Evaluation of the Cash and Counseling Program in Illinois

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BACKGROUND

Providing individuals who need long-term services and supports with the opportunity to self-direct has been an option in a select number of states and through the Veterans Administration for more than four decades (Benjamin & Fennell, 2007). Nationally, such programs have excluded persons because of old age or certain types of disability. An expansion of the self-direction concept to include a wide range of age and disability groups was comprehensively tested through the National Cash and Counseling Demonstration and Evaluation, implemented between 1999 and 2003 (Doty, Mahoney, & Simon-Rusinowitz, 2007). Using a randomized research design the demonstration found that individuals who self directed, including older people, did considerably better than the control group on a wide range of outcome measures including satisfaction with services, unmet needs, reduced nursing home use, and health and safety outcomes, such as falls. The research results were so convincing that the major funders of the initial demonstration, The Robert Wood Johnson Foundation (RWJF) and the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services (ASPE) authorized a replication project. With supplemental funding from the Retirement Research Foundation, Illinois was added to the 12 state replication project implemented between 2004 and 2008.

The Illinois program is administered by the Department on Aging and was piloted in four regions of the state, (Decatur, Peoria, Kankakee, East-St. Louis area). Pilot sites ranged in geographic location, and population to be served. A variety of host agencies including Catholic Charities of Joliet, Autonomous Case Management, the Macon County Health Department, and Southwestern Illinois Visiting Nurses Association were included as pilot sites (see Table 1). Addus HealthCare was chosen as the Fiscal/Employer Agency and was responsible for payroll,

tax withholding, worker criminal background checks, and monthly account communication with participants. Program enrollment began in October of 2007 with a pilot phase goal of 200 participants, which was reached in February of 2008.

Table 1
Illinois C&C Case Coordination Units and Area

Case Coordination Unit	Counties
Catholic Charities of Joliet	Kankakee
Macon County Health Department	Macon
Autonomous Case Management	Marshall, Stark, Woodford, Tazewell (City of Peoria to be added at a later time)
Southwestern Illinois Visiting Nurse Association	Bond, Clinton, Madison, Monroe, Randolph, St. Clair, Washington

Because of the extensive resources put into the evaluation of the initial Cash and Counseling Demonstration, the replication effort used the available grant resources for state implementation and technical assistance, rather than for research purposes. However, as part of the implementation process several states have included an evaluation component in their pilot program. In Illinois, the Department on Aging commissioned an independent evaluation of the program in response to state interests. The evaluation, which focuses on the initial 200 participants, addresses the following questions:

1. What are the characteristics of participants in the Cash and Counseling Pilot Program? How do these individuals compare to those enrolled in the ongoing Community Care Program (CCP)?

2. What are the service and administrative costs of participants in the Cash and Counseling Pilot Program? What types of goods and services do participants purchase? How do the service and administrative costs of Cash and Counseling consumers compare with those enrolled in the ongoing Community Care Program?

3. How satisfied are C&C participants with the help received through the program? What is the level of unmet needs reported by participants?

4. What are the rates and reasons for participants leaving the program?

METHODOLOGY

The evaluation relies on two major sources of information: (1) data collected by Cash and Counseling and CCP staff as part of ongoing program operations; and (2) data collected through telephone interviews with Cash and Counseling participants by research interviewers. Where possible, the evaluation uses the ongoing CCP participants as a comparison group for the Cash and Counseling Pilot participants. Although random assignment, the approach used in the original C&C evaluation, is the most powerful research design to evaluate a program of this nature, such a design was not practical in this study.

Data collected on Cash and Counseling participants by program staff included: participant characteristics, enrollment and termination data, and the fiscal intermediary (Addus) information on cost and type of expenditures. Program data were supplemented with telephone surveys. The surveys were conducted with Cash and Counseling participants who had been enrolled in the program for at least three months by Illinois Department on Aging staff and Scripps research interviewers. Sixty-nine participants completed the telephone survey, for a response rate of 54%. Questions focused on the degree of reported unmet needs and satisfaction with services from their direct service provider, case managers, and the fiscal intermediary.

A sample of 400 CCP participants who were receiving services in the four pilot regions of the Cash and Counseling implementation sites were selected as a comparison group. Program data for the sample included demographic and functional characteristics and service satisfaction data. We used this approach to have the Cash and Counseling sample and the CCP sample be as

similar as possible. Only CCP statewide averages for the satisfaction data were available and because of comparability issues these results could not be used in the analysis.

RESULTS

C&C and CCP Participant Characteristics

Both the Cash and Counseling pilot and the Community Care Program are designed to provide individuals age 60 and over who experience disability with the opportunity to receive long-term services and supports in the community. Both programs target individuals with high levels of physical and/or cognitive limitations. The demographic profile of participants served is presented in Table 2. Both programs serve individuals who are older, female, and not typically married. Although the two groups of participants are somewhat similar, there are significant differences between the two programs. The C&C group is less likely to live on their own (51% vs. 70%) and more likely to be non-white (51% vs. 31%). The C&C group is also less likely to be female (68% vs. 79%).

