

**Implementing Self-Direction Programs
with Flexible Individual Budgets:**

**Lessons Learned from the
Cash and Counseling Replication States**

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Executive Summary

Self-direction is a service delivery model that gives public program participants (hereafter called participants) greater choice and control over the long-term services and supports they need to live at home and participate in community activities. Self-direction represents a major paradigm shift in the delivery of publicly-funded home and community-based services (HCBS). Self-direction has two basic features—the employer authority and the budget authority. The employer authority enables individuals to hire, supervise, and dismiss individual workers (e.g., personal care attendants and homemakers). The budget authority gives participants a flexible budget to purchase a range of goods and services to meet their needs. Many programs offer the employer authority only, whereas virtually all programs that offer the budget authority also offer the employer authority.

Cash & Counseling (C&C) is a national program initiated in 1995 by The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation in the United States Department of Health and Human Services (ASPE/DHHS). The C&C program introduced the budget authority feature in the Medicaid program.

The C&C program has had two distinct phases: a 3-state C&C Demonstration and Evaluation (CCDE) and a 12-state C&C Replication Project. Both phases involved competitive grant awards to states to develop and implement options for Medicaid participants to direct individual budgets, and the provision of technical assistance to Grantees. Both phases were carried out by or under the aegis of the C&C National Program Office (NPO), located originally at the University of Maryland, College Park Center on Aging and, subsequently, at the Boston College Graduate School of Social Work.

Following the success of the CCDE, which was confirmed by the findings from the controlled experimental research design, the RWJF encouraged the replication of the C&C model by issuing competitive grant awards to 11 States in October 2004; the Retirement Research Fund awarded a grant to Illinois the following year. ASPE and the Administration on Aging co-funded the provision of technical assistance from the C&C National Program Office. The 12 States that received C&C Replication grants are

Alabama	Michigan	Rhode Island
Iowa	Minnesota	Vermont
Illinois	New Mexico	Washington
Kentucky	Pennsylvania	West Virginia

This report documents the Replication States' experience developing and implementing their new programs. The Grantees' experience can be divided into three stages: (1) planning, (2) design/development, and (3) implementation/enrollment. In each phase, Grantees encountered many challenges and addressed many issues. Understanding how they dealt with these issues and challenges provides valuable information for other states interested in creating

or expanding self-direction programs generally and programs with the budget authority specifically.

Overarching Lessons Learned

Three lessons learned cut across the three program stages of planning, design, and implementation.

Involving Participants and a Broad Range of Stakeholders in the Planning, Design, and Implementation of a New Program is Essential. Allowing participants to direct their services and to manage the budget for those services constitutes a major paradigm shift in the long-term care service delivery system and some stakeholders may not support—or may actively oppose—a new self-direction program. States need to conduct a stakeholder analysis to identify the new program’s likely supporters and opponents and to develop a plan to address both general and specific concerns.

The involvement of participants and their families and advocates will help to ensure that the new program will meet their needs, but can also be very effective in defusing opposition. For example, while case managers may feel free to tell state officials that they do not think participants are capable of directing their services, they are much less likely to express this view if potential participants are at the table stating they want the opportunity to do so.

Delineate Roles and Establish an Effective and Efficient Communication System. If multiple agencies are involved in program development and implementation, even if they have a solid working relationship, it is essential that each agency’s role be clearly delineated and that an efficient and effective communication system is established. If not, agencies tend to disagree about who has the authority to make policy, which delays timely decision making.

While states generally recognize the importance of involving stakeholders and the need to coordinate activities among multiple agencies, they often underestimate how much commitment, staff time, and resources are required

Develop a Formal Communication Strategy. A communication strategy serves many purposes: (1) disseminating information about the new program to potential participants, (2) educating everyone who will work with the program directly or indirectly about their roles and responsibilities, (3) addressing specific stakeholder concerns, (4) countering misinformation—both intentional and unintentional, and (5) dealing with outright resistance.

Although some components of the strategy may be emphasized at particular stages (e.g., disseminating information to potential participants during enrollment), all components are needed during all three program stages: planning, design, and implementation.

Many of the Replication States faced opposition to the new program among traditional case managers due to both lack of understanding about how the new program worked and negative views about the ability of participants—particularly elderly persons—to direct their services. In

such instances, a communication strategy needs to be targeted to address specific concerns using a variety of approaches: education, training, and working with influential opinion leaders whose support for the new program will be more effective in changing attitudes and overcoming or neutralizing the resistance of their colleagues than will the exhortations of state officials and program staff.

Lessons Learned in the Planning and Design Stages

A self-direction program with budget authority has three key components: (1) Counseling, (2) Financial Management Services, and (3) the Individual Budget. States faced a number of challenges in designing these program components.

Counseling. The provision of counseling services in a self-direction program generally entails some change in the role of traditional case managers, even if just a requirement to coordinate their activities with a counselor. One of the key lessons that many of the Replication States learned is that case managers' support for these changes can not be taken for granted. The more changes in their traditional role that the new program entails, the more likely that the State will face challenges, particularly if the new program is designed to have case managers provide counseling services and handle enrollment.

Before spending any time and resources designing a new program's counseling service, states need to determine the extent of case manager support for any changes in their role. If resistance or lack of support persists after initial information, education, and training is provided, states may want to consider other approaches, such as having a distinct role for counselors that will not alter the role of traditional case managers. If case managers and counselors have separate and distinct roles, it is essential that both program staff and participants understand these roles; conducting joint training for counselors and case managers is one option to ensure they understand each other's roles.

While it may seem obvious that states need to ensure that counselors understand the target population, two States faced situations where this did not happen. In programs that serve multiple populations—elderly, younger adults with physical disabilities, and persons with developmental disabilities—states should ensure that their recruiting and contracting policies—as well as their education and training—will produce a cadre of knowledgeable and qualified counselors.

Similarly, it may also seem obvious that states need to have a sufficient number of counselors available. However, it can be difficult to balance this need with counselors' need to have a sufficient number of clients to make their role financially viable. Having a large number of counselors with a small number of clients may result in some counselors leaving the program. If the initial response to a new program is greater than expected—as it was in some States—an insufficient number of counselors can lead to enrollment delays, which can dampen enthusiasm for the program.

Financial Management Services. Designing financial management services (FMS) and obtaining an FMS provider was a major challenge for many of the Replication States, which recommend allowing sufficient time and resources to find a reliable FMS entity (or entities) because they are key to the success of a new budget authority option. The States also recommend purchasing the best technical assistance available to save money in the long run and having an FMS subject matter expert on staff prior to implementation, or, at a minimum, a consultant who understands internal revenue service (IRS), state contract, and program requirements. Ideally, states will designate a staff person to stay current on all of the laws and regulations related to the provision of financial management services.

Individual Budgets. Designing the methodology for individual budgeting and dealing with concerns about the new program's costs were major challenges for the Replication States. While Medicaid does not require a self-direction program to be budget neutral relative to traditional services delivery, state legislatures and budget offices may require program staff to demonstrate that the new program will not cost the state more money than the traditional service delivery system, and program staff must be prepared to do so.

Program staff must also be prepared to spend a considerable amount of time educating all stakeholders about the budget methodology. Given that participants in the traditional service system in many states are not receiving all of their authorized services—but may do so once they can hire their own workers and purchase the goods and services they need—some States felt they had to discount the budget, which led to negative perceptions about the program in several states and slowed enrollment in others.

States are understandably concerned that serving participants in a new self-direction program could cost more than serving them in the traditional service system. But if the cost differential is due to the failure of participants to receive their authorized services in the traditional system, then states need to address this problem.

Finally, for all three program components—counseling, financial management services, and individual budgets—designing flexible policies and procedures from the outset will allow changes to meet unanticipated problems with a minimum of administrative burden.

Lessons Learned in the Implementation/Enrollment Stage

A key decision when implementing a new program is whether to pilot it, phase it in, or implement statewide from the outset. The consensus among the Replication States is that piloting or phasing in a new program affords an advantage because it gives program staff time to identify issues, and to refine policies, outreach techniques, and approaches to measuring quality prior to statewide implementation.

As noted earlier, a formal communication strategy is needed during every program stage. Communication strategies specific to the enrollment stage are (1) outreach and education to ensure that all eligible, and potentially eligible, individuals know about the new program; and

(2) the provision of sufficient information to enable potential participants to decide if the new program is right for them.

These activities often take much more time than anticipated, and the Replication States stress the importance of setting aside sufficient time and resources to plan and design materials for diverse populations and to involve the target audiences in these activities to ensure their effectiveness.

Because strategies that are successful in one state may not always work in another, states should examine others' communication strategies (e.g., letters, brochures, and outreach videos) and ask themselves whether there is some reason the same approach would not work in their state. (Many of these materials are available at http://www.cashandcounseling.org/about/participating_states.)

To ensure a smooth enrollment process, states need to be flexible, address problems quickly, and be prepared to change policies and procedures as better ways of doing things become clear. What seems logical in theory may not work in practice. For example, Michigan had to refine its budget template numerous times to increase the template's ability to accurately reflect participants' needs and service preferences, and Vermont changed its initial plan to have case managers provide counseling services when it became clear that they did not want to assume this role.

A key lesson learned by both the original three CCDE States and several of the Replication States is that dedicated enrollment staff can help to increase enrollment, particularly when a program is first implemented. If a state cannot afford dedicated staff as an ongoing expense, it should consider covering it for the first 6 months of a new program.

Minnesota contracted with three Centers for Independent Living for a 9-month period to provide enrollment assistance services in specific counties, which increased awareness of the new program among the target population, the counties, and managed care organizations (MCOs). Acceptance of the new program by MCOs was especially important because most older adults in the State's Elderly Waiver are enrolled in a managed care plan for both their health care and their waiver services.

Finally, a simple and efficient enrollment process is essential. Kentucky's initial enrollment process had over 40 separate steps and took 8 to 10 weeks to complete; since it was simplified, the enrollment process now takes 8 to 10 days.

Outcomes

The major outcomes for the C&C Replication Project are (1) the number of programs implemented and (2) the number of individuals enrolled. Eleven of the Replication States implemented their programs by the grant's third year; one State will implement its program in February 2009. In response to unavoidable delays in program implementation, many of the States did not implement their programs until the end of the second year or the third year of their grants. As a result, the grants were extended to a fourth year.

Given the delays, the two States with the highest enrollment targets—Minnesota and Iowa—established more realistic enrollment targets. The revised combined enrollment target for the 11 States that implemented their programs was 4,786 participants by September 30, 2008.

By December 31, 2008, the number enrolled across the 11 programs was 6,620. However, this number obscures considerable variation. Seven of the 11 States have not met their enrollment targets, though most soon will if current enrollment patterns hold. Three States exceeded their targets—New Mexico and Kentucky by a significant margin.

Discussion

The Replication States had to deal with many factors that delayed the development and implementation of their new self-direction programs.

Medicaid Policy Changes. While changes in Federal Medicaid policy throughout the grant period firmly established self-direction—and the budget authority in particular—as a mainstream option in the Medicaid program, they required additional work and caused major unanticipated delays for most of the Replication States, particularly for Alabama and Pennsylvania.

Bureaucratic Resistance. Some States had to contend with more resistance within their own bureaucracies to the paradigm shift from traditional to participant-directed services and had more inter-agency conflict than did others.

Problems with Existing Self-Direction Programs. Some States' existing self-direction programs had problems that needed to be addressed before the State would undertake the implementation of a new budget authority program.

Administrative Disruptions and Budget Shortfalls. Many States experienced disruptions that were not directly related to the new program, but which affected it nonetheless. Disruptions included changes in the priorities of key leaders, reorganization of the state administrative structure, cutbacks and turnover in state personnel, and budget crises that decreased support for the program. These disruptions made it difficult to give the new program the priority and resources it needed, or else complicated its development because too many other changes were taking place.

Once the program was implemented, several factors slowed enrollment in many of the Replication States.

Availability of Other Self-Direction Options. Many of the States had long-standing self-direction programs in which many participants already had the authority to hire and direct their own workers. In these States, the C&C grant served only to develop and implement a budget authority to allow participants to direct an individual budget and purchase goods and services. The new option proved confusing for many participants, case managers, and state staff, many of whom did not understand the value the budget authority offered.

Case Manager Resistance. Resistance from case managers has been greater and more difficult to overcome in some States than in others, and some States had more success in designing effective strategies for dealing with it than did others.

A Complex and Lengthy Enrollment Process. Kentucky and Washington experienced initially slow enrollment until they fixed problems with their enrollment process.

The major factor that facilitated enrollment was under-service in the traditional system. States that had a serious under-service problem—such as Kentucky and New Mexico—found it easier to enroll participants as did States that had minimal self-direction options available prior to receipt of the C&C Replication grant.

With regard to slow enrollment, two points are key. Before undertaking the extensive work needed to design and implement a budget authority program, states need to first gauge the underlying interest in the budget model among eligible individuals and try to predict take-up rates. Take-up rates will be affected by how appealing the new program is to potential beneficiaries and by specific concerns they may have.

Based on the CCDE and the Replication States' experience, states should anticipate that take-up will be quickest and highest when individuals have experienced a lot of difficulty obtaining traditional services or are very dissatisfied with the types of services traditionally available, or with provider quality. In states with this history, the program needs to have sufficient staff to process enrollment without delays by having the counselors and the FMS provider(s) ready to “hit the ground running” because they will not have the luxury of a slow learning curve. If a state already allows program participants to hire their own workers, experience suggests that the state may need to pay particular attention to developing a formal communication plan about the new option or program, which explains and emphasizes the “value added.”

