don't have to depend on mom. Call the cab. Call the bus. I'm out of here.

Yes, yeah, with being able to hire people to help with daily living type things and to do other things I'm not able to do on my own.

The workers and the people who help me alleviate a lot of stress for me, which allows me to concentrate on the things I think are important. Before [my illness] I could pay my bills or do laundry all on my own, but now that I can't, I need to depend on people that I can trust. I can send [my worker] out grocery shopping and give her a list of things.

## Activities Inside Home

All participants who felt that they needed help to do the things they wanted to do inside of the home said that they were getting as much help as they needed. Over half of the participants described how their workers helped them inside the home. The most common assistance mentioned was help with housekeeping/cleaning and cooking.

Yes, my housekeeper does things I can't see to do. I do my best but I miss things.

It's helped a lot because [the housework], it's not killing you. You're not pulling your hair out because you know someone's coming to help you. In case something worse happens, it's all in place. It can happen at any hour. You're not thinking, "Well, what would I do?" Like with my knees. With my knees, they pop out anytime and you can't do nothing so it's nice to know someone will come up and fix something for you or clean for you.

Now I do since I have [my worker]. I could move furniture. It was difficult. [My worker] helped me repot my plant. I had a housekeeper for two hours but I said I didn't need this. I like doing things myself. It makes me stronger.

Yes. Light housekeeping, cooking, shopping, medication management. Laundry.

A few participants said they really like having someone to help with tasks inside the home as needed, but they also felt the desire to do some housekeeping themselves because it fostered their sense of independence. As people's health or sense of independence improves, they might need to renegotiate how much support they want from their workers.

## Activities Outside Home

Most participants felt that the supports and services they had purchased through Real Choice had improved their ability to participate in activities outside of the home. Many participants had help with transportation which enabled them to get out the house and participate in activities such as shopping, going to the mall, spending time with family and friends, recreational and outdoor activities, and community activities.

Yes, the movies. I went to the malls. The [location deleted], I've been to the [location deleted] to go shopping and to get into the community. It's not a big deal, but it is to get out and about. It's an enrichment to your life. They've done that for me. Real Choice.

Yeah, glass blowing class, pottery, jewelry. Going to [a Clubhouse]. Volunteering too. I have a life. I can go grocery shopping without asking anybody. It's just a big turnaround. With the mental illness, like maybe it's a nice day out and to have someone to come and say maybe you should go outside.

Well, yeah, because of transportation. I have a worker that takes me to my sister's house and to go grocery shopping and to go to the mall.

Some participants also mentioned that money from the Pilot had allowed them to participate in activities outside the home by being able to pay for activities or purchase equipment that increased their mobility.

Yes, by going bowling, skating. Stuff like that. I've done that because of Real Choice. With my daughter. They paid for transportation, a cab. They sent me a check. So me and my daughter could go out.

Yeah, like I could take off with the scooter if there's no snow on the road. I've gone up the road. Now I can go out and get a book to read. I read a lot now. I can read again [because of getting new glasses].

Yes, go outside in my chair, and go to the neighbor's. I have a friend I visit. I can't complain.

Yes, I've been able to go to parks, visit with family and friends, get to medical appointments without the need of an ambulance.

A couple of people were still not participating in activities outside of the home, but it seemed to be a personal preference rather than a lack of supports.

I don't have that many activities outside home except for shopping, errands, and going to the doctors or to a pharmacy. I mean obviously, if I have to go to the pharmacy, they drop me right off at the pharmacy.

Right now I'm really not doing anything. Still volunteering three days a week.

### **Things You Need in Place for Independence**

Participants were asked what things they needed in place to have independence. The two most common responses were transportation and access to appropriate supports, including workers and equipment.

### *Transportation*

The driver. That's the most important thing. I couldn't go anywhere without him.

Well, I think the transportation, most definitely.

... a car to drive so you can go places.

Transportation is the biggest thing, to have independence to get places. That's a very important thing.

... transportation.

### *Appropriate Supports*

Workers and equipment were also identified as necessary for independence.

The walker, the wheelchair, the lift that's in, that's probably not working [at the moment].

[I] have been able to get out of the home more this year than the prior three years. [I] was homebound. That's because of the medical supplies we purchased.

One of the first things is that what needs I do have are being met, like the shopping that I need done, picking up the prescriptions and organizing them for me. The needs I do have are being addressed and taken care of. That my bills all get paid for me on time. It alleviates a lot. The workers and the people who help me alleviate a lot of stress for me, which allows me to concentrate on the things I think are important.

