

How Did Cash and Counseling Participants Spend Their Budgets, and Why Does That Matter for CLASS?

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The Community Living Assistance Services and Supports (CLASS) Plan – a groundbreaking component of the Affordable Care Act – creates a voluntary federally-administered insurance program to help individuals pay for needed assistance in a place they call home if they become functionally limited. Implementation will require knowledge translation from various sectors, including research and existing public and private programs. This Technical Assistance Brief Series seeks to answer questions pertinent to developing and implementing the program.

This brief addresses some similarities between the Cash and Counseling (C&C) model and CLASS, including participant control over a cash benefit, the ability to develop an individualized spending plan, the ability to hire family members as workers, and the availability of a range of programmatic supports to help participants manage their responsibilities. This brief describes how C&C participants have used their cash allowance, and suggests how these findings can inform CLASS implementation.

Introduction and Overview of Cash and Counseling

Cash and Counseling (C&C) is one of the most flexible models of participant-direction (also called consumer-direction or self-direction) in personal assistance services (e.g., help with daily living activities such as dressing, eating, using the toilet, etc.). The model offers participants who have disabilities and are eligible for publicly-funded supports the authority to manage a personal assistance budget. Flexible spending accounts, which are integral to the C&C model, provide an individualized budget comparable in amount to what the individual would have received through state Medicaid services (less administrative costs). C&C participants develop a spending plan for administering the budget. Participants can hire, supervise, and dismiss their own workers, set the schedule to meet their own daily rhythms (including evenings or weekends), and pay their worker more or less wages depending

on the circumstances. Participants can also use their funds to buy goods or services that support their independence (e.g., transportation, home modifications, and assistive devices). The litmus test of an appropriate spending plan is that it meets personal assistance needs and helps the participant to stay independent in the community. Counselors (also called support brokers or consultants) provide advice and program information, quality monitoring of services, and informal training in budgeting, planning, and recruiting and hiring workers. Some participants need more contact with counselors, while others have no difficulty independently managing their workers or their budgets. A participant who feels unable or unwilling to manage all tasks can appoint a representative such as a trusted family member, who acts as an advocate, decision maker, and spending plan manager when needed.

Over 5,500 elderly and adult Medicaid consumers in Arkansas, Florida, and New Jersey participated in the original Cash and Counseling Demonstration and Evaluation (CCDE) – a real world

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test of this model in which participants manage their own budgets (there were also about 1,000 children with developmental disabilities enrolled in Florida’s program; however, they are not included in this discussion as children are not eligible to participate in CLASS). Half were randomly assigned to manage their own budgets (C&C participants), while the remainder used traditional agency-directed services. Use of representatives by C&C participants ranged from 47% to 70%. Almost all participants chose to use agencies to handle financial management and payroll. C&C participants were highly satisfied, and 85-98% said they would recommend the program to others.¹ Compared with those who received traditional agency services, C&C participants reported more flexibility, control, and greater satisfaction with overall quality of life and experienced no greater adverse health events.² Over time, the C&C model has been shown to generate program cost savings by reducing institutional care.³ Reports also suggest that this model of service is successful for individuals with diverse disabilities, including those with physical disabilities as well as those with dementia⁴ and other mental health diagnoses.⁵

Why is C&C Experience Relevant for CLASS?

When designing and implementing C&C, program designers were faced with many of the same challenges that face CLASS. For example, program designers asked the following questions: What service design features would make the program most attractive and useful for potential

participants? What would participants want to purchase with their benefit, or what purchases are appropriate? What mechanisms would expedite these purchases? Who could participants hire as workers, and how would these hires be accomplished? What support services were needed and what might these services look like? How are employment and payroll obligations met? Currently there are approximately 17,500 C&C participants in 15 states who are managing individual budgets. C&C programs offer a rich source of information for CLASS designers and implementers. One of the major lessons to emerge from C&C data collection and experience is the importance of a broad and flexible definition of personal assistance spending. Participants have shown amazing creativity in using their budgets to meet their specific needs. Our experience is with a low income population; however, the lessons are transferrable to a broader audience – especially lessons pertaining to the various ways participants used their resources.

