

Focus Groups with Community Liaisons, Workers, and Caregivers

**Prepared for:
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Executive Summary

The Real Choice Pilot is a self-directed model in which participants use a flexible budget to purchase the supports and services they need to live in their community. Key elements of the program include:

- The support broker (also known as community liaison)¹ who is available to train individuals as well as to assist them to develop a spending plan and monitor their expenditures.
- The fiscal intermediary who performs employer-related responsibilities such as payment of taxes, unemployment insurance, and processing of payroll. The fiscal intermediary also purchases one-time items and/or services and supports as outlined in the spending plan.
- A representative who individuals may appoint to assist them with making decisions. To avoid any conflict of interest, the individual chosen to be a representative cannot also be a paid worker.

The Real Choice Pilot is currently taking place in two geographic regions of the Commonwealth: Southeastern and Central Massachusetts (Worcester). Fifteen MassHealth members with diverse disabilities and at least two unmet needs related to activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) were chosen to participate. Currently there are thirteen participants (one moved out of state and one passed away due to a terminal illness).

In March of 2005, three subcontractors were identified to implement the model:

- Southeast Center for Independent Living (support brokerage agency for Southeastern Massachusetts participants),²
- Elder Services of Worcester Area (support brokerage agency for Worcester area participants), and
- Stavros Center for Independent Living (fiscal intermediary support for all Pilot participants)

Implementation of the Pilot will continue through 2009. The first year of the Pilot was funded through the Real Choice grant while the remaining three years will be funded through state funds. The lessons learned will drive the development of a similar model on a larger scale through the Community First Waiver.

¹ Community liaison is the term used to describe the individual paid for by the Support Brokerage Agency (also known as the Consumer-Directed Agency) to train the Pilot participants and/or representative of their roles, identify available community resources, assist in the design of the spending plan, and monitor spending plan expenditures. The Community liaison meets monthly with the Pilot participants to perform duties. Community liaisons can be independent contractors chosen by the Pilot participants and then hired by the Support Brokerage Agency or direct employees of the agency itself.

² As of April 1, 2006, United Cerebral Palsy's Options Program (Taunton, MA) continued with implementation of support brokerage in Southeastern Massachusetts in the place of Southeast Center for Independent Living.

As a component of a larger evaluation of the Real Choice Pilot, the University of Massachusetts Medical School's Center for Health Policy and Research (CHPR) conducted focus groups with 1) paid workers, 2) unpaid caregivers and representatives, and 3) community liaisons. A total of six focus groups were held in the two geographic areas. In addition to the focus groups, two individuals who were not able to attend the focus groups were individually interviewed by phone. Letters describing the focus groups and their purpose were sent to all individuals who met the criteria of one of the three groups (totaling 41 individuals) asking them to participate in the focus groups. Focus group data was retrieved from a total of 14 people (see report section, Challenges of Recruitment). Pilot participants' perspectives related to the Pilot are being captured through a separate report completed by Consumer Quality Initiatives, Inc. (See Appendix II).

Overall, findings from the focus groups were positive. Community liaisons, paid workers, and caregivers/representatives generally praised the Pilot for its benefits to the participants. Several caregivers felt that if it were not for the Pilot, their loved one would either be placed in a long-term care facility or require frequent hospitalizations. The need for more education and training about the Pilot and difficulties with the fiscal intermediary were most frequently cited as problems among focus group participants.

The information obtained through these focus groups, though limited by the small number of participants, may be valuable for the future implementation of such services. Analysis of focus group results would be stronger with increased focus group membership. It may be beneficial for future evaluations to attempt to clarify the reasons for the low rate of participation.

The accompanying report provides details about the focus groups and the major themes that emerged.