The second point is that states need to have realistic enrollment expectations, recognizing that growth takes time and it may take several years for a new model to take hold. Self-direction—and the budget authority in particular—is not for everyone, but is an option that everyone should be able to choose. While sufficient enrollment is needed to sustain a program's infrastructure, the actual numbers enrolled or the percentage of eligible participants selecting self-direction is not as important as the positive difference it makes in the lives of those who choose it.

Nearly all of the Replication States' lessons learned are consistent with those of the three original CCDE States—as well as those of the States that received CMS-funded Systems Change Independence Plus grants to implement budget authority programs. Most of the challenges that these States have faced are so nearly universal that states planning to implement similar programs should be prepared to address them from the earliest stages of the planning process.

Although it is helpful to hold focus groups and conduct preference surveys, the resources to do so are not always available. But reading focus group and survey reports from other states can provide insight into the kinds of fears, misconceptions, distrust, and other resistance that program

administrators are likely to encounter from persons eligible to participate in the program, from traditional providers and case managers, and from within state government agencies.

The Replication States benefited from a considerable amount of technical assistance from the C&C NPO. For example, the NPO helped two States—New Mexico and Illinois—to obtain affordable workers’ compensation insurance for their self-direction programs, and sponsored training for fiscal employer agents. A great deal of this information is available at the Cash & Counseling website—<http://www.cashandcounseling.org>. In addition to communication plans, outreach and education materials, and various forms, the website also has resources specifically developed to help States address common challenges. For example, a tool kit for working with providers and addressing resistance is available, along with numerous other tools and materials that will enable states to design their program materials without “reinventing wheels” and spending resources unnecessarily.

Increasing Self-Direction Options

Funding for the C&C National Program Office ended with the completion of the C&C Replication Project. To enable other states to receive the technical assistance provided to the C&C Grantees to help them plan, design, implement, and evaluate self-direction programs—including help with specific issues such as obtaining workers’ compensation coverage—a new National Resource Center for Participant-Directed Services has been established.

The Center is funded by The Robert Wood Johnson Foundation, Atlantic Philanthropies, the Administration on Aging, and the Office of the Assistant Secretary for Planning and Evaluation, USDHHS. Its website is www.nrcpds.org. Resources available at the C&C website will remain available and will also be accessible from the new Center’s website. The Consumer Direction Module, a secure web-based software application specifically designed to support self-direction programs that allow individual budgets, will also be available through the new Center.

Finally, the RWJF has also funded the development of a detailed guide for developing self-direction programs—*Developing and Implementing Self-Direction Programs and Policies: A Handbook*—that is available on the C&C website at <http://www.cashandcounseling.org/resources/handbook>.

In sum, the experience of the Replication States demonstrates that it can take a long time for a state’s long-term care system to make a paradigm shift to a system that allows participants to have maximum control over the services they receive. Because state staff have little to no control over many factors that can significantly delay a new program, states that want to offer an entirely new self-direction program or a new option in an existing program should allocate at least two years for planning and development.

Despite the considerable time, effort, and resources needed to implement a new budget authority program, program staff in the Replication States believe it is well worth doing because the ability to direct services and supports makes a positive difference in the lives of many individuals with disabilities and their families.

Introduction

Self-direction is a service delivery model that gives public program participants (hereafter called participants) greater choice and control over the long-term services and supports they need to live at home and participate in community activities. Self-direction represents a major paradigm shift in the delivery of publicly-funded home and community-based services (HCBS). In the traditional service delivery model, decision-making and managerial authority is vested in professionals who may be either state employees/contractors or service providers. Self-direction transfers much (though not all) of this authority to participants. Many self-directing participants share authority with or delegate authority to family members or others close to them. Designation of a representative enables minor children, adults with cognitive impairments, and others who need assistance to participate in self-direction programs.¹

Self-direction has two basic features—the employer authority and the budget authority. The employer authority enables individuals to hire, supervise, and dismiss individual workers (e.g., personal care attendants and homemakers). The budget authority gives participants a flexible budget to purchase a range of goods and services to meet their needs. Many programs offer the employer authority only, whereas virtually all programs that offer the budget authority also offer the employer authority.

Cash & Counseling (C&C) is a national program initiated in 1995 by The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation in the United States Department of Health and Human Services (ASPE/DHHS). The C&C program introduced the budget authority feature in the Medicaid program.

The C&C program has had two distinct phases: a 3-state C&C Demonstration and Evaluation (CCDE) and a 12-state C&C Replication Project. Both phases involved competitive grant awards to states to develop and implement options for Medicaid participants to direct individual budgets, and the provision of technical assistance to Grantees.² The first phase is described briefly in the box on the following page.

Cash and Counseling Replication Project

Following the success of the CCDE, which was confirmed by the findings from the controlled experimental research design, the original funders decided to encourage the replication of the C&C model.³ The RWJF made competitive grant awards to 11 states in October 2004 and the Retirement Research Fund (RRF) awarded a grant to Illinois the following year.⁴ The 12 states are

Alabama	Michigan	Rhode Island
Iowa	Minnesota	Vermont
Illinois	New Mexico	Washington
Kentucky	Pennsylvania	West Virginia

The Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation, and the Administration on Aging (through ASPE) provided funding for technical assistance to the Grantees. The technical assistance was provided or arranged by the C&C National Program Office (NPO) at the Boston College Graduate School of Social Work. During the replication phase, the C&C NPO developed additional tools to help the States to implement the C&C model (e.g., the Consumer Direction Module software program and a specific workers' compensation rate code). States were encouraged but not required to use these tools. The 4-year C&C Replication Project ended in the fall of 2008.⁵

All C&C Replication States had to agree to implement self-direction programs that conformed to the C&C model and to offer the new program to elderly persons and younger adults with physical disabilities, at a minimum. Inclusion of other groups, such as children and/or adults with mental retardation or other developmental disabilities (MR/DD), was optional.

Study Methods

Information about the Grantees' initiatives was obtained over a 2-year period from Grantees' presentations at meetings and on technical assistance calls sponsored by the C&C NPO, as well as from written progress reports compiled by the C&C NPO. Grant project directors were the primary source of information for this report and the State Liaison Mentors assigned to each State by the C&C NPO were secondary sources.

The Cash & Counseling Demonstration and Evaluation

The 3-state CCDE employed controlled experimental design methods to measure the impact of the C&C self-direction model compared to traditional modes of delivering Medicaid State Plan personal care services and Medicaid home and community-based waiver services. The demonstration states—Arkansas, New Jersey, and Florida—implemented their experimental C&C programs under Section (§) 1115 Research and Demonstration waivers between 1998 and 2000.¹

While the term “Cash & Counseling” was used to describe the national program and the specific self-direction model, the States adopted their own local program names. Arkansas's program is called *Independent Choices*, New Jersey's is called *Personal Preference*, and Florida first called its program *Consumer Directed Care* and later renamed it *Consumer Directed Care Plus*.

The CCDE States were required to adhere to the basic C&C model and to meet certain requirements necessary for the controlled experimental design evaluation but otherwise were given the flexibility to implement their programs in accordance with their own service delivery systems and political environments. Data collection for the CCDE ended in 2003, although the individual state programs themselves continued and are still operating in 2008.

During the first phase of the C&C initiative, the grant funding and the evaluation data collection had ended by late 2003. The major evaluation findings from all three States were published by July 2005.¹

In the same year, Congress enacted legislation that enabled states to implement C&C service delivery options in Medicaid without having to seek §1115 waivers, effective in 2007. This provision recognized that the C&C model had proved its value and thus was no longer considered an experimental model.

Project directors prepared summaries of their grants using a template developed for this study. The study's project director reviewed the summaries and conducted in-depth phone calls with the grant project directors and other staff to discuss the summaries' content, clarify ambiguities, and obtain additional information. Each State's summary was revised based on the initial phone discussion and returned to the grant staff for their review to confirm its accuracy and to answer any remaining questions. Subsequent discussion about revisions took place via e-mail and during final calls to the Grantees. The final summaries approved by the grant project directors provided the primary data for this report.

The Grantees reviewed this report and were provided an opportunity to update information about their grant a week prior to publication.

Content and Organization of Report

This report is not an evaluation of the impact of States' self-direction programs on participants' satisfaction with or access to paid services, nor does it evaluate the programs' impact on other outcomes of potential interest, such as Medicaid costs and take-up rates for Medicaid-funded home and community services. Rather, it presents the experiences of the Replication States, focused on (1) the major issues and challenges they had to address when planning, designing, and implementing their programs; (2) how they addressed these issues and challenges and whether they judged their efforts to be successful or not; and (3) the lessons they drew based on their experience.

The first section of this report provides an overview of the States' grant initiatives—their primary purpose and major goals. The following three sections describe the issues and challenges the States faced in three areas—program planning, program design, and program enrollment—and how the States addressed them. The content of these sections is organized by topic areas (e.g., financial management services, counseling, and individual budgets) and each topic area includes several lessons learned. The final section presents information on program enrollment and conclusions that can be drawn from the Grantees' experiences.

The Appendix includes an in-depth description of each State's grant experience. The descriptions are not intended to be comprehensive but, rather, to provide sufficient information for understanding issues the Replication States had to address when planning, designing, and implementing their new programs.

Overview of States' Initiatives

All of the C&C Replication States agreed to implement both the employer and budget authority in their self-direction programs.⁶ Within this broad framework, the goals of the C&C Replication States varied considerably. (See Exhibit 1.) Some States, such as Alabama and Illinois, planned to pilot their new programs in a limited geographic area before expanding statewide, whereas New Mexico planned from the outset to implement its new program statewide. Though some States planned to offer the budget authority as an option in an existing program and others offered it through a new program, this report refers in both cases to new programs unless a distinction is needed.

States also varied with regard to the Medicaid authorities they planned to use and whether they planned to implement a new waiver program or amend an existing one.

- Minnesota had already amended several Section (§) 1915(c) waivers to allow budget authority prior to obtaining its C&C Replication grant.
- Vermont planned to add a self-direction/budget authority option to a §1115 waiver application that had been submitted to CMS but was still pending approval when the State applied for the grant. (Approval was received shortly after the grant was awarded.)
- Iowa, Kentucky, Michigan, Pennsylvania, and West Virginia planned to amend existing §1915(c) waivers.⁷
- Rhode Island and Washington planned to obtain new §1915(c) waivers.
- New Mexico planned to obtain two new §1915(c) waivers to operate a single new waiver program.
- Alabama planned to obtain a new §1115 waiver but Medicaid policy changes required them to use a different authority.
- Illinois planned to pilot a self-direction/budget authority option in a program that serves both Medicaid-eligible and non-eligible adults over age 60. To avoid having to amend the 1915(c) waiver under which Medicaid-eligible participants receive their services, the State did not seek federal financial participation for Medicaid-eligible pilot participants.

Based on changes in Medicaid statute and CMS policy during the grant period, some States revised their original plans regarding which Medicaid authority to use. Due to internal issues, other States were not able to amend as many waivers as they had initially planned. Unlike two of the States in the CCDE—Arkansas and New Jersey—none of the Replication States planned to implement a new budget authority program under the Medicaid State Plan Personal Care Services option. A few of the Replication States already offered participants the employer authority (i.e., the ability to hire, manage, and dismiss workers) in their State Plan Personal Care programs. But at the time the grant was awarded, adding the budget authority to these programs would have required the States to apply for a §1115 waiver, which would have been more difficult and time consuming than amending a §1915(c) waiver.

