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Where are they now? Cash and Counseling successes and challenges over time

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Abstract

The positive results of the Cash & Counseling Demonstration and Evaluation (CCDE) led to the funding of a replication project that included 12 more states in 2008. Since then, the political and economic environments have changed. The authors sought to investigate how well the three original and 12 replication CCDE programs are coping with current challenges, and how their experiences may inform the growth and sustainability of emerging participant-directed programs. Semistructured telephone interviews were conducted with the 15 Cash & Counseling state program administrators. Key topics addressed included: successful aspects of state programs, biggest challenges for each program, and information program administrators would like to learn from state colleagues. Themes related to budget issues (e.g., staff shortages and program funding cuts) and non-budget related issues (e.g., understanding of program operations) emerged from the interviews. State program administrators also discussed program successes. To promote the

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sustainability and growth of participant-directed programs, existing participant-directed programs should be tied to national policy trends as well as review whether or not the programs address participant-directed principles. The development of new participant-directed programs should be based on other states' experiences as discussed in this paper.

Keywords

participant direction; employer authority; budget authority; long-term services and supports

The Centers for Medicare and Medicaid services (CMS) recognizes two basic models of participant-directed (PD) long-term services and supports (LTSS). Employer authority gives participants the ability to employ workers directly, while budget authority gives participants the ability to manage an individual budget and make purchases related to personal care. In the 1990s, a majority of states began to develop employer and budget authority PDLTSS programs, with perhaps the most important being the Cash and Counseling Demonstration and Evaluation (CCDE) –a large, randomized experiment of a budget authority PD model. The three-state (Arkansas [AR], Florida [FL], and New Jersey [NJ]) comparative effectiveness study has the largest research base and the strongest evidence of efficacy of any PD program. The CCDE showed significant outcome differences between participants in Cash & Counseling (C&C) programs and their peers who were participants in the agency-based system. Independent evaluators concluded that individuals who participated in C&C reported fewer unmet personal care needs and improvement in a number of health outcomes and were more likely to be satisfied with the quality of their care and their caregivers (Carlson, Foster, Dale, & Brown, 2007). The positive results of the CCDE led to the funding of a replication project, and by 2008, 12 more states had introduced budget authority programs modeled after the original Cash & Counseling Demonstration.

The success of the CCDE also encouraged changes in federal law, regulation, and policy, which facilitate the inclusion of PD services in LTSS programs. CMS has revised the §1915(c) Home-and Community-Based Services (HCBS) waiver application to include participant direction options, which mainstreamed both employer and budget authority programs. Congress passed the Deficit Reduction Act of 2005, which created new Medicaid statutory authorities for participant direction, including the §1915(j) that allows states to offer budget authority to Medicaid State Plan personal care services participants without having to operate under the §1115 demonstration authority.

Increasing interest in PD services has led to other grant programs. In 2007, the Administration on Aging (AoA) initiated the Nursing Home Diversion Modernization Grants Program (later the Community Living Program), which represented a significant non-Medicaid movement to consider PD services using the C&C design. The Veterans Health Administration (VHA) and the AoA joined in late 2008 to develop a program in the C&C model called Veteran-Directed Home-and Community-Based Services (VD-HCBS) to meet the needs of the growing numbers of veterans with service-related and/or chronic disabilities. Over a 12-month period (as of 2011), the impact of the changes in federal law,

policy, and programs resulted in approximately $10 billion of program costs across 298 participant-directed LTSS with about 810,000 program participants (Sciegaj et al., in press).

The growth of PDLTSS has been a positive development for consumers needing these services. However, times have changed, both politically and economically, since the original CCDE states and the 12 replication states developed their programs. Funds allocated for program start-up expenses have ended, and at the same time, many states have faced increasing economic uncertainty. In light of these changes, we sought to investigate how well the 3original and 12 replication CCDE programs are coping with current challenges and how their experiences may inform the growth and sustainability of emerging PDLTSS programs.

Project Significance and Purpose

Over the years, policymakers and program administrators have shown a keen interest in the performance and outcomes of the original 3 and 12 replication C&C states. Many changes have occurred since the conclusion of the original demonstration and evaluation in 2004 and the conclusion of the replication project in 2008. Since the grant funding has ended, state programs have been coping with the severe economic downturn. Policymakers have been looking at efforts to “rebalance” public funding on LTSS, including shifting spending from nursing homes to HCBS, in hopes of cutting costs and providing services more consistent with participant preferences (Doty, 2010; Walls et al., 2011). Simultaneously, federal policies have increasingly encouraged a PD model of HCBS, and there has been growth in the number of PD programs and participants (Sciegaj et al., in press).

