

Real Choice Personal Interviews

Two month participant interview report

May 2006

Two month interviews conducted between August 2005- January 2006

Prepared for:

**University of Massachusetts Medical School,
Center for Health Policy and Research (UMMS/CHPR)
and the Real Choice Collaborative Team**

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CQI

Consumer Quality Initiatives, Inc.

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

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Project Description

The “Real Choice” self-directed care pilot project is funded by the Centers for Medicare and Medicaid Services (CMS) and coordinated by the University of Massachusetts 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 program.

Methodology

The qualitative interview guide was developed with consumer input. All fourteen (14) participants were interviewed after they had been in the program 2-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

- The participants’ development of their spending plans not only allowed them to address their specific needs, but also gave them much desired control over the employment of workers and their lives in general.
- Most participants greatly appreciated the support they received from their Community Liaison, and they felt much more supported in the community by having someone to whom they could talk on a regular basis.
- Participants who received written information about available community resources from their vendor said that the information was invaluable and that it had never been provided to them before.
- At two months, most participants had made meaningful gains in their independence and quality of life. Participants whose spending plans were fully implemented were getting out of the home more frequently and were getting the help they needed to do daily tasks.

Most Challenging Aspects of Real Choice Pilot

- Some participants felt uncertain about developing a budget, and what items could be requested in the initial budget.
- Some participants struggled with the process for changing/amending their budget.

Recommendations

- Make sure participants have a variety of choices when selecting a community liaison, and opportunities to change their community liaison if needed.
- Make sure the community liaisons are fully trained on the Real Choice model, including: how to support the consumer in a consumer-driven program, how to develop and make changes to the spending plan, how to hire and supervise workers, purchase spending plan items, as well as available community resources. Community liaisons need to provide thorough initial and ongoing training to participants in all aspects of the model.
- Provide comprehensive training materials to participants, in accessible formats when needed.
- Community liaisons should provide extra support and attention to participants who have high needs, such as those transitioning out of a nursing home, or who have barriers, such as limited English skills or those who are particularly low-income and are faced with instability in their housing situation.
- Do not require participants to purchase spending plan items out of pocket.

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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 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 UMASS Medical School Center for Health Policy and Research (UMMS/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 program.

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METHODOLOGY

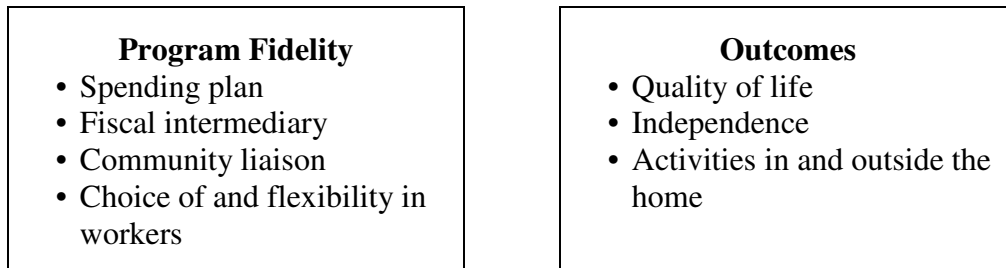
Instrument Development

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, UMMS/CPHR 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, UMMS/CPHR Program 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.



With the draft interview guide in hand, CQI held meetings with four (4) 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 (2-5) people, with a total of twelve (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 program (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.

Interviewing

CQI's consumer and/or family member interviewers conducted face-to-face interviews at each participant's home or in one case a coffee shop. We interviewed all fourteen (14) Real Choice participants between August 2005 and January 2006. The interviews were scheduled to take place after a person had been in the program for two months.¹ Most participants had already developed their spending plan and had purchased some, but not all of the items in their spending plan. At the time of the interview, most participants who set aside money in their spending plan for workers had conducted an initial round of hiring and had workers in place for as little as a couple weeks or as much as a couple of months.

¹ Participants' length of time in the program at the time of the interview varied based on when CQI got contact information for each participant and how soon they were available for an interview. Two participants who were overdue for an interview had been hospitalized. Four other participants' interviews were one or two months late because CQI had difficulty getting contact information from the vendor agency.

Analysis

Interview notes were taken either by the CQI interviewer, or in some cases by another CQI staff member. All the interviews were tape recorded. Except for a couple cases, 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.

Demographics of Participants

We did not collect demographic information on the participants. That information is being collected in other components of the evaluation.

Of note, only one participant had a legal representative, someone who would help the participant make decisions about their care.

| | |
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| 4 | FINDINGS |
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I. Participant Experience of Program Operations at Two Months

A. Initial Experiences

How Participants Found Out about Real Choice

Most participants learned about the Real Choice in Flexible Supports and Services pilot project (“Real Choice”) through a current vendor agency. Others were referred from a social worker at a psychiatrist’s office, a case manager at Department of Mental Retardation (DMR), or via a flyer at a Clubhouse or another agency that serves those with disabilities.

Below are a few comments about what participants were expecting:

More or less it was to help you get integrated more in the community if you lacked things like skills in the home or in your life period. It was going to help you.

They could help in certain areas and affording things, getting out and about, transportation, activities. It would help me be out and about rather than just homebound and sick.

[I found out about Real Choice] through Bridges and one of the former Real Choice employees, who doesn't work for Real Choice anymore. The way it was presented to me was, "We want to find a way that will improve your quality of life, considering what you've been through and the losses at an early age. We see you have a lot of potential and we want to see you make use of it." It was like, "Wow! I still have a lot of potential. There are still a lot of people who think I have potential."

The Assessment Process

Overall people were satisfied with the assessment process. Most did not remember initial meetings with specificity, either because it went smoothly, because it was one of many meetings they had at the time, or because they were dealing with other pressing issues. Below are two comments from participants about the assessment process:

In the assessment they asked a lot of questions, health questions. They were very nice. We talked about what would give me a little more independence. I had no difficulties with the assessment.

[They asked about] things that I wanted to do. We talked about that. Things that I want to do that I don't do. [It was] alright. No concerns. The questions were alright because they were asking questions about things that I don't do that I want to do.

B. Spending Plan

Respondents were asked about how their spending plan was developed and their total budgeted allotment. We also asked if they wanted changes made to their spending plan, whether and how the changes were made, and their control over the spending plan.