Introduction

The Real Choice Pilot, a self directed model in which participants use a flexible budget to purchase community focused services and supports not covered by Medicaid, has been in existence for about a year. As a component of a larger evaluation of the Real Choice Pilot, in the spring of 2006 the University of Massachusetts Medical School's Center for Health Policy and Research (CHPR) conducted focus groups with paid workers and community liaisons, who provided services and supports to the Pilot participants and to family members or informal care givers of the Pilot participants. The intent of the focus groups was to evaluate what parts of the Pilot went well and to identify areas for improvement that could be applied to the future implementation of this or a similar model. The larger evaluation plan also included obtaining information about the Pilot from the thirteen Pilot participants completed through Community Quality Initiatives, Inc. This report outlines the focus group process, common themes, and recommendations based on that information.

Focus Group Preparation and Outreach Methodology

In preparation for focus group recruitment, an application that included sample letters to focus group recruits, consent forms, and sample scripts was submitted to the University of Massachusetts Medical School Human Subjects Research Office. The application received expedited approval and procedures for recruitment were implemented. This report outlines the objectives of focus groups for the three constituencies, major themes and ideas for potential improvement.

Focus Group Participant Identification and Recruitment

Focus group participant identification came from a variety of sources. The fiscal intermediary supplied CHPR with a list of 28 paid workers to solicit for focus group participation. Some participants had more than one paid worker while one paid worker in each geographic area was also a family member. Paid workers were the most difficult participants to recruit. Several people only worked with the participant for a short period of time and were not interested in discussing the program; others were students or had other responsibilities that impacted their ability to participate. Despite attempts to contact workers on multiple occasions and at different times of the day, paid worker representation in the focus groups was minimal.

Community liaisons were identified through the support brokerage agencies where they were employed. Eleven community liaisons were contacted in the Southeast area and four in the Worcester area. Worcester area community liaisons who attended the focus group worked with more than one program participant. Three out of four community liaisons participated in the Worcester focus group and five out of eleven in the Southeast area focus group.

Overall, community liaisons were responsive to communication from the focus group facilitator and willing to participate in the focus groups. This group showed a significantly higher response than the paid workers. The higher community liaison response may be due to several reasons including the fact that community liaisons are employees of support brokerage agencies (and therefore may feel more connection to the Pilot and/or more responsibility to respond). The proportionately lower response from community liaisons in the Southeast area may be related to the fact that some of the community liaisons were employed by the Southeast Center for Independent Living, the support brokerage agency prior to Options¹, and therefore did not feel the same loyalty to the Pilot as employees of the present community liaison.

Pilot participants were requested to identify informal caregivers and/or representatives to participate in focus groups. Most of the family members who were reached by phone to assess their interest in a focus group seemed eager to participate. However, there were six participants whose family members were not interested or unavailable. Only two out of a potential five informal caregivers from the Southeast and one out of four caregivers in Worcester attended a group. In addition to the single Worcester caregiver who was interviewed in person, an additional caregiver and a representative from the Worcester area were individually interviewed by phone because their schedules did not permit them to attend a group.

All potential focus group participants were offered a \$35 gift certificate to a local mall and assistance with transportation as an incentive to attend a two-hour focus group at a convenient location. Focus groups were held in each of the two Pilot areas. The Southeastern area focus groups were held at a local library and the Worcester area focus groups were held at CHPR in Shrewsbury. A letter signed by the Real Choice Project Director, describing the evaluation objectives and asking for their assistance was sent to all potential focus group participants. The letter also included a self addressed stamped return envelope with a form requesting information about convenient times to attend a focus group. Numerous groups at various times including the evening were scheduled. Because of time constraints on the part of the interviewers, the time between notification and the scheduled focus group was two to three weeks. This may have been one reason for the minimal response. The facilitator offered to interview people on the phone in order to increase the number of respondents because the level of interest in focus group participation was minimal and because some individuals could not attend the focus group in person. The UMass Medical School Human Subjects Office approved an amendment to the original focus group protocol to accommodate this methodology.

