New State Strategies To Meet Long-Term Care Needs

ABSTRACT Consumer-directed long-term care service programs give participants the flexibility they want, while reducing unmet need for home and community-based services and supports. States’ efforts to expand such programs under Medicaid, including those supported by federal Cash and Counseling demonstration and evaluation grants, are often hindered by challenges related to costs, staffing and organizational issues, new infrastructure requirements, and resistance from stakeholders. Yet states have developed a number of successful strategies for overcoming these challenges, even in financially trying times. Their experiences offer valuable insights, guidance, and encouragement to other states contemplating consumer-directed service expansions.

The consumer-directed service delivery approach gives people with disabilities, as well as their families, the opportunity to exercise greater choice and control over the publicly funded long-term care services and supports they receive. The Centers for Medicare and Medicaid Services (CMS) recognizes two basic models of consumer-directed services. The first model, called employer authority, gives participants the right to hire, fire, schedule, and supervise aides of their choosing (including family members), instead of relying on the services of aides arranged by home care agencies. The second (and newer) budget-authority model goes further by allowing participants to manage a specific monetary allowance; this may be used not only to employ aides, but also to purchase related services and goods not otherwise covered by Medicaid, such as transportation services, rehabilitation services, assistive technologies, and installation of ramps and home modifications.

From the mid-1990s through the early 2000s, several evaluations reported favorable results. These included including increased satisfaction with services and quality of life when comparing the employer-authority model with professionally managed, agency-delivered aide services. There were similar positive findings for programs providing individualized budgets to people with intellectual or other developmental disabilities.

The three-state (Arkansas, Florida, and New Jersey) Cash and Counseling demonstration and evaluation, launched between 1998 and 2000, encompassed the first large-scale budget-authority programs incorporating a controlled experimental design for purposes of evaluation. The results, published between 2002 and 2005 and widely disseminated, have proved influential in bringing about changes in federal law, regulation, and policy that encourage and facilitate the inclusion of consumer-directed services in state Medicaid programs. State policymakers now see these alternatives to professionally managed services as desirable—or at least worthy of consideration. Federal Medicaid officials report that states are increasingly offering them.

Accordingly, policy research focus has shifted away from evaluating the relative effectiveness of consumer-directed services and professionally managed services and toward providing technical assistance with implementation of consumer-
directed service options at the state level. Philanthropic and federal funding now primarily supports efforts that enable states to analyze, share, and learn from their implementation experiences and to obtain specialized technical assistance, such as that provided by the National Resource Center for Participant-Directed Services at Boston College.

In the course of conducting a comprehensive inventory of publicly funded consumer-directed service programs, researchers affiliated with that center identified, as of October 2009, 180 such Medicaid programs (both employer authority and budget authority). States often have multiple programs targeted to different populations (for example, the elderly, physically disabled adults, and children and adults with intellectual disabilities; see Exhibit 1).

Although an estimated 2.8 million Medicaid beneficiaries receive home and community-based services, there are no reliable national statistics on enrollment in consumer-directed service options. Systematic program data including enrollment figures on budget-authority programs are readily available only for the fifteen programs launched under the Robert Wood Johnson Foundation’s (RWJF’s) Cash and Counseling initiatives, with additional support from the U.S. Department of Health and Human Services and the Retirement Research Foundation. These include programs in the three states (Arkansas, New Jersey, and Florida) that participated in the original Cash and Counseling demonstration and evaluation (programs launched between 1998 and 2000) and in the twelve “second-generation” states (Vermont, Rhode Island, Pennsylvania, West Virginia, Alabama, Kentucky, Illinois, Michigan, Iowa, Minnesota, Washington, and New Mexico) that participated in the replication initiative (programs launched between 2004 and 2009).

As of October 2009, these programs had 15,000 participants. Even though most of the