Money Allotted

Of those who knew the amount of their total budget for the year, about a third of participants said they were allotted between \$6000-7000. Slightly more than a third were allotted between \$11,000-17,000. Slightly less than a third were allotted either \$21,000 or \$35,000. Some participants were unsure how much they had been allocated. Those allotted the most money in their budget were making a transition out of a nursing home or needed more support in the home, and therefore needed more money the first year to establish independent living.

Developing a Spending Plan

Community liaisons (CLs) were instrumental in working with participants to develop their spending plans. In regards to developing the spending plan, CLs helped by:

- ☞ Coming to the participant's home to go over the spending plan;
- ☞ Being available by telephone for questions;
- ☞ Writing down participants' ideas and completing necessary paperwork;
- ☞ Helping the participants determine how much to budget for items in their spending plan;
- ☞ Help with making amendments and changes to the spending plans;
- ☞ Gathering further information for participants; and
- ☞ Being a liaison between Real Choice/UMASS staff, vendor agencies, the fiscal intermediary, and other relevant agencies or suppliers.

A couple comments from participants about working with their CL to develop their spending plan are below:

My community liaison has been very helpful. He comes twice a week. He takes time to explain things. What's allowed. Not allowed. He does a lot of the leg work. Amending the spending plan. He's good enough to do that.

Yes, [my CL] asked me what kinds of things I would want or need. She wrote down things that weren't covered by anything else. We fit in what we could. If I changed it, we rewrote it and submitted it.

There were a few instances of dissatisfaction with the process of developing the spending plan. In one case, the participant felt the process was taking too long, particularly the approval of specific items. Another was dissatisfied with how much money was allocated to pay for his worker.

Participants' experiences of how they determined their worker's rates of pay differed. Some were given a list of commonplace rates of pay for different types of workers and they used this list to determine their workers' rates of pay. Others said they were given no guidelines and had to guess at how much to pay their workers.

While the process was fairly smooth, some felt they had to do a lot of guessing to develop their spending plan. It was clear that several participants could have benefited from more in-depth training and guidance from their CL during the beginning of the program.

We really didn't know. It was guessing. So she just asked me what things I was looking for and I told her; what did I want to do and I told her. We didn't

know if it was going to be approved or not, or what to ask for. It was really a guess.

Detailed information about what was eligible for inclusion in a spending plan helped to minimize the guesswork and insecurity about what to ask for. One person noted:

[My CL] assigned dollar amounts, but we had a guide book to go through of agencies.

Changes to the Spending Plan

Roughly one-half of participants wanted changes to spending plans that had been developed and approved. Reasons included:

- A new need emerged after the initial budget was developed and approved;
- A line item was not utilized, so the participant wished to shift that money to other needed items;
- Participants had gotten a better sense of what items would be approved, or learned of an item that was eligible (i.e. an air conditioner) but had not considered putting in their original spending plan.

Some participants had already submitted amendments to their spending plan, but others were thinking about changes they wanted but had not pursued the amendments yet. This was usually because they just got their initial spending plan approved and in place, and had not yet had the time to go through the amendment process.

For those who did submit amendments, changes were generally made with the assistance of their CL who submitted the changes for approval.

I wanted to substitute some things. I talked to [my CL], submitted to [my CL], she turned it in to [the vendor agency]. I wanted to spend it on [a couple small items]. I asked for reimbursement. What I was asking for is, I was not using all the transportation funds that they gave me for the month, so if I'm not meeting what they gave me, I wanted to substitute that for other things that would be useful to me. I talked to [my CL] about that. She put in paper work into [the vendor agency] and they rejected it because it wasn't in my spending plan.

Feeling in Charge of Spending Plan

Almost all of the participants felt that they were mostly, but not entirely, in charge of their spending plan. Some seemed to prefer not being completely in charge, and wanted to share the decision making with their CL. As one person noted: "I don't consider it being in charge. I consider it working together."

Only one person said he did not feel in charge at all. This person was dissatisfied with the dollar amounts that ended up in the final budget. He wanted to pay his worker a higher wage than what was approved by his CL. In retrospect, he said would have forgone other items in his budget, such as a hospital bed, to pay his worker a higher wage since she was so valuable to him and was considering leaving for a higher paying position.²

Challenges with the Spending Plan

Developing and managing the spending plan was one of the most challenging aspects of the Real Choice Pilot for participants. The major issues with developing and implementing a spending plan included:

- Participants' and CLs' uncertainty about developing a budget, including the items that could be requested;
- Participants' and CLs' uncertainty about the process for changing or amending the budget;
- Some CL's did not provide sufficient training for consumers regarding the spending plan, particularly as the program started;
- Some participants experienced challenges with finances, including difficulty waiting for reimbursements when individuals had to pay out of pocket for items, coordinating paperwork with the FI for payment to workers, and feeling worried about not having extra money set aside for emergencies.³

C. Community Liaison

Community liaisons (CLs) are critical to a participant's success in the Real Choice program. They train the participant on the Real Choice model, help them develop and implement their spending plan, and continue to be a resource to the participant for information, problem-solving, and help with making choices.

To better understand each participant's experience with their community liaison, participants' were asked about:

- How they selected their CL;
- The role of their CL;
- The support offered by the CL to oversee workers and the spending plan;
- The training and education provided by the CL;
- Information given to the participant about community resources

² Participants should be able to determine rates of pay for their workers, but also must balance those costs with other items they need to maintain independence in the community. This participant had a high level of need and had one of the highest budget totals. His spending plan included other needed items related to maintaining his independence in the community.

³ There is emergency money set aside at the program level, but not in consumer budgets. Participants were likely worried because they were not aware that emergency funds were available if needed. Those who mentioned emergency funds said they wanted a line item in their individual budget for emergencies.

- Any other help provided, and
- Any other help the participant needed and/or changes to the CL.

Community Liaison Selection

A few participants chose a family member or a friend as their community liaison. But most participants chose someone who worked for one of the vendor agencies as their CL. A few participants had a prior relationship with someone from the vendor agency, and chose that person. In other cases, they were given a choice of a couple vendor agency staff members. Ultimately, participants did control this decision, although in some cases they were presented with only one or two possible people to choose from if they did not have any other individuals in mind.

