

Introduction

The Real Choice Pilot represents a type of service delivery that is currently not widely available to Massachusetts consumers. Thus, service providers, agency staff, consumers, and state policy makers, as well as the general public are still relatively unfamiliar with this model. Given the general public's unfamiliarity with this model, subcontractors had the formidable task of conducting outreach and enrolling up to 20 participants in Southeast and Central Massachusetts. This section will describe the applicant and participant characteristics and some of the issues and potential solutions to outreach and enrollment identified through this Pilot.

Eligibility Criteria

To be eligible for the Pilot, an individual had to 1) have MassHealth (the Massachusetts Medicaid program) or meet the eligibility criteria for MassHealth, 2) have two or more unmet needs related to activities of daily living (ADL's) (e.g., using the toilet, eating, and bathing) and/or *instrumental* activities of daily living (IADL's) (e.g., managing finances and managing medications), and 3) not be eligible for the Personal Care Attendant Program.¹ The Real Choice Pilot was intended to be a cross-disability Pilot, and targeted the following groups: elders, people with mental health disabilities, people with mental retardation, people with developmental disabilities, etc. The clinical eligibility for this Pilot was intentionally low to examine the use of this model with people with types and levels of needs different from those of participants in the current self-directed Personal Care Attendant Program.²

Outreach Methods

Between mid-November and mid-December 2004, ESWA and SCIL conducted outreach to recruit participants.³ SCIL and ESWA used a variety of outreach methods to recruit participants. SCIL conducted outreach to both consumers and provider agencies. To reach providers, SCIL called providers in their coverage area and mailed Pilot brochures. SCIL staff mailed outreach materials to approximately 150 provider agencies. To reach consumers, SCIL conducted direct outreach with their current clients and placed advertisements in the local

¹ These eligibility criteria were intended to build on the current consumer-directed PCA Program while not duplicating the Program. Specifically, the Pilot sought to serve primarily individuals with supervision or cueing needs rather than hands-on needs. Furthermore, while the PCA program allowed only the hiring of one's own workers, the Pilot allowed enrollees to use a budget to purchase other services, besides workers.

² Eligibility for PCA program included 2 or more hands-on unmet needs with activities of daily living and the ability to manage your own personal care attendants (or to appoint a surrogate if necessary).

³ Outreach was originally planned for June 2004. However, during 2004, the Collaborative Team and the Consumer Planning and Implementation Group delayed outreach while determining how to sustain the Pilot once grant funding ended.

media. SCIL also sent letters to local politicians to inform them of the Pilot. ESWA focused their efforts on calling providers and mailing Pilot brochures to these providers. ESWA staff contacted 68 provider agencies using this method. In addition, ESWA conducted meetings with their own case managers to inform them about the Pilot. ESWA senior staff also conducted presentations to boards of affiliated organizations. Both ESWA and SCIL contacted providers whose clients included the Pilot target groups (see Table 1 for a breakdown of outreach methods by agency.)

Table 1: Real Choice Pilot Outreach Methods by Agency

Outreach Methods	ESWA	SCIL
Telephone calls to local service providers	✓	✓
Follow-up calls to these agencies	✓	✓
Outreach materials mailed to local service providers	✓	✓
Internal outreach through information meetings	✓	✓
Direct outreach to consumers		✓
Presentations to boards of affiliated organizations	✓	
Press release to local newspapers		✓
Letters to local and state politicians		✓

Source: CHPR Analysis of ESWA and SCIL’s Outreach Data

As noted earlier, ESWA and SCIL had about one month to conduct outreach to potential Pilot participants.⁴ According to outreach staff who participated in a focus group, neither ESWA nor SCIL were able to tap into all their agencies’ outreach methods because of the limited time. For example, ESWA had one full-time staff devoted to outreach for other ESWA’s programs. This individual held information meetings with nursing facilities, hospitals, and other settings. However, ESWA staff said they were not able to use this staff person because they did not have enough time to coordinate with this resource. Instead, Real Choice staff at ESWA conducted outreach themselves. Similarly, SCIL did not make use of all their outreach methods available to them. In the past, for example, SCIL conducted outreach using public announcements on cable television. This was not a viable option of their outreach for the Pilot due to the limited time. Despite the limited time available for outreach, it appears that subcontractors were able to successfully recruit people diverse in ethnicity and disability, as noted below.