How C&C Participants Spent Their Budgets

Due to substantial cross-state differences in the services covered, maximum hours of service allowed, and area wage rates, the median monthly budget for C&C participants varied widely across the three original CCDE states (Arkansas: \$313; Florida: \$829; New Jersey: \$1,097). All three programs verified worker time sheets and requests for checks against spending plans before disbursing funds. In general, invoices for expenditures had to be submitted; however, up to 10% of

the budget in Arkansas and New Jersey and up to 20% in Florida could be used by the participant for incidental expenses (such as taxi fare) for which invoicing was impractical.⁶ When surveyed at nine months, between 32% and 59% of participants reported that they had used cash for incidentals in the previous month (depending on the state and age group).¹

Bulk of Budget to Hire Workers

Participants' spending plans were sometimes influenced by state program participation, design features, and rules. When spending plans were reviewed in the eighth month of participation, in general, about 85% of those participants who were receiving an allowance had hired a personal assistance worker. A lower figure (63%) for hiring by non-elderly adult C&C participants in Florida reflects the inclusion of Florida's developmental disability waiver programs, which offered a range of support services in addition to personal assistance. Some Florida participants had service plans that included only supplies, equipment, or therapy. In most programs, payment of workers represented about 75% of participants' budgets (43% for non-elderly adults in Florida).¹ Fringe benefits, including health insurance, life insurance, disability insurance, paid sick leave, paid holidays, paid vacation, free housing, reduced rent, free meals, or free use of the client's car, were negotiated individually between C&C participants and their directly-hired workers. Workers' compensation insurance or other liability insurance is an important benefit as it can protect participants from liability should any worker injuries occur.⁷ Approximately

30% of the agency workers reported that they received some fringe benefits during the CCDE. Directly-hired workers were much less likely than agency workers to receive fringe benefits (ranging from 6% to 18% depending on the type of worker and state).⁸

Florida and New Jersey allowed participants to hire legally liable family members (such as spouses) as workers, but Arkansas did not, partly out of concern that it would be politically controversial. In all three states however, participants could hire other relatives. More than half of the C&C participants chose to hire relatives to address unmet personal assistance needs, while only a small percentage of participants (about 5.5%) hired workers who were not previously known friends or family.⁹ Due to worker shortages in many areas, it is possible that some participants may have hired relatives due to a lack of other options. However, focus group and interview data have told us that many participants preferred hiring relatives because they found them reliable and sensitive to their physical and emotional needs.¹⁰ In turn, related workers were generally satisfied that the small amounts of pay they received enabled them to devote time to care for their loved ones. As a result, C&C participants were more likely than agency clients to get paid help with housekeeping and with routine health care, including help with medications, blood pressure checks, and physical exercise.² C&C participants reported higher levels of satisfaction with the job done by their hired workers, who were more likely to arrive on time and complete their work. They were more

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likely to receive paid service at crucial times such as evenings and on weekends. Benjamin et al. suggest that once related workers enter the labor force, effective retention practices may help them stay in the field permanently after their initial work with their loved ones is over.¹¹

Creative Purchases Enhance Participant Independence

C&C participants have exhibited a great deal of creativity in using program funds to purchase goods and services to meet their needs. Equipment, goods, and services are logical complements to human assistance, and in some cases can serve to substitute for that assistance. It is also worth noting that the budget option allows personal assistance services to be “unbundled” or customized to support the strengths and preferences of both the participant and their workers. For example, some participants and workers may prefer to use a laundry service, while others may include laundry in a worker’s assigned tasks.

Participants’ use of their budget allowances to purchase goods and services varied across age groups, states, and types of purchases. For example, program records at eight months indicate that about half of Arkansas participants purchased personal care supplies (such as incontinence supplies), compared with between 15% of Florida participants and only about 1% of New Jersey participants. Of non-elderly adult participants in Florida (mostly adults with developmental disabilities who were least likely to have hired a personal assistance worker), 32% used their allowance to purchase community services such as day care or housecleaning.

However, rates of purchase for these community services ranged from only 3% to 19% for the other state/age groups, who were more likely to have hired a personal assistance worker.

We examined fiscal records for 556 New Jersey participants (mean length of program participation was 14.9 months) to better understand purchasing patterns.¹² The financial management agency in New Jersey had recorded at least one assignment of funds for a good or service that was other than employment of a personal assistance worker, for 84% of these participants. Entries recorded over 325 different descriptive purchase labels (e.g., cleaning, laundry), and we grouped these purchases into 25 categories. Categories most often purchased were transportation (46%), laundry service (37%), and insurance (36%). CCDE program staff advised that insurance was usually purchased to protect against liability for in-home workers, although in some cases participants may have been insuring purchases like automobiles or computers. No other category of goods or services was purchased by more than 10% of participants, indicating the wide variation in the purchases participants make to meet their needs

Other items (or categories of items) purchased by approximately 5-10% of participants include:

- small kitchen appliances (e.g., toasters, microwaves, blenders)
- other small appliances (e.g., clocks, watches)
- durable medical equipment (e.g., braces, wheelchairs, scooters)

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- pharmaceutical items (e.g., diapers, pads, creams)
- prepared food
- large appliances (e.g., dishwashers, refrigerators)
- help with shopping or errands
- home modifications and furniture (e.g., mattresses, chairs, ramps, grab bars)
- miscellaneous personal assistance or companion service.