Some of the CLs had a disability. Participants said they appreciated having a CL they could relate to because they felt the person better understood their struggles. At the same time, some participants were concerned that their CL had a lot to handle and hoped the person was given enough support themselves. This concern for their CL seemed to equalize the relationship and create a sense of shared empathy. It was also a source of encouragement and inspiration.

She has a vested interest in working at the [vendor] agency. She drives. She's kept her job for 6 years. She's really quite remarkable.

[He] is blind. He goes everywhere. He takes the bus, but the bus doesn't take him everywhere. I feel better about the program because of [him] and his challenges. He helps a lot of people but he doesn't have a lot of help himself. He has to go to 4-5 houses a day to interpret. He deserves more help for his condition.

Role of CL

Community liaisons had multiple components to their role and were cited as doing the following:

- ☞ Visiting participants to talk and go over Real Choice information;
- ☞ Explaining the program and other information;
- ☞ Communicating with Real Choice or vendor agencies when questions or issues arose;
- ☞ Talking and support for life in general;
- ☞ Handling the budget; and
- ☞ Support for problem solving and decision making.

It seemed that participants were particularly satisfied with their CL when they had developed a personal bond with him/her, or when they felt that their CL went above

and beyond the call of duty.⁴ Even when participants could not fully articulate the CL role, they still were able to explain how the CL had helped them.

She's bent over backwards. Sometimes she'll just call to see how I'm feeling. When she's around, I feel good. She doesn't mind sitting here. It takes 10-15 minutes to do the monthly [report], but she stayed and shot the breeze for another 15 minutes. She's a credit. If they get more community liaisons like her, they'll be all set.

To help me to communicate to get help. When I don't understand, I ask for his advice. He's very helpful and takes a lot of time with me.

As a community liaison, with me it's been just coordinating the program. I tell her of things that are going on. So she's an information collector. She brought me shopping with [my personal assistant]. She's a social coordinator. We're going into Boston to meet with representatives. She gives me information and takes information. When I have questions, I leave messages for her and she gets back to me.

She helps me with my spending plan and budget and figuring out what can fit in. I don't know budgeting. I haven't had this problem but she would help support me if any issues came up with the workers. She would not talk to them but talk to me about how to talk to them.

A few participants felt like they had not gotten enough help from their CL. A couple participants said they did not want to say anything bad about their CL, and did not want to address a specific complaint. Although some participants did not want to blame their CL, the CL seemed to be the source of some of their dissatisfaction because they did not feel they were getting the information or items they needed.

She hasn't helped me out. I think she has been having family problems with the hurricane. I haven't had much contact with her. She helped me put together the budget.

What she's supposed to be doing is to give me the paperwork so I can pay the workers. Nothing else I've seen. It would be nice. It would be nice if I felt that the people who are involved in this project care a little bit about the people who are in this.

Some met with their CL often, as much as weekly or bi-weekly. Others met with their CL once a month, or only when needed.

She meets with me weekly, which I know is fortunate. I know she doesn't need to be here but to do her monthly visit.

⁴ In a couple cases, the participants were unhappy about program in general, but were satisfied with their community liaison.

Level of Support

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

| | Percentage | N |
|-------------------------|-------------------|----------|
| More help than you need | 21% | 3 |
| Just enough help | 57% | 8 |
| Not enough help | 21% | 3 |

Respondents who said they got ‘more help than needed’ saw that as a positive—that their CL was going above and beyond for them. Comments indicated that participants felt their CL supported them by being available and accessible, by spending time with them, by listening, and by providing them with needed information.

Providing just enough help. By coming every week, once a week. Making sure things are going all right here. I tell her what’s going on.

Providing just enough help, and more, extra. She provides a lot of help by talking. Sometimes I just talk and talk. If I called her now she’d check her book and come if she could. A couple of times, she came right here from her job.

If I need something he’s right there. If I call him to ask him a question of Stavros [fiscal intermediary], he’s there.

Support to Oversee Workers and Spending Plan

Participants were asked, “Has the community liaison provided you with the personal support to employ workers and oversee a spending plan?” There were mixed responses as to whether CLs were providing the personal support needed to hire workers and oversee a spending plan. Most participants said “yes,” they were receiving support. Others said “no,” but then explained how the CL had helped.

There seemed to be varying levels of involvement by the CL, from doing most of the leg work for the participants to having the participant do most of the work. Some CLs were more involved than others. It is unclear from the data why some CL’s were more involved than others. Some participants were confident in their ability to hire their own workers and were quickly able to hire workers with just some initial guidance or advice from their CL. Therefore the CL’s role in overseeing workers was limited to periodic check-ins and advice. A few others either needed or wanted their CL to deal with the paperwork, which was a barrier to them, or needed more hands on

help finding workers and hiring them. A couple of these participants had not hired workers yet, and were looking for more help from the CL.⁵

Some participants seemed unclear about what they should expect their CL to do for them. For the most part, it seemed the CL provided support to the participant, particularly when developing the spending plan. After the spending plan was in place, the task of overseeing workers was mainly left to the participant. From that point on, the CL's main function was to check-in and provide advice or support if problems arose. Those who struggled to hire workers, struggled to understand how the CL was supposed to be helping them, and often wished their CL was providing more information and advice about how to hire workers.

Below are several comments from participants who said they got some help from their CL to develop a spending plan and oversee workers, but not in a way that was totally satisfactory. Some participants felt like they took most of the responsibility for doing both tasks, particularly hiring and supervising workers.

No. I was told what I needed to do and I did it to the best of my ability. [My CL] told me I needed to hire people.

No. In the beginning he asked me names of people I would like for housekeeping and transportation. He hasn't given me any other help with it. But yes, he comes once a month and goes over all the paper work with me.

Not in the way that I want, but he helps.

Below are a couple of comments from participants who said their CL was providing a lot of support to develop their spending plan and oversee workers.

Yes, I would say she has. Well, she more or less takes over for me, you know, and gets everything in order. You know, when you're dealing with bureaucracy, there's 10 pieces of paper for anything you do. That's what she's doing.

Yes, about how many hours. What I can spend, expenditures. He comes by my house. When he can't come by, he calls me. Always checks in with me every week.

Training and Education/Community Resources

The best source of training for participants was conversations with their CL.