Despite these national policy trends, some policymakers are now targeting Medicaid HCBS expenditures for budget cutting because they are optional Medicaid services (e.g., nursing home services, a more expensive option, are a required Medicaid service.) Although this cost-cutting approach may address an immediate budget need, there is evidence indicating that cost savings from HCBS accrue over time (Kaye, LaPlante, & Harrington, 2009; Mollica, Kassner, Walker, & Houser, 2009).

Given these circumstances, the National Resource Center for Participant-Directed Services (NRCPDS) – whose mission is to infuse PD options into LTSS nationwide –conducted a study in 2011 to determine how the 3 original CCDE states and the 12 replication states were faring and to learn about states’ technical assistance needs. Findings from the study concerning challenges which state programs face can inform policymakers as they make difficult program and budget decisions. National demonstration projects are seldom studied after the original project has ended, and these study findings offer lessons for states wanting to establish, sustain, and/or expand PD service programs. In addition to challenges state programs face, state program successes were also captured that can inform PD LTSS programs.

Methods: Data Collection and Analysis

The NRCPDS research team conducted semistructured telephone interviews lasting approximately 1 hr with each of the 15 C&C state program administrators (representing 16 programs)[1], between October 2010 and March 2011.

NRCPDS staff guided the development of interview questions, and Center membership records helped identify interview respondents. The research team piloted the interview guide with program staff from two states, and made revisions based on their comments. Interview questions included the following topics: key program features, information which respondents thought could be useful to receive from their state program colleagues, the most successful, aspects of each state program, and the two biggest challenges faced by each program. Two team members independently analyzed all responses and identified the themes which emerged, as well as the responses which were unique. The independent analyses were then compared to achieve group consensus on any interrater differences.

Results

Several overarching themes emerged from the interviews with state program administrators. These included budget issues (e.g., staff shortages, inability to enroll additional program participants, and program funding cuts) and non-budget-related issues (e.g., understanding of program operations and the acquisition of goods and services). In addition to these issues, administrators also reported several program successes that they felt would be useful to share with other state program administrators.

Budget Issues

Although we did not ask a specific question about the impact of budget constraints on program administration, most of the program representatives discussed financial issues when asked about program challenges. Three overarching themes emerged from the interview data: staff shortages and related difficulties in administering PD programs efficiently, program budget cuts, and enrollment limitations as a result of budget cuts.

Staff Shortages—Many respondents spoke about staffing problems for their programs. Half of the state representatives reported “staffing hits” in the past year because of budget cuts and the detrimental impact of these cuts on program administration. In one state, it had become increasingly difficult to generate data describing their program status because of staff losses. Other states also reported staff shortages due to budget constraints, with one indicating that their staff hiring was limited despite continued program growth. As a result of staff shortages, there was a need for state employees (e.g., program managers) to take on additional roles.

[1]The states were Alabama, Arkansas, Florida, Iowa, Illinois, Kentucky, Minnesota, Michigan, New Jersey, New Mexico, Philadelphia, Rhode Island, Vermont, Washington, and West Virginia. Florida has two consumer-directed programs, one for adults and children with developmental disabilities and one for older adults.

> [Because of] staffing issues, [there is the issue of] only being able to hire a certain amount of people in a division and a shortage of staff with continued program growth.

One respondent reported that because of the number of responsibilities acquired by state employees, it was difficult to pay close attention to all program details.

> [Because of the] number of responsibilities as a state employee, [it is] difficult to give attention to all [we] want to.

As a result of understaffing, one respondent reported that those who remained on staff did not necessarily understand participant direction concepts and program design.

> [We] have learned when [we] have program, people contract with the FI [fiscal intermediary] to provide the service, and the finance people in the waiver agents don't understand this service…[it] gets messy.

> Contractors need to understand the balance between offering assistance and allowing the participant to self-direct--such as when a contractor avoids going the extra step to educate a participant for program improvement when that education outreach is not specifically defined in their scope of work. This relates to the need for greater responsiveness and customer service improvements.

When discussing staff shortages, respondents explained that remaining staff were additionally challenged as they needed to function in multiple roles.

Inability to Enroll Additional Program Participants—State respondents reported a total enrollment of 20,500 participants. Despite program success, one state froze enrollment in its pilot program because of minimal administrative infrastructure to support the program. Another respondent feared that if enrollment opened statewide, it would be difficult to fund all program participants. As one program staff member explained:

> [There is an] uncertainty of state funding, tight funding of individual budgets, and concern over being able to expand statewide based on budgetary concerns.