Exhibit 1. Overview of Cash & Counseling Replication States' Initial Goals

Lead Agency & Program Name	Populations Served	Initial Grant Goal(s)
Alabama Department of Senior Services <i>Personal Choices</i>	Aged & Disabled ¹	<ul style="list-style-type: none"> Implement a pilot C&C program in two waiver programs in a seven-county region
Illinois Department on Aging <i>My Choices</i>	Adults aged 60 or older	<ul style="list-style-type: none"> Implement a demonstration project in a program (with a 1915(c) waiver component) that serves Medicaid and non-Medicaid eligible older adults, in four geographic locations to represent the State's rural, urban, small city, and mixed areas
Iowa Department of Human Services <i>Consumer Choices Option</i>	Aged, Disabled, MR, AIDS/HIV, Brain Injury, Ill & Handicapped	<ul style="list-style-type: none"> Amend six waiver programs to offer employer authority and budget authority for both personal care and goods and services Develop the infrastructure for the new self-direction option Enhance the quality assurance systems for all waiver participants
Kentucky Department of Medicaid Services <i>Consumer Direction Option</i>	Aged & Disabled, MR/DD, Brain Injured	<ul style="list-style-type: none"> Amend three waiver programs to offer employer authority and budget authority for both personal care and goods and services Develop the infrastructure to support the self-direction option
Michigan Office of Long-Term Supports & Services <i>Self-Determination in Long-Term Care</i>	Aged & Disabled	<ul style="list-style-type: none"> Develop a self-direction program to be available statewide Amend the <i>MI Choice</i> waiver to include a self-direction option
Minnesota Department of Human Services <i>Consumer Directed Community Supports</i>	Aged & Disabled	<ul style="list-style-type: none"> Implement a budget authority option (already offered in one waiver) in two additional waivers, a state program, and the Title-III-funded National Family Caregiver Support Program, with a primary focus on increasing enrollment among older adults Expand essential services that support the new program and ensure their quality and availability statewide

(continued)

Exhibit 1. Overview of Cash & Counseling Replication States' Initial Goals

Lead Agency & Program Name	Populations Served	Initial Grant Goal(s)
New Mexico Aging & Long-Term Services Department, Elderly & Disability Services Division <i>Mi Via (My Way)</i>	Aged & Disabled DD, HIV/AIDS, Medically Fragile, Brain Injured	<ul style="list-style-type: none"> Establish a comprehensive self-direction program under two new waivers (one for a nursing facility level-of-care and one for an ICF-MR level-of-care) to serve individuals eligible for four current waiver programs and a new population—individuals with brain injury
Pennsylvania Governor's Office of Health Care Reform <i>Services My Way</i>	Aged, Disabled, MR, Technology Dependent	<ul style="list-style-type: none"> Implement the C&C model in the Aging waiver statewide and in six other waiver programs in selected counties
Rhode Island Department of Human Services, Center for Adult Health <i>PersonalChoice</i>	Aged & Disabled	<ul style="list-style-type: none"> Develop the infrastructure for a new self-direction program Transition participants who want to be in the new program from two existing waiver programs (one traditional and one with employer authority)
Vermont Department of Disabilities, Aging & Independent Living <i>Flexible Choices</i>	Aged & Disabled	<ul style="list-style-type: none"> Develop and implement a self-direction option in the State's new §1115 research and demonstration program for long-term care services for elderly persons and adults with physical disabilities
Washington Aging & Disability Services Administration <i>New Freedom</i>	Aged & Disabled	<ul style="list-style-type: none"> Develop a new waiver program to provide an individual budget option Develop the infrastructure for the new program Integrate the new waiver's quality assurance (QA) policies and procedures with the existing state QA system
West Virginia Bureau of Senior Services <i>Personal Options</i>	Aged & Disabled	<ul style="list-style-type: none"> Implement a self-direction option in the Aged & Disabled waiver and use this experience and lessons learned to develop and implement the same option in the Mental Retardation/Developmental Disabilities waiver

¹ Aged & Disabled is a Medicaid category that includes older adults and younger adults with physical disabilities.

Lessons Learned in the Planning Phase

Numerous policy, administrative, and political issues can significantly delay or completely derail a new program and need to be identified and addressed in the initial planning phase. These issues are complex and may take a long time to resolve. This section discusses the Replication States' experiences and lessons learned in three areas: selecting a Medicaid authority for the new program; obtaining stakeholder buy-in; and organizational, administrative, and political issues.

Understand the Pros and Cons of the Different Medicaid Authorities and Allow Sufficient Time to Obtain Them

When the C&C Replication grants were awarded in 2004, States had two options for offering a program with the budget authority under Medicaid: a §1915(c) waiver or an §1115 Research and Demonstration waiver.⁸ If they chose the §1915(c) authority they had to decide whether to amend an existing waiver or apply for a new waiver. CMS policy regarding self-direction changed during the grant period, delaying program implementation in many States, particularly Alabama, Iowa, Michigan, and Pennsylvania. (See box below.)

Changes in CMS Policy During the Grant Period

Starting in 2002, CMS encouraged states to apply for separate §1915(c) Independence Plus waivers to offer the budget authority option using an Independence Plus waiver template.¹ However, by the time the grants were awarded, CMS began incorporating self-direction options—including budget authority—into the regular §1915(c) waiver application template. The revised application made it much easier for all states to add self-direction options, including the budget authority, to existing waivers.

However, its introduction and subsequent revision during the grant period created a considerable amount of extra work for most of the Grantees because the new application required States to provide a great deal more information about how they planned to implement their waiver programs, with respect to both standard and participant-directed services. In some cases, this additional information revealed or highlighted aspects of states' waiver administration (sometimes longstanding) that had to be changed to comply with CMS waiver approval requirements before waivers could be renewed or amended.

Another major change during the grant period was the amendment of the Federal Medicaid statute under the Deficit Reduction Act of 2005 (DRA-2005) to create a new State Plan authority under §1915(j) of the Social Security Act for "cash and counseling" type programs.¹ As a result, the federal government would no longer approve applications to offer self-direction in the State Plan Personal Care option under the §1115 Research and Demonstration authority.

Although these policy changes caused delays for many Grantees, they made self-direction a mainstream service delivery option in the Medicaid program.

After spending over a year developing a §1115 waiver application, Alabama had to instead prepare an application to offer its new program—*Personal Choices*—under the §1915(j) authority. Alabama became the first state to have a §1915(j) State Plan amendment approved by CMS. Alabama recommends this authority to other states because a State Plan amendment is easier to prepare than a waiver amendment and no renewals are required. This has enabled staff to better support the new program because of the reduction in paperwork associated with periodic waiver renewals.

Iowa had to use the new waiver template to amend six waivers to add a self-direction option, and because it required information the State had not previously submitted, the waiver amendment process took over 2 years to complete. Pennsylvania’s State Medicaid Agency resisted using the new template until late 2006, which caused a major delay in preparing the required waiver amendments. The delay was compounded when two of the agencies that administer waiver programs encountered major issues with CMS while attempting to secure their respective waiver renewals.⁹

Because both the employer and budget authority options can now be offered under both authorities—§1915(c) and §1915(j)—states need to understand their specific provisions to determine which is the best fit with existing programs.¹⁰ If states choose the §1915(c) waiver authority, they have to decide whether to amend an existing waiver or implement a new one. Most states may find it preferable to amend existing waivers to ensure a smooth and rapid transition for participants choosing to leave traditional services for self-direction, and also for those who want to leave self-direction and return to traditional services. However, if a state wants to include a group not covered by an existing waiver—such as individuals with acquired brain injury—then a new §1915(c) waiver will be needed.

If states want to pay cash directly to a Medicaid participant or to offer the budget authority to participants in a State Plan Personal Care program, they must use the §1915(j) authority.¹¹ However, it is important to note that a state cannot amend its State Plan to use the §1915(j) authority unless it already offers personal care services under the State Plan or through a §1915(c) waiver program. If the latter, when beneficiaries move from a §1915(c) waiver to a §1915(j) State Plan program, the state still has to maintain the §1915(c) waiver that confers eligibility for §1915(j) and must periodically renew it.¹²

Obtain Stakeholder Buy-In

Potential participants are the most important stakeholders and should be involved in program planning and design. It is also important to involve participants’ families—who often play an important role in decisions about services—and aging and disability advocacy groups. New Mexico involved participants, family-members, caregivers, and advocates in the early planning process as well as the design, development, and implementation of its new self-direction program—*Mi Via*—in order to ensure acceptance of the program by its target population.

A new budget authority program can affect every process associated with a state’s current service delivery system—from referrals to transferring funds. Thus, states need to have a communication plan to help local, regional, and state staff and service providers understand the new program. Lack of state staff support, in particular, can significantly slow program implementation and delay enrollment. While states may intuitively understand the need to obtain state staff support, they often underestimate the time, effort, and resources needed to do so.

States can take steps to increase their support by conducting a stakeholder analysis to identify concerns and develop a communication plan to address them. However, lack of support may not be fully apparent until program enrollment begins.

Pennsylvania’s experience exemplifies the need to obtain the support of state staff and potential participants. When Pennsylvania received its grant, it already provided employer authority in eight waivers and two of these offered a limited budget authority. As a result, a frequent response to the new program from state staff was “we already do this.” Current waiver participants also misunderstood the new program, thinking it would have a negative affect on their existing ability to hire their personal care workers. Individuals in the developmental disabilities community were positive about the new program—but their support was based in part on a misconception that it would increase funding for their service system.

To address the lack of understanding and misconceptions, Pennsylvania’s project staff created an Advisory Committee with representatives from a broad range of stakeholder groups. This committee provided a venue to address stakeholders’ concerns and obtain their input.

During the grant’s first year, the grant manager had to spend a great deal of time attending Advisory Committee meetings as well as meeting with state staff and individual stakeholders.

When introducing a new self-direction option, considerable time and effort may also be needed to educate service providers and overcome inertia and/or resistance. For example, because

Minnesota’s managed care organizations (MCOs) operate according to a medical model, their management staff did not immediately accept self-direction or understand how it could work to their and their members’ benefit. Additionally, MCO care coordinators found it difficult to make the shift from a mindset focused on ensuring health, welfare, and safety to allowing individuals to make service decisions for themselves. Grant staff’s educational efforts have helped them make this shift and a few MCO care coordinators now assist in training efforts and help reduce resistance among their colleagues.

States should conduct a stakeholder analysis to identify potential issues that can cause delays and setbacks and champions who can help address problems. Once identified, states should develop a communication plan to promptly address stakeholders’ concerns.

In addition to creating and working with a stakeholder group, Minnesota’s grant staff noted the importance of working intensively to obtain the support of one or more influential entities—be it an MCO or an Area Agency on Aging (AAA)—so they can then serve as a program “champion”

or a role model and assist with educational efforts. For example, case managers who support the new program can help to reduce resistance among their colleagues. Rhode Island grant staff also noted that changing the views of just a few or even one influential individual or entity can have a major positive effect and that including home health agency staff and administrators in program design helped to reduce their resistance.

Michigan used a unique and innovative approach to ensure case manager and local staff buy-in, which was very successful. The *MI Choice* waiver is operated through an Organized Health Care Delivery System, which contracts with 21 waiver agents who in turn subcontract with service providers to deliver services to waiver participants. “Waiver agents” is the term Michigan uses for the entities—such as AAAs—that operate *MI Choice*. In addition to subcontracting with service providers, waiver agents provide some services, primarily case management.

To ensure that waiver agents’ perspectives and interests were the foundation of the new budget authority option in the *MI Choice* waiver, Michigan provided grants to waiver agents to pilot the new option in four “pioneer” sites. Waiver agents had to apply for a grant, which required them to describe their interest in and commitment to changing the system to allow participants more choice and control. Although grants were provided to the sites, each site had to provide matching funds and in-kind contributions to support this effort. The State selected the four waiver agents with the most positive plans who were also seen as leaders among the waiver agent system.

Michigan state staff worked with the waiver agents to design and implement the new option in the pioneer sites, which was critical to the program’s ultimate success. Waiver agent staff at the pioneer sites had expertise that was essential in the design and development stage as well as during implementation and quality monitoring. They also had the needed credibility to conduct training for Care Managers/Support Coordinators who provide both case management and counseling services. Michigan’s approach ensured the full cooperation of the entities responsible for the initial implementation of the new option, and the four pioneer waiver agents served as “champions” for the program when it was expanded statewide.

Early and continuing involvement of key stakeholders in a new program’s design is essential to ensure their understanding and buy-in. Although involving stakeholders is challenging and time-consuming and requires resources, it will help to improve program design, policy and practice; enrich participants’ experience; and ensure successful outcomes. Using a skilled facilitator is also valuable in helping stakeholder groups reach consensus.

At the same time, involving Michigan’s waiver agents in program design was challenging because each has its own distinct organizational culture and numerous groups of stakeholders had to evaluate the services available, determine which services most lent themselves to self-direction, and create new services to support self-direction, such as fiscal intermediary services. To be effective, implementation strategies, participant education materials, and policies and procedures had to be accepted by waiver agents as both realistic and reasonable.

It is important to note, however, that significant effort does not always ensure success. Vermont developed a strategy to obtain the support of key stakeholders—including home health agencies, AAAs, and aging and disability advocates—and spent considerable time educating them about the budget authority model both before it applied for the C&C Replication grant and after it was awarded. However, despite numerous attempts to understand and address providers’ concerns—including attending one-on-one and group meetings, making presentations, and forming a stakeholder advisory board—some providers remained concerned about the potential of the new self-direction option to take away their clients. In such cases, states need to determine ways to ensure that lack of support does not manifest in ways that undermine the new program.

Understand How Organizational, Administrative, and Political Issues Can Affect a New Program

In addition to the lack of state staff support (discussed above), Pennsylvania had to deal with a combination of organizational and political issues that significantly delayed the new program’s development. Medicaid budget constraints that occurred in the grant’s first year (but did not exist when the State applied for the grant) raised concerns in the Governor’s Budget Office that the new option would increase Medicaid costs—leading to a complete halt in program planning and design for over 2 years, until May 2006.

Because the grant was administered from the Pennsylvania Governor’s Office of Health Care Reform (GOHCR), staff assumed that its authority would be sufficient to deal with any resistance to the program. However, when program planning finally began, competing initiatives and administrative reorganizations led to the re-assignment of management staff as priorities changed and, as a result of inconsistent management, the project lacked the authority to make the new budget authority option a priority.

In addition to a longstanding lack of collaboration between the two departments that administer the waivers in which the budget authority option was to be implemented, the staff in these departments were suspicious of and resistant to initiatives coming out of GOHCR, making it very difficult to work collaboratively with them.

Ideally, the agency that administers a program will be responsible for implementing a new self-direction option in the program.