⁵ We will attempt to capture more about the CL's involvement in overseeing the spending plan and workers during the 9-month interviews, but a better understanding how CL's understand their role would also be an interesting area of exploration with a focus group of CL's.

One vendor agency provided participants with a binder filled with information about the program, contact numbers, worker training information, community resources, etc. This was a very helpful resource for most of those who received this. Although not all who had a binder read through it entirely, several pulled it out as a reference during our interview in order to look up information they could not remember. The binder was not as helpful for those who could not read, due to blindness, a language barrier, or literacy issues.

[The vendor agency] provided a manual for in-home services: podiatry, hair, and path labs. [Services that were] all right within the home, which has never happened. And [my CL] found that out through the training. Part of the training was things you could get involved in, a list of numbers of things you could get involved in. It went in to detail. If you couldn't get out of the house to shop, who to call.

Some did not get such a manual, and they were much less informed about available community resources.⁶

They gave me a binder but I can't read so I never had the opportunity to sit down with anyone and have them explain what the program could do for you. [A vendor agency staff member] was very good but she came later.

Most respondents felt mostly satisfied with the training they got from their CL, but several could have used more training in the beginning.

I think I need education because it was a guess of what I was going to get. What kind of things they would allow you to get with this grant. I still don't know what things are available to me yet—things that I could have asked for but didn't. I called Stavros Center for Independent Living. They have a lot of grants and programs but they didn't know much about the Real Choice program because it was new. I asked for paperwork to see what things or services I could get other than what I asked for and with that I got a lot of run around. They didn't know and didn't call me back. I'm still unclear. I talk to [my CL] and she has experienced it too. No, she has not been helpful with finding out because it's new to her too. I could have asked for other things and then after I got [my spending plan], I asked if I was able to get other things that I needed, and she said that you haven't put that in your spending plan. Well I said, "How am I going to put it in a spending plan if I don't know about it?"

My initial spending plan isn't finalized yet. There are things I'd like to add to it. A lot of that was because I was hospitalized and because I had a community

⁶ All consumers were supposed to receive the guidebook from the vendor agency and receive it in an accessible format. The binder, for those who got one, included a list of community resources and items that were possible for inclusion in a spending plan.

liaison who didn't know what was going on. It's like being in a class without a syllabus.

Other Help Provided

Most said they appreciated having the community liaison as someone to talk to in general about how things were going. They felt supported knowing that someone was available for them to call if they needed something or for visits.

She's just been there to talk and visit with me which is greatly appreciated. Isn't that enough, really?

Stability as far as how I feel. It's a foundation, I would say. [...] He would come by the hospital or call me at if I need milk. He'll pick me up milk or a loaf of bread. That's the type of guy he is. He was my social worker at Community Health Link. I asked him [to be my CL]. He said sure.

I mean she dots her I's and crosses her T's. She says she's going to do something, she follows through.

Just being available if I need any thing or have any questions.

Changes to CL Role and Other Help Needed

Most said they did not believe that changes to the CL role were necessary. (Though three said they could use more help or more information about the program).

Also, most participants did not feel they needed any additional help at the time we interviewed them. A few of the participants who were not satisfied with how their plan was going, wanted some additional help from their CL.

We don't really have time to talk, and when we do she has other things to do. She's busy.

The information I need about what I can spend on.

D. Hiring and Supervising Workers

Who Are the Workers?

Most workers were hired to do housework, to run errands, and to provide transportation for shopping and appointments. Some workers were personal care attendants and provided personal care support, such as dressing and bathing, rather than homemaker services alone.

About half of the participants either used family members or friends as their workers or got referrals for workers through them. The other half found workers through their CL or through a home health agency. Workers who were family members or friends were more likely to do a combination of tasks, such as cleaning and transportation. Workers hired through an agency generally did one type of work, so a couple different workers were often needed for transportation, home making, and personal care.

Hiring and Supervising Workers

Participants overwhelmingly felt in control of this process. About a third of participants had some difficulty finding or retaining quality workers. Even when workers did not work out, participants seemed satisfied with the process they went through to replace their workers. Participants took most of the responsibility for hiring and overseeing their workers. Almost all the participants felt they were easily able to make changes to the type of support they received as well as the days and times.

Difficulties Obtaining Workers

Some participants had no difficulty hiring workers. They identified the personal contact or agency they preferred, and then hired them. Several others did encounter problems getting their workers set up. A few participants needed more training or clarity from Real Choice staff about the hiring process.

Below are comments from participants who did not have a problem obtaining their workers:

No problem because she's family. I don't have any problems finding workers.

None. [The vendor agency] took that initiative and everything worked out just fine.

No, I found the third worker through word of mouth. There are three or four others that would be hired in an emergency.

A few people had difficulty figuring out the process for hiring and would have liked more help with hiring:

I had no idea what I was doing. I'd never done anything like that. I was completely ignorant. It would have been a good idea to have a training. Get everyone together. Like a mini-seminar a couple of times. Rather than just having someone coming in for a couple of minutes and then going.

Once I found the program or agency I wanted to use, it was difficult for the agency I was using for cleaning and home health aid to find out what I needed to get started. How would they go about it for billing? Stavros gave them the run around. They would call me and say Stavros didn't know. The cleaning agency would call me. I'd call [my CL]. It took awhile.

A few people had problems working out scheduling, retention, and hours with the workers in the beginning.

Maybe the schedule. Theirs and mine. So I don't know. At first deciding when people could work. At first I was like "whenever", but I figured I needed to have a schedule just for order. In the summer they were more open but in the fall they had more of a schedule with work and school.

In the beginning a lot [of problems]. I had two people to be my driver and they both quit. They hadn't even started and they quit. One got sick and one got a full time job. I've had no problem with the housekeeper.

Through friends or family members I knew certain people. Some said not enough hours. Some said they didn't want to work a lot of hours.

Changes in Type of Support

The large majority of participants felt that they would be able to make changes to the type of support they received from their workers, if necessary. A few said they would just have to talk to their CL about it and possibly move some money around in their budget. Only a couple said they were "pretty sure" they could make changes.

No problems. They do a lot for me. One comes Wednesday or Friday, but not all the time. Last week it was a Sunday. So it's whenever I want it.

Oh, yeah. That's the difference in hiring who you're related to and who you aren't.