Program Funding Cuts—Two state representatives reported program budgets being reduced, whereas seven representatives reported financial challenges potentially negatively impacting program process and enrollment. One respondent expressed concern about the uncertainty of state funding and the impact of this uncertainty on program expansion and individual participant spending plans amounts. Another state representative reported that they needed to revise the way individual budgets were formulated based on state financial restraints. A third state reported that the general assembly significantly reduced their existing budget. Even in states where the initial program budget was approved, program representatives still faced additional budget cuts.

> [We] had planned to ask for additional slots for the program and specific funding to grow the program. [But we are] currently facing proration where [there has been a] decrease [in the] amount of state dollars we get, even though the initial budget was approved. [We] face the possibility of further cuts.

Non-Budget Related Challenges

When discussing other non-budget related challenges, program managers mentioned concerns about participants' and employees' understanding of program operations and challenges faced in the acquisition of goods and services.

Understanding of Program Operations—Even though state staff reported being proud of empowering participants via PD programs, they still faced challenges regarding the individual budgets. One program reported that spending plan creation was quite cumbersome. Developing a budget and receiving services involves a vast amount of paperwork and complicated processes. Some consumers did not fully understand their role as an employer and the accompanying obligations of that role (e.g., submitting a budget). Another state reported an administrative challenge related to varying levels of support needed among consumers. It was difficult to devise a flexible support broker role that could accommodate these differences.

> To get [the]FI [fiscal intermediary] and the individual budget and the participants using the budgets and those authorizing the budgets on the same page… coordination among these entities [is difficult.]

The Acquisition of Goods and Services—Goods and services are a key foundational aspect to budget authority participant direction. Of the 16 program representatives who were interviewed, 10 spoke specifically about the acquisition of goods and services in their programs. Of those 10 representatives, 4 respondents reported that their programs have a list of permissible goods and services, 2 reported a list of non-permissible goods and services, 1 had both lists, and 3 respondents indicated that their programs have no list at all and work on a case-by-case basis.

Representatives also reported variations in how consumers might save for more expensive purchases. For example, if participants wanted to save for a wheelchair ramp, generally, the participant or their authorized representative established how much money to set aside each month towards the purchase. However, in one state, participants must obtain three estimates for the cost of the wheelchair ramp, and the care coordinator reviews the estimates and works with the participant to decide on a vendor.

Based on the 10 states that discussed their programs' goods and services benefits, states' processes for approval of goods and services varied considerably. Clearly, states have much to learn from one another regarding approval procedures. State representatives also indicated that they would like to learn from one another in regard to other aspects of the goods and services benefit. Some topics included the following:

- Addressing concerns about fraud regarding goods/services not included on lists of permissible services/goods

  > How [are states] addressing allegations of fraud? Fraudulent billing by [the] employee or member…[I] would want to hear from other states how they deal with Medicaid fraud investigators.

- Learning design details about the goods and services benefit by sharing information with peer state programs

  > [Do] other states have manuals with details for their operations? …That kind of manual is useful… [and] has been a useful tool in [our state] for standardization and information. [I]would be interested to see what other states' manuals would look like.

- Learning from other states how to help people be creative in developing their spending plans to meet their service needs

  > …how the person creates a budget and …puts the services on that instrument that allows them to make payments…

- Learning about other states' policies for saving to make a large purchase

  > For example, [you] learned that you could buy something upfront if [it is] specific to [your] medical need, so that looks different than your saving for 4months then making the purchase. What are the policies and procedures related around that?

State Program Successes

When asked to discuss their program successes, the state representatives described some examples. The following themes illustrate some of those areas.

Five interviewees volunteered that they had a good relationship with the financial management services (FMS) and had an FMS system in place. One respondent added that having both support brokers and FMS providers under one umbrella was useful for consistency of information. One program representative indicated,

> Excellent financial management services (FMS) as well. They offer customer service help [as well as] assist and teach people how to direct their own services.

Four respondents reported that they were proud of the program flexibility and, in turn, the ability to meet the needs of a diverse population. For example, one respondent credited two program features with the program's ability to meet individual needs by participants choosing their own workers, and using their budgets to buy various goods and services. Other respondents reported that individuals were empowered to be independent and control their care, and they would not be able to do so in the traditional agency model.

> The participants are more empowered and are taking more of a role of how their care plans are made out…participants understand [their] care needs better.

> Hear from people that [the program] have been a godsend. [It] has diverted nursing home placement.

> Participants, and family members continue to report an improved quality of life… because of the program.

Several state representatives explained that the program philosophy was supported and appreciated at the consumer level, and there was also program "buy in" across

administrative levels. This support was evident by program enrollee retention, support available at the program manager level (e.g., people knew they could call the program manager to ask questions about any aspect of the program), support at higher levels, as well as support with key partners and lead agencies across the states.

