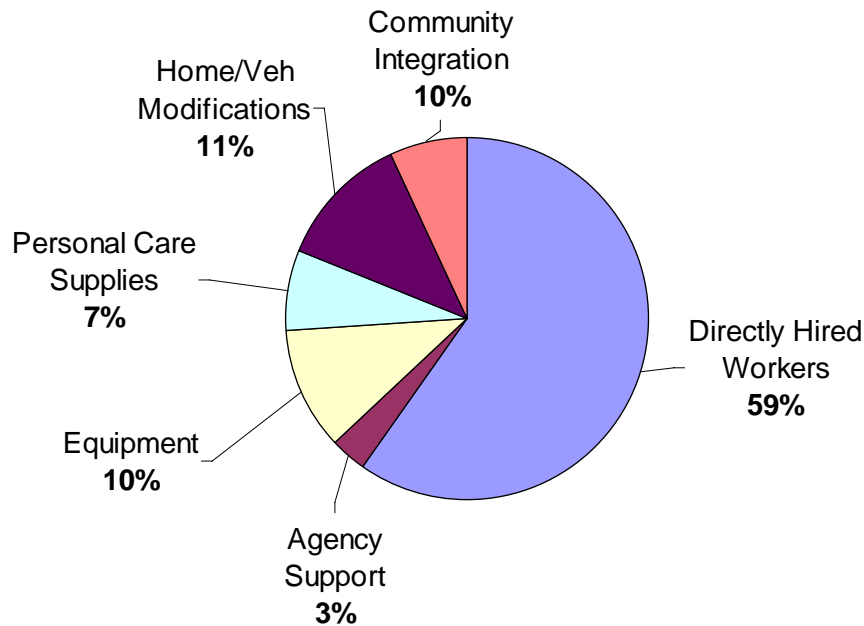


Introduction

The flexibility of the individual budget allows participants to craft (and re-craft) a spending plan based on their unmet needs related to their instrumental/activities of daily living (as identified in the assessment). In general, purchases to meet these needs can be broadly categorized as directly hired workers, agency supports, equipment, home/vehicle modifications, personal care supplies, and community integration. (These broad categories also represent how the spending plan document is organized).

During the first year of the Pilot, purchases in all of these broad categories were made. Twelve of the 14 enrolled participants used their individual budgets in the first year. (While the Individual Budgeting Report makes reference to 15 approved budgets, this Spending Plan section will describe data for 12 participants who actually purchased services using their Pilot budgets during the first budget cycle). Of these, the most common service was directly hired workers (to provide homemaking and/or transportation), followed by home/vehicle modifications and equipment. See Figure 6 for how budgets were spent by type of support.

Figure 6: Real Choice Pilot Budgets Used as of October 30, 2006 by Type of Support



Source: CHPR Analysis of Participants' Financial Statements

Each type of purchase will be described in more detail below.

Directly Hired and Agency-Based Workers

Workers for IADL/ADL Support

At the time of the initial spending plan approval, every participant was planning to hire either an individual or agency-based worker for assistance with activities of daily living (ADL) or instrumental activities of daily living (IADLs). Although most participants needed mostly workers for IADL and ADL assistance, a few participants received worker assistance for nursing and financial management services. In the first budget cycle, 12 out of the 14 participants had spent a total of \$71,285 on workers. This represents 58 percent of the actual amount spent and \$5,940 per participant per year.

Worker to Help to Self-Direct Services

Although all individuals were required to receive support brokerage services, some individuals required additional day to day support to assure transition from a nursing home or ongoing success in a consumer-directed model, e.g., completion of appropriate forms for spending plan purchase. This type of support was provided in the form of a case manager, nursing facility transition coordinator, or an “assistant”. It is likely that this support is comparable to what a representative might have provided. Although the Pilot did not mandate the use of a representative, purchase of this type of support suggests that participants identified this need and were able to meet it. See Table 3 for the types of activities that workers were hired to perform.

Table 3: Activities of Workers Hired Using Real Choice Pilot Budgets

	No. of Participants with Worker Performing These Tasks
Homemaking	10
Transportation	9
Personal care	8
Assistance in doing errands like shopping	7
Skill training	1
Assistance with Self-Direction Tasks	1
Case Management	1

Note: Some participants may have had other worker support from other funding sources, e.g., visiting nurse, case manager.

Source: CHPR Analysis of Participants’ Spending Plans

Workers' Relationships to Participants

About half of the participants hired family members or friends for ongoing support, while the other half hired either individuals they did not previously know or used agency-based workers. In general, participants who were able to hire their family members or friends to provide assistance were more likely to retain these workers than participants who hired non-relatives or friends. Specifically, about six of 12 participants hired friends or family as *ongoing* workers for ADL/IADL support. As of June 2006, these workers were still working for these participants. In contrast, five participants hired either agency-based workers or had workers whom they did not know for ongoing support. These participants experienced worker turnover at least once during the first year of Pilot participation.