Yes. It's just a matter of switching around the hours in the budget. The housekeeping person gets paid so many hours for so much per hour. If I needed her more or less, I would take some money from some other place.

Changes to Day or Time of Support from Workers

Most participants were satisfied with the flexibility they had to schedule the days and times they received support from their workers. Most said that if they needed to change a day or time, they would discuss it with their worker and would be able to work something out.

Yeah, I usually give them leeway. I allow them to come when they want. They come on their own time. I don't care when it's done.

We work things out. I've got time on my hands so basically I work things out with them.

It depends on my workers but it's pretty flexible. They've been pretty flexible.

Knowing How to Make Changes to Support

We asked participants, "Do you know what to do if you want to change something about the help you are receiving?" Several said "yes," they knew what to do. Several others felt that they could access the information from their CL or from written materials they had. A few said that they did not know what to do if they needed to change something about the help they were receiving. Those who had gone through the process already were, understandably, more likely to know what to do.

Yeah. I talk to my CL first and we decide. She gives me her input. If I agree with her, I do it, and if I don't agree, then I do what I want.

I do but I don't. If I'm confused, all I have to do is call Gladys and she'll explain it to me.

No. That I don't know. I called [my CL] when I couldn't find the drivers.

I know it's written down.

Choosing Workers

All but one of the participants felt they were able to choose their own workers. Some chose family members or friends, got referrals from friends, and/or found workers through the vendor agency. This gave participants a few different options for finding workers, thereby increasing their choice. For those who chose family members or friends, it was often an opportunity to offer employment to someone in their social network who needed it.

Yes, one of them is a friend's daughter. She's had a rough life. I thought I'd help her out like that. [An advocate at the vendor agency] got me my driver. I tried to get one on my own but I couldn't. I just call him when I need a ride. He's flexible. I try not to call him at the last minute.

I was able to choose anyone I wanted. I said I didn't know anyone, so [the vendor agency] introduced me to [my worker]. She's doing just fine.

Yes. Actually I got referrals from a friend. I was going to start advertising but he knew people who wanted to work for him but he needed more hours or something.

Yeah. [My CL] asked me who I wanted and I said [my two relatives]. They are the two I can count on right now. They are close to me.

II. Participant Outcomes at Two Months

A. Independence

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.

What Independence Feels Like

Participants were asked to give examples of **what it feels like to be independent**. A common response was that independence is the ability to do things *on your own* and/or *what you want to do, even if you need someone to help you*.

It means I don't have to depend totally on someone else. For a while, I had to. I'd call every couple of hours and get fluids when I was in the elderly apartment.

To be able to go and do things on your own to be able to have self-dignity. To go to a movie or grocery store.

It means everything. Not having to call someone to help me. I can just go out the door. It's a total new way of living. Yeah, having to call someone and beg for a ride when I had a doctor's appointment.

For some, **independence also means** being able to make your *own choices and decisions*. These participants needed autonomy and choice to have independence.

Obviously, I don't have much independence [at the nursing home]. Independence to me is next to happiness. Some people like to be monitored and guided. Not me. I like to think for myself.

Freedom to make my own choices. Freedom to be more independent. Independent is to rely upon myself to make intelligent, rational decisions. I haven't been independent in a long time.

I'm still asking for help with the grant but with the grant I'm becoming more independent with what I'd like to do and how I'd get there. It's my interests—not just sitting in a day program. Independence is based on my interests, not somebody else's.

Participants were also asked to give examples of **what feels like to not be independent**.

It's a choice between feeling helpless or not. If someone were to take away your house keys and car keys and say you couldn't go anywhere when you're used to going where you pleased, it's kind of like that.

I feel down, I'm less motivated.

Not being independent means depending on someone else to do something. That's why I have a "do not resuscitate" bracelet. I don't want to end up totally dependent on anything.

Not being able to get out of my house. I can get out of my house but I can't get anywhere because I can't get off that porch.

Real Choice Helped Increase Independence

The participants noted a variety of ways in which the Real Choice program was helping them become more independent, including transportation, accessing assistance to get out and do activities in the community such as shopping and errands, living in the community versus an institution, and being able to purchase items that help with daily living.

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

Knowing there are people out there to help you.

Definitely. Transportation. My housekeepers been very very helpful too.

I can see [with my new glasses]. The scooter if I want to be by myself. I can't wait for the teeth! Be able to chew a piece of steak.

I would say so. Definitely. I mean pick one? In every way. The financial backing. Friendship. Just doing things like going to the post office. Getting a hair cut. Shopping.

Living in a private home versus in an institution improves my quality of life.

A few participants said that “no,” they had not been helped to have more independence. They had not yet experienced changes in their independence, in most cases because their spending plan was not fully implemented.

Not yet, but I’m hoping it will.

No, it’s the same.

Not really. Cause I’m not really independent because I need someone to talk me. That’s not being independent. Not really anything that can be changed. It’s me, my life.

Activities Inside Home

Most participants said they were getting as much help as they needed to do the things they wanted inside the home. Only a few elaborated, saying their workers (sometimes family members) helped them inside the home. A few said they were getting more help inside the home due to Real Choice, but not as much help as they needed. For a couple participants, not all their services were in place, so they had not yet experienced much improvement in their activities inside the home. Below are a few comments about how people were doing more activities they wanted inside the home:

Well, I don’t dance every Friday night [laughs], but I’d guess you’d have to say it’s helped me. It’s helped, no question, with the hospital bed. I’m able to change the position with my back.

Definitely. My brother-in-law is one of the most wonderful guys. [participant lives with family who is compensated by Real Choice for personal care].

Yes, I’ve got enough help. I could get a homemaker but I have my nieces [who are paid by Real Choice to assist me] and that’s good. My sister had a homemaker and she got robbed.

Right now, almost. Almost. I need help organizing things. This house is so disorganized! I always was so orderly [before my illness].

Activities Outside Home

For those who had all their budget items in place, there were major improvements in their ability to engage in desired activities outside of the home. Participants had help with transportation, and thus got out more regularly for shopping, doctor’s appointments, social outings and errands. Some also mentioned having money for activities or equipment to help them be more mobile.

Yes, getting out. Doing things. Going on trips. Going shopping on my own.

Everything, yeah. I wouldn't be able to get out of this place and shop and get a haircut and go to the post office without them. All kinds of things.