A few other participants mentioned internal qualities and changes needed to become more independent.

To choose what I'd like to do in life and partake in.

The opportunity to do it. The chance to do for myself. The desire. The initiative to help myself and those around me. By doing that I have self worth.

The transition psychologically has not been easy. For instance, I hadn't prepared my own meals for two years. How much work could I do? I am so much stronger since I've been out of the

nursing home. I'm doing everything I need to survive. Emotionally, I feel much better.

## B. Quality of Life

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### Participants' Self-Reported Quality of Life: Before Real Choice and at nine-months

As was the case during the two-month interview, participants were asked during the nine-month interview to rate their quality of life: 1) just before they entered the Real Choice Pilot (retrospectively), and 2) at the time of the interview (approximately nine months into the Pilot). Respondents were asked to rate their quality of life on a seven (7) point scale, ranging from Terrible to Delighted.

1-Terrible	2- Unhappy	3- Mostly Dissatisfied	4- Mixed	5- Mostly Satisfied	6- Pleased	7-Delighted
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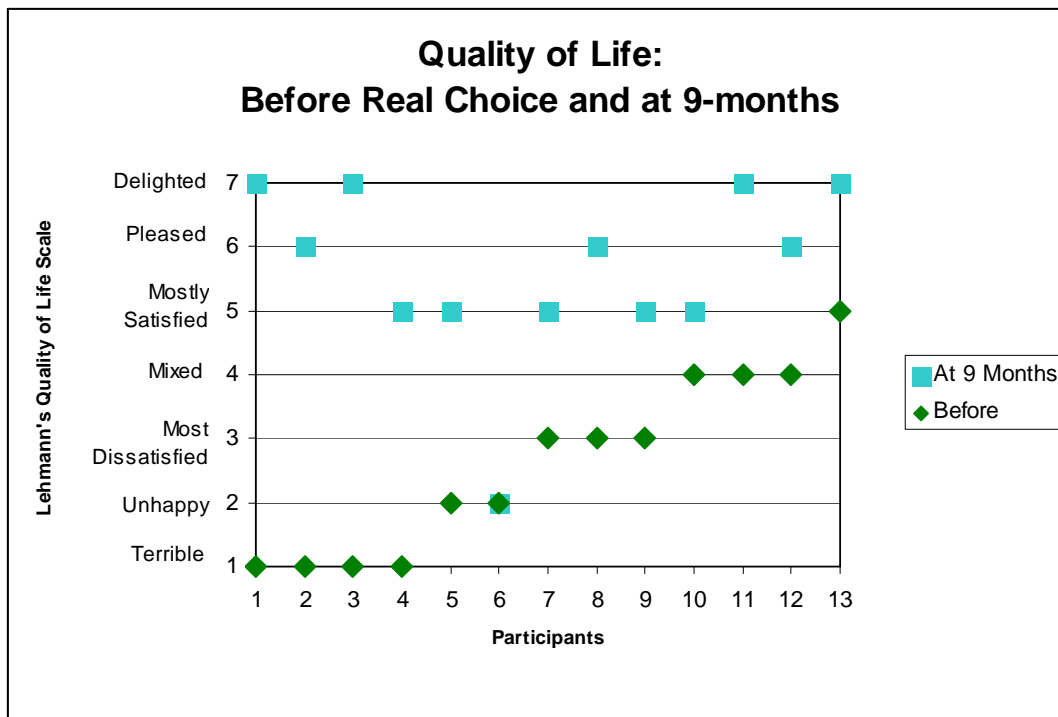
The average Quality of Life rating before participants started the Pilot was 2.6 (median= 3; standard deviation=1.4), which is between Unhappy and Mostly Dissatisfied. The average Quality of Life rating after approximately nine months of Real Choice was 5.5 (median=6, standard deviation=1.4), which is between Mostly Satisfied and Pleased.

As the chart below illustrates, when asked at nine months to rate their quality of life before Real Choice and at nine months, most participants reported an improvement in their quality of life.

**Table 2: Participant Self-Report Quality of Life (both measured at nine months)<sup>7</sup>**

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<sup>7</sup> Measurement of quality of life before Real Choice was done retrospectively. Participants were asked to think back to before they started the program and rate their quality of life at that time.