¹ As of April 1, 2006, United Cerebral Palsy's Options Program (Taunton, MA) continued with implementation of support brokerage in Southeastern Massachusetts in the place of the Southeast Center for Independent Living.

In all, six focus groups and interviews were conducted in May and June 2006. The chart below provides an illustration of focus group attendance and interviews:

Focus Group Type	Worcester Attendance	Southeast Attendance
Community Liaison	3	4 3 from Options 1 from SCIL
Paid Worker	2 Groups scheduled but no participants	2 plus 1 family member also from caregiver group
Caregiver/Family	1 in focus group, 2 tel. interviews	2

Focus Group findings/themes

Community Liaisons

There were three community liaison focus groups scheduled. Two groups were held in the Southeast and one in Worcester. The community liaison questions focused on obtaining information about how well the community liaisons understood the objectives of the Pilot and on the roles of the various players. Questions on the players included questions on how they use the assessment tool, the strength of Pilot training, how well the model was meeting the Pilot objectives, what had worked well, and any suggestions they might have for improvement.

Understanding of the Pilot and the Roles of the Players

Of the four focus group participants in the Southeast, one community liaison had worked with the Pilot for one year while three participants had been working with the program for only a month. The community liaison who had been with the program the longest was an employee of the Southeast Center for Independent Living (SCIL), the previous support brokerage agency. The other community liaisons were employees of Options.

All of the community liaison focus group participants from the Southeast area seemed to have a consistent understanding of the Pilot and their roles. They described their primary role as helping the participant maximize his or her independence and live in the community. They also commented on the importance of assisting Pilot participants to develop a spending plan and on encouraging them to make their own decisions rather than to make decisions for them. The Southeast area community liaisons indicated that this role was very similar to their skills trainer role working for Options or the Southeast Independent Living Center with non-Pilot consumers. The major difference in their two roles was the availability of discretionary funds and the fact the

participant had the flexibility to make their own choices. One community liaison expressed it this way, “I like being able to have money to spend on things that are needed and not have to beg agencies for it”. The other focus group participants echoed this sentiment. Of note, since the money belongs to the Pilot participant not to the community liaison, they were speaking on behalf of the participant.

When asked about the most challenging aspect of their role, all pointed to time management and the need to be very organized as they were constantly faced with challenges. They also felt it was important to be “flexible” and patient when working with participants and important to be willing to learn as they go along. For example, they noted that if they could develop the spending plan for the Pilot participant, it would be a lot less complicated and take less time than having to explain the process and help the participant come to a decision. Community liaisons in the Southeast spent on average about three hours a month with each of their Pilot participants.

Community liaisons in the Worcester group had all been with the Pilot since inception. They worked for a provider agency in the Worcester area that served people with mental health disabilities. They had a slightly narrower view of the Pilot objectives than the previous group. For example, they talked about how the Pilot allowed people to move to the community from nursing homes or prevent people from having to move to nursing homes. These community liaisons saw their role as “the go between” linking the support brokerage agency and the participant. They also felt strongly that their role was to provide “support without getting too engaged or involved”. In their opinion, people chosen for the Pilot should be fairly independent as criteria for participating and they did not see the community liaison’s role as one of teaching the participant to become independent. Worcester community liaisons spent on average two hours a month with their participants.

Community liaisons in each focus group identified fiscal challenges related to working with Stavros, the fiscal intermediary. Problems cited included slow processing of reimbursement checks for participants as well as a lag in sending monthly statements. They also noted that the concept of having the participant pay for an item first and then get reimbursed did not work well for all participants, as some items were very expensive and the initial out of pocket expense could be burdensome. They suggested a system of vouchers or that the store or vendors bill the fiscal intermediary directly.²

² The Pilot had two payment mechanisms. One was for the fiscal intermediary to pay for the item directly and a second was for the participant to pay up front and get reimbursed. These comments may indicate the information about direct payment to a vendor by the fiscal intermediary had not been communicated to the community liaisons effectively.