Yes. It's a lot easier to know I can just call someone and just go and do different stuff and having the money available to sign up for extra things. It's on my budget to join a gym. So I will be doing that at some point soon.

Until we got this chair transfer, we would have to have two people carry her out of the house. She's been out of the house more in the last month than the last 2 ½ years because of the chair lift.

Things You Need in Place for Independence

Participants were asked what things they needed in place to have independence. The most frequent response was transportation.

A car. Someone to take you out.

Transportation. I'm not able to drive because of black out spells. I had a bad accident. [I prefer] taxi services. Buses are a hardship. I could slip or fall.

I just need transportation. That's the most important thing.

A couple respondents said their independence improved because they could purchase a walker or scooter, which increased their personal mobility.

Just need a lift and my walker. It'd be nice if I could get my license but I can't do that.

Take the scooter for a ride and stay away from Rt. 12. Even just up to the bridge. Sometimes you have to change the scenery.

A few participants mentioned other items that improved their independence, such as the financial resources to meet their daily needs.

A place to live, food on the table, clothes to wear, pay my own bills.

Being able to pick how I want to be more integrated into the community and activities. More choice of services.

Mobility, accessibility, funds, money.

B. Quality of Life

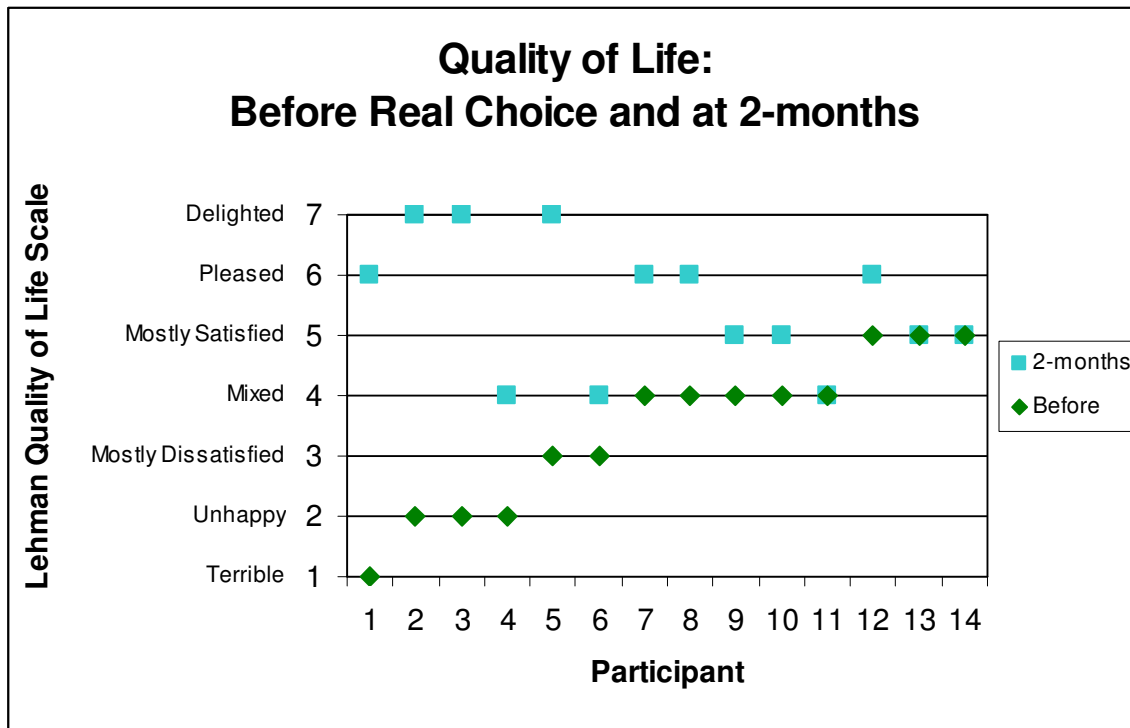
Participants' Self-Reported Quality of Life: Before Real Choice and at 2-months

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

As the chart below illustrates, most participants reported an improvement in their quality of life. Participants who reported a low quality of life before the program had the most significant improvements. Those who were “mostly satisfied” with the quality of their life prior to the program reported little to no improvements at two months.

The average Quality of Life rating before participants started the pilot was 3.4 (median: 4; standard deviation=1.2), which is between Mostly Dissatisfied and Mixed. The average rating after approximately two months of Real Choice was 5.5 (median=5.5, standard deviation=1.1), which is between Mostly Satisfied and Pleased.

Table 2: Participants Self-Report Quality of Life⁷



⁷ 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.

Comments on Quality of Life before Real Choice

Participants who reported a low quality of life before they started the pilot said they were not getting out of the home and that they did not have the desired control over their lives. The comments below are illustrative:

Unhappy. I was more or less a shut-in. No outlook for anything. Real Choice has brought that back into my life. I've seen the light with them. Things or situations are much better in my life.

Unhappy. Well, living in a nursing home I couldn't have any control over my diet. I'm very health conscious.

I wouldn't say terrible. So that's not it. Mixed. Cause I wasn't really getting out of the house.

I wanted to do things and I didn't know how I would do them but I wasn't terribly unhappy.

The program has given me more choices and made my life more convenient. I would say I was Mixed--in the middle.

Comments on Quality of Life at 2-months

Of those few participants who did not see an improvement in their quality of life, two participants were still waiting for items to be purchased. The third respondent was still dealing with a difficult emotional loss, though the program did have a positive impact on her overall. The comments below are illustrative:

Pleased. It's gone up a little. I was in a nursing home. I have more freedom. I can go for a walk, go to the movies, go to the Y if I want to exercise. At the nursing home I was restricted.

Delighted. Even people who come to see me, friends and family say I'm more full of life. Not laying around, depressed.

Delighted. I got the computer. I can get out. I've made a lot of nice friends from Stavros and [the vendor agency]. I'm just happy.

Pleased. Because I know there are things I can get help with even though I don't qualify for with a bigger agency or more involved program. My needs are being met. It's up to me so I like that too.

Improvements in Quality of Life

Participants most commonly cited increased freedom and independence as the reasons for improved quality of life. Also cited were the feeling of support participants got from having people to whom they could talk. Some felt an increase in their support from and connection to the community. Also mentioned was the helpfulness of the education the program provided.