Overall, participants reported significant increases in their perceived quality of life with Real Choice.

Note that one participant did not see any improvement in his quality at the time of the nine-month interview which he attributed to returning to the nursing home a couple months before the nine-month interview. He did report an increase in quality of life at the time of the two-month interview, so his quality of life did go up with Real Choice initially and then down once he had a setback in his health. He did expect his quality of life to go back up after leaving the nursing home.

For more analyses of the nine-month Quality of Life ratings compared to the two-month ratings, see Appendix A.

**Comments on Quality of Life before Real Choice**

Participants who reported a low quality of life before they started the Pilot said that they were not getting out of their home and that they did not have the desired control over their lives. Some others also noted that they had unsatisfactory living situations and that they had lacked access to needed supports and equipment before Real Choice.

Below are participants' descriptions of their quality of life before Real Choice:

Mostly dissatisfied. I lived in Brockton a couple of years ago, so I had lots of public transportation. [Where I live now] the cabs don't come

here until I'm going to Brockton. It costs too much for gas money. So, I was stranded here until Real Choice.

Terrible because I couldn't go anywhere because I had no wheelchair. ... I moved a year ago, before Real Choice. I was on the third floor and couldn't get outside.

Unhappy. I had no motivation. Nothing to look forward to. No means to even do all the things, three quarters of the things I do now. I was fine staying in the house so it changed a lot. Overall it has changed. Mentally and physically. You get out more. You become more active. You socialize. I volunteer a lot now at [Name deleted] Clubhouse. That kind of thing. It stops you from getting sick [depressed]. When you're stressed, you get sick.

Unhappy. Because I wasn't accomplishing anything. I was vegetating, in a rut. Dissatisfied routine, wasn't nothing different. Go to bed. Get up. Eat. Smoke. Watch TV. Eat. Smoke. Nothing Constructive.

Mixed. I wasn't chewing well, seeing well and I didn't know where that would come from.

### Comments on Quality of Life at Nine Months

At nine months, only one participant did not see an improvement in her quality of life. Yet, even she was hopeful this would change once she moved from a congregate living situation she was currently in to her own apartment with the Pilot's help. The comments below describe participants' quality of life at nine months:

Delighted. Because I have my independence. Yeah, because I have Real Choice in my life now.

Mostly Satisfied. Because Real Choice has opened up more avenues and opportunities for me. It's really change my life, my way of life.

Pleased, because I can do more now that I could before. Like if I want to go out just because I want to go out, I can go out.

Delighted...This is how life should have been 10 years ago.

### Improvements in Quality of Life

Again, almost all participants felt that Real Choice had helped to improve their quality of life. Participants most commonly cited increased freedom and

independence as the reasons for improved quality of life. Also cited was how the Pilot enabled participants to access desired and needed supports and services. Some felt an increase in their support from and connection to the community. Also mentioned was improved mental health.

They gave me a driver. I'm independent. I can come and go as I please. I've got the computer and I can go online, shop online, chat with people online. It's opened my world to know other people.

Yes. In every way. I never had nothing until I got into Real Choice. I never had anything. I only had one pair of pants and two socks, no food. I went to a shelter to eat. I went to skid row with drug addicts. I was miserable. Real Choice gave me purpose. An ability to help myself by giving me choices. I was able to see both sides of the coin.

Yes. Very much so. It made me feel that I'm a completed person. Even though I'm disabled or handicapped, people aren't looking down at you. You feel more like a completed person when they're in your life.

Just put 'everything'. I get more exercise. I'm in touch with much better people. I get sleep, minor things. My own food, I'm very picky. Sunshine. Going out. I'm in charge of my own life. Just everything.

Yeah, it increased my independence. That was a very major thing for me. I cherish my independence and as I gradually improved my needs decreased and I was able to do more things. Before I couldn't take a shower by myself. Now I couldn't imagine having someone in the shower now. Being able to go out on my own. Being able to seek out different things, my own interests my own. There's a lot of things, a lot of things. Opened up my world. When you're in a situation like mine when you have a disability, when you are able to take care of yourself all by yourself, go out by out all by yourself, that's a miracle and that's because of Real Choice.

Yes, just having more options because when I moved out of my family's house, before Real Choice, I was told if I needed any help it would be from PCA's. And since I don't qualify for PCA's, there is another option there for me. I get more help with household stuff so it makes it less stressful for me. Just not as stressed.