Community liaisons from both groups described having minimal contact with participant's family members. When they did have contact, the interactions were positive, and family members appeared to be supportive of the model. One community liaison did note, however, that in her opinion, the mother of one participant interfered with that participant's ability to make truly independent decisions.

Using the Assessment Tool

Pilot participants received an initial assessment as well as periodic re-assessments through the support brokerage agency to determine their level of functioning and their support needs. Community liaisons in the two Pilot areas differed with regard to their access to the completed assessments. Community liaisons in the Southeast reviewed the initial assessment and at least one follow up re-assessment. They reported that the assessment tool was "very useful" and helped them to be more effective in communicating when they were working with Pilot participants to develop their spending plan.

Community liaisons in Worcester had only reviewed their participants' initial assessment. They seemed to think they were "not allowed" to see subsequent evaluations and expressed frustration at that fact. They felt the assessment would help them be more effective in working with the participant to identify items or services for their spending plan. Having access to the assessments could also eliminate miscommunication issues on the part of the participant. It is unclear at this time why community liaisons in Worcester were not able to review the reassessments.

Training for the Pilot

Community liaisons from both groups felt strongly that training for this Pilot was not adequate to prepare them for situations, particularly around spending plan issues they faced. They also felt the participants should have been trained beyond receiving a manual. Of note, the role of community liaison was to provide further explanations about the Pilot to the participant beyond what is contained in the manual. While the manual appears to have been useful as a reference, the information related to the Pilot methods may have been overwhelming.

In addition to initial orientation and training, community liaisons were required to attend monthly meetings with Kenneth Schlosser, MSW, to discuss Pilot challenges. This additional training was an opportunity for community liaisons to clarify their role and any concerns they might have about how the Pilot works. The community liaisons' responsiveness to this monthly meeting was mixed. Worcester community liaisons did not feel the meetings were useful in terms of helping them to become better community liaisons. Most people found it more helpful to be able to get answers to questions or have concerns addressed from people at the support brokerage agency on a real time basis rather than waiting for the monthly meetings. Quarterly meetings/trainings rather than monthly seemed to be preferable.

Based on the focus group discussions, community liaisons had the following suggestions for improving training: provision of examples of what items and services could be included on the spending plan, how to work with participants in developing a spending plan, and ongoing training on expense reports. It is important to note that examples of what items could and could not be included in the spending plan were included in the manual, and therefore, some community liaisons may have needed more training on manual contents. Community liaisons also noted that the manual should be translated into the primary language of the participant for more efficient use. This was a requirement for the support brokerage agency, but appears not to have been fully implemented.

Meeting Pilot Objectives and What Works Well

All community liaisons enthusiastically agreed this program had met the objective of maximizing independence and allowing participants to live in the community. In some cases, the Pilot had appeared to prevent participants from moving to a long-term care facility. Even so, one community liaison talked about a participant in a nursing home whom she felt did not understand the program well enough to take advantage of the opportunity to transition to the community.

Having the flexibility to purchase needed goods and services not traditionally covered by Medicaid was the most often cited variable benefit to keeping people in the community. Purchases like home modifications, eyeglasses, dentures,³ and transportation for shopping and social events have been key to the success of participants. One community liaison said the greatest gift to his participant was the “peace of mind” that came from not having to worry about money for support.

Suggestions for Improvement

The community liaisons from the Worcester area felt participants should have been more carefully screened for a program like this. They were of the opinion that people who were already fairly independent would be the best candidates.⁴ They recommended increasing the training (see above) for both community liaison and participant and making the manual more user friendly. Surprisingly, this group did not see their role as one of training Pilot participants to become more independent. Rather, they saw their role as merely providing advice about what to put in a spending plan. One community liaison described herself as a middle person between the support brokerage agency and the participant.

The Southeast groups echoed the need for more initial training on spending plans but did not have the same belief about the level of independence Pilot participants should have to qualify for the program. One person who was Spanish speaking suggested that having the manual in Spanish would have

³ At the time of Pilot implementation, MassHealth was not covering adult dental services.