Eventually, the Governor issued an executive order to create a new entity—the Office of Long-Term Living, a joint office of the two departments.¹³ All of the grants and initiatives in the GOHCR were transferred to the new office along with many staff. Although the new office provides a standardized and less fragmented structure for accomplishing initiatives, many concerns remain about how the office will work with other agencies and divisions. As a result of all the issues and setbacks, Pennsylvania scaled back its initial goal of amending six waivers to add a budget authority option and now plans to amend two waivers and begin program implementation in five counties in February 2009.

Vermont, Kentucky, and Alabama also faced major administrative and/or political challenges. Soon after Vermont received its grant, a major departmental reorganization made it difficult to get staff to focus on the new program. As a result, much of the initial planning was carried out with little involvement from other state staff, which would have been helpful to increase buy-in by the State's field staff (e.g., RNs who perform assessments in the new program).

When multiple agencies are involved in program development, outreach, training, and implementation, it is essential to have a clear delineation of each agency's role and an efficient communication system. Without clearly defined roles there is a tendency for departments to disagree about who has the authority to make policy, which delays decision making.

Kentucky's newly-elected Governor ushered in a change in political party and a major turnover in top leadership. During the grant period, the State had four different Medicaid directors, and experienced lack of support and some opposition from Medicaid agency staff as well as changes in the staff responsible for the new program's implementation, all of which caused delays. Consequently, to meet the grant's timelines, implementation was rushed without first establishing all of the program's operational policies and procedures. As a result, they had to be frequently revised to reflect experience gained and to address problems encountered.

The frequent changes led both counselors and financial management services providers to lack confidence in their ability to serve potential and current participants; they were also frustrated with the amount of time and effort required to keep up with these changes. Participants were similarly frustrated with the frequent changes. Kentucky eventually developed a procedure manual that was distributed to everyone connected with the program, and program staff held trainings in-person and via video conference on a wide range of program topics. They also developed Provider Guidelines to answer questions, and hired a nurse consultant and social workers to be liaisons to the AAA's for troubleshooting program issues and to facilitate communication. These efforts, taken together, successfully addressed the initial challenges.

States should not undertake a new self-direction program without support from decision makers at the highest levels of state government.

In Alabama, although the three Departments that collaborated to design and implement the program have a very good working relationship, a considerable amount of discussion, negotiation, and experimentation was needed to arrive at a model that was workable for all agencies; and to educate state staff who have to deal with the

program, either directly or indirectly. Project staff did not fully anticipate how much time would be needed to educate and obtain buy-in from all stakeholders and how this could delay implementation. Several trainings were needed with case managers, counselors, and Medicaid program and financial staff, many of whom found it difficult to make the paradigm shift from traditional service delivery to allowing participants to have an individual budget to purchase and manage their services. Project staff found that having smaller break-out meetings during

trainings to discuss the concerns of individual groups enabled them to resolve many issues in a timely fashion.

In sum, it is clear that political change and agency re-organization is a fact of life in state government and delays are inevitable. States need to develop contingency plans to maintain enthusiasm for the new program and to make incremental progress. Some States planned an incremental approach from the outset. For example, West Virginia used a CMS-funded Systems Change grant to first develop much of the infrastructure for a new self-direction program and then used its C&C Replication grant to build on that effort.

If two or more agencies will operate a new program, states must ensure that they develop and sustain a commitment to coordinate and collaborate, which requires time and resources to enable staff to attend numerous committee and workgroup meetings.

Lessons Learned in the Program Design Phase

Medicaid self-direction programs that offer both employer and budget authority have three distinct and unique components not present in the traditional service system: counseling, financial management services, and individual budgets. Designing these program components is a complex task. States have multiple options to consider and decisions to make and the three components must work well together. This section discusses the challenges the Replication States faced in designing these components and their lessons learned.

Counseling

Counseling is a key supportive service that includes two broad activities—providing information about self-direction and providing assistance and training as needed with self-directed tasks using a person-centered framework. States use a variety of terms to describe the counseling role, including support broker, service coordinator, flexible case manager, consultant, advisor, and community guide. This report uses the terms counselor and counseling except when discussing specific state programs.

Self-direction programs vary in how they provide counseling services and in their use of traditional case management. In many programs, both case managers and counselors assist participants. In others, case managers assume the counseling role in addition to carrying out some or all of their traditional responsibilities, such as performing assessments and making level-of-care determinations.¹⁴

To promote the provision of high quality services, the self-direction philosophy and quality management strategies should be part of the design process and incorporated into solicitations for obtaining counseling and financial management service providers—and also in their contracts.

As part of its stakeholder analysis in the planning phase, states need to determine whether the new program has case manager support, and if not, develop a plan to obtain it. One way to do so is to include case managers in the program design process. Doing so will help to ensure their buy-in as well as to develop “champions” who can help to educate and reduce skepticism among their colleagues.

Clarify Differences Between Case Management and Counseling Services

Minnesota’s new program used both traditional case managers (called “required” case managers) and counselors (initially called “flexible” case managers). Required case managers carry out traditional responsibilities and their cost is not included in the participant’s individual budget. Flexible case managers provide education about the enrollment process and forms, and help the participant to write an individualized community support plan, employ and manage workers, and purchase goods. Their services are optional and their cost is paid from participants’ budgets.

After the program was implemented, widespread confusion among participants—and case managers themselves—about the differences between required and flexible case management led the State to substitute the term “support planner” for flexible case manager.

Generally, the Replication States’ programs have either distinct counseling and case management services or their case managers perform both roles. In contrast, Kentucky’s program was designed to have support brokers provide both counseling and some traditional case management services. However, the tasks, responsibilities, and parameters of the support brokers’ dual role were not clearly delineated prior to implementation of the new program, which caused problems. Some support brokers thought their role was limited to self-direction tasks while others thought they had a broader responsibility to ensure participants’ health and welfare, as do traditional case managers. Additionally, because implementation was rushed, some individuals who lacked case management qualifications and/or experience were initially hired to be support brokers.

To address these problems, Kentucky provided additional training for support brokers to reiterate their responsibility to ensure that all of a participant’s needs are met. The State also conducted conference calls with support brokers to clarify policies and procedures and answer questions, and added links on its website to other sources of information, such as the University of Kentucky’s Disability Resource Manual. Finally, the State developed a policy and procedures manual for the program, which discusses support brokers’ roles and responsibilities, and assigned state staff as liaisons to each of the AAAs (who hire support brokers) to answer any additional questions about the program. Support brokers who did not meet the qualifications for waiver case managers were reassigned to other jobs.

Ensure that Case Managers Understand and Support Changes in Their Role

Lack of case manager support and outright resistance to a new self-direction program was a major problem in many of the Replication States. To understand why, the C&C NPO conducted focus groups with case managers in several states.¹⁵ Case managers who participated in focus groups in Alabama and Iowa expressed concerns that (1) participant control over a budget would lead to fraud and abuse; (2) case managers would have to learn new tasks such as providing training to participants about how to be an effective employer; (3) the new program would change their role and reduce the personal satisfaction they gain from their work; and (4) they did not understand how the program worked and, in particular, the differences between their roles and responsibilities and those of counselors.

Alabama developed training materials that specifically addressed these concerns and held a 2-day training for waiver case managers in the counties selected for their pilot program. The training focused on shifting their mindset about self-direction as well as providing information about the new program’s policies and procedures. Project staff also trained the pilot area’s lead counselor and her backup on how to deliver the program’s communication plan messages to all of the target audiences. The trainings involved small groups—fewer than 15 case managers—which enabled them to participate in exercises designed to shift their thinking about the ability of their clients to direct their services. When the trainings began, none of the case managers said

they knew a client who would be appropriate for the program, but by the end of the training all said they knew at least one.

Based on the case manager resistance encountered during the pilot phase of the program, Alabama realized that extensive education for case managers will be needed prior to statewide expansion. Because small group training proved to be most successful in reducing resistance and obtaining support, the State plans to continue using this approach.

Iowa also conducted trainings to address the concerns raised in the case manager focus groups. Project staff first attended communications training sponsored by the C&C NPO, which helped them to develop specific training and communication strategies to address the case managers' concerns, to help counter their resistance, and to obtain their support. In addition, the Department of Human Services sent a letter supporting the new program to case managers.

Because not all case managers are state employees, Iowa could not mandate that case managers attend the training and the State lacked the time needed to amend administrative rules to allow such a mandate. Project staff believe that mandatory training would have helped to decrease some of the confusion and misconceptions about the new option. In retrospect, they felt they should also have combined the training for independent support brokers and case managers so that each would have had a better understanding of their respective roles.

States should anticipate resistance from traditional case managers and have a communication plan and resources for education and training to address it.

Because the provision of counseling services virtually always entails some type of change in traditional case managers' roles—even if just establishing a need for them to work collaboratively with counselors—obtaining their support is critical. Most Grantees found that doing so requires persistence, patience, and ongoing effort. Given that most Grantees had to address challenges related to case manager resistance, efforts to ensure their buy-in and support should be undertaken during the initial planning phase of a new program.

Allocate Sufficient Time and Resources to Provide Training

Many of the Replication States had to provide more training for counselors and case managers than they had planned originally, particularly about person-centered planning (PCP), which is common in the MR/DD service delivery system but much less so in the systems that serve elderly persons and younger adults with physical disabilities.¹⁶ Several States reported the need to provide both initial and ongoing training in person-centered planning for individuals who provide counseling services.

Pennsylvania noted that because case management provided through the AAAs has traditionally been furnished in a prescriptive and paternalistic manner, project staff were concerned that case managers would find it difficult to make the transition to using person-centered planning. To

assist them, the State conducted a 2-day comprehensive training on participant-directed services and PCP practices, which was attended by about 200 case managers and related staff in the new program’s planned pilot areas. A second training session was conducted in the fall of 2008.

In Kentucky, initial monitoring revealed that support brokers were using the PCP process, but only working with participants and not involving family members and other informal supports and service providers.¹⁷ To address this problem, the State revised its PCP training for counselors and also provides PCP training for participants, family members, community providers, and participants’ employees so that everyone is aware of what person-centered planning should involve. AAAs are required to monitor counselors to document whether and how they are using person-centered planning to develop individual budgets and service plans.

While Michigan has long used person-centered planning as the foundation for individual service plans and budget development in the MR/DD service system, prior to receipt of the C&C grant it had not provided statewide sanctioned PCP training or guidelines for providers serving elderly persons and younger adults with physical disabilities in the *MI Choice* waiver.¹⁸ Attitudinal barriers were widespread; many providers did not understand the PCP process or its purpose, or were defensive about it—feeling that they already used the process and did not need training.

To ensure the use of person-centered planning in *MI Choice*, program staff formed a PCP Action League to handle PCP implementation in the long-term services and supports system generally, and *MI Choice* in particular. A PCP training curriculum was developed for all stakeholders, including care managers and other program staff, participants, and service providers; and the State conducted PCP training in various venues statewide—at conferences, meetings, and other venues. The State also developed PCP guidelines for entities that administer the waiver program.

New Mexico found that putting the PCP philosophy into practice entailed a challenging paradigm shift for all stakeholders, including *Mi Via* participants. Some consultants (i.e., counselors) had case management experience in traditional HCBS waiver programs but not with person-centered planning and self-direction. Third-party assessors—review staff—are nurses with extensive experience working with elderly persons and younger adults with disabilities, but primarily in the medical model. State agency staff also had limited experience with person-centered planning and self-direction.

Person-centered planning—a critical component of self-direction—helps individuals to exercise autonomy, choice, and control over their services. Individuals may assume very different levels of responsibility: from taking complete charge of their planning, service arrangements, and budgets to relying on a representative or family member to assist them with most or all tasks. Given the wide range in individuals’ abilities and preferences, states need to design flexible counseling services that will provide the level of support, assistance, and training needed.

For many *Mi Via* participants, taking charge of their lives and developing their own plans and budgets through a PCP process was also a new experience. While the early enrollees welcomed the opportunity to take charge, some—especially those transferring from waivers with traditional case management services—had to learn to handle tasks that they initially expected others to do for them. To help the various constituencies become more knowledgeable about and comfortable with self-direction, the templates for the service and support plan and the budget templates were revised to provide much needed structure to the planning and budgeting processes. By the end of the first year of program operation, many reported a positive change and had a better understanding and appreciation of self-direction and person-centered planning.

Everyone involved in developing and implementing a self-direction program needs to make a paradigm shift from a medical model focused on protecting participants to an independent living model focused on the rights of participants to make choices and to assume any risks attendant on those choices. To make this shift, States need to educate program contractors about the need to achieve a balance between autonomy and protection. No one cares more about participants' health and welfare than the participants themselves and their families, and contractors need to learn to allow them the freedom to make choices they consider in their best interest.

Ensure that Counselors Understand the Target Population

While this “lesson learned” may seem obvious, counselors’ lack of knowledge and expertise was an issue in a few States. Kentucky implemented its new budget authority program in three waivers—the Elderly and Disabled waiver, the Acquired Brain Injury waiver, and the Supports for Community Living waiver that serves persons with developmental disabilities. However, the State designated AAAs to provide counseling services and their support brokers had experience only with Elderly and Disabled waiver participants. They were not knowledgeable about the unique and varied needs of individuals with developmental disabilities and acquired brain injuries or the specific services and resources available for these populations, such as supported employment.

To address this problem, the State had to provide additional training for support brokers working with participants in the Acquired Brain Injury waiver and the Supports for Community Living waiver. However, despite receiving considerable training, most of the AAA support brokers did not feel comfortable arranging services for these waiver participants. Thus, the State decided to expand the pool of individuals who could be support brokers beyond those who worked for AAAs to other entities or individuals, such as case managers in Community Mental Health Centers, who were then trained to perform support broker tasks.