Yes, my mental health has improved. I don't feel like a caged bird. There were things out there but I could never get out there to experience or attain them.

## Improvements in Health

One thing that seems to be driving improvements in participants' quality of life is improvement in health. On an anecdotal level, a few participants seem to have and reported having improved overall health since the two-month interviews. Although our interview guide does not measure improvements in health in a quantitative way, some reported feeling better overall.

## IV. General Experience of Pilot at Nine Months

### A. Overall Impressions

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#### Meeting Expectations

Most participants said the Pilot was meeting their expectations.

Yes, it turned out better than I thought it would. Now I can see and chew. I really had none [no expectations]. I was a very leery person until I learned. Always leery with a government program. How many times has the government screwed up? The government giving you something for nothing, there had to be a catch somewhere.

Yes, it is very much so. Well, like I said. a better life. A better home environment, cleaner. It's been just like I expected to get out more and be more independent. To have the transportation, to get out. What I've expected, the program has given it.

About one hundred times greater than my expectations. Someone is actually doing something that makes me feel good. It's too good to be true.

Yes, because when the people have Parkinson's they shake and the food was always dropping down. I have my table now so I can eat without food falling on my and I have a walker too, when I'm tired of the wheelchair, I try to walk.

#### What Participants Like Most about Real Choice

Participants were asked to describe what they liked most about the Real Choice Pilot.

##### *Freedom, Independence and Control*

Several participants said they liked most that Real Choice provided them with greater freedom, independence, and control.

The independence, opportunity. It gives you something to look forward to day to day. You're able to experience and do things you'd never be able to do before. If you're fighting depression or ailments or anything.

Just being able to do things that I want to do.

That they're giving ill people and elderly people more independence.

That I'm able to have the people that I want to work for me, to work for me. That I'm able to pursue my own interests through the facilitation of this program. That I can set goals for myself. Those things I can reach for like education and employment. Because if it's possible, I'd like to go back to work.

### *Support from Pilot Staff*

A few participants said what they liked best about the Pilot was the support of staff and the help they received from their community liaison, including help with their spending plan.

They're helping me. They make me understand what it is.

In other words, if you need something they're there for you.

They treat me very good.

### *Everything*

A few participants said that they liked everything about the Pilot.

Everything. Everything. I can't pinpoint one thing. It's everything.

Everything. In other words, if you need something they're there for you. It helped me to be a better person; you feel better as a person, not sick and down and out since Real Choice has been in my life.

### *Access to Care, Supports and Equipment to Meet Needs*

A few participants said that they liked that Pilot allowed them to meet their needs by providing access to care, supports and equipment.

That they sent a check for me to go to the dentist.

It's a program that really seems to be helping people because without it we wouldn't be getting glasses we needed or something like that.

Having options, just like the availability of people and supports to help me with normal stuff I would need help with.

The flexibility and the community liaison to come up with a plan for [me].

### **First Thing You Would Change**

#### *Nothing to Change*

Several participants said there was nothing they would change about Real Choice.

Nothing. Nope. Nope.

I wouldn't 'cause it's a good program.

Nothing to change.

#### *Difficulty with Reimbursement and Spending*

At least two participants mentioned having difficulty paying out of pocket for ongoing expenses and then having to wait for reimbursement. Their limited incomes made paying out of pocket difficult, if not impossible. Others found working with the fiscal intermediary to get items purchased quickly was difficult for them. Several said there was not a quick and efficient system for purchasing set up that they were aware of. The Pilot needs to find ways to pay for items up front, without taking the purchasing power out of participants' hands.

Well if I was in charge, I would make it so the out of pocket isn't paid. A gift card or account. Break it down once a month so you don't have to spend because clients don't have money to pay and wait. That's the main thing. You want to go to the store but you just paid rent and you can even go get a can of shaving cream. The things you need for your essential needs to survive with.

The budget—being able to have a prepayment to spend so you don't have to wait for reimbursement.

One thing I can tell you absolutely I would change is working with my fiscal intermediary. There needs to be specific contracts with stores where clients, consumers, can purchase items where there's a specific contract with the Real Choice program with these stores so you don't have to go through so much run around. ... It would facilitate the purchasing. That's been one of the toughest things. ... Somebody needs to take a lead on this. [The person who manages the paperwork at the fiscal intermediary] is very, very organized about what she does.

#### *Information*

A couple of participants wanted more information about the Pilot and/or more guidance with a specific aspect of the Pilot.