⁴ This statement is in direct conflict with the basic purpose and philosophy of the Pilot model, which is based on helping people learn to become independent by providing resources such as flexible funding and supports.

added to her participant's sense of independence. As noted earlier, assuring documents were accessible and in the requested language was a mandate of the model. This mandate does not appear to have been known by all community liaisons nor completely implemented by at least one of the support brokerage agencies.

Paid Workers

As mentioned earlier, paid workers were the most difficult group to recruit. The objectives of the focus groups for paid workers were to learn the following: how well paid workers understood the Pilot and the roles of individuals, the services they were providing to the participant, the training and supervision they received from their employers (the Pilot participants), how their work in the Pilot differed from care they may have provided through traditional avenues, their perception of how the model was meeting its objectives, their perceptions of the overall strengths and weaknesses, and their lessons learned for improvement.

Understanding of the Pilot and Roles of Other Players

Two paid workers attended the Southeast area focus group. Pilot participants had employed both paid workers for approximately five months. A third paid worker was also the mother of a participant and therefore participated in the Caregiver focus group. Her remarks as they apply to paid work are included in this section as well as the caregiver section.

The two paid workers who attended the Southeast focus group were unclear about the purpose of the Pilot. They were not aware it was a "Pilot". They understood that the participants they worked for had discretionary funds to purchase services and that this contributed to their independence. The third paid worker who is also the mother of the participant had the best understanding of the Pilot, but even she felt she did not have as much knowledge as she would have liked. None of the paid workers had a clear understanding of the fiscal intermediary's role or the community liaison's role although they had heard the terms.

Training and Supervision

There were no formal training sessions or written guidelines for paid workers. When asked about supervision, one paid worker from the Southeast cited his participant as his direct supervisor while the second paid worker at first said the CHPR Project Director was her supervisor then on further questioning thought maybe it was the community liaison.

Services Provided

All three paid workers interviewed had the primary responsibility for providing transportation to services and events not traditionally covered by Medicaid. This involved the transportation of the participant to the grocery store, social events, and the pharmacy. Although Medicaid will pay for transportation to medical

appointments, these workers also provided this transportation on occasion since the Medicaid vendors who provided transportation to medical appointments reportedly had inflexible hours and were unreliable.

The paid worker who was also a mother did not think her daughter was getting the maximum benefit from the program that she could. She was planning to join her daughter's meeting with the community liaison in the near future to express her opinion and determine what more could be done.

How is this Work Different from Previous Work?

Both paid workers commented on the positive aspect of the high degree of flexibility in their arrangements with the participant. One person had been a personal care attendant (PCA) in the past and felt this program (the Pilot) was superior because it gave her the flexibility to arrange her schedule around the particular needs of the participant she worked for. She commented that when she was a PCA she would go to the house for a block of time and there was not always enough work, so she would waste time. Now, because of the flexibility of scheduling, she is more efficient with her time. She also liked accompanying the participant out in the community. The second paid worker talked about the ability to provide services while meeting the needs of his own schedule and that he had more of a "partnership" with the participant rather than a typical employer/employee relationship. Both of these paid workers intended to continue in their jobs as long as possible.

The paid worker who is also a mother seemed to be somewhat conflicted about her role as paid worker vs. her role as mother. She said she was doing the same tasks for her daughter as she always has but now she was paid for providing transportation. It is interesting to note that transportation was an identified unmet need for this participant in her assessment. Prior to becoming a paid worker, her mother was not always able to meet her daughter's transportation needs because of her schedule. However, her daughter has now hired her mother to perform this role. During the conversation, this mother said her daughter had recently talked about hiring someone else to provide transportation. There seemed to be some reluctance on the mother's part to accept this as a solution at this point. She noted that when her daughter is married and moves out of the house in the next year, "the program will take over". This statement is perhaps indicative of her current reluctance to give up her role as mother and care taker, therefore impeding her daughter's ability to be truly independent.