RC has made a difference. Having people to talk to makes me feel good. And knowing there are more people in the community to help you out. Being able to talk to people.

In all ways. Every way. Independence. Freedom. Peace of mind. Confidence in myself. Ability to know that I can succeed if I try. I need a little encouragement too. I have good info coming in all the time. I don't feel lonely. When I was in the nursing home I felt lonely and depressed.

Quite or few ways. Recreational wise, feeling of life fullness. Not as sad feeling. Better outlook. Freedom, not housebound. I can go do things.

People to look after me and emotional support. They'll help me with just about any problem I have as they arise. Companionship. Especially in this place [nursing home]. It's difficult to find emotional support.

Quality of life huge, huge. I know its grant program but really hope it continues. I think Quality of Life is at its highest.

Yes, mingling with other people and the education.

It's good to know that I've got this program, you know. In other words, I can still go to the hospital, if need be, but I haven't been to the hospital in a couple of months.

A few participants did not see an improvement in their quality of life, but even they were hopeful this would change as they got further into the program.

Not yet, but I hope it will. I'm hoping that I can use this program to expand my life into the areas I thought were lost to me.

A little [improvement]. Because of the table and the shoes. I am still waiting for the scooter but it will help.

III. General Experience of Program at Two Months

A. Overall Impressions

At the time of the interview, seven (7) out of fourteen (14) participants (50%), were unequivocally satisfied with their experience so far in the Real Choice program. In a couple of cases, participants were awaiting the approval of some spending items, but they did not attribute the delay to the Real Choice program.

The other seven (7) participants, (50%), had some issue that they were dissatisfied with and for which they were awaiting a resolution. In these cases, the participant was waiting for Real Choice to take some action to resolve their concern. In almost all of these cases, the participant was waiting for items in their spending plan—either for items in their budget to be approved or for items to be purchased. During these times of waiting, the participants felt in the dark about the process and therefore felt some loss of control over their decision making in the program. They were afraid they would not get the items they needed.

Meeting Expectations

Most participants said the program was meeting their expectations.

It exceeds my expectations. Believe me, I have no complaints.

Yes, the way it's organized and the job. It exceeded my expectations. The way [The vendor agency] communicated with me. [...] I wish I had the information [the vendor agency] gave 8 years ago.

A few said they were waiting to see if the program would help them, but they were hopeful. A couple people said they had no expectations and were satisfied with the program.

It's hard to have expectations because I don't know what I'm entitled to. But I'm glad I did it.

Yeah, I think so. I'll know more as it goes on. I think it's right in it's infancy from what I can see. So, everybody's trying to learn

I like it so far, even though I haven't gotten into it too far with spending and hiring people. That will come.

I feel good about the program because now I will get the help I really need.

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 opportunity for freedom and independence. The potential that it offers is exhilarating. The opportunity for freedom and independence. I mean you can't even imagine.

Having opportunities that I do have that I didn't have before.

It's like its name: Real Choice. It makes me feel important that I can make my own decisions. To live a normal and abundant life. It makes me feel important-to get credit for having some intelligence.

Getting Out in the Community

A couple of participants mentioned that the program helped them get out of their homes more often.

Getting out of the house. I don't like staying here 24 hours a day. It's so boring!

Just being able to get out.

Support from Program Staff

A few participants said what they liked best about the program was the help they received from their CL, including help with their spending plan.

[My CL] is helping me. I feel like he is like family too. Without him I couldn't make it.

I like [my CL]. She's fabulous. She helped me get the handicapped placard for the van. We wouldn't have thought about it.

The people are nice. I like the CL, the way she broke down my spending plan. By me telling her what I need and that's how she broke it down. She broke it down in order, the way I wanted it to be.

Everything

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

First Thing You Would Change

Nothing to Change

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

I wouldn't change a thing. Not a thing.

I don't know. There is nothing they haven't addressed.

Difficulty with Reimbursement

Two participants mentioned having difficulty paying out of pocket for ongoing expenses and then having to wait for reimbursement. Their limited incomes make paying out of pocket difficult, if not impossible. The program needs to find ways to pay for items up front, without taking the purchasing power out of consumers' hands.

You have to pay for it and they reimburse me. I think they should change that. Social Security goes for bills and medications. You don't have money. Cab fare is \$24 to go to the movies. They should send you money and let people send the receipts in. A trust situation. I don't think people would abuse that. I haven't used any money in my budget for transportation. The first reason is because I don't have any extra money. The second reason is that I've been very sick.

How you have to pay out of pocket up front when you're on a fixed income. How do they expect you to pay things up front and you really don't have the means to do it? You really don't have the money. They won't bend. Even if they sent the check for Red Cab ahead of time or write a check out to them. They should take care of that because that holds you back.

Planning for Emergencies

A couple of participants were concerned about emergencies arising, and suggested that the program have an appropriate procedure in place. One participant suggested having money set aside in the budget in case of an emergency.

It would be nice if I had an emergency budget of \$1000. It takes 4-8 weeks to process MassHealth, although they say it's faster. I'm planning that for next year.

Anything Else

A few participants added that they were amazed the program was available. A few others hoped it would continue to be available in the future.

'It's a dream come true' is not good enough to describe it. [...] The only thing I'm afraid of is that it won't be available in the future. The only thing is I wish it was unconditional that there would be money to help me every year.

Just that I'm just totally amazed that they have a program like this out there for people like me. I was shocked that I got it.

A few participants added that the program has been very beneficial for them.

The program is good but you need the determination to succeed. It's good for people like me, people in nursing homes are unhappy, miserable. It's a real good program.

Just that it's good to have my nephew and nieces to come and help and take me out in the car. I'm satisfied with how I am.

It's okay—great. It's compatible. I'm a man with not too many needs. I just need to feel comfortable and safe. I'm happy. If they don't give me anything else...The only thing on my mind now is to stay in the community.

Only two participants concluded with negative comments. In both cases, the participant felt the process was taking too long. One participant had become hospitalized during the budgeting process, and felt that the staff did not follow through with her during her hospitalization. This impeded her progress with Real Choice.

I'm not happy with how long it's taking. I'm not happy about it at all (waiting to get spending plan going). [...] We haven't gone through the numbers together. I got a letter about [my budget amount]. It told me how much I would get. I've been waiting a few months.