---

**EXHIBIT 1**

Options For Consumer Direction Available In Medicaid

<table>
<thead>
<tr>
<th>State-plan optional personal care services benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program participants must need human assistance with tasks such as bathing, dressing, transferring; no federal cost-control requirements; no enrollment caps permitted; must be open to all who meet financial eligibility and functional need criteria</td>
</tr>
<tr>
<td>Employer authority; i.e. individual providers, exercised at state option since late 1960s, explicitly authorized in federal regulations published in 1997</td>
</tr>
<tr>
<td>Widely used; several large programs (for example, in CA, MI, MA, MO, NY); many smaller programs (for example, NH, VT, OK, MD)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1915(c) home and community-based services waivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiver participants must be eligible for institutional level of care; federal requirement for “cost-effectiveness” vis-à-vis cost of institutional care; enrollment caps and programs targeted to different groups permitted</td>
</tr>
<tr>
<td>Employer authority available since 1981 (for example, long-standing programs in OR, WA, KS, ME, WI); availability of budget authority clarified/broadened through Centers for Medicare and Medicaid Services policy guidance, 2002-2005</td>
</tr>
<tr>
<td>In 2002-2003, special federal incentives for states to develop budget-authority programs via Independence Plus waivers (for example, SC, NC, LA, NH, CT, DE, MD) and/or Real Choice/Systems Change grants (12 Independence Plus grants); programs have proliferated since 2005</td>
</tr>
<tr>
<td>Consumer direction is also available in managed care under combination 1915(a) or 1915(b) and (c) waiver authority (for example, TX, WI, MN)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1915(j) state-plan “Cash and Counseling” authority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid beneficiaries must be otherwise eligible for state-plan personal care or home and community-based services waiver services; enrollment caps permitted</td>
</tr>
<tr>
<td>Budget authority created in Deficit Reduction Act of 2005, available as of January 2007; unique in allowing payments in “cash” directly to program participants</td>
</tr>
<tr>
<td>Costs cannot exceed those of services for which participants would otherwise be eligible; approved state-plan amendments in AR, NJ, FL, OR, AL, CA, TX as of October 2009</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1915(i) state-plan home and community-based services</th>
</tr>
</thead>
<tbody>
<tr>
<td>May not be limited to participants eligible for institutional long-term care, but restricted set of services compared to 1915(c) or (j) authority; no federal cost containment requirements; enrollment caps permitted</td>
</tr>
<tr>
<td>Employer or budget authority created in Deficit Reduction Act of 2005, available in January 2007; consumer direction included only in CO, as of October 2009</td>
</tr>
</tbody>
</table>

twelve second-generation Cash and Counseling programs were less than three years old at that time and four were not yet operating statewide, four already had 1,000 or more participants, and seven had enrolled 10 percent or more of the eligible population. Participation rates have varied across states, in part because several (Washington, Minnesota, and Vermont) offered employer-authority programs to certain target populations before offering them budget-authority programs. Generally, participation in Cash and Counseling programs has grown faster, and reached higher levels, in states that previously offered no or very limited opportunities for consumer direction and where such programs were introduced to address complaints about insufficient access to and quality of existing services.

Along the way, individual states have faced, and overcome, a number of challenges to implementing, expanding, and sustaining budget-authority consumer-directed service options within their Medicaid programs. In this paper we draw on experiences from the fifteen programs launched under the original and replication Cash and Counseling initiatives to examine four of the implementation challenges most frequently identified as major by state program administrators—and, therefore, the ones for which they most often seek external help (such as technical assistance from consultants with specialized expertise and practical advice from experienced program administrators in other states).

These four major challenges are as follows: (1) adverse budgetary conditions that intensify demands for cost control and cost-effectiveness; (2) personnel shortages, conflict, and organizational and leadership changes within state government that pose special dangers for new programs; (3) the need to develop new elements of infrastructure (key program components that are either unique to or have more complex requirements in the budget-authority model of consumer-directed services); and (4) resistance from stakeholders in the status quo, especially traditional service providers and case managers. Although other challenges have arisen—such as curbing fraud and abuse and dealing with induced demand for services stimulated by program creation—state officials rarely describe them as major.

Although none of the major challenges has proved to be easily addressed or overcome, state Cash and Counseling program officials have nevertheless identified a number of successful strategies and learned important lessons that could benefit policymakers in other states seeking to implement budget-authority consumer-directed service options.

Study Data
Our principal data sources include the original Cash and Counseling demonstration and evaluation implementation report and the Cash and Counseling replication report. These published sources summarize states’ implementation experiences based on states’ final grant reports and semistructured interviews with state officials. They are supplemented by the authors’ own observations, as well as those of other experienced federal and state officials and technical assistance contractors.

Four Major Challenges To Budget-Authority Programs’ Success

CONTROLLING COSTS Since 2008, a national economic crisis has put severe pressure on state budgets. During this latest and lowest down cycle in what knowledgeable observers have often referred to as the “roller-coaster” budgetary conditions with which states must contend, state officials clearly cannot afford to ignore the budget consequences of implementing new programs.

The evaluation of the original Cash and Counseling programs found that in all three states, costs for personal assistance services were significantly higher for program participants than for those receiving only traditional services (\(p < 0.01\)). In Arkansas and New Jersey, traditional services included only agency-delivered aide services, whereas in Florida, traditional services included other services that a professional case manager could authorize (such as adult day services, or “habilitation,” and associated transportation services for adults with intellectual disabilities). Because experimental program participants’ individual budgets were based on the expected cost of the services to which each would otherwise have been entitled, the difference was primarily attributable to the lower likelihood of traditional services users’ receiving all authorized services.

For example, in Arkansas, participants in the comparison group, permitted to access only agency-delivered personal care, received only two-thirds of their authorized aide services. The shortfall was attributable to problems with recruiting and retaining aides, which left many traditional providers chronically short of workers, especially in rural areas. The greater difficulty obtaining authorized services experienced by traditional service program recipients in both Arkansas and New Jersey was, in turn, associated with greater nursing home use. The impact of the Cash and Counseling alternative on spending was particularly large and long-lasting in Arkansas, where, within three years, reduced nursing...
home use generated sufficient savings to offset participants’ higher personal assistance spending.15

Even so, Arkansas officials had to find ways to cut costs associated with their Cash and Counseling program, called Independent Choices, to ensure budget-neutrality under the terms of the research and demonstration authority: a Medicaid Section 1115 waiver, which did not take into account savings from reduced nursing home use. The solution was to reduce payments for the budget management support services provided to program participants. These costs, representing the administrative overhead of Cash and Counseling, were originally equal to the overhead costs of traditional agency providers. Arkansas was able to reduce them without adverse effects on program participants, who continued to receive sufficient counseling and financial help to manage their budgets. Because direct costs were the same for traditional agency-provided services and for Independent Choices’ cash-and-counseling services, but the final cost of agency overhead was roughly three times greater for the former, the per unit cost of service delivered was lower under Independent Choices.