Minnesota had the opposite problem as a majority of the support planners who provided counseling services had worked in the DD service system and were unfamiliar with the needs of elderly individuals and younger adults with physical disabilities. To address this problem, program staff recruited individuals with experience in the aging network to become support planners for older adults (e.g., those who had worked with AAAs and Title III services, and

private pay case managers working with elderly persons). They also facilitated connections with the Aging network through trainings, meetings, and network groups to help broaden their experience and provide the expertise needed to work with elderly persons. Both these approaches have been successful.

Minnesota also developed additional standards for support planners that require them to have knowledge of the service systems for all three populations, developed a curriculum based on the service standards to ensure competence and service quality, and now requires that support planners be recertified every 2 years. A few counties—and the support planners themselves—have initiated several networking groups around the State to discuss operational and practice issues and are working to improve the quality of their services statewide. The State obtains input from these groups on a wide range of services issues and support planners communicate routinely with the State through various state-supported methods.

Have Sufficient Counselors Available

This is another “lesson learned” that may seem obvious, but when starting a new program, it may be very difficult to predict the level of interest and to have sufficient counselors ready to work with potential participants. Counselors need to have a minimum number of clients to make their role financially viable, to successfully carry out their responsibilities, and to be well versed in the program.

If initial enrollment is slow, and the State has a large number of counselors, some may lose interest and leave the program. On the other hand, if interest in the new program exceeds counselors’ capacity to work with and enroll individuals in a timely fashion, the subsequent delays can decrease interest in the new program and lead some potential participants to remain in the traditional system.

During implementation of New Mexico’s *Mi Via* waiver program, the consultant contractor agency (CCA) that hires consultants to provide counseling services initially lacked the capacity to handle the number of inquiries about the program. The problem was compounded because some *Mi Via* participants had difficulty letting go of the case management model they were accustomed to in the traditional waiver; they required more support from their consultants than was originally anticipated to help them through the eligibility and enrollment process and to assist them with the development of their service and support plans and budgets.

Other problems included complaints about the CCA’s poor communication, time lags in training and hiring individuals selected by participants to be their consultant, and administrative and consultant staff turnover. The State quickly responded to these problems by working with the CCA’s leadership to address complaints, identify what caused the staff turnover, and take necessary corrective actions. The CCA hired additional consultants and installed a new phone system to better handle the volume of calls. Steps were taken to improve communication among all contractors, participants, potential participants, and traditional case management agency staff.

New Mexico also convened a Consultant Issues Workgroup—comprising participants, families, advocates, and state agency staff—to identify outstanding issues related to the role of consultants and to recommend changes. As a result, the CCA’s communication processes have improved, more new staff have been hired, regional offices have been opened, and consultant training has been conducted in selected regional sites.

Be Prepared to Make Changes and Address Problems Quickly

Even with the best planning and extensive efforts to engage case managers, states may still face resistance and find that they have to pursue a different approach than originally envisioned for the provision of counseling services. For example, Vermont initially limited enrollment to participants already assigned to a case manager. Because enrollment was very slow, Vermont worked with the C&C NPO to conduct focus groups with case managers and eligible non-enrollees to determine what issues were interfering with enrollment. The case manager focus group revealed on-going lack of understanding and suspicion of the program. The non-enrollees focus group revealed considerable suspicion of the State, in general, and thus the program.

Meetings with the case management agency leadership suggested that considerable retraining would be needed to have case managers assume the counseling role, and not a single case management agency responded to an RFP for consultant services due to concerns that reimbursement rates were too low. Home health agencies also expressed concern that the contract specifications would prevent counselors they employed from developing budgets that included services to be purchased from their agencies.

For all these reasons, the State abandoned the idea of using case managers to provide counseling services and instead hired a small agency that provides a similar service in another program. Because enrollment in the new program is still low, two individuals (one full-time and one half-time) provide counseling services for all of the program’s 70 participants. If interest in the program increases substantially, the State will likely have to redesign its counseling infrastructure to support a larger number of participants.

Even if a state’s counseling service is working well, unanticipated events in other program areas can necessitate a change in the scope of counseling services. For example, prior to the introduction of its new budget authority program, Kentucky paid home health agencies \$100 to conduct assessments and re-assessments for level-of-care determinations. Historically, many agencies deemed this amount insufficient but performed the assessments because they could recoup losses through the provision of services. Thus, they had no incentive to perform the assessments for participants in the new self-direction program who were not using their services, particularly given the lack of payment for transportation costs to remote areas and high gas prices. As a result, potential and current participants were unable to find home health agencies to conduct their assessments and reassessments.¹⁹

To address this problem, the State changed the program’s policies to allow support brokers to conduct assessments and reassessments for individuals who choose the new self-direction option,

and provided training on conducting the assessment. (Unlike most States' C&C programs, which provide participants with distinct counseling and traditional case management services generally furnished by two different individuals, Kentucky uses support brokers to provide both services.) The support broker sends the assessment form to a state-contracted Quality Improvement Organization, which reviews the assessment and makes the level-of-care determination.

Finally, Iowa had to make a major change to its support broker service when the Iowa State Work Force Development Department determined that independent support brokers have to be treated as independent contractors—not employees—which required changes in the method for calculating individual budgets. Additionally, some independent support brokers were concerned about assuming responsibility for payment of self-employment taxes, and others thought being an independent contractor carried a higher liability risk and stopped providing services. To address the liability concern, the State provided additional education to assure support brokers that being an independent contractor does not pose an additional liability risk.

Financial Management Services

A financial management services (FMS) entity (1) assists participants to direct and manage funds in their budgets; (2) acts as participants' agent for employer responsibilities such as processing payroll, withholding and filing federal, state, and local taxes, and making tax payments to appropriate tax authorities; and (3) performs fiscal accounting and required reporting.

Financial management services are key to the success of a new budget authority program, as they ensure appropriate spending and address policy makers' concerns about fraud and abuse. Additionally, if participants were required to handle employer-related financial tasks themselves, it is likely that many would be deterred from enrolling in a self-direction program.

Allow Sufficient Time to Find a Reliable FMS Provider

Several States had difficulty recruiting reliable FMS providers. Iowa planned to recruit credit unions and banks because program staff felt that they were already set up to handle electronic deposits and had extensive experience monitoring and balancing accounts. In addition, they could offer other financial services to participants and their worker/employees, such as financial counseling and savings accounts. However, when program staff issued a Request for Information to determine credit unions' and banks' interest in providing financial management services, they received no response. The State eventually contracted with a credit union that had been working with another grant dealing with self-direction for children before the C&C Replication grant was awarded. To meet CMS requirements that participants have a choice of providers, the State is continuing its marketing and outreach efforts to other credit unions and banks.²⁰

When Kentucky issued an RFP for FMS providers, only one proposal was received and the services it offered were not affordable. To prevent a delay in program implementation, the State quickly contracted with the fifteen Area Development Districts (ADDs) that provide a variety of

financial services for AAAs and the State. The State then hired a consultant to train the ADDs to monitor timesheets and budgets, make payroll, and keep required records.

Vermont twice issued FMS solicitations for bids and contracted with two out-of-state providers only to have each withdraw from the contract mid-term. As a result, the State has had to rely on a small local company to provide financial management services, but the company has limited reporting capacity, which limits the type of data the State can collect. The State considered using the Consumer Direction Module (CDM) software application to support the program but its Information Technology staff were not interested, believing that the current system was good enough and that they did not have the capacity to support the CDM.²¹

States should have a subject matter expert on financial management services on staff prior to program implementation, or a consultant who understands the state's contract requirements as well as program and IRS requirements. Ideally, a designated staff person would be responsible for staying current on all of the laws and regulations related to the provision of this service. States should pay for the best technical assistance available to save money in the long run.

While Michigan had a cadre of fiscal intermediaries providing financial management services in the mental health-MR/DD delivery system, they were not familiar with the *MI Choice* waiver and had no experience working with elderly persons and younger adults with physical disabilities. To use the existing fiscal intermediaries in the new program, the State had to provide training for those who were interested in serving a new client base and were willing to do all the required tasks. State project staff obtained technical assistance from the C&C NPO to develop a readiness review process based on standards for essential tasks that fiscal intermediaries have to meet before they can provide services, and an NPO consultant provided training for this review process to interested fiscal intermediaries.

Obtaining Affordable Workers' Compensation Insurance is Possible

Obtaining affordable workers' compensation insurance coverage has been a major challenge for many States' self-direction programs. However, the technical assistance provided by the C&C NPO—and in some cases a consultant hired with grant funds—was key in helping some States, including New Mexico and Illinois, to offer this coverage.

Stakeholders wanted New Mexico's *Mi Via* program to provide workers' compensation insurance for employees, but the State initially had difficulty finding a model that would work with the program. Project staff researched different approaches and worked with the NPO's consultant and determined that Massachusetts' model afforded the best fit. Project staff then worked with the State Insurance Department to meet its requirements.

The National Council on Compensation Insurance, Inc., which administers some state workers' compensation programs including New Mexico's, wanted the State to use a code that covered home health agencies, where employees have a much higher risk of injury because they deal with

many more clients than do workers in *Mi Via*. However, New Mexico was able to assemble data to support the argument that a self-direction program posed much lower risks. As a result, New Mexico's workers' compensation insurance was able to establish its own Code (0918) for Domestic Service Workers-Inside-Physical Assistance-Consumer Director Programs.

Workers' compensation insurance coverage is required for all *Mi Via* employees providing the following services: homemaker/companion; respite; transportation/regular driver; and private duty nurses for adults. Payment for this benefit comes directly from the participant's budget along with employees' salary and taxes. Initially, the workers' compensation cost began at 3.09 percent per \$100 of payroll for each employee but it has since been reduced based on low cost rating experience.

State agencies that administer self-direction programs need to establish effective working relationships with their State Workers' Compensation Insurance Associations and with any other state agencies or organizations that regulate domestic employment and deal with labor issues, such as State Labor Departments.

Individual Budgets

Individual budgets are the funds or resources available to participants to meet their needs. Participants may directly manage their services and expenditures or assign responsibility for this task to a representative who can express the participant's preferences. An individual budget is the key program element that increases participants' choice and control. Management of an individual budget affords participants both the greatest flexibility and the greatest responsibility.

Nine of the Replication States reported challenges related to individual budgets, most frequently, negative perceptions about the adequacy of the budget and concerns that the new program would cost more than the current program.

Be Prepared to Address Multiple Concerns About Individuals Budgets

In virtually all of the Replication States, participants in the traditional service systems do not receive all of their authorized services due to worker shortages and other factors. Thus, States had to address concerns that if participants are given the dollar amount of their authorized service plan, total costs under self-direction may be greater than if they remain in the traditional service system. This was a particular concern in Iowa, because the State planned to add the new budget authority to six waivers.

To address this concern, Iowa's program staff developed a budget methodology to ensure that the new option would not increase waiver costs. The methodology is based on the past service use of all participants—not each participant—so it can be used for new participants with no service history as well. The methodology also allows budget changes to address participants' changing needs, whether for additional services or increased amounts of current services. The State is monitoring service utilization in the new option and continues to look at the budget

methodology to ensure that budgets both meet participants' needs and do not cost more than traditional services.

To address overall cost concerns, Kentucky placed a cap on budgets, which is based on historical service use. The cap has been a source of contention because service utilization in the traditional system is generally much less than what is authorized and so using historical costs, in most cases, created inadequate budgets for participants. To address this concern, the State developed a system for participants to request adjustments to their budgets to increase services to meet initial and changing needs and to add services if necessary.

Budgets in Minnesota's new program were based on average authorizations in the traditional program in 11 different resource utilization groups and were therefore lower than the maximum possible amount that might have been authorized in each group in the traditional program. Focus groups conducted with care coordinators, supervisors from counties and MCOs, support planners, fiscal support entities, and other stakeholders found a common belief that the current budget amount is not sufficient for participants in some needs assessment categories in the Elderly waiver. Many also believed that participants' budgets are inequitable compared to resources available to individuals electing traditional service options. The State continues to solicit input regarding the impact of established limits on individual budgets and is looking at other options for increasing budget amounts.

Be flexible and prepared to change as better ways to do things become clear. What seems logical in theory sometimes does not work in practice. Michigan had to refine its budget template numerous times to increase its ability to accurately reflect participants' needs and service preferences.

Negative views about the sufficiency of the budget slowed enrollment in Iowa, Minnesota, and Vermont. Because Vermont's new self-direction option for elderly persons and working-age adults with disabilities is in a \$1115 waiver program, the State felt it had to discount individual budgets to meet budget neutrality requirements. Waiver participants who exercise employer authority use about 75 percent of their authorized services, whereas, in the States' Developmental Services program, participants with budget authority use closer to 90 percent of their budgets. For this reason, the State initially applied a 15 percent discount rate to individual budgets. However, discounting was very negatively perceived and discouraged enrollment. Even individuals for whom it did not represent a real loss, given their current utilization, felt they were losing something.