Every time I end up in the hospital, I barely hear from any of them. It's as though I get lost in myself and they get lost. I'd think they'd want to be involved because I am one of their participants, but never have I felt they were involved with me at all, in any way in the least. I don't expect them to hold my hand.

Cost Savings to System

A couple participants noted that although Real Choice was providing them with a good sum of money for their budget, that sum was small compared to what would have been spent if they stayed in a nursing home.

It's a 4 year program. The state is saving with paying \$21,000 for Real Choice versus a nursing home.

You can't take care of somebody in a nursing home for \$36,000 a year. That's for sure.

5

DISCUSSION

Based on the findings from personal interviews with all program participants, the Real Choice Self-Directed Care 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.

Some participants were confused about how to develop and implement a spending plan. The most significant barriers were confusion about what was allowable in the spending plan and the process for making changes to the spending plan after it had been approved.

Below are commendations and recommendations based on feedback from consumers during personal interviews at two months about their experience in the Real Choice pilot:

Commendations:

The program is to be commended for the following:

Overall Satisfaction

- Most participants were satisfied with the Real Choice program, as well as satisfied with the main components of the program. Participants were delighted to have a program that put control into their hands, and were hopeful about the potential of this program to greatly improve their lives.

Participants Gained Control Over Their Lives

- Participants' development of a spending plan not only allowed them to address their specific needs, but also gave them much needed and desired control over their lives.

Increased Independence and Quality of Life

- Most participants experienced improvements in their independence and quality of life, and a few participants successfully transitioned out of a nursing home into the community.

Participants Felt in Control of Hiring Process

- Participants felt in control of hiring and overseeing workers.

Participants Felt Supported by Community Liaison

- Most participants greatly appreciated the support they received from their CL, and felt much more supported in the community by having someone to whom they could talk on a regular basis.

Received Valuable Information on Community Resources

- Those participants who received and could access the information provided on available community resources said this information was invaluable and wished they had been provided with it a long time ago.

Recommendations:

Although most participants had a positive experience with the program overall, several aspects of the program need strengthening, particularly training and information. Because this is a new service model for providers and consumers, there is a need for even further development to make sure all aspects of the program are consumer-driven.

Community Liaisons

Insure Choice of Community Liaisons

- Make sure the participants have multiple choices for a community liaison and support requests for a new CL if desired. CLs are critical to a participant's success in the program. Yet, some participants appeared to have more choices than others about potential CLs.

Individualize Level of Support from Community Liaison

- The level of involvement by each CL can be different, but should be based on the needs of the consumer. CL should not be "doing for" the person, but creating an atmosphere that supports and encourages independence. CL's should provide support and independence by providing very good information to consumers. The CL should not be less supportive because Real Choice is a consumer directed program, but merely involved in a different way.

Provide In-Depth Training to Participants

- Make sure community liaisons are fully trained and are providing good training to participants. Some participants were satisfied with the training they received, but many others wished for more extensive training from a well informed CL.
- CL's should be fully trained on the Real Choice model, including: how to support the consumer in a consumer-driven program, how to develop and make changes to the spending plan, how to hire and supervise workers, purchase spending plan items, as well as available community resources. Community liaisons need to provide thorough initial and ongoing training to participants in all aspects of the model. Because this is a new way of accessing services for consumers, they need ongoing training to ensure they

fully understand how the program works. One time training at the beginning of the program is not sufficient.

Spending Plan Development

Consumer-Direction in Spending Plan Development

- Spending plans should be consumer-directed, and based on consumer needs. Vendor agencies should not put agency-defined parameters on spending plan items or sections (i.e. so much for transportation). Participants should work with the CL to weigh the costs and benefits of different items so their needs are provided for within the budget amount, but the final decisions about item inclusion and cost should be the consumers.

Clarify Allowable Spending Plan Items

- Provide training materials that detail, to the degree possible, allowable and non-allowable services that can be included in the spending plan, the process for making changes in the spending plan, and information on community resources. Make this material accessible to those who have reading or language barriers. If an updated list of allowable and non-allowable expenses has been developed since the start of the program, this should be provided to all participants.

Train Participants in How to Make Changes to Spending Plan

- Participants generally did not know the process for making changes to their spending plan until they were faced with needing changes. CLs should train participants up front about what the process will be for making changes.

Hiring Workers

Strengthen Training on Workers' Rates of Pay

- 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.

Assess Support Needed to Hire Workers

- A few participants needed more training or clarity from Real Choice staff about the hiring process. CLs should assess how much guidance participants want or need in hiring workers, and work to make sure the participant is able to hire their workers as desired.

Risk Planning

Conduct Risk Planning and Facilitate Transitions Back Into Community

- There should be risk planning so that participants avoid hospitalization, nursing home stays, or undesired changes in housing. For instance, if a participant struggles with depression, there should be an action plan in place for how Real Choice could minimize the risk of an out of community placement in case the participant experiences symptoms related to their depression.

If a participant does need to be hospitalized, there should immediate plans for transitioning back into the community. CLs should continue to visit with participants if they are hospitalized and continue with Real Choice planning. For a couple participants', their spending plan development halted due to hospitalization. Delays should be avoided if at all possible, based on the consumers' desires for continuation.

Finances

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

Inform Consumers about Availability of Emergency Funds

- Participants should be informed that there is money set aside in the program fund in case they have an emergency.

Conclusion

At two months, most participants were satisfied in general with the Real Choice pilot program. Participants either experienced an increase in their independence and quality of life, or they expected improvements in the near future. Most participants felt strongly that the program gave them much needed control to make decisions and meet their needs.

Nonetheless, some participants experienced difficulties with how the program was implemented in the beginning, particularly with the training they received on developing their spending plan. The Real Choice self-directed care model can be effective only if the vendors, community liaisons, and participants have a good communication plan and if they receive a very thorough training on every aspect of the program. The program's rules and processes must be clear to everyone in order to ensure participants' needs are met in a timely fashion. Also, the program and program staff must be flexible and responsive when participant needs change and personal crises emerge.

According to program participants, the Real Choice model has a strong potential to make make significant differences in their lives. Participants expected positive outcomes when they were well trained on the model, had an effective relationship with their community liaison, and were able to quickly purchase items to address their self-identified needs.