Items that were purchased by less than 5% of participants were:

- grooming equipment and services
- housecleaning
- telephone or telephone service
- postal or office supplies
- advertising
- outside chore services
- moving expenses
- vehicles or vehicle modifications
- computers and computer equipment
- massage therapy
- exercise equipment
- personal alarm systems
- miscellaneous self-help equipment (e.g., shoehorns).

Participants View Flexible Spending as an Important Program Feature

Interviews with counselors in Vermont (one of the 12 C&C replication states) provided many examples of clients’ creative uses of flexible spending plans. For example, one participant paid for a service dog that provided assistance with mobility along with cognitive and psychological support. Another

participant regained access to the community once he was able to repair his retrofitted van. Another participant bought home exercise equipment to maintain a consistent exercise regime, as it had been hard for him to attend physical therapy sessions during the winter months.¹³ New Jersey counselors provided examples as well: “I have a client who used some of the money to redo her bathroom... they redesigned the bathroom...so she can wheel herself right into the shower. They raised the toilet, they put in bars... she needed a lift so she can get in the wheelchair by herself.”¹²

Many participants viewed the flexibility to choose how they wanted to spend their money as a key program feature, and they provided their own examples that demonstrated the enormous value they derived from their creative uses of the flexible spending plan. They reported increased safety, comfort, mobility, independence, and ability to perform tasks. In addition, they often spoke of being able to get more for their money by comparison shopping, and by purchasing some items used. For example, one Vermont client reported that after she purchased an air conditioner, her ability to breathe more easily had significantly reduced her visits to the emergency room. Arkansas focus group participants were similarly forthcoming and mentioned a variety of modifications, equipment, goods and services, including help with appropriate grooming. “[With]...the money she gets, she gets her hair done, her toiletries”; “Yes, my daughter takes my mother to church and I give her money for gas”; I purchased a used washing machine and dryer”; “I had rails (installed) beside

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my tub and my commode.” Participants described the control over their own spending as empowering in the face of coping with functional limitations. This theme of personal individuality was repeatedly part of the focus group discussions as participants reinforced their program experiences with examples of unique purchases that had special personal relevance.

Flexible spending plans not only improved physical health and enhanced emotional well-being for participants, but they also had strong implications for state health care expenditures. In addition, flexible spending plans enabled participants to purchase goods at lower prices than the agency had paid in the past.

Demographics Influence Purchases

In a review of purchases in both Arkansas and New Jersey, the groups who were least likely to report purchasing equipment for personal activities prior to enrollment in C&C (males 65 and older in both states and females under 65 in Arkansas), showed the largest increases in the percentage of participants reporting these purchases during the first nine months of enrollment. The impact of the budget option for purchasing goods and services appears to have been greatest on what may have been the most underserved groups.

In our in-depth review of New Jersey individual spending plans, we found no significant differences by race or ethnicity for having made any purchase of goods or services (versus no purchase) with CCDE funds. However, there were some significant differences in the types of

items purchased. White participants were more likely to have purchased shopping and errands, housecleaning, computer equipment and supplies and massage or therapy, but less likely to have purchased laundry service. Black participants were more likely to have purchased laundry service, large appliances, and exercise equipment. Asian participants were more likely to have purchased outside chore services. Hispanic participants were more likely than Non-Hispanic participants to have purchased transportation and laundry service, although less likely to have purchased pharmaceutical supplies, home modifications, agency worker services, vehicle modifications, computer equipment and supplies, and therapy or massage.¹² Differences in the types of items purchased by participants of different racial or ethnic backgrounds most likely reflect a variety of social factors such as different rates of home and vehicle ownership, different cultural patterns of family connectedness, and different household traditions and priorities.

Savings

CCDE participants explained in focus groups that the ability to save funds was important.¹² All programs allowed for saving funds from month to month for a specified planned large purchase. To help participants make large purchases, New Mexico allowed participants to “borrow” money from their future budget allocation rather than accumulate money over time. While this approach helped participants with purchases, the state had difficulty if participants left the program before accumulating spent funds (i.e., repaying the “loan”).

The issue of saving funds for unspecified reasons, however, was more complicated. Program administrators tended to view unbudgeted funds as unneeded, while participants felt more comfortable having “rainy day” funds to cover unexpected expenses. New Jersey was the first to develop a specific policy stating that at the end of the year, any funds which were not earmarked for a specific purpose were returned to the state’s general fund. Under this policy New Jersey recouped \$3 million by 2005.⁸ Accumulation of unexpended funds is a sensitive issue, and programs need to reach a balance between encouraging thrift and economy (as well as acknowledging that participants may have unanticipated needs), versus allowing participants to accumulate unbudgeted funds left over from months when their personal care needs were met without these funds.