Applicants’ Characteristics

Given the newness of this model, it may be helpful to review the characteristics of individuals who applied to participate in the Pilot. Although the information found below may provide a glimpse into the level of interest this model may

⁴ Pilot and enrollment of participants started later than expected because Consumer Planning and Implementation Group and Collaborative Team members had to agree upon a method to sustain funding for the Pilot beyond the first year.

attract, it is also important to note that the time restraints and the processes used for outreach most likely impacted noted characteristics.

Number of Applicants: A total of 46 applications were received for the Real Choice Pilot between November 2004 and February 2005. ESWA received a total of 29 applications; 19 of which were received before the application deadline, while an additional 10 applications were received between December 7, 2004 (application deadline)⁵ and February 23, 2005. One individual who submitted an application to ESWA actually lived in the Southeast area and therefore was eventually served by SCIL. SCIL received a total of 17 applications between November 8 and the application deadline of December 7, 2004.

Ineligible Applicants: Of the 46 applications received, 13 (or 28 percent) were ineligible for the Pilot. Of these ineligible applicants, six were under 22 years (Pilot intended for 22 years of age or older) and five did not have MassHealth. One individual decided to remain in the nursing home and another individual qualified for the Personal Care Attendant Program.

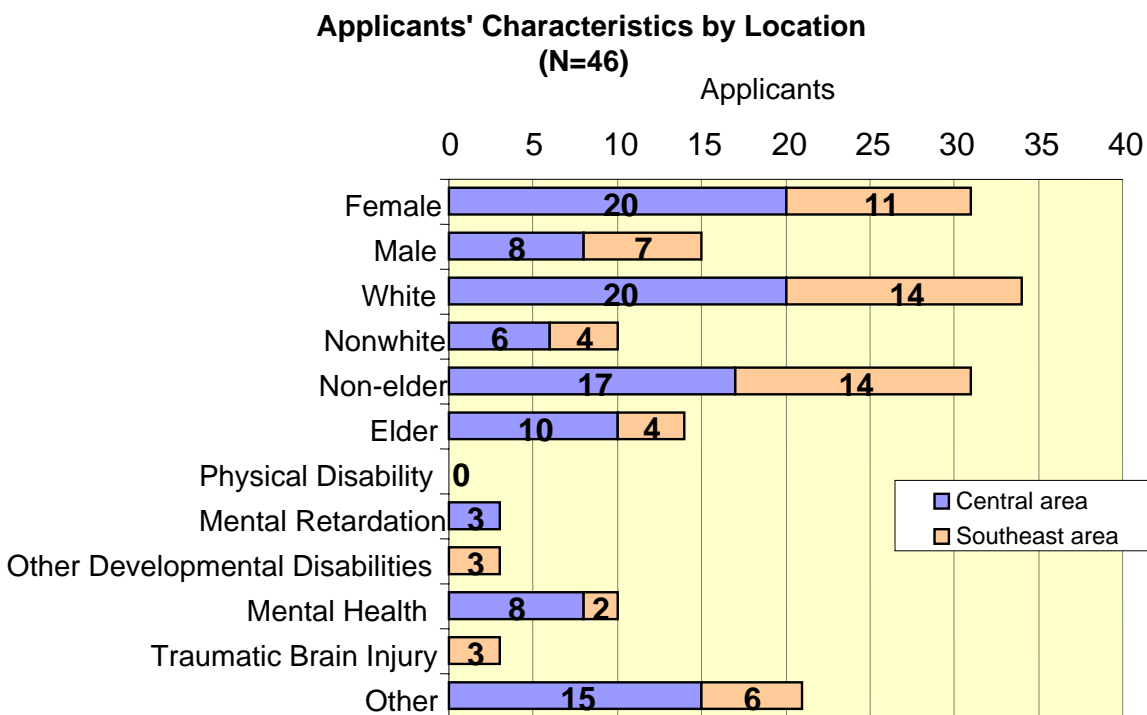
Demographics: Of the 46 applicants, 31 applicants (or 67 percent) were women while 15 (33 percent) were men. Thirty-four of the 46 applicants (or 74 percent) indicated that their race was “white” while 10 applicants (or 22 percent) self-identified as Hispanic (six applicants) or African-American (4 applicants). Two individuals did not provide ethnicity information on their applications. Fourteen (or 30 percent) of all applicants were people 60 years of age or over.