Due to very slow enrollment in the first 6 months, Vermont eliminated the discount rate. While enrollment remains slow, it is considerably faster than when the discount was operative. Prior to elimination, only 12 percent of current waiver participants who expressed interest in the new option subsequently enrolled. After elimination, about 85 percent of individuals expressing interest in the program enrolled. However, service utilization rates are in the 90 to 95 percent range, which is not fiscally supportable over the long range given the requirement for budget

neutrality in the §1115 waiver program. The State is examining several approaches to address this problem.

In Iowa, a lower percentage of Elderly waiver participants enrolled in the new self-direction option in the initial months than did participants in the Brain Injury, AIDS/HIV, and the MRDD waivers. Focus groups conducted with case managers to determine the reasons why found that many held stereotypes of frail elderly persons as incapable of directing their services. But the major reason for case managers' reluctance to enroll older persons is a very low cap on services in the Elderly waiver; both they and potential participants believe that individuals who enroll in the new option may not receive the same amount of services they would under the traditional system.²²

Project staff attempted to counter negative views regarding elderly persons with education about their successful participation in self-direction programs in other states, and also conducted extensive outreach and education with the Department of Elder Affairs. To address negative perceptions about the budget, project staff developed communication strategies to deal specifically with this concern among both case managers and waiver participants. It is too early to determine empirically whether the budget methodology has had a negative impact on enrollment, but the State is conducting ongoing analyses to ensure that the budgets are meeting participants' needs. The State may also consider increasing the service cap in the Elderly waiver in both the traditional and self-direction programs.

Lessons Learned in the Enrollment Phase

The initial enrollment decision states must make is whether to pilot a program in a few areas prior to statewide implementation, phase it in gradually by starting with a few geographic areas or counties, or make it available statewide from the outset. Whichever strategy a state selects, the program must have a sufficient number of participants to sustain the infrastructure that supports self-direction (i.e., counselors and FMS providers). The Replication States used different approaches. Michigan piloted its program in four “pioneer sites”—an approach that program staff believed provided invaluable input and time to identify issues and to refine policies, outreach techniques, and approaches to measuring quality prior to statewide implementation.

West Virginia purposely limited initial enrollment to 15 current waiver participants per month for the first 2 months in order to carefully monitor the process and make changes as needed.

Limiting enrollment to current waiver participants also ensured that program staff would not be overwhelmed with new referrals, which could have led to a delay in providing services. After the first 2 months, the State began enrolling new waiver applicants statewide. Program staff noted that this approach allows sufficient time to determine what is and is not working in the enrollment process and to make needed changes.

Phasing-in a program provides time to determine what is and is not working in the enrollment process and to make needed changes with a manageable number of enrollees. It also provides more time for program staff and contractors to identify issues and to refine policies and procedures prior to statewide implementation.

New Mexico implemented its program statewide, but noted that in some instances phasing-in a new self-direction waiver program might work better than launching statewide because it provides an opportunity to work through complexities and glitches with a more manageable number of enrollees, and provides more time for program staff and contractors to develop knowledge and expertise.

Develop a Targeted Communication Plan for Outreach and Education

Outreach and education about the new program is needed during the preparation and design phases to inform stakeholders about the program, counter misinformation, and defuse opposition. It is also needed during the enrollment phase for these reasons but, more importantly, to ensure that all eligible and potentially eligible individuals know about the new program and have the information they need to decide if it is right for them.

Most of the Replication States’ program staff attended RWJF-sponsored communications training and developed a communication plan to address the information needs of various stakeholder groups and diverse target populations.²³ A major component of their communication plans was the use of key messages and strategies so that information about main program features was presented in ways meaningful to the various target audiences. Depending on the target audience, the States provided information using numerous media, including in-person

training, conference calls, written bulletins and brochures, DVDs, and the establishment of a toll-free number to answer questions about the program. Several States noted that multiple trainings may be needed for the same groups and that training activities need to be ongoing.

Outreach and education are key to enrollment, particularly when the program faces skepticism and resistance. States should develop a carefully researched communication plan and design outreach, marketing, and educational strategies to reach diverse populations. Information about the program must demonstrate the specific benefits it can provide.

Vermont’s program staff stated that it is important to not be too general about the program or to overstate its benefits; marketing the program as the “best thing ever” aroused suspicions among potential participants, who wondered “what the State was up to.” Project staff in Iowa noted that even though it was difficult to reach potential participants and their families, they should have conducted more outreach and educational activities because it would have given potential participants a better understanding of the program and its benefits, which would have helped to counter resistance from some case managers.

Involve the Target Audience in the Development of Education Materials

It is important to involve the target audiences in both developing marketing materials and testing their effectiveness before spending significant resources, as the same or similar strategies can have different results in different states. For example, West Virginia and Rhode Island had a very positive response to mailed promotional materials but Vermont and Minnesota did not. West Virginia mailed a postcard and a letter from the Governor about the new program to current waiver participants and the two mailings generated over 450 calls. Similarly, Rhode Island’s mailing of promotional materials to 1,000 current waiver participants receiving traditional services resulted in over 500 calls to support broker agencies within a week.

However, the large response in Rhode Island prevented the support broker agencies from responding in a timely way and the time from referral date to initial assessment took as long as 3 months. To address this problem, the State reduced the size of the mailings to 300 packets every other week and recruited additional agencies to assume support broker functions. As a result, the time from referral to assessment is now about 30 days.

In marked contrast, Vermont’s four mailings to waiver participants—with various materials about the new program—generated only a few calls. A focus group conducted shortly after the final mailing revealed suspicion of direct mail outreach generally and of the State specifically. Focus group members said they thought that the State was trying to “put one over on them.” Minnesota also had a minimal response to its initial postcard mailing to all current waiver participants.

Design Materials for Diverse Populations

Considerable planning and resources may be needed if a state has to reach a very diverse population. In New Mexico, eligible populations for *Mi Via* include individuals from four HCBS waivers—Disabled and Elderly, Developmental Disabilities, Medically Fragile, and AIDS—as well as individuals with brain injuries. Also, among the five populations there are three distinct groups: (1) individuals eligible to transfer from one of the four traditional waivers to *Mi Via*, (2) individuals newly eligible for one of the four waivers and who need information to make a decision between traditional HCBS waiver services and *Mi Via*, and (3) individuals who are entering *Mi Via* through the new eligibility category for individuals with brain injuries. Finally, the State has a large Native American and Spanish-speaking population, not all of whom can read.

Early on, New Mexico’s program staff recognized that crafting one message for all populations would present quite a challenge. They worked with participants, families, representatives, advocates, and providers to identify and respond to common information needs among the various populations while being sensitive to differences. In addition to general materials relevant to all eligibility groups, the State developed materials tailored to specific populations.

New Mexico’s program staff also translated written materials into Spanish and held numerous outreach activities and trainings statewide—at pueblos, reservations, senior centers, independent livings centers, and advocacy group meetings. To share up-to-date information about the program, the State developed a user-friendly website, and to reach a broad audience among various disability and cultural groups, the State produced a video about the program featuring *Mi Via* participants, available in four languages: English, Keres (or Pueblo), Spanish, and Navajo.²⁴

Address Misconceptions and Misinformation Promptly

Several States had to deal with situations where inaccurate information was being circulated—either unintentionally or deliberately. If misconceptions and inaccuracies appear to be common and/or widespread, an excellent approach to deal with this problem is to develop a Frequently Asked Questions brochure and to distribute it widely in print and through websites.

Rhode Island noted that the initial information provided should not “oversell” the new program, as this can create misconceptions and lead to dissatisfaction. Participants in Rhode Island thought there were no restrictions on what goods and services they could purchase. Project staff believe this stemmed from outreach and education materials that did not clearly describe CMS requirements and restrictions. Preliminary training materials included the example of an air conditioner in a spending plan and although it may sometimes meet CMS criteria (i.e., meet a medical/disability need) it does not in all instances. To address the misconception, project staff modified the training materials and sent a letter to participants explaining CMS requirements and restrictions and apologizing for the confusion.

Home health agencies may oppose and attempt to undermine a new self-direction program if they think it will lead to a loss of workers and revenue. In Kentucky, agencies would not provide information about the new program to their clients, or they provided inaccurate information to dissuade clients from transferring to the new program. West Virginia’s project staff heard anecdotal reports that some agency case managers were actively discouraging waiver participants from selecting the new option, or were telling them they could not handle its responsibilities.

To address this problem, Kentucky invited representatives of the home health agencies to serve on the new program’s Advisory Board, which provided a forum for them to share their concerns and obtain more information. This approach helped to defuse some of their fears about losing revenue. To counter inaccurate information, Kentucky frequently sent program information to current waiver participants and provided it to new applicants. Additionally, the Kentucky Department of Medicaid Services (DMS) contacted the Executive Director of the State Association of Home Health Agencies to discuss the problem. DMS asked the Association to send a memorandum to the home health agencies clarifying the facts about the program and their responsibility to provide accurate information to their clients. Currently, the State is not hearing complaints about the provision of misinformation.²⁵

West Virginia included service providers in planning sessions to develop the new program, but when this did not appear to reduce their resistance, project staff adopted a communication strategy specifically targeted to provider agencies. Its goal was to help them understand that many of the best candidates for the new program are clients they are having difficulty serving. These efforts were successful to some degree because agencies started to provide referrals to the new program.

The State also implemented a new electronic database system to receive complaints from waiver participants—including those about providers discouraging enrollment. The State is tracking these complaints, identifying trends and taking action to address them. Resistance is now much less than it has been in the past as agencies have come to realize that the new self-direction program is a complement to agency-delivered services. The State is now developing a brochure listing all of the options for receiving home and community services, including the use of agency workers, which will further help to assuage any concerns that self-direction is being promoted at their expense.

Sometimes, traditional providers may feel that they are at a disadvantage when outreach and education materials about a new program—that does not include them—are distributed. While it is important to have separate and distinct educational materials about a new self-direction program, states should consider developing additional materials that provide information about all of the service models available—traditional and participant-directed—and the differences among them. Doing so allows participants to select the best option for them and may lessen providers’ fears that their services are not being promoted.

Ensure That Enrollment Staff Fully Understand and Support the Program

When Minnesota began enrollment for its new program, competing demands for the attention of case managers and MCO care coordinators, as well as a lack of interest in learning about the program, slowed enrollment. Among those who may have wanted to learn about the program, heavy caseloads and a steep learning curve were challenges. Initially, many case managers and care coordinators thought the new Minnesota program was too complex and difficult for participants to handle and that no one on their case load was appropriate for the program.

Subsequent focus groups with case managers and MCO care coordinators revealed that resistance or unfamiliarity with the program persists. Many case managers and care coordinators remain unconvinced that the program is a good option for their clients/members either because (1) they think that the individual budgets are too low to meet participants' assessed needs, (2) have concerns about the program's complexity, or (3) think that older participants will be taken advantage of by family members.

To address continuing resistance, Minnesota's project staff developed and conducted a range of activities, including: (1) small group technical assistance sessions and larger meetings for case managers, AAAs, fiscal support entities, and support planners; (2) large group technical assistance sessions via statewide videoconference and teleconference; and (3) regional conferences. In addition, project staff continue to encourage case managers who lack experience with the program to speak with those who do have experience. It appears that a paradigm shift for case managers is occurring because project staff hear less frequently that case managers are discouraging enrollment.

To ensure buy-in from traditional case managers, States should hold regularly scheduled trainings with them and their supervisors; be readily available to dispel myths; and offer group opportunities for trouble shooting, to answer questions, and to provide technical assistance.

In Washington, case managers are required to educate potential participants about all service options and are responsible for enrolling individuals in the new program. Project staff recognized that case managers already have a demanding workload and must comply with many regulatory requirements. Thus, to ensure their support, project staff worked with them to design the enrollment process to be as streamlined and operationally efficient as possible.

The State developed a manual to provide guidance to case managers and their supervisors and asked them to contribute to the chapter on implementing the new program and enrollment procedures. Once implementation was underway, the chapter was revised with input from case managers to further streamline the process. Associated documents related to marketing, referral, and enrollment were also collaboratively developed and made available electronically for easy access by case managers.

Track Enrollment to Identify and Address Challenges and Barriers

Many factors can affect enrollment and states need to understand these factors so they can tailor outreach and educational materials to address them and better target the population to whom they will market the new program. For example, the availability of other self-direction options in a state is one of the most important factors that can influence interest in, support for, confusion about, and opposition to a new program providing flexible individual budgets. Prior to receiving their C&C Replication grants, all of the States had implemented at least one self-direction program while some had several, as shown in Exhibit 2.

For a self-direction program that offers a flexible individual budget to attract enrollees, individuals need to perceive a problem with their current service delivery that the new program will solve. If participants already have employer authority, the greater flexibility afforded by an individual budget may not provide sufficient motivation to assume the responsibilities of managing a budget.

For example, when Washington received its grant, the majority of waiver participants already directly employed personal assistance workers and many were satisfied with this arrangement. Additionally, many waiver participants were satisfied with the traditional case management system and preferred to have case managers take the lead in arranging and providing for other services.

Another major factor influencing enrollment in an individual budget program is the availability of a wide range of services in the traditional system. Vermont experienced extremely slow enrollment not only because case managers did not support the program and participants were suspicious about it, but also because waiver participants already had the option to hire their own workers and had a fairly rich service package. New waiver applicants, however, may be more interested in the flexible budget option.