Meeting Pilot Objectives

Increased independence was the most positive outcome for their employers in the opinion of these focus group participants. Both provided transportation for their employers and they felt that freedom to get around and to participate in social events was an essential component of independence. One paid worker said her employer had a partner who provided a great deal of support so she was not sure how much the program enhanced his ability to socialize. The second

paid worker was certain the program had enabled his employer to be more independent.

Increased safety was another important outcome of the program for participants according to the paid workers. Such things as a ramp to the house, a better walker, and just knowing that help was available were cited as examples of improvements in living situations.

Overall Strengths and Weaknesses of the Pilot

The fact that the Pilot was meeting the objective of increasing participant independence was its greatest strength according to these paid workers. A second strength was the socialization opportunities afforded the participants by having extra funds to enable them to participate in community-centered activities.

As did the community liaisons, paid workers also noted the limited training for participants as a weakness. Paid workers saw the community liaisons as having responsibility for informing participants about the use of spending plans and felt that they should have provided better explanations to the participants. One paid worker in particular felt her participant was not clear on how to fully use his spending plan. The mother who is also a paid worker echoed this opinion about her daughter's knowledge.

Caregivers/representatives

Caregivers expressed the most enthusiasm about the program when contacted by phone. However, only two people from the Southeast agreed to attend a focus group and three people from Worcester (including one representative) were interviewed.⁵ The various relationships of the caregivers to participants included sister, representative, legal guardian, wife, and mother. They had been very involved with the participant before the Pilot and were able to assess the impact the Pilot had on their own lives and the lives of the participants.

The objective of caregiver focus groups and interviews was to learn about their understanding of the Pilot and the roles of the players, their perception of how the Pilot impacts on their role as caregiver, their perception of how the spending plan assists the participant to stay in the community, their perception of the overall strengths and weaknesses of the Pilot, and their perception of the quality of the services purchased.

Understanding of the Pilot and the Roles of the Players

All of the caregivers seemed to have a good understanding of the Pilot and the roles of the fiscal intermediary, the community liaison, and paid workers. The guardian appeared to have less knowledge about the community liaison than other caregivers or family members and was a little unsure of how much the

⁵ See Focus Group Preparation and Outreach Methodology page 3 for a more detailed explanation of caregiver responses to the focus group recruitment.

community liaison could do. He left that up to the representative to monitor. The wife seemed to be most involved with the community liaison by participating in meetings and having opinions about how to use the spending plan.

Impact of the Pilot on the Caregiver Role

Caregivers in general said they had more personal freedom since the inception of the Pilot. The sister said she felt “relieved” that she did not have so much responsibility and she now had a better sibling relationship with her sister in which they could enjoy doing things together. The representative who had twenty-four hour responsibility for a participant with multiple medical needs said she was now able to go away overnight and not worry because she was able to hire competent staff to care for the participant. The wife echoed this “gift of time” to engage in her own social activities as well. As noted above, the caregiver who was a mother to the participant as well as a paid worker expressed feelings of role conflict. She accepted payment for providing transportation for her daughter, which she had provided previous to the Pilot but did not feel right about accepting payment for performing other “maternal” tasks like cooking or laundry.

Impact of the Pilot on the Participant

All but one person stated that the Pilot had a very positive impact on the participant. The wife said her husband was doing more for himself and was more relaxed since he was not worrying so much about money. The sister stated her sister was more independent and was learning new ways to cope with her vision impairment now that she had the ability to purchase special equipment. The representative was able to purchase special supplies for the participant and as a result the participant had not been admitted to the hospital this year. In previous years, she reportedly had been admitted two to three times.