Target Groups: Applicants were categorized into a disability target group based on their own self-reported primary diagnosis to ensure a cross-disability representation in the Pilot. The primary diagnosis and the age of applicants formed the basis for determining their target group. Fourteen (or 30 percent) applicants were in the elder target group. Ten applicants (or 22 percent) were in the mental health target group. Three applicants reported having traumatic brain injuries, three applicants reported having mental retardation, and three reported having non-mental retardation developmental disabilities.

Twenty-one of the 31 eligible applicants also had disabilities that were designated as “other” disabilities. Within this group, the most common diagnoses were HIV, hepatitis, arthritis, and asthma. These are not mutually exclusive categories as some of these applicants had multiple conditions. Figure 1 shows the demographic data and diagnosis data of applicants by region.

⁵ Applications received after the application deadline were still considered in order to maximize the applicant pool.

Figure 1: Gender, Race, Age, and Primary Disability (Self-Reported) of Pilot Applicants by Location (N=46)



Source: CHPR Analysis of Pilot Applications

Pilot Participants

The enrollment process consisted of several stages to ensure a diversity of Pilot participants and to ensure input from the Consumer Planning and Implementation Group (CPIG). A Selection Committee was formed with consumer representatives from the CPIG. Grant staff categorized every eligible applicant into one of the target groups based on their self-reported primary disability⁶. The Selection Committee then randomly selected individuals from each target group until they reached 10 individuals for each area. Once applicants were selected using this method, these applicants were advanced to the assessment phase, the next step in the enrollment process.

The assessment phase was designed to determine applicants’ needs and goals and to provide the basis for estimating the individual budgets. ESWA and SCIL were responsible for conducting assessments using the Real Choice

⁶ Grant staff also removed the identifiable information from the applications. Selection criteria drafted by grant staff and approved by the Collaborative Team identified a target range of applicants to represent each disability group.

Assessment Tool.⁷ The assessment tool gathered comprehensive information on the individuals' functional abilities and level of independence in performing activities of daily living and instrumental activities of daily living.