Information access. When you're introduced to it, you need to be informed more, what it is, what's going to happen. What you can do and can't do. Just those kinds of things. ... And to have things more thought out about monies and how things are going to be purchased instead of telling people how or them telling you to go out and find a way yourself. I haven't found a way and neither has [my community liaison].

Except this paperwork [about taxes and workmen's compensation for hired workers]. Knowing what to do with these papers would be a big help.

### Anything Else

A few participants added that the Pilot has been very beneficial for them, in particular the assistance of Pilot staff.

Just that my community liaison, she is absolutely wonderful. I would scream if they got rid of her. I can call her anytime. The last [community liaison] I couldn't get in touch with even if I needed to.

My life is a complete turnaround. Between Elder Services and my community liaison -- they've all made a difference in my life.

Elder Service's understanding of people with a higher level of need. Medical needs. [...] Whoever designed it to be flexible, it's working great. It's the best program I've been apart of. And I've been through DMR for a long time. When you get a medical diagnosis and look at individual need. [...] I think Elder Services should work with DMR [to teach them about individual needs].

A couple participants concluded with negative comments. In both cases, the participant felt that their relationship and communication with the fiscal intermediary could be improved.

Oh, I think we should be able to be in touch with the fiscal intermediary and we are told we can't call there which I think is totally ridiculous.<sup>8</sup>

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<sup>8</sup> This is not policy. Participants should be able to communicate directly with the fiscal intermediary.

**5****DISCUSSION**

Based on the findings from personal interviews with all Pilot participants, the Real Choice Self-Directed Supports and Services Pilot helped most participants make meaningful gains in their independence and quality of life. Participants whose spending plans were fully implemented were getting out of the home more often, were getting the help they needed to do daily tasks, and generally felt more content and better connected with their community. Participants who at nine months had not purchased all the items on their spending plan were satisfied with Real Choice overall, but were less satisfied with how efficiently the Pilot was being implemented for them.

CQI made recommendations for the Real Choice Pilot in our two-month report. We noticed some attempts to further solidify aspects of the Pilot based on these recommendations. For instance, in our two-month report we recommended that participants should not have to pay out of pocket for spending plan items. There was a policy change around this aspect of the Pilot, although at nine months a few participants were still struggling with this. Additionally, it is encouraging that some attempts have been made by the fiscal intermediary and other involved parties to problem-solve around the purchasing issues participants faced. There also seemed to be an attempt on the part of community liaisons to clarify what are allowable expenses and to encourage participants to submit for all identified needs if they seemed to fit within the general guidelines.

The biggest changes between two and nine months came for those who got a new community liaison. Our recommendation of giving participants multiple choices for community liaisons seems to have been followed, as participants were given several community liaisons to choose from and were able to interview them as they would any other worker. These new community liaisons seemed to allow for more consumer-direction and to provide better training to participants, most likely because they were better trained before working with participants.

Some issues identified at two months persisted through nine months, including training and education from the community liaisons and troubles with purchasing items. As noted above, some Pilot stakeholders are collaborating to remedy some of these issues. Nonetheless, ongoing attention should be paid to these issues, given that they prevent some participants from fully participating in and benefiting from Real Choice.

Below are our recommendations based on feedback from participants during personal interviews at nine months about their experience in the Real Choice Pilot. We have \* next to recommendations that also appeared in the two month report.

## **Recommendations at Nine Months**

### ***Ensure Consumer-Direction, Satisfaction, and Fulfillment of Needs***

#### **Use Consumer Friendly Language if Encouraging Representatives**

- If having a representative is helpful for success in the Pilot and is recommended by Pilot staff, consider changing the title to something more collaborative such as “Real Choice Support Partner.” For consumers, the term ‘representative’ or ‘legal representative’ connotes a loss of control over decision making which is at odds with the consumer direction goal of this Pilot. Nonetheless, some consumers might benefit from someone other than the community liaison to help them manage paperwork, which is overwhelming to some. Realizing that some consumers are more isolated than others and therefore have fewer natural supports, the Pilot should be sensitive to the fact that not all consumers will know a trustworthy person to take on this role. Others will simply prefer to manage the Pilot on their own.

#### **Periodically Confirm that the Community Liaison Relationship is Working, especially around Mental Health and Cross-Disability Needs**

- The quality of the relationship that develops between the community liaison and the participant can have a big impact on a person’s experience with Real Choice. Although the program is consumer-directed, community liaisons are key providers of information, problem solving, and support.