Number of Workers per Participant

Most participants hired one to three workers, while a few hired more than three. Due to worker turnover, the number of workers hired in the Pilot was higher than previously planned at the time of the initial spending plan development. Another reason for some participants hiring more than one worker was that some workers could not be available at all days/times the participant needed assistance and therefore the participant had to hire multiple workers. By June 2006 (into the second budget cycle for nine individuals), the 13¹ participants had hired 32 workers. One of these 13 participants was the participant who passed away in December 2005. Initially, participants planned to hire 24 workers at the initial spending plan development. Twenty-seven out of the 32 workers (84 percent of all hired workers) were directly hired by the participants while five workers were associated with provider agencies. See Figure 7 for a summary of these data.

Figure 7: Number of Hired Workers in Real Choice Pilot



Source: CHPR Analysis of Financial Statements

¹ As of June 2006, the number of participants using their Pilot budgets increased from 12 to 13.

Biweekly worker hours ranged from two hours to 72 hours, with an average of 50 hours every two weeks.² The hourly wage for directly hired workers ranged between \$10 and \$16. Worker wage was decided entirely by the participant. (Currently, the wage for personal care workers hired through the MassHealth Personal Care Attendant program is \$10.84³). Because participants must pay 11 percent in employer taxes when hiring workers directly, the real average cost of hiring direct workers was approximately \$18 per hour.

Back-up workers, which were required for every direct worker, were generally paid slightly higher than regular workers. All participants in the Central area also had a second-level of back-up that was provided by an agency. The hourly rate for these agency back-up workers was \$23.96.⁴

*Worker-related Difficulties*⁵

During the first annual budget cycle, five participants experienced worker-related difficulties. Two participants had workers who did not report to work on agreed upon times and days: one was using agency-based workers and the other was directly hiring workers. Both participants eventually found directly hired workers, who at the time of this writing were performing satisfactory work. Another participant's two workers resigned because they found the participant difficult to work for. This participant eventually found another worker with whom he was satisfied at the time of this writing. The other eight participants who hired individual workers experienced very low direct worker turnover. This low turnover was also the case with one participant who used agency workers. It may be noteworthy that all five participants who experienced worker-related difficulties reported having a mental health or psychiatric disability.⁶

Transportation by Worker and Agency

Transportation was another common purchase that participants made with their budgets. In fact, all of the 14 participants reported in their initial assessments to have difficulty in obtaining transportation. Nine out of 14 participants (64 percent) paid out-of-pocket for transportation each month. The average out-of-pocket transportation cost for these participants was reported to be \$47 per month at the time of their initial assessments. At the second assessment, the out-of-pocket expenditures were slightly more.

² Workers were paid every two weeks.

³ The PCA program also includes payment of employer taxes.

⁴ To Pilot a second-tier emergency back up system, ESWA agreed to contract with the local home health agency for emergency back up support.

⁵ Community liaison contact reports were the data source of these worker related difficulties.

⁶ Worker management difficulties did not arise for the Pilot participant with cognitive impairment because her adult foster care provider hired and supervised her workers, who were relatives of the foster care provider.

Consistent with the unmet need of transportation, 13 out of the 14 participants⁷ had a worker who provided transportation support by June 2006. In addition to transportation provided by individual workers, two participants used their budgets on a more regular basis to purchase transportation from sources such as cabs or shuttle services. These purchases underscore what advocates and providers have recognized as a major unmet need for people with chronic conditions living in the community.

Personal Care Supplies, Medical Equipment, and Home Modifications

In general, ongoing expenses in the form of workers represented the majority of the total budget utilization. Other expenses were agency supports, such as transportation, equipment, home modifications, personal care supplies, and community integration (some of which was also transportation). One-time purchases included mostly personal care supplies, computer or durable medical equipment, home modifications, community integration costs (such as classes that require upfront payments), and one-time costs to transition to the community from a nursing facility. See Table 4 for a review of some of the more common purchases.

Table 4: Common Purchases during the First Budget Cycle in the Real Choice Pilot

	Number Purchased (Planned)	Unmet Needs
Computers	4 (7)	Employment, Educational and Community Integration
Scooters	2 (3)	Mobility
Eyeglasses	2 (5)	Personal Care
Dentures	2 (3)	Personal Care
Exercising equipment	2	Physical Health

Source: CHPR Analysis of Spending Plans and Financial Statements

Scooters were sometimes purchased due to strict MassHealth eligibility standards. Eye glasses and dentures were sometimes purchased due to their exclusion from MassHealth payment at the time.

Purchases Related to Nursing Facility Transition

One-time Purchases for Transition

In general, individuals who have transitioned from nursing facilities back to their own independent housing (versus settings such as shared living arrangements, etc.) have needed about \$1,500 in one-time purchases, such as rent deposit, food, and furnishings.⁸ Based on the experiences of the Pilot, some transition

⁷ The one participant who did not have a worker assistance for IADL is the same participant who did not use her budget at all during her first annual budget cycle.