Table 2
Demographic Comparison of C&C and CCP Programs*

Characteristics	C&C Percent	CCP Percent
Age (Mean)	75.6**	78.4
Female	67.7**	78.5
Non-white	50.9**	31.2
Married	19.3	16.0
Living alone	50.8**	70.0
	(N = 183)	(N = 400)

*November 2008 Data, **p.05

In looking at functional characteristics, we again see a common profile, but with some significant differences between programs (see Table 3). Both groups report a high degree of functional impairment as measured by the participant's ability to perform activities of daily living (ADL). To calculate an overall ADL score, we identify limitations in each of six areas — eating, continence, dressing, grooming, transfer, and bathing — and add the number of impairments to achieve a total score. Limitations are determined by whether the C&C program participants can perform their tasks on their own or with assistance from another person[1]. C&C participants average almost four ADL limitations, compared to three for the CCP participants. On individual items, C&C participants showed significantly more impairment. For example, seven in ten C&C participants were impaired in dressing and grooming, compared to half of the CCP group.

Table 3
Activities of Daily Living (ADL) Comparison of C&C and CCP Participants*

ADL items	C&C Percent	CCP Percent
Eating	35.5**	26.0
Continence	48.6**	34.0
Dressing	69.4**	48.5
Grooming	70.0**	51.0
Transfer	75.4**	58.2
Bathing	91.3**	78.0
ADL (Mean)	3.90**	2.95
	(N = 183)	(N = 400)

*November 2008 Data, **p.05

[1] A 0 or 1 for the activity of daily living score indicated participant could perform activity and 2 or 3 indicated that the participant could not perform activity.

A review of cognitive functioning as measured by the Mini Mental Status Exam (MMSE) showed similar patterns, with a sizable portion of the sample experiencing limitations in this area (see Table 4). The MMSE is used to assess cognitive functioning by asking a series of questions that focus on time, orientation, recall, and language. The maximum score on the exam is 30 and a score of 23 or less is considered to be an indicator of cognitive impairment. About one-third of the C&C group was classified as having normal cognitive functioning, compared to half of the CCP group. On the other hand, 16% of the C&C group was classified as having severe cognitive limitations and 32% as moderate, compared to 7% severe and 21% moderate for CCP. The C&C group recorded a mean score of 19 compared to 23 for the CCP group. Finally, both programs use a calculated numerical rating, the Determination of Need (DON) score (range 29-89, with high score meaning more disability), to allocate resources to participants. The C&C participants recorded a mean score of 56, compared to 48 for the CCP sample. In summary, these data indicate that while both programs serve a severely disabled population, the C&C group is significantly more disabled on both cognitive and physical functioning when compared to the CCP sample.

We also present the profile of C&C participants by region. As shown in Table 5 there were significant differences in the demographic and functional characteristics of participants across the four sites. Average age ranged from 73 in the Macon site to 77 at the Southwestern Illinois Visiting Nurses Site. The DON score, which measures level of disability varied significantly across the sites as well. The average DON score of a participant in Macon was a 46 whereas those participating in C&C in Joliet had a DON score of 66. Understanding the differences in the target population being served by site will be an important question for ongoing program analysis.

Table 4
Comparison of C&C and CCP on DON Score and MMSE

Category	C&C Percent	CCP Percent
DON score (Mean)	55.5*	48.4
MMSE		
Normal	33.3	50.0
Mild	19.1	23.0
Moderate	31.7	20.5
Severe	15.9	6.5
MMSE (Mean)	19.0*	23.3
	(N = 183)	(N = 400)

*p.001

Table 5
Comparisons of Select Variables Across the C&C Sites

	N	Female Gender Percent	Family Help Percent	Authorized Representative Percent	DON	Age
Macon	43	68.0	56.0	40.0	45.5	72.7
VNA	41	75.5	42.9	49.0	49.2	77.4
Joliet	46	69.8	41.5	20.8	65.8	74.3
Autonomous	53	62.9	62.9	29.0	52.5	74.7
Total	183	68.7	51.4	34.0	53.4	74.7

The comparison between C&C and CCP participants identify some important differences between groups. The higher levels of disability experienced by C&C participants have also been found in other states and may be important as the state continues its efforts to keep individuals in their own homes as long as possible.

Services and Supports

Virtually 100% of the participants reported using the bulk of the allocated funds to purchase assistance with personal care (see Table 6). In addition, about three in ten reported using funds to purchase an emergency response system, such as Life-Line. One in five reported purchasing a range of goods to assist with life activities including such items as a microwave, a lift chair, a washing machine, and eyeglasses.