Many participants have a mental health disability, or underlying mental health issues, in addition to their physical or developmental disability. If the support broker agencies focus on one population, such as elders, or a particular physical disability, support broker staff would likely need additional training in working with people who have serious mental health needs. The two participants who were not able to transition into the community by nine months had significant mental health needs, and it was clear that community liaisons and support broker agencies could have benefited from additional awareness and training to meet their unique needs.

Community liaisons should have strong cross-disability training in order to fully meet the complex needs of participants in the Pilot. In the case of mental illness, which can be cyclical in nature, community liaisons should be trained to identify warning signs of deteriorating mental health so that they can help the participants get additional needed supports to stay in the community. Community liaisons must also be trained to work collaboratively with traditional mental health systems.

**Provide Ongoing Participant and Community Liaison Training\***

At nine months, some participants still reported not feeling fully trained on overseeing a spending plan and hiring workers. Participants in the Southeast who got a new community liaison felt better trained than they were in the beginning of the Pilot, but others felt they could have used some additional training.

Community liaisons should recognize the need for ongoing training, especially since the training protocol seems to have been implemented inconsistently in the beginning and because this is a Pilot program which continues to develop as time goes on. Participants need to be updated of changes and have the opportunity for a refresher training periodically. A few participants indicated an interest in attending a group training on the Real Choice model, rather than relying solely on training from their community liaison.

Also, all training materials should be made available in accessible formats.

**Conduct Case Review Consults as Needed**

- Because CQI, a consumer-directed evaluation organization, has taken on the role of independent evaluator, we had the opportunity to visit with participants in their homes and help ensure the quality of care in this Pilot by assessing the participants' experiences and relaying that information to various stakeholder groups. In some cases, this independent assessment has helped CHPR to intervene if a participant was not getting his or her needs met.

We feel that having an independent party assess consumer satisfaction is particularly necessary for those participants who have not achieved their stated goals and/or report that not all their needs are being met. We suggest case review consults as a possible method of oversight. Because the relationship between the participant and the community liaison is so critical to success and satisfaction, participants should be asked to assess the effectiveness of their community liaison in helping them meet needs. Because of the consumer-directed nature of this Pilot, feedback should be gathered directly from consumers whenever possible.

If participants are not maximizing their potential in the Pilot, it may be due to an ineffective relationship with their community liaison and the Pilot should consider directly asking participants whether they wish to make a change to their community liaison. At nine months, a few participants expressed some dissatisfaction in their relationship with their community liaison, but would not necessarily initiate a change on their own.

**Implement a Process for Communicating Policy Changes**

- If policy changes are implemented, all participants should be informed in a consistent way and in a timely manner. Participants should also be

informed through multiple methods of communication, ideally in writing as well as in person by their community liaison.

### ***Financial Considerations***

#### **Develop a Consistent Policy Regarding Workers' Rates of Pay\***

- Based on participants' experiences, there seems to be some inconsistency with information community liaisons provided to participants regarding workers' rates of pay. This is an important issue to participants because they feel a good rate of pay will secure them competent and reliable workers. As stated in the two-month participant interview report, there needs to be consistency in the guidelines provided to participants about workers' rates of pay. There should be training on the pros and cons of certain rates, and the going rates for different types of care providers. Nonetheless, determining workers' rates of pay should be consumer-directed, and participants' concerns about rates of pay should be acknowledged and problem-solved. If limits or ceilings must be placed on rates of pay, they should be consistent across participants and support broker agencies.

#### **Promote Consumer-Driven Communication with Fiscal Intermediary**

- Managing the budget and purchasing items is the central component of this program. In order to be truly consumer-directed, participants need to be free to contact the fiscal intermediary if they have questions or concerns. Although community liaisons can and should usually be the first point of contact when concerns arise, participants should have the freedom to go to the source of their complaint directly if desired. Participants should drive the communication process.

#### **Develop Procedures to Avoid Paying Out of Pocket\***

- Develop procedures so that participants do not have to pay for spending plan items out of pocket. Most participants are not in a financial position to wait for reimbursement. When consumers have had to pay out of pocket, they either go without needed items or are financially strained by having to wait for payment.