The influence of the availability of a comprehensive service package in the traditional service delivery system is exemplified by Iowa's experience: a few individuals enrolled in the new program—*Consumer Choices Option*—primarily to obtain home and vehicle modifications through their individual budgets while they continued to receive other services through the traditional system. Once the modifications were completed, they disenrolled.

Minnesota's Medicaid State Plan and HCBS waiver programs, as well as the state-funded Alternative Care program, also cover a comprehensive range of services. These programs serve many people who are satisfied with the traditional system and have strong relationships with their case managers, which they say they do not want to change. Consequently, they are not motivated to even learn about the new program.

Exhibit 2. Self-direction Programs Prior to Receipt of C&C Grant

Alabama	<ul style="list-style-type: none">▪ Small state-funded program with employer authority.
Illinois	<ul style="list-style-type: none">▪ A program that serves both Medicaid-eligible and non-eligible persons offers employer authority.▪ Family Caregiver Initiative provides direct payments upon verification of expenses or allocates a specified dollar amount annually for respite and other services.
Iowa	<ul style="list-style-type: none">▪ Six HCBS waivers have employer authority through an option called Consumer Directed Attendant Care.²⁶
Kentucky	<ul style="list-style-type: none">▪ Two small state-funded programs together serve about 800 people. One offers employer authority to individuals mentally capable of instructing and supervising attendants and handling employer responsibilities; the other is a grant program that provides budget authority to recipients to purchase and manage supports and services.
Michigan	<ul style="list-style-type: none">▪ MR/DD waiver offers participant-directed budgets.▪ Medicaid State Plan Personal Care program since 1981.▪ Small pilot program offers self-direction to people in recovery from serious mental illness.²⁷
Minnesota	<ul style="list-style-type: none">▪ Mental Retardation and Related Conditions waiver offers both employer and budget authority, though the option is not available statewide.²⁸▪ Medicaid State Plan, all five waiver programs, and a state-funded program offer employer authority using an agency-with-choice model.
New Mexico	<ul style="list-style-type: none">▪ Medicaid State Plan Personal Care program offers employer authority.▪ State-funded program offers employer authority for individuals on the DD waiver waiting list.
Pennsylvania	<ul style="list-style-type: none">▪ Eight HCBS waivers offer employer-authority, though not available statewide in all waivers. Two of these waivers (serving individuals with MR) offer an agency-with-choice model and budget authority (though not for goods and services).▪ State-funded program for people with physical disabilities offers employer authority.
Rhode Island	<ul style="list-style-type: none">▪ Two programs with employer authority—a state-funded program for persons with developmental disabilities and a model waiver program for adults with physical disabilities, which was capped at 125 participants (discontinued after the new self-direction program was implemented).
Vermont	<ul style="list-style-type: none">▪ The Medicaid State Plan program for children offers the employer authority and an agency-directed option. The two programs for adults (both Medicaid State Plan and a state-funded program) offer only a self-direction employer authority option.▪ Statewide §1115 waiver called <i>Choices for Care</i> offers employer authority.²⁹
Washington	<ul style="list-style-type: none">▪ Medicaid State Plan Personal Care program offers employer authority.▪ Aged and Disabled waiver offers employer authority.³⁰
West Virginia	<ul style="list-style-type: none">▪ A state-funded program with 26 participants offers employer authority.

However, while many individuals may be satisfied with the employer authority and a rich service package, project staff noted that many have also clearly conveyed their desire to assume more control of their services and to access a wider and more flexible array of waiver services; Minnesota's new program targeted the latter group. Although enrollment in the State's other self-direction programs had initially been slow, nonetheless, Minnesota wanted to boost initial enrollment in the new budget authority option and engaged in a multi-pronged approach to do so.

First, program staff worked closely with case managers and associated administrative systems to increase understanding of the new program and its enrollment process. Project staff met regularly with case management supervisors and staff to address specific participant issues, explore potential referrals, and respond to questions about the new program. Program staff also routinely touched base with case management supervisors in the field to inquire about concerns and obtain input for improving the program's operations. Second, they sent postcards targeted to eligible persons who might be interested in the new program. The postcard directed recipients to call the Senior LinkAge Line[®] or Disability Linkage Line[™] for additional information. However, the postcard mailing resulted in few new enrollees.

Third, Minnesota entered into a 9-month contract with three Centers for Independent Living (CILs) to provide enrollment assistance services in the 29 counties they served. The CILs' activities included outreach, initial education about the program, and technical assistance to case management agencies. The CILs employed various means to carry out these activities, including direct mailings, telephone calls, and in-person visits to eligible persons. By the summer of 2007, awareness of the new program among the target population, the counties, and the MCOs had grown. Acceptance of the new program by MCOs is especially important because most older adults in the Elderly waiver are enrolled in a managed care plan for both Medicaid health services and home and community services.

In conjunction with the CILs contract, Minnesota staff planned and developed regional meetings with local stakeholders to address enrollment, to help facilitate communication about roles and responsibilities, and to foster working relationships. Project staff also developed a wide range of informational and educational materials for participants, case managers, and providers; and a web page with program information, tools, resource materials, and participants' personal stories, which are excellent education tools. They obtained input from stakeholders when developing these materials to ensure that they would be understood by the target audience. With the exception of the postcard mailing, these strategies helped to boost enrollment.

Using dedicated enrollment staff for a new self-direction program, particularly in the first six months, will help ensure that potential participants are not influenced by negative views about their ability to handle responsibilities in the new program held by some traditional case managers.

Another factor that can slow enrollment is a complex and time consuming enrollment process. Kentucky's initial enrollment process had over 40 separate steps and some of the entities involved caused delays by not processing paperwork in a timely manner, sometimes taking a

month to review individual budgets. As a result, enrollment was taking 8 to 10 weeks and several AAAs had waiting lists. The long delays led some potential participants to remain in the traditional service system. An interdepartmental team worked to reduce the number of required enrollment steps and forms and it now takes only 8 to 10 days to complete the enrollment process. The State also capped the number of clients that a support broker could serve at any one time at 40 and some AAAs hired more support brokers.

Vermont also took specific steps to address slow enrollment, including consolidating the enrollment and support broker functions, thereby allowing individuals who expressed interest in the program to obtain information from an expert who supported the program. This approach also limited the number of people individuals had to deal with, improving continuity and making the process more efficient.

Outcomes

The major outcomes for the C&C Replication Project are the number of programs implemented and the number of individuals enrolled. With the exception of Minnesota, which amended its waiver prior to receiving the C&C grant, eight States did not begin enrollment until late in the second or the third year of their grant, due primarily to delays in developing waiver applications and obtaining CMS approval. Because of the delays, the grants were extended for a fourth year. Pennsylvania is the only State that had not implemented its program by the end of the fourth year of the grant. The State is planning to implement its program in February 2009.

The Replication States had to set specific enrollment targets for their grant and most committed to enrolling the lesser of 10 percent of the eligible pool or 400 participants by the third year of the grant. Two States—Alabama and Illinois—planned to pilot the program on a limited basis before expanding statewide and had lower enrollment targets.

Initially, the combined enrollment target for all of the States by the third year of their grants was over 10,000 participants. Delays in program implementation led the two States with the highest enrollment goals—Minnesota and Iowa—to set more realistic targets, and the other States extended the time frame for achieving their targets. Pennsylvania dropped its original enrollment target but has not yet set a new one.

The revised combined enrollment target for the 11 States that implemented their programs was 4,786 participants by the end of the grant period—September 30, 2008. Exhibit 3 presents the enrollment figures as of December 31, 2008.

Excluding the pilot programs with low enrollment targets—Alabama and Illinois—two of the States with the lowest enrollment figures—Washington and West Virginia—did not begin enrolling participants until the third year of their grants. As a result of the delays, as of December 31, 2009, 6 of the 11 States had not met their enrollment targets but most will soon meet their targets if current enrollment patterns hold.³¹ Three States have exceeded their targets—New Mexico and Kentucky by a significant margin.

Four factors delayed program implementation.

1. ***Federal Medicaid Policy Changes Throughout the Grant Period.*** While these changes firmly established self-direction—and the budget authority in particular—as a mainstream option in the Medicaid program, they required additional work and caused unanticipated delays for most of the Replication States, particularly for Alabama and Pennsylvania.
2. ***Bureaucratic Resistance.*** Some States had to contend with more resistance within their own bureaucracies to the paradigm shift from traditional to participant-directed services and had more inter-agency conflict than did others.

Exhibit 3. Enrollment in 11 States as of December 31, 2008

State	Date Enrollment Began	Number of Months Since Implementation	Enrollment Target	Participants Enrolled
Alabama ^a	October 2007	13 months	195	31
Illinois ^a	October 2007	13 months	200	185 ^b
Iowa	December 2006	27 months	400	984
Kentucky	September 2006	30 months	500	1,442
Michigan	December 2006	30 months	600	659
Minnesota	November 2004	48 months	743	673
New Mexico	December 2006	27 months	400	1,649
Rhode Island	March 2006	33 months	450	336
Vermont	July 2006	29 months	250	83
Washington	May 2007	19 months	400	230
West Virginia	May 2007	19 months	648	333
TOTAL			4,786	6,620

^a Pilot program. ^b Enrollment was capped at 200 and 15 disenrolled.

3. ***Problems with other Self-Direction Programs.*** Pennsylvania’s self-direction programs had been operating for years prior to the establishment of CMS requirements for financial management services and the receipt of the C&C grant. As a result, many of the FMS entities operated under inconsistent policy and questionable federal compliance. In order to implement the new program, Pennsylvania had to first establish certification standards for all FMS entities—not just those providing services under the new self-direction option—which delayed implementation.
4. ***Administrative Disruptions and Budget Shortfalls.*** Many States experienced disruptions that were not directly related to the new program, but which affected it nonetheless. For example, elections leading to a change in party affiliation and priorities of key leaders; a complete reorganization of the state administrative structure and transfers of responsibility for the program from one to another office; cutbacks and turnover in state personnel; and budget crises that affected the attitudes of budget personnel to the program, so that higher level support evaporated or became unreliable.

These internal conditions appeared to have presented the most challenges for the Replication States. They made it difficult to give the new program the priority and resources it needed or complicated its development because too many other changes were occurring simultaneously.³²

Once the new programs were implemented, several factors slowed enrollment. First, many States purposely limited initial enrollment in order to “get the kinks out of the program.” Several noted that doing so provided invaluable information that was used to “fine tune” the program before it was expanded. The approaches States used to limit initial enrollment are listed in Exhibit 4.

Exhibit 4. Approaches to Limit Initial Enrollment

Enrollment limited to small geographic area	IL, WA, AL, PA, MI (initially)
Planned phase-in	IA, MI
Enrollment limited to evaluate program prior to expansion	IL
Initial enrollment limited due to insufficient staff	RI, NM
Enrollment initially limited to current waiver participants	WA, VT

Several other factors slowed enrollment.

1. **Availability of Other Self-Direction Options.** Many of the States had long-standing self-direction programs in which many participants already had the authority to hire and direct their own workers. In these States, the C&C grant served only to develop and implement a new budget authority to allow participants to have a flexible individual budget with which to purchase goods and services. The new option proved confusing for many participants, case managers, and state staff, and many did not understand the value the budget authority offered.
2. **Case Manager Resistance.** Resistance from case managers has been greater and more difficult to overcome in some States than others, and some States had more success in designing effective strategies for dealing with it than did others. Some case managers—as well as state staff and service providers—continue to believe that many individuals with disabilities, particularly elderly persons, are unable to exercise control over their services.³³ In general, most States attempted to counter resistance with training, but although necessary, it can also be costly in terms of money, time, and personnel. |
3. **Skepticism about the State’s Motives in Introducing a New Program.** In Vermont, potential participants in Vermont already had employer authority and comprehensive waiver services and were skeptical about the new program and the State’s intentions in offering it. Because the program initially discounted the budget, some thought the State was using the new program to reduce services.³⁴
4. **A Complex and Lengthy Enrollment Process.** Kentucky and Washington experienced initially slow enrollment until they resolved problems with their enrollment process.

The major factor that facilitated enrollment was under-service in the traditional system. States that had a serious under-service problem—such as Kentucky and New Mexico—found it easier to enroll participants, as did States that had minimal self-direction options available prior to receipt of the C&C Replication grant.

Some States faced unique or unusual challenges with respect to program implementation, which slowed enrollment. In other cases, States’ unique challenges appear to have affected how well or smoothly the program was implemented but did not, seemingly, discourage enrollment.

For example, Minnesota implemented its new program shortly before the State incorporated HCBS waiver services into managed care plans and required all Medicaid-eligible individuals to enroll in these plans. During the same period, the federal government required all dually-eligible (Medicare/Medicaid) individuals to choose a Part D prescription drug plan. The result was decision overload for potential participants and heightened resistance to recommending enrollment from care managers—many of whom were also making the transition to managed care and were overburdened with this transition and having to enroll dual eligibles in Medicare Part D.)

On the other hand, although Kentucky experienced unusually great political and bureaucratic turmoil, it does not appear to have negatively affected enrollment. However, the resulting delays caused implementation to be rushed in order to meet the grant’s deadlines and some support brokers had to begin serving participants before they had received adequate training.

Discussion

With regard to slow enrollment, two points are key. First, before undertaking the extensive work needed to design and implement a budget authority program, states need to first gauge the underlying interest in the budget model among eligible individuals and try to predict take-up rates. Take-up rates will be affected by how appealing the new program is to potential beneficiaries and specific fears they may have.