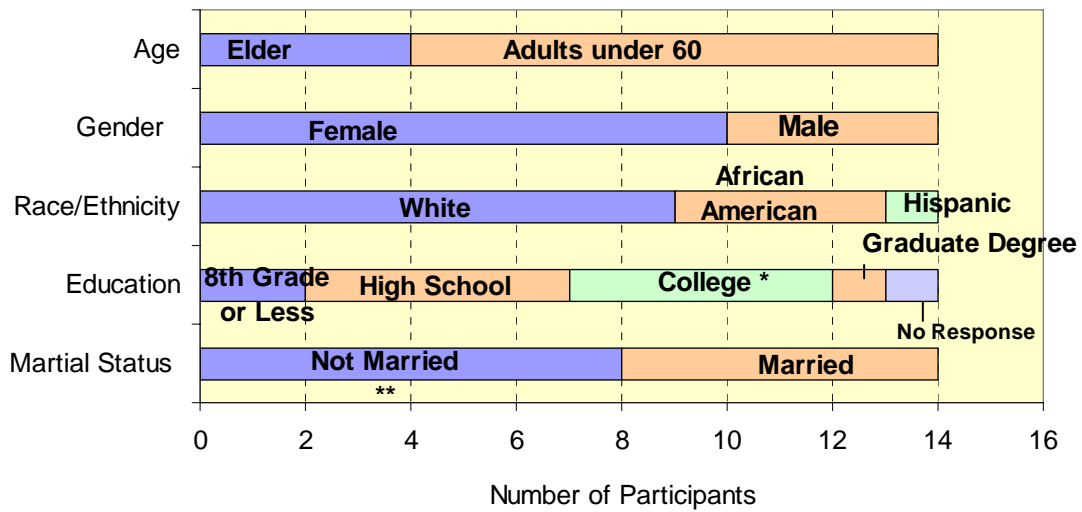
During the selection process, 15 individuals and several alternates were selected by the Selection Committee to advance to the assessment phase (alternates were to be enrolled if one of the 15 did not enter the Pilot or if Pilot funds could support more than 15 individuals). Of these 15 individuals, seven individuals were SCIL applicants and eight were ESWA applicants. All SCIL applicants who were selected were eventually assessed and enrolled. Of the eight ESWA applicants, four individuals were assessed and enrolled. Four individuals refused an assessment because they were unaware that a Pilot application had been submitted on their behalf and were not interested in participating in the Pilot.

Consequently, the Selection Committee then engaged in additional selection to enroll applicants for the Central area. In these selection rounds, three individuals were selected, assessed, and approved to enroll in the Pilot. One individual was assessed but chose not to enroll in the Pilot after the assessment because of concerns about directing her worker. The individual was planning on hiring her mother who was not interested in being paid. Four more applicants were later selected and assessed but were denied enrollment in the Pilot. These individuals were not enrolled because of a lack of state agency sponsorship after the Pilot, for example, or the lack of clarity pertaining to unmet needs. In the end, 15 participants were enrolled and moved forward with assessments and spending plan design.

Demographics of Pilot Participants: By August 2005, although 15 people had enrolled, one participant from the Central area disenrolled reportedly because she did not need the service. Another participant from the Southeast area moved out of state leaving 14 participants. Of these 14 participants, ten were white while four were non-white. Even with the small number of participants, the Pilot had enrolled participants of diverse ages and disability groups, as well as race and educational levels. Of these individuals, nine were women and five were men. Nine out of 14 participants were under the age of 60 while five were over the age of 60 (see Figure 2 for key characteristics of Pilot participants).

⁷ The Real Choice Assessment Tool was developed with the 2001 Massachusetts Real Choice grant funding. It was intended to be used for different target populations regardless of service needs, and was being Piloted within the Real Choice Pilot.

Figure 2: Demographic Characteristics of Real Choice Pilot Participants (N=14)



Note: Age is as of November 2006, time of writing.

Note: Elder denotes individuals 60 or older.

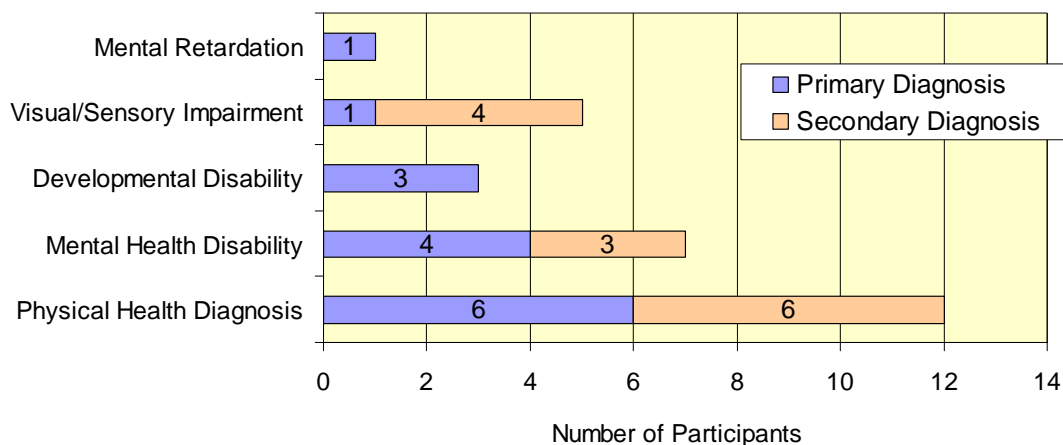
*College includes responses of “Some College” and “Bachelor’s Degree”