#### **Ensure Consistent Turnaround Time for Payment and Payroll**

- The turnaround time for payment and payroll should be consistent and timely. If there are errors in paperwork that participants submit, the fiscal intermediary should communicate this to the participant and the community liaison as soon as possible. Resolution should occur within a short turnaround period. Participants should not be made to wait and wonder for weeks when they payment they are depending on is coming. Even a one to two week delay in payroll or payment could result in the loss of a worker or a critical need being unmet for a participant.

## **Conclusion**

Most participants continued to have increased independence and quality of life at nine months. Some implementation issues still exist, but most participants experienced improvements in how the Pilot was functioning since two months.

Changing support broker agencies in one region seems to have had a significant impact on participants' satisfaction with the Pilot for those who chose a new community liaison. Having multiple choices allows for more consumer direction. While the majority of participants were doing well, a couple participants were hoping Real Choice would do more to help them live independently in the community. Their needs were complex, so these participants provide an example of how diligently self-directed services and support programs need to be about working closely with and fully preparing the participant in the process to meet their needs.

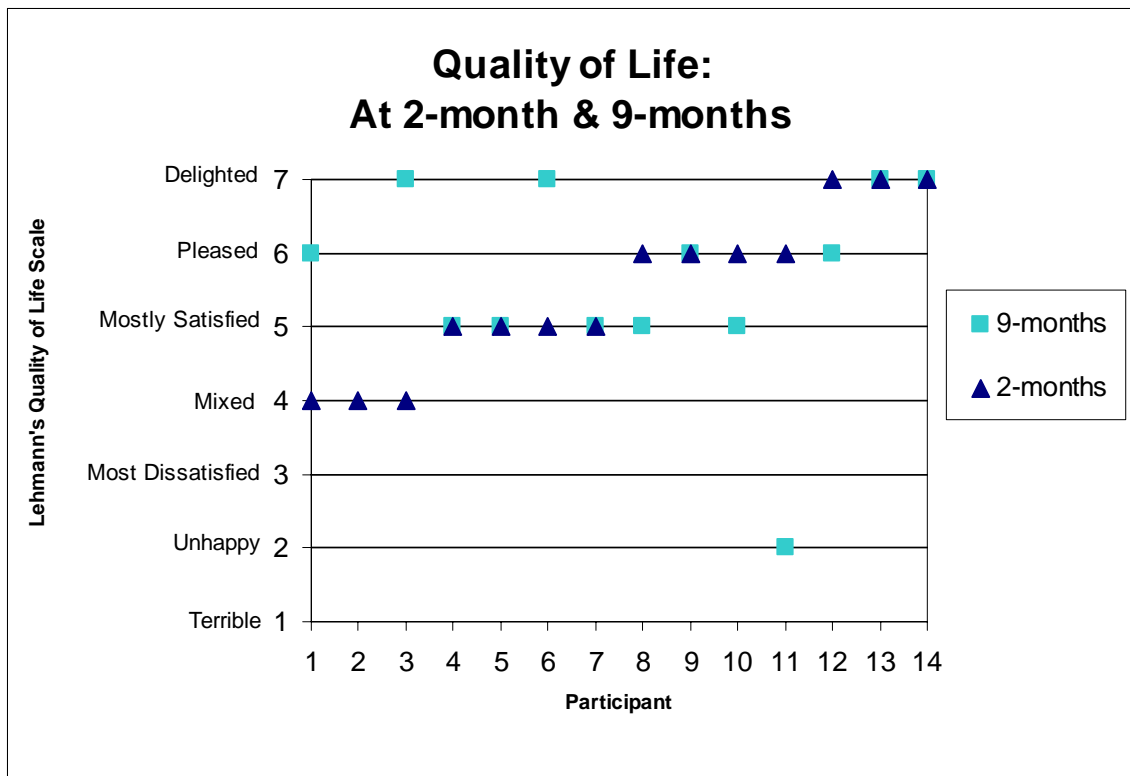
**APPENDIX A**

**Real Choice Personal Interviews: Nine month participant interviews report**

**Participants’ Self-Reported Quality of Life:  
Before Real Choice and at 2-months and Before Real Choice and at 9-  
months**