The only person who did not feel the program had an impact on the participant was the mother. She did not see an increase in independence and once again stated she thought her daughter was not taking advantage of everything the program had to offer. She was thinking of becoming her daughter’s representative.⁶

Impact of Spending Plans on Ability to Stay in the Community

Information provided by caregivers who were interviewed makes it very clear that the spending plan is the key to helping people with disabilities and elders stay in the community and improve their quality of life. People have unique needs and the Medicaid program has minimal flexibility to allow for non-traditional purchases that may allow an individual to be more independent in the community. By providing flexible funds, caregivers report that this program allowed individuals to identify what worked best for them and to obtain it.

⁶ This is ultimately the daughter’s decision since she is over 18 years of age.

Quality of Services Delivered

Most of the caregivers and representatives interviewed (except one person) had some experience with either a paid worker or community liaison that “did not work out” and had to be replaced. The most frequent reason was the paid worker did not meet expectations regarding the quality of their work or the community liaison would not return phone calls or answer questions. The representative felt the participant had higher quality workers now that she is able to recruit and pay for them herself.

Strengths and Weaknesses of the Pilot

Caregivers also noted that having to pay for items up front and be reimbursed was an issue.⁷ Training or better information on how the Pilot works was also cited as a need. Except for training and reimbursement, those interviewed felt the model was perfect and would not change anything else.

Summary and Impressions

In the opinion of focus group participants and interviewees, the Real Choice Pilot has more than met the objective of increasing independence for the participants, maximizing their potential to live in the community and increasing their quality of life. Those interviewed cited numerous examples of how the program has contributed to a better quality of life.

The common thread among all was the need for training and more information about the Pilot and the spending plans. For example, participants who purchase items and services need more information about what would be allowed and not allowed. Although training took place during orientation, people appeared to still have questions and felt ill prepared during the spending plan development phase. It appeared that the community liaisons’ monthly meetings were not always meeting their needs. Training in the form of case studies or role-play might be alternative methods in which to educate community liaisons and caregivers about the model. Although focus groups did not include Pilot participants it may be beneficial to consider similar ideas for participants as well, given this is a consumer-directed model.

The community liaisons and caregivers also mentioned problems with the fiscal intermediary such as slow payment or not sending financial statements in a timely manner.

⁷ As noted in footnote #2, reimbursement is only one method of paying for items on the spending plan. That community liaisons and caregivers were unsure of the policy indicates more training around this issue needs to occur.

Conclusion

Challenges of Recruitment

Although a lot of valuable information was gained from the focus group format, the rate of participation was less than desirable. As noted previously, out of forty-one letters sent to community liaisons and paid workers, three individuals responded and telephone and E-mail messages were often not returned. Many people who were finally reached were not interested in participating, cited schedule conflicts with other jobs or school, or no longer worked for the Pilot participant.

Given this response rate, an alternative mechanism for obtaining information such as individual interviews or written surveys, although more time consuming and costly, might result in greater participation. Another mechanism for increasing participation might have been to offer cash in an amount greater than what participants would have gotten for the equivalent numbers of hours worked. Anecdotally, it appeared as though the individuals who attended the focus groups found them to be valuable. They had an opportunity to express their concerns and questions and the group setting was a venue for gaining information and in some cases support from one another about various aspects of the program.

Recommendations

Based on these focus groups, the following recommendations can be made:

- Community Liaisons:
 - Evaluate the role and use of the monthly community liaison meetings.
 - Role clarification and training on flexibility and how to educate and support the Pilot participants to be more independent.
 - Possibility of reviewing all periodic assessments to assist them when designing and modifying the spending plan.
 - Re-training on the content of existing materials and accessible format requirements.
 - Ongoing training on use of expense reports.
- User Manual:
 - Translate into primary language of the Pilot participant.
 - Make less complicated and more “user friendly”.
- Family Members/Unpaid Caregivers:
 - Written material explaining the Pilot and what to expect from the various roles.
- Fiscal Intermediary:
 - Timely reimbursement of funds and sending out spending reports.
 - More responsiveness to customer inquiries.