**Not Married denotes “Never Married”, “Widowed”, “Separated or Divorced”

Source: CHPR Analysis of Participants’ Assessment Data

Disabilities/Diagnoses: Most participants had complicated medical needs, although participants with the most intense ADL needs were concentrated in the Central area. Mental health disability was reported by half of the participants. When selecting target groups, seven individuals reported having mental health disabilities and one participant reported having mental retardation. One participant reported having a traumatic brain injury. Other diagnoses included Parkinson’s disease, spina bifida, leukodystrophy, and multiple sclerosis. Visual impairment was present to a significant extent, e.g., due to ophthalmic disorder or strokes (see Figure 3 for disability types of the participants.)

Figure 3: Primary and Secondary Diagnosis of Real Choice Pilot Participants (N=14)



Source: CHPR Analysis of Participants’ Assessment and Re-Assessment Data

Issues Encountered During Outreach and Enrollment

A number of lessons learned emerged from the outreach and enrollment process, although this process involved only a short time period. These are described below.

Mixed Consumer and Provider Reactions during Outreach

Outreach staff who participated in the focus group stated that they received a mix of responses from provider staff and consumers themselves. These reactions suggest that outreach could benefit from a well-crafted message to be disseminated during outreach. Specifically, outreach materials and staff should emphasize opportunities available through this model while addressing common concerns. A balanced presentation of the model is crucial to ensure that participants understand the model well before enrolling in it. Specific responses and concerns communicated during the outreach and enrollment process are described below.

Benefit of Flexible Budgets: The majority of provider staff who were contacted about the Pilot had a positive response and thought this Pilot was a good option. In addition, most participants enrolled in the Pilot were excited about the program because there was “this pool of money that they could use to help themselves” in ways not possible through traditional services.

Worker-Related Concerns: There was some apprehension because the model was new. Some individuals expressed concern that they would have strangers coming in and out of their home, or “have things stolen” as in nursing homes. Although this reaction is based on traditional models of service delivery where

consumers do not hire, manage, and fire their own workers, it suggests that outreach materials could proactively address these concerns. SCIL staff thought that consumer trust of the agency conducting the outreach helped to soothe some of these concerns.

Difficulty in Collaborating with Other Agencies during Outreach

SCIL and ESWA were encouraged to collaborate with other agencies during the outreach process in order to reach all target groups. SCIL contracted with the Cape Organization for Rights of the Disabled (CORD) to conduct outreach for Cape Cod and the Islands. ESWA contracted with Easter Seals and the Center for Living and Working (an independent living center and an administering agency for the Personal Care Attendant program) to recruit participants for the Pilot in the Central area.

The roles of subcontractors varied for ESWA and SCIL. ESWA worked with Easter Seals and the Center for Living and Working to identify agency service providers and consumers outside of ESWA's provider network. These subcontractors then were responsible for conducting outreach to these groups. SCIL originally delegated the outreach and assessment work to CORD for any participants in CORD's service locations. However, after internal CORD resource changes made their staff unavailable for Pilot work, SCIL took on these responsibilities for both service locations. Similarly, ESWA staff cited some difficulties in working with their subcontractors. ESWA noted that it was a challenge to ensure that activities subcontracted out were completed in a timely manner given the time restraint. Since the Pilot (and the type of service delivery) was new to most providers in Massachusetts, having another provider conduct outreach made it difficult for ESWA to ensure that the Pilot was explained or presented accurately to others. It appears that confusion among providers as to how this model differed from the current PCA Program also caused challenges in effective outreach and enrollment.