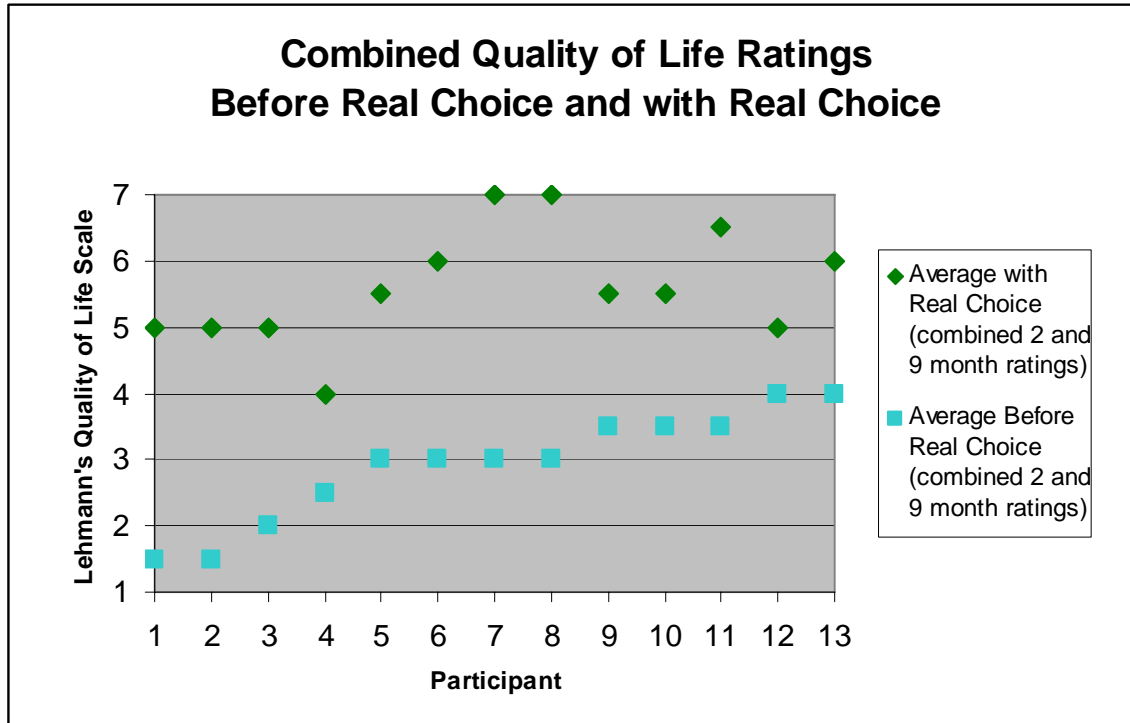
During the 2-month interview, participants were asked to rate their quality of life: 1) just before they entered the Real Choice program (retrospectively), and 2) at the time of the interview (approximately 2-months into the program). Participants were asked to rate their quality of life on a seven (7) point scale, ranging from Terrible to Delighted. This was repeated during the 9-month interviews, so that participants rated their quality of life before Real Choice and at 9-months.

As the chart below illustrates, between 2 months and 9 months, over half of the participants’ ratings of Quality of Life shifted one or two points in either a positive or negative direction. It is necessary to keep in mind that Quality of Life ratings are highly context dependent. That is, a person’s assessment of their quality of life depends greatly on how they feel when they are asked and how they feel about their quality of life in comparison to other periods of their life. Therefore, it is not surprising that participant’s ratings of their quality of life before Real Choice and with Real Choice at 2 and 9 months varied somewhat. Overall though, all but one participant (who was back in a nursing home) reported that their quality of life at 9-months was between Mostly Satisfied and Delighted.



Also, by combining participants' ratings of their quality of life before Real Choice and with Real Choice at 2 and 9 months, we are able to see that almost all participants saw an improvement in their quality of life. Participants felt that Real Choice made a difference in their overall Quality of Life, and in general moved them from dissatisfaction to satisfaction.

**Table 2: Participants Self-Report Quality of Life<sup>9</sup>**



The combined rating of quality of life before Real Choice, which were reported by participants retrospectively at 2 and 9 months, was 3.0 (median= 3.0). Therefore, on average participants rated their quality of life before Real Choice as Mostly Dissatisfied. The average combined rating of quality of life with Real Choice was 5.5 (median=5.5), which is between Mostly Satisfied and Pleased.

Though the “Before Real Choice” quality of life ratings were collected retrospectively, these data show that participants reported *an overall increase in their Quality of Life with Real Choice*.

<sup>9</sup> Measurement of quality of life before Real Choice was done retrospectively. Participants were asked to think back to before they started the program and rate their quality of life at that time.