Vermont’s experience illustrates this point. While the State was designing its new budget authority option—called *Flexible Choices*—for adults in a waiver program, it also began developing a budget authority option for the *Children’s Personal Care Services* offered under the Medicaid State Plan program. The latter program began enrollment on June 1, 2008, and in just 5 months, the number enrolled exceeded the number enrolled in *Flexible Choices* over a 2-year period. The differences in enrollment reflected the budget model’s greater appeal to parents of children with disabilities than to adults with disabilities.

Based on the CCDE and the Replication States’ experience—and that of the CMS-funded Systems Change Independence Plus Grantees—States should anticipate that take-up will be quickest and highest when individuals have experienced a lot of difficulty obtaining traditional services and are very dissatisfied with the types of services traditionally available or with provider quality. In States with this history, program staff need to ensure that sufficient staff are prepared to process enrollment without delays by having the counselors and the FMS provider(s) ready to “hit the ground running” because they will not have the luxury of a slow learning curve.

If a state already has programs that allow participants to hire their own workers, experience suggests that the state may need to pay particular attention to developing a formal communication plan about the new option or program that explains and emphasizes the “value added.” For example, will there be more flexibility to hire relatives under the new option? More flexibility to pay workers higher wages? What goods and services will beneficiaries be able to

purchase that will reduce dependency on aides or make aides more productive? Are these goods and services not available in the current program?

The second point is that states need to have realistic enrollment expectations, recognizing that growth takes time and it may take several years for a new model to take hold. Self-direction—and the budget authority in particular—is not for everyone but is an option that everyone should be able to choose. While sufficient enrollment is needed to sustain a program’s infrastructure, the actual number enrolled or the percentage of eligible participants selecting self-direction is not as important as the positive difference it makes in the lives of those who choose it.

While the Replication States varied considerably in how their long-term care systems are financed, designed, and operated, they faced common challenges and reported similar lessons learned throughout the C&C grant experience. Nearly all of their lessons learned are consistent with those of the three original CCDE States—as well as those of the States that received CMS-funded Systems Change Independence Plus grants to implement budget authority programs.³⁵

While some States implementing self-direction programs with the budget authority faced idiosyncratic challenges—such as Minnesota and Vermont—most of the challenges States have faced are so nearly universal that states planning to implement similar programs should be prepared to address them from the earliest stages of the planning process.

Although it is helpful to hold focus groups and conduct preference surveys, the resources to do so are not always available. But reading focus group and survey reports from other states can provide insight into the kinds of fears, misconceptions, distrust, and other resistance program administrators are likely to encounter from persons eligible to participate in the program, from traditional providers and case managers, and from within state government agencies.

The Replication States benefited from a considerable amount of technical assistance from the C&C NPO. For example, the NPO assisted two States—New Mexico and Illinois—to obtain affordable workers’ compensation insurance for their self-direction programs, and sponsored training sessions for fiscal employer agents. A great deal of this information is available at the Cash & Counseling website—<http://www.cashandcounseling.org>.

This website contains a wealth of information and resources from the 15 states that received C&C grants, including communication plans, outreach and education materials, and various forms. It also has resources specifically developed to help States address common challenges. For example, a tool kit for working with providers and addressing resistance, along with numerous other tools and materials that will enable states to design their program materials without “reinventing wheels” and spending resources unnecessarily. The toolkit is available at http://www.cashandcounseling.org/resources/20080415-145147/index_html.

Increasing Self-Direction Options

Funding for the C&C National Program Office ended with the completion of the C&C Replication Project. To enable other States to receive the technical assistance provided to the C&C Grantees to help them plan, design, implement, and evaluate self-direction programs—including help with specific issues such as obtaining workers' compensation coverage—a new National Resource Center for Participant-Directed Services (hereafter the Center) has been established.

The Center is funded by The Robert Wood Johnson Foundation (RWJF), Atlantic Philanthropies, the Administration on Aging, and the Office of the Assistant Secretary for Planning and Evaluation, USDHHS. Resources available at the C&C website will remain available and will also be accessible from the new Center's website at www.nrcpds.org. The Consumer Direction Module, a secure web-based software application specifically designed to support self-direction programs that allow individual budgets will also be available through the new Center.³⁶

The RWJF has also funded the development of a detailed guide for developing self-direction programs—*Developing and Implementing Self-Direction Programs and Policies: A Handbook*—that is available on the C&C website at <http://www.cashandcounseling.org/resources/handbook>.

In sum, the experience of the Replication States demonstrates that it can take a long time for a state's long-term care system to make a paradigm shift to a system that allows participants to have maximum control over the services they receive. Because state staff have little to no control over many factors that can significantly delay a new program, states that want to offer an entirely new self-direction program or a new option in an existing program should allocate at least 2 years for planning and development.

Despite the considerable time, effort, and resources needed to implement a new budget authority program, program staff in the Replication States believe it is well worth doing because the ability to direct services and supports makes a positive difference in the lives of many individuals with disabilities and their families.

Endnotes

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- ¹ Cognitive impairment may be due to a wide range of conditions, including developmental disabilities, brain injury, dementia, or serious mental illness.
 - ² These grant programs were carried out by or under the aegis of a National Program Office, located originally at the University of Maryland, College Park Center on Aging and, subsequently, at the Boston College School of Social Work, directed by Kevin Mahoney, Ph.D.
 - ³ Research findings from one of the demonstration states—Arkansas—became available in 2002.
 - ⁴ Two Grantees competed for and won supplemental funding for additional activities: Minnesota to offer the C&C model to elderly persons receiving services funded by the Older Americans Act (OAA) and New Mexico to conduct additional outreach and education to ethnic minority groups—Native Americans and the Spanish-speaking population—to ensure their participation in the new program.
 - ⁵ Illinois and Pennsylvania had their grants extended through December 31, 2008.
 - ⁶ Early in the replication phase, it became evident that some of the States did not understand which features were considered the essential elements of the C&C model that they were required—as a condition of their grants—to implement. For example, two states submitted HCBS waiver requests to CMS that included only employer authority. To clarify the required design features, the C&C NPO developed and disseminated the C&C Vision Statement, which is available at: <http://www.cashandcounseling.org/resources/20060807-100150>.
 - ⁷ WV and KY first amended their §1915(c) waivers to allow hiring of participant-directed workers and then later amended their waivers to add goods and services.
 - ⁸ Both §1915(c) waivers and the State Plan Personal Care option have always allowed states to offer the employer authority (i.e., letting participants hire, supervise, and dismiss their own workers). Sections 1915(c) and 1115 are sections of the Social Security Act.
 - ⁹ As a result, Pennsylvania abandoned its initial plan to amend six waiver programs to add a new budget authority option. It now plans to implement the C&C model in two waivers in five counties in February 2009.
 - ¹⁰ See Chapter 2 in *Developing and Implementing Self-Direction Programs and Policies: A Handbook*. The Handbook is available at: <http://www.cashandcounseling.org/resources/handbook>.
 - ¹¹ The §1915(j) authority is required regardless of whether the entire cash benefit will be provided directly to the participant or to an FMS entity, and even if only a small cash advance or cash reimbursement is given to participants.
 - ¹² Although the §1915(j) State Plan amendment does not need to be renewed, the State Plan amendment must itself be amended if the state makes major changes to the program. The notice of final rule was published in the October 3, 2008, issue of the *Federal Register* and it will be effective November 3, 2008.

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- ¹³ The office was formed to assist with rebalancing Pennsylvania's long-term living system and in providing opportunities for persons of all ages with disabilities to live independently.
- ¹⁴ Randall, J. and Bekteshi, V. *Enacting Support Brokerage in the 12 Cash & Counseling Expansion States*. Paper available from the C&C National Program Office.
- ¹⁵ Focus groups were conducted in Alabama, Iowa, Michigan, Vermont, and West Virginia.
- ¹⁶ See *Participant Goal Setting in Cash & Counseling*, a tool created by Scripps Gerontology Center to help participants in self-direction programs to set personal goals. Available at: http://www.cashandcounseling.org/resources/20080303-130304/index_html.
- ¹⁷ Inclusion of family members and other informal supports is not required, but is at the participants' request. However, participants who do not know that they can involve others are less likely to request their inclusion in the PCP process. Clearly, it is considered desirable when a participant lives with other family members and has informal caregiver support; and it is essential for participants who have cognitive impairments, as they typically require representatives to participate in a self-direction program.
- ¹⁸ Training and guidelines were available for providers in the mental health-MR/DD system.
- ¹⁹ A few agencies continued to conduct assessments, predominantly for participants receiving medically-oriented agency services in addition to services covered under their individual budgets.
- ²⁰ Lombe, Margaret. (November 2008). Breaking barriers to asset building among people with disabilities: A collaboration of home and community-based intervention and a credit union. *Journal of Social Work in Disability and Rehabilitation*. 7(4).
- ²¹ The Consumer Direction Module (CDM) is a secure web-based software application specifically designed to support self-direction programs that allow individual budgets. The CDM can also be linked to states' MMIS and assessment databases, if a state elects to do so. Additional information about the CDM can be obtained at: <http://www.cashandcounseling.org/search?TextIndex=CDM>.
- ²² However, follow-up quality assurance interviews with individuals who enrolled have found that in some cases, participants are receiving more services in the new option than they did in the traditional system because they are able to hire their own workers.
- ²³ Information about developing communication plans is available at: <http://www.cashandcounseling.org/resources/20060519-134758/>.
- ²⁴ Available on the *Mi Via* website at: <http://www.mivianm.org>.
- ²⁵ A tool for addressing provider resistance is available at: http://www.cashandcounseling.org/resources/20080415-145147/index_html.
- ²⁶ Mental Retardation, Ill and Handicapped, Physical Disability, Elderly, Brain Injury, and AIDS/HIV.
- ²⁷ Michigan uses the term self-determination rather than self-direction but to prevent confusion, this report uses the term self-direction throughout.
- ²⁸ In fall 2007, the Minnesota MR/RC waiver was renamed the DD waiver.

²⁹ About 650 participants (or their surrogates) in Vermont currently hire, supervise, and dismiss workers. The State also has a program called *Developmental Services*, which covers individuals with developmental disabilities who live in a type of fostering arrangement in the home of a paid Home Provider. The Home Provider can hire additional support staff, respite staff, or both, the cost of which is paid from the consumer’s overall budget. Prior to receipt of the grant, a small number of individuals and their families had been “self/family managing” and as C&C grant activities were getting underway, *Developmental Services* awarded a grant to an organization to provide these individuals with support brokerage services.

³⁰ Waiver and State Plan participants in Washington State may receive personal care services from a licensed home care agency or independently employ and supervise workers. The majority of waiver participants receiving in-home services directly employ personal assistance workers.

³¹ In terms of enrollment numbers, the Replication States may appear, in the aggregate, less successful than the CCDE States—Arkansas, Florida, and New Jersey. However, the CCDE States had to meet specific enrollment requirements for the controlled experimental design evaluation and were chosen specifically because they—in contrast to most other states—had large pools of eligible Medicaid beneficiaries.

To recruit sufficient enrollees, two of the three States implemented their programs statewide and the other, while not implementing statewide, covered a large population in a broad geographic area. The CCDE States were also chosen because they offered very limited, if any, other opportunities for self-direction that might provide eligible and interested individuals with an attractive, competing alternative to enrolling in the new program.

³² Environmental turmoil within the State can be especially difficult for state program administrators to deal with because only those further up the chain of command may be equipped to take the necessary steps to decrease it or protect the program from it. Sometimes, the C&C NPO provided assistance to several States because it was easier for the NPO director to gain access to high ranking state officials and make them aware of threats to the success of the grant project than it was for state officials several bureaucratic levels below to do so.

³³ Case manager resistance was more prevalent in the Replication States than it was in the original CCDE; only Florida had this problem because it was the only CCDE State to use HCBS waivers as the “feeder” programs. Arkansas and New Jersey used their Medicaid State Plan Personal Care Services (PCS) programs, which did not have traditional case managers. Opposition from traditional PCS providers was defused by developing an alternative “referral” system and using newly recruited counselors who were not wedded to the traditional system at all.

³⁴ In Vermont, a climate of serious distrust of state officials and their motives among potential participants—not related to the new program but based on previous experience—caused them to be suspicious of the new program and was a major disincentive to enrollment. This resistance may have been related to suspicion about the State’s goals in reforming the entire long-term care system under a §1115 research and demonstration waiver.

³⁵ Phillips, B. et al. (2003). *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida and New Jersey*. Washington, DC: Department of Health and Human

Services, Assistant Secretary for Planning and Evaluation. Available at: <http://aspe.hhs.gov/daltcp/reports/cclesson.htm>; Phillips, B. et al. (2007). *Implementation Lessons on Basic Features of Cash & Counseling Programs*. Boston, MA: Cash and Counseling National Program Office. Available at: http://www.cashandcounseling.org:80/resources/20070404-152907/index_html; and O’Keeffe, J. et al. (2007). *Increasing Options for Self-Directed Services Initiatives of the FY 2003 Independence Plus Grantees*. Baltimore, MD: USDHHS, Centers for Medicare and Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/2134>.

³⁶ States that received C&C grants were offered the opportunity to help develop and/or adopt the CDM; Alabama, Rhode Island, and West Virginia participated in the CDM’s development and are using the CDM to some extent in their programs.