Several state respondents expressed pride in their communication with program participants, and others noted the good communication between the state and all program components. Other respondents expressed pride in their high quality program design and services.

Discussion

Total participant enrollment was 6,620 prior to the end of the Robert Wood Johnson Foundation (RWJF) funding across 11 of the 12 replication programs (O'Keefe, 2009). Despite a very difficult economy, significant budget cuts, and the end of RWJF funding in 2009, all of the C&C state programs (original CCDE and replication states) were operational and had a total 20,500 participants in 2011. Kentucky and New Mexico had total participant enrollment figures of 6,800 and 1,206 as of December 2012 and November 2012, respectively (DeMilto, 2013a, 2013b). These numbers suggest that despite funding challenges, programs persist and continue to grow.

Although struggling with tough economic times, all programs have survived and program staffs remain enthusiastic about the many positive aspects of PD services. However, state program staffs were eager to learn about many implementation issues from one another. In particular, they wanted to know how others were managing in the midst of budget cuts.

The poor economy continues to pose threats to PD programs as states make more budget-cutting decisions. These decisions are not necessarily informed by data and are not focused on maintaining PD principles. Two recent examples illustrate the need for vigilance with an eye toward preserving programs based on PD principles:

1. Minnesota introduced a policy to pay family caregivers 20% less than workers who are not related (Access Press, 2013).
2. U.S. Department of Health and Human Services, Office of Inspector General (OIG; 2012) issued a new report entitled Personal Care Services: Trends, Vulnerabilities, and Recommendations for Improvement. The report states that self-directed Medicaid service models are particularly vulnerable to fraud and cites one incident. However, there are no data to substantiate this claim. The report, and its claims that self-directed Medicaid service models are particularly vulnerable to fraud, may lead to negative policy implications. For instance, state administrators may cite the report to justify the termination of existing self-directed programs, which in many cases may be unwarranted. The NRCPDS has written to the OIG to request further evidence and information from OIG audits or elsewhere that support this generalized claim about self-direction.

The 16 C&C programs were developed with significant resources (e.g., RWJF grants, ongoing technical assistance, a network of peer states), and they benefited from this support in designing and implementing their programs. Yet, we learned that these states, which were

resource-rich at start-up, are now struggling in this economy. States developing new PD programs and expanding existing ones also need start-up resources. Yet grant funds for this support are not as readily available. For example, funding initiatives such as the CCDE, Next Steps Replication Project, and the CMS New Freedom Initiative, which funded program start-ups, have ended.

Recommendations

In-depth evaluation data and program experience have indicated that the PD option is an effective service model and can help reach LTSS goals which support health care reform. For example, this service model is a cornerstone of current efforts to rebalance public funding from institutional care to community-based services. However, states need resources to establish and maintain these programs. These resources are a wise investment to maintain programs which have the potential to offer high-quality services to participants with diverse needs.

Based on the rich information provided by C&C program administrators, the following recommendations offer potentially promising approaches to sustainability and growth of PD programs.

1. PD programs could be tied to national policy trends toward rebalancing and, most importantly, the Patient Protection and Affordable Care Act (ACA) of 2010 policy incentives to shift LTSS from nursing homes to HCBS (e.g., Community First Choice Option and Money Follows the Person). In addition, the trend toward rebalancing is consistent with the mission of the relatively new Administration for Community Living (2013) and the Veterans Administration's priorities (e.g., VD-HCBS program; Aging and Disability Resource Center, 2013). Another approach could be to develop further information related to cost savings and PD programs. The financial incentives provided by the ACA can give a financial boost to states wanting to create/expand PD programs; however, better data are needed to document PD program costs and potential cost savings of a C&C service model.
2. With many states developing managed LTSS programs in the hopes of cost savings, there is a need to review programs for PD principles because PD programs could be discontinued if these principles aren't a priority within the managed care programs. Special attention should be paid to the more complex aspects (e.g., goods and services) when following up with PD programs. Aspects of PD programs such as employer authority are likely to be preserved, whereas more difficult aspects of programs are likely to vary, such as varying needs of participant support.
3. The flexibility of PD programs (and extensive data documenting this program advantage) can help address the varying needs of an older population with disabilities. States that are developing new C&C programs can learn important lessons from the extensive evaluation data, program design materials, and special studies that have amassed during the past decade (Dale & Brown, 2005; Foster, Brown, Phillips, Schore, & Carlson, 2003; Phillips & Schneider, 2003). Program planners would be wise to build their programs on other states' experience, where

applicable. They can also obtain technical assistance from experienced experts through the NRCPDS.

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