Table 6
C&C Services Description and Use of Budget

Average allocated budget (month)	$1,049[1]
Type of worker (%)	
Family	51.4[2]
Friends	31.8
Other	3.3
Missing	12.6
Service use (%)	
Have an authorized representative (%)	34.1[2]
Home care	100.0[3]
Emergency response	31.3
Goods	20.3
Examples: microwave, glasses, lift chair, washer	

[1]April 2008 Data (N = 147). [2] Four C&C site report (Nov. 08)
[3]ADDUS data November 2008 (N = 182)

A review of the type of worker hired by C&C participants showed that more than half hired family members (51.4%) and an additional 32% hired friends. More than one-third of participants reported using an authorized representative to assist in managing their care and expenditures.

Across the four sites, there were significant differences in the type of worker used and in the number of participants who chose to use an authorized representative (see Table 5).

Less than half (42%) of the participants in Joliet decided to hire a family member, whereas 63% of participants at the Autonomous Case Management agencies did. One in five participants used an authorized representative in the Joliet site, compared to nearly 50% in the Southwestern Illinois Visiting Nursing site. Again understanding these site differences will be an important quality monitoring function for the ongoing program.

Program Costs

Based on the DON score, determined through a comprehensive assessment (mean = 56), the average allocation for C&C participants was $1,049. Of this amount, $75 was allocated to the Fiscal/Employer Agency and the remainder was used by the participant for the purchase of services, equipment and goods. In calculating costs for the CCP participants the DON score allocation methodology was also used. However, as an additional step, CCP participant allocations were reduced based on a further review of need done during the assessment process. Additionally, in many instances the CCP participants did not receive the entire service allocation (worker no shows, visiting a family member during service hours) and actual utilization is often lower than the allocated amount. These two factors result in program costs for CCP participants to be 66% of the total allocation, or approximately $700 per month.

Previous cash and counseling programs have identified this trend of higher personal assistant services expenditures for self-directed participants. Self-directed consumers get their full service allocation leading to higher monthly costs than traditional consumers who typically do not receive 100% of allocated services during a month. In the case of the Illinois C&C program, policies have enhanced this cost differentiation. Cash and Counseling participants are not subject to the same cost adjustment at assessment that CCP enrollees

receive, resulting in a higher initial allocation. Because C&C participants are clearly more disabled on average, some cost differential would be expected. It should also be noted that the National Cash and Counseling Evaluation found reduced nursing home use in subsequent years, which also effected the cost/benefit calculation for the program (Dale & Brown, 2007). These cost differential issues will need to be examined in an ongoing program.

Satisfaction and Unmet Needs

To supplement program data, research interviews were conducted with C&C participants who had received services for three months or longer during the pilot phase. Sixty-nine respondents agreed to be interviewed over the phone in November, December, and January. The telephone instrument used questions primarily from the Participant Experience Survey developed by Thomson/Medstat, with some additional items specifically developed for the Illinois program.

Satisfaction questions focused on three dimensions of service received by participants; direct care workers, case managers, and the fiscal intermediary (see Table 7). The highest level of satisfaction was reported for the direct care workers, with 93% reporting that workers spent the majority of their time working, 94% reporting that their worker listens, and 97% indicating that their worker was respectful. An overwhelming majority of respondents had only positive comments about their workers such as doing everything they ask and having no problems with them.

Reports about case managers were also generally high with 97% feeling that their case manager was respectful. Nine in ten reported being able to talk with their case manager when needed, and 85% found the case manager to be helpful. Some of the comments provided by respondents about the program suggest some confusion about the different steps

involved in self-direction that could be answered by case managers. For instance, questions arose about how to contact case managers, what purchases could be made with the budget, how to use the budget to get the maximum hours, and whether there was a timeframe for purchases to be made. As the program continues, a closer examination into the information provided to participants by case managers may need to be explored.

Table 7
C&C Participation Satisfaction

Question item	C&C Percent*
Workers	
Spends majority of time working	92.5
Respect from worker	96.9
Worker listens	93.9
Case managers	
Case manager helpful	85.1
Can you talk to your case manager when you need to	88.7
Case manager respectful	97.0
Fiscal intermediary	
Can talk to PI when need to	82.3
Get info from PI that you need	58.5
PI staff treat with respect	91.1
	(N = 69)

*Yes, responses

Results concerning the Fiscal/Employer Agency were more mixed, with more than nine in ten reporting being treated with respect, but one in five reporting not being able to talk to the fiscal agency when they needed to and four in ten reporting not getting the necessary information. Respondents indicated that on some occasions they didn't receive their information on time, didn't get satisfactory answers, didn't like the attitude of the representative, and were told to contact their case manager which caused some confusion. As

the program moves to full implementation phase it will be important to continue to track participant reports in this area.