Participants’ Concerns about Program Procedures

In consumer focus groups during the CCDE, the majority of participants expressed overall approval of the program and appreciation of the difference their purchases had made in their lives. However, participants’ concerns about some program procedures are instructive. Arkansas participants felt that the record keeping and state oversight was more burdensome than necessary. Participants offered such comments as: “You have to write down and make a log of every dime we spend of the cash allowance. Before, we didn’t have to do that. ... I’m

not that educated and I’m not that crazy about writing,” or, “... They are asking for more records, receipts, bookkeeping. I appreciate what I’m getting, but I don’t think it’s anyone’s business how I spend it.”¹² While participant accountability is an important issue, budget option programs need to limit the record keeping burden imposed on participants. Additional training for participants may be useful as well.

New Jersey participants had a related concern about a lack of information about “their” funds. They suggested, “Make the consultants more aware of how to explain what is available to you,” or, “We don’t know what the balance is at the end of the month so we can’t utilize it.” It is important to have clear accounting and reporting for participants.

Finally, some participants and counselors were concerned about a lack of clarity regarding the decision process and rules for approving purchases. It is a difficult task to keep a program flexible enough to meet the needs of individuals and to allow for creativity in meeting those needs, while at the same time giving participants enough sense of program boundaries and limits. States have responded to these concerns by simplifying processes where possible, as well as by providing a variety of online and printed informational materials for participants and counselors, which include examples and scenarios of possible purchases.

Considerations for CLASS Plan Design and Implementation

In summary, extensive research and experience from 15 C&C states provide valuable lessons to inform CLASS design and implementation. We offer the following lessons and recommendations:

Individuals with Disabilities Possess the Capacity to Manage Resources.

C&C research and experience indicates that participants of all ages with diverse disabilities – including intellectual disabilities – can be successful in this participant directed budget model.

Supports (Counseling and Financial Management Services) are Important to Successful Participant Experience.

Participant supports, including counselors, financial services, and the ability to assign representatives, are essential for program success. Almost all participants used financial management services. These supports provide “checks and balances” regarding participant health and safety outcomes and appropriate use of public funds. Within the limits of the administrative cost cap, CLASS design should include funds for technical assistance in developing these services as well as training and supporting personnel who will offer them.

The Ability to Hire Relatives is Important to Participants. Most CCDE participants hired relatives as paid workers (including legally liable relatives when allowed). This is guaranteed in CLASS legislation.

Health and satisfaction outcomes for participants who were given the option to hire relatives were positive, and concerns about fraud and abuse unfounded. Clearly, the ability to hire relatives is an important program feature.

Program Features That Enhance Worker Recruitment and Retention are Critical.

Features such as the ability to offer fringe benefits can attract workers and help them stay satisfied with direct service positions. Within the limits of the administrative cost cap, CLASS designers would be wise to help participants offer fringe benefits on a large group basis and to encourage the creation of worker registries to help participants needing to locate workers.

A Flexible Budget Including Purchasing Goods and Services is Key. While C&C participants spent the bulk of their funds on personal assistance workers, the ability to buy a wide variety of goods and services was essential to their enhanced independence. Some types of purchases may substitute for human assistance, while others are intended to maximize the value or increase the retention of human assistance. Many purchases clearly benefit both the participant and workers (e.g., air conditioning, pest control) as both parties inhabit the same environment. Additionally, any purchase that helps the worker to be more efficient (e.g., a dishwasher) or to avoid burnout (e.g., respite, fringe benefits) ultimately benefits the participant. Participants used their budgets creatively, and their purchases of goods and services varied by type of disability, culture, and age. CLASS designers should maintain this flexibility to purchase a wide range of goods and

services (i.e., not just durable medical equipment and ramps but microwaves, refrigerators, air conditioners, etc.) so participants can reap the important benefits of this program feature.

Savings are Desirable to Participants.

C&C participants thought it was important to be able to save or accumulate “rainy day” funds, and they strongly preferred minimal record keeping. The CLASS legislation mandates record-keeping and implies that records would be audited periodically, such as when the individual comes up for a reauthorization of continued eligibility for benefits. However, the legislation does not say how detailed the record keeping has to

be. Participants also wanted a system that allows them to easily monitor their budget expenses and remaining balance. CLASS designers can incorporate this information about participants’ views regarding thrift and simplicity.

The extensive evaluation data and program experience gleaned from 15 state programs is a valuable resource to guide CLASS designers as they meet upcoming challenges. In particular, C&C participants clearly reported that the ability to purchase a variety of goods and services provided flexibility needed to help them maintain their independence in their communities.

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