Although subcontracting a specific function in a pilot program with few participants did not prove effective or efficient for the subcontractors, collaboration during the outreach phase could be useful in a larger implementation, especially to help some support brokerage agencies reach populations not typically served with consumer-directed models.

Clear Written Outreach Materials

Pilot experiences underscore the need to refine and clarify outreach materials, including written brochures and applications. Furthermore, it is crucial to provide materials in languages spoken by the target populations as well as in accessible formats such as Braille and large print.

Real Choice Pilot Brochure: The brochure was developed as a reference to explain the Pilot and to help interested persons decide whether to apply based on their needs and eligibility. While the brochure was only one of several ways an individual could obtain information about the Pilot, it was the official Pilot “advertisement” because it was used by all Pilot subcontractors. Focus group participants observed that while the brochure presented information on eligibility and contact information sufficiently, it did not include sufficient information on the Pilot itself. As a result, both ESWA and SCIL drafted introductory letters to accompany the brochure mailings to help people better understand the Pilot. In addition to providing supplemental information, the introductory letter lent a more personal air to the Pilot.

Outreach staff who participated in a focus group also voiced a need for the brochure to present a more balanced view of the program. While Pilot participants would have significant control over how their supports would be delivered, this control required increased consumer responsibility and initiative. Understanding this responsibility could help the applicants decide whether the Pilot was suitable for them and better prepare applicants for enrollment.

Real Choice Application Form: The application form for the Real Choice Pilot was designed by CHPR, with input from the ESWA and SCIL. It was designed to screen out individuals who did not meet the Pilot financial and clinical eligibility criteria. In addition, it was designed to capture diagnostic and demographic data to ensure that target groups and minorities could be served to the maximum extent possible. The application had four main sections: 1) basic demographic information, 2) MassHealth and PCA eligibility, 3) primary and secondary diagnosis, and 4) types of assistance needed, if any, with daily activities.

Focus group participants suggested several changes to the application to streamline the application process for applicants as well as for subcontractors. Recommended changes to the demographic section are as follows:

- Add “contact person” on the application. This addition is important because some applicants have guardians and/or caregivers who support them.
- Condense the section on “with whom are you living” since this information was not important to determine Pilot eligibility, target groups, or minority status. This information, however, was required in needs assessments to help determine informal caregiver support.
- Clarify eligibility criteria on the application. In the Pilot, the applicant had to be Mass Health eligible. However, the application form asked the applicant to choose among four choices: 1) have MassHealth, 2) do not have MassHealth but eligible and applying, 3) eligible for MassHealth but not applying, and 4) unsure if eligible for MassHealth. This made it unclear whether having MassHealth was a prerequisite for the Pilot. In addition, focus group participants felt that the application form should note that

- applicants cannot be eligible for the PCA program. Similarly, applicants were asked on the application whether they were eligible for the PCA program, ineligible, or unsure of their eligibility (giving the false impression that eligibility for the PCA program was not a disqualifying factor).
- Provide a list of diagnosis options. Having a list of diagnosis options may increase the possibility of receiving more complete information on diagnosis and save time for the applicant. In the Pilot, some applicants stated only their primary diagnosis, while omitting secondary diagnosis data altogether. Having a list would also be useful because some applicants cannot recall or report *all* their diagnosis without some prompting.