The survey also examined participant reported unmet needs (see Table 8). Unmet needs were lowest for core activities of daily living such as getting to the toilet (3.9%) and transferring, bathing, and meal preparation (between 10 and 12%). Areas of greatest unmet need were transportation (17%) and housework (24%). It will be important for the program to track these unmet needs over time to both get a better idea of the type of challenges faced by consumers and whether the program is able to have an effect on this dimension of life.

Table 8
C&C Participants' Reported Unmet Needs

Participant Reported Unmet Needs	C&C Percent
Toileting	3.9
Transferring	10.6
Bathing	12.1
Meals	10.6
Housework	24.2
Transportation	16.6
	(N = 67)

Rates and Reasons for Cash & Counseling Disenrollment

The pilot began in October of 2007 and by November of 2008, 50 participants were no longer enrolled in the program (see Table 9). Of those leaving the program, 60% of participants died during that time period, reflecting the frailty of this group. One quarter of the disenrollments involved individuals who moved from the area or chose to move in with family members or others. Eight percent entered a nursing home and 8% transferred back to

the original Community Care Program. One of the questions about self-directed programs for older persons is will participants and their families be able to handle the administrative complexities of the program? That four out of the more than 200 individuals participating in the program returned to CCP suggests that such an issue did not prove to be a concern. Another important finding is that C&C participants leaving the program are less likely to return to a nursing home (8% of those leaving, compared to 21% in CCP).

Table 9
Disenrollment From C&C and CCP

Reason	C&C Percent	CCP Percent
Died	60.0	28.4
Entered nursing home	8.0	20.5
Transferred back to CCP	8.0	NA
Other (Moved out of area, moved in with family)	24.0	51.1
	(N = 50)	(N = 1825)

*Four C&C site report

SUMMARY OF FINDINGS AND STUDY RECOMMENDATIONS

The evaluation findings include:

- Overall C&C participants have a high level of physical and cognitive impairment and on average are significantly more impaired than a sample of CCP enrollees from the same four regions of the state.

- There were significant differences in the functional characteristics of participants, the type of workers used, and the use of an authorized representative across the four Cash and Counseling sites.

- Cash and Counseling participants receive a monthly allocation of $1,049, an amount $350 higher than CCP enrollees. The majority of C&C funds are used for personal care, but about three in ten use an electronic monitoring device and one in five purchase goods such as a microwave or chair lift.

- Cash and Counseling participants report very high satisfaction rates with their direct care workers, high satisfaction rates with case managers, and mixed satisfaction with the Fiscal/Employer Agency.

- Cash and Counseling participants report low to moderate unmet needs with activities of daily living, but high unmet needs for housework and transportation.

- During the first year of the program, 50 individuals left the program, with 60% dying in this period. Eight percent left to receive care in a nursing home and 8% returned to CCP (4 persons out of 200 who were enrolled).

STUDY RECOMMENDATIONS

- The fact that the program is serving individuals with very high levels of disability is important to note and could result in reductions in nursing home use over time. The program should continue to track disenrollment and create a mechanism to compare rates to the Community Care Program.

- C&C is a family program. Families are heavily involved and in many instances are either representatives or providers. This results in C&C participants being more impaired than CCP consumers because they are able to remain at home with this family support. C&C participants are less likely to be placed in nursing homes and over time we believe that C&C participants will have lower nursing home use rates when compared to CCP.

- The cost differential between C&C and CCP should be addressed to some degree. An easy first step is to use the same budget adjustment for C&C as is now used for CCP when developing the initial service allocation amount. Because C&C is serving a more impaired population some cost differential is anticipated and the state should calculate what those differences should look like. As noted above, the state should carefully track nursing home use of C&C and CCP participants in the future to assess whether additional funds are saved through a reduction in nursing home use.

- On a related cost issue we recommend that the DON score allocation methodology be reviewed. C&C participants are significantly more impaired in physical and cognitive functioning yet they receive the same budget allocation from the DON score groupings.

- The mixed satisfaction scores reported for the Fiscal/Employer Agency suggests that a mechanism to assess participant views needs to be an ongoing component of the program. It is possible that as the program reaches a steady state some of the fiscal agency performance issues will change, but efforts to assess and improve are critical.

- State efforts to collect comparable satisfaction and unmet needs data for C&C and CCP participants is critical to ongoing program evaluation activities.

- Unmet needs appear to be high in the homemaker and transportation services. Further data collection with participants and case managers would be useful to gain a better understanding of this finding. This was an area that recorded large positive impacts in the initial national demonstration.

- The pilot has been able to implement the program in four sites across the state. As C&C moves to full implementation it will be necessary to build on the experiences of the pilot phase to assure a successful transition to a statewide program. Although the pilot experience indicates that the program design and structure provide a good foundation for statewide implementation, the variation in participant characteristics and circumstances found across the four sites need further study.

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