⁸ This estimate was identified by the Bridges to Community Systems Change grant.

purchases can be planned (i.e. furniture and first month utilities) while others will be less predictable (i.e. shopping for food the day of discharge). Nevertheless, proper planning can help to minimize unforeseen purchases while maximizing the extent to which purchases can be made prior to the actual move, even when these purchases may not be available until the day of the move.

Targeted Case Management for Transition

For the two individuals who were living in nursing facilities, their success in returning to the community was partly attributed to the intense assistance they received to move out of the nursing facility, e.g., looking for housing and setting up home-based supports. One individual received this assistance from a case management program specializing in nursing facility transition⁹ while the other individual's source was staff at the local independent living center. Regardless of the source, this type of intense support is critical in assisting individuals' transitions into the community and should be paid for, either through the individual budget or through administrative costs.

By January 2006, two participants had used their individual budgets to move from a nursing facility to the community. One of these individuals, however, was re-admitted into a nursing facility for rehabilitation in 2006, but is looking to return to the community once again. (Use of the budget will be involved for the transition). See Table 5 for key characteristics of these two participants and their use of the budgets.

⁹ This program, Bridges to the Community, was funded by the Nursing Facility Transition grant from the Centers for Medicare and Medicaid Services and assisted individuals in the Central Massachusetts area to transition from nursing facilities to the community.

Table 5: Transitioning to the Community of two Real Choice Pilot Participants

	Participant 1	Participant 2
Identified needs prior to transition	Bathing, meal preparation, shopping, transportation, managing finances, and housework, education, skills training, and companionship	Bathing, meal preparation, housework, paying bills, shopping, and transportation
Spending plan	Worker for transportation and homemaking support Financial management worker One time transition items, deposits, clothing, furnishings	Worker for transportation and homemaking support Medical supplies and physical therapy related to osteoarthritis Computer One time items related to transition (deposits, home furnishings)
Informal caregiver support	None reported	None reported
New living setting	Own apartment	Own apartment
ADL/IADL functional score	19	9
Budget Allocation	\$35,000	\$21,000
Transition-related Requested Items	\$2,000	\$5,300
First Year Budget Utilization	\$28,000	\$8,000
Self-reported primary and secondary disabilities	Psychiatric Disability, Diabetes	Psychiatric Disability; Osteoarthritis

Source: CHPR Analysis of Spending Plans, Budgets, and Assessment Data

Unusual Requests for Spending Plans

While the vast majority of spending plan purchases conformed to the Pilot's policies on allowable versus non-allowable purchases, unusual requests for purchase arose. Although rare, these requests required time and coordination among the community liaison, their support brokerage agency, and CHPR, to decide whether such requests could be approved. See Table 6 for some of participants' requests for purchases, whether or not they were approved, and the rationale.

Table 6: Examples of Unusual Requests and their Outcomes

Requests	Denied or Approved	Rationale
Rental deposits for moving to another apartment	Approved	To cover some costs of moving after a fire in his apartment forced him into another apartment. In this case, the Pilot was able to help this individual to avoid homelessness
Air transportation for approved community integration activities	Approved	Air transportation for trip with building residents as part of previously approved community integration expense
Outstanding phone bills	Approved	Individual needed telephone for emergency access when transitioning from a nursing facility. Other methods to pay the delinquent phone bill were exhausted and an expedited payment source had to be identified as soon as possible to avoid compromising any safety issues.
Decorative household items	Denied ¹⁰	Unrelated to unmet needs
Attorney fees related to obtaining Custody	Denied ¹¹	Unrelated to unmet needs as identified on assessments

Source: CHPR Analysis of Spending Plans and Monthly Meetings of Pilot Subcontractor Agencies

Given the flexibility of the budget, it is evident that participants' requests for purchases may challenge mainstream thinking about what MassHealth funds should be used for. Moving forward, the administration of the model should include a process for review of nontraditional or unpredictable requests for purchases. Methods should respect the individuality and flexibility of the model while assuring public funds are used appropriately. To expedite this process, it is clear that guidance on allowable and non-allowable purchases be as clear and up to date as possible. In addition, participants should understand that they have the right to dispute a decision related to non-allowable purchases.

Conclusions

Once budgets were approved, budget utilization showed that most participants hired workers to help meet their unmet needs, underscoring that people with chronic conditions living in the community often need worker assistance for shopping and home care. Participants' use of their budgets also indicated the importance of a flexible budget to meet non-traditional needs, such as community integration, as well as unanticipated needs, such as moving costs after a fire. Overall, participants used their budgets judiciously and their purchases, such as computers, demonstrate that flexible budgets offer a useful complement to traditional supports to meeting needs and improving quality of life.

¹⁰ Participant used the appeal process and was subsequently denied given the lack of connection to long-term supports in the community.

¹¹ Participant did not appeal the decision.