Ample Time for Outreach

Limited time was one major barrier that ESWA and SCIL faced during outreach and enrollment. The outreach and enrollment timeframe was shortened due to the delay for identifying sustaining funds and due to the limited time left within the Real Choice grant. A major impact of limited time was that subcontractors used mostly telephone or mailing outreach, instead of direct outreach, which, in turn, created ripple effects. According to subcontractor staff, telephone outreach was not highly effective because subcontractor staff could not convey information as fluidly as during in-person outreach. A likely factor for using telephone outreach was the limited staff for the Pilot administration. Direct outreach would have required more resources than available.

In addition, limited time during outreach and enrollment reduced the effectiveness of subcontractor collaboration. Collaboration takes time. However, subcontractors were pressured to meet outreach goals and had little time to build productive working relationships or to provide support and training on the Pilot to partners. Consequently, the productivity of outreach efforts may have been compromised. Aside from the time necessary to train and support partner agencies, time was also necessary for Pilot subcontractor staff to learn the Pilot model of service delivery themselves. SCIL staff stated that they became more comfortable with their own knowledge of the Pilot as the outreach phase progressed.

For future implementation of a similar program, sufficient time in the early phase of the program is critical to allow program staff to learn the model and to be comfortable with their knowledge before they can explain it to others. In addition, consumers need time to receive and review comprehensive information on the program and to ask questions. Such tasks may require more than one visit or telephone call to determine whether to apply or enroll.

In-person Outreach

In-person communication was viewed as one of the key components to successful outreach. In-person communication is important because it allowed Pilot staff to simultaneously convey information accurately, answer questions, and provide written materials for future reference. In-person communication seems more useful than outreach by phone because the number of ESWA applications received in response to telephone outreach was meager despite the large number of providers that ESWA staff telephoned.

In-person outreach can take the form of conducting informational meetings directly with consumers, families, and direct service provider staff, as well as with state agency staff. Pilot experiences suggest that to the extent that outreach can be conducted by various types of agencies, e.g., case management agencies, independent living centers, or supported living-based entities, a diverse pool of consumers can be reached. While direct outreach to consumers and families is critical, outreach should also include provider staff, given their role in the overall system of care.

Formal Mechanism to Assist Applicants

A mechanism to help potential applicants to learn about the model and to apply may be useful. This intake process appears to be possible in-person or by phone, depending on available resources. Some potential benefits are provided below.

- Intake staff could help applicants complete their application to ensure that it is accurate and comprehensive. This preliminary process could also ensure that applications were not submitted without the applicant's approval or knowledge.
- Intake staff could assist applicants in obtaining MassHealth eligibility documentation or other required documentation, if needed.
- Intake staff could use this opportunity to adequately inform applicants about their role and responsibilities as participants and answer any questions the consumer or the consumer's representative may have about the program prior to enrollment. The educational aspect of intake is crucial because it could help applicants make an informed decision about whether the program is right for them, thereby potentially reducing disenrollments. Conversely, it could help participants to start thinking about the support they may need if they decide to enroll.

Conclusion

Outreach and enrollment was an arduous phase in the Pilot implementation. Fewer individuals moved beyond the application phase than originally expected because they did not meet the eligibility criteria or were not aware that an application was submitted on their behalf. This indicated that applicants did not have an accurate understanding of the Pilot eligibility criteria, and that Pilot

outreach and education to provider staff could be improved. ESWA and SCIL were able to successfully enroll 15 participants by February 2005. One of these 15 participants disenrolled in August 2005.

For future implementations of this model, sufficient time and resources should be devoted to outreach and enrollment. Time and resources are necessary to conduct adequate consumer and community outreach and education. Increased consumer and community education could reduce the likelihood that ineligible individuals will apply for the program. Nevertheless, enrollment is likely to be slow—as with most new programs. The three original Cash and Counseling states experienced lags in enrollment, despite having staff solely dedicated to outreach and enrollment. Therefore, realistic goals for enrollment should be established, taking into account ineligibility and disenrollment rate, while allocating adequate resources and time to achieve those goals.