For this and other reasons, Arkansas officials are convinced that in the long term, the Cash and Counseling service delivery mode generates cumulative savings; at the same time, it does a better job of ensuring that program participants actually receive enough services to address their most pressing needs.16 After nine years, the state’s official 1115 waiver closeout budget-neutrality cost report credited Independent Choices with $5.6 million in savings—even though savings resulting from reduced nursing home use were excluded.17

We emphasize Arkansas’ successful cost containment efforts because the state’s officials have been willing to share in great detail what they learned about cutting costs without compromising improved access to and quality of paid care. Arkansas officials continue to periodically review and update comparative cost analyses of Independent Choices and regular state-plan personal care services, including related patterns of use and cost for other Medicaid expenditures. This ongoing activity has helped ensure continued support from state policymakers for initiatives currently under way to further expand consumer-directed service options.

Outside the context of Section 1115 research and demonstration waivers, states do not always expect budget-neutrality for consumer-directed service options. In fact, only the three states that participated in the original 1115 waiver demonstrations were required to meet a federally imposed budget-neutrality test, and all three now operate their programs under Medicaid state-plan authority with no such requirement.

States can choose to offer home and community-based long-term care services under one or more of several Medicaid statutory authorities. The types of services (consumer-directed and other) that may be covered and the extent of consumer direction permitted vary (see Exhibit 1). Arkansas has always provided personal care services under the state plan as an entitlement to all who qualify, as legally required, and made the Cash and Counseling alternative similarly available.

However, many other states have elected to cover home and community-based services under Section 1915(c) home and community-based services waiver authority, subject to enrollment caps. Targeted exclusively to people who qualify for institutional care, such coverage typically consists of a professionally managed service plan that, on average, may cost as much but no more per person served than institutional care. Professionally managed and consumer-directed services may be covered, but until recently, coverage was often restricted to the former.

Use of enrollment caps to control costs often results in lengthy waiting lists. As the ranks of Medicaid recipients wait-listed for benefits grow, so does policymakers’ (especially elected officials’) awareness of the potential political costs of ignoring the plight of the wait-listed individuals and their family caregivers—and of the discontent of those who, having reached the head of the line, cannot obtain all authorized services because of shortages of traditionally authorized providers. The effectiveness of home and community-based alternatives to deter institutional placement is compromised when people with severe disabilities must wait for coverage (often for two years or more). It is further eroded if they subsequently have difficulty obtaining professionally managed services that are in short supply, especially when nursing home placement requires no wait.

Officials in these states are increasingly turning to consumer-directed budgets as the most cost-effective way to reduce and eventually eliminate waiting lists and assure access to services by allowing the use of nontraditional providers. In this respect, state officials (especially those in other poor, rural states) find Arkansas’s Cash and Counseling experience useful and encouraging. The lesson: People entitled to personal care Section 1115 waiver, which did not take into account savings from reduced nursing home use. The solution was to reduce payments for the budget management support services provided to program participants. These costs, representing the administrative overhead of Cash and Counseling, were originally equal to the overhead costs of traditional agency providers. Arkansas was able to reduce them without adverse effects on program participants, who continued to receive sufficient counseling and financial help to manage their budgets. Because direct costs were the same for traditional agency-provided services and for Independent Choices’ cash-and-counseling services, but the final cost of agency overhead was roughly three times greater for the former, the per unit cost of service delivered was lower under Independent Choices.

For this and other reasons, Arkansas officials are convinced that in the long term, the Cash and Counseling service delivery mode generates cumulative savings; at the same time, it does a better job of ensuring that program participants actually receive enough services to address their most pressing needs.16 After nine years, the state’s official 1115 waiver closeout budget-neutrality cost report credited Independent Choices with $5.6 million in savings—even though savings resulting from reduced nursing home use were excluded.17

We emphasize Arkansas’ successful cost containment efforts because the state’s officials have been willing to share in great detail what they learned about cutting costs without compromising improved access to and quality of paid care. Arkansas officials continue to periodically review and update comparative cost analyses of Independent Choices and regular state-plan personal care services, including related patterns of use and cost for other Medicaid expenditures. This ongoing activity has helped ensure continued support from state policymakers for initiatives currently under way to further expand consumer-directed service options.

Outside the context of Section 1115 research and demonstration waivers, states do not always expect budget-neutrality for consumer-directed service options. In fact, only the three states that participated in the original 1115 waiver demonstrations were required to meet a federally imposed budget-neutrality test, and all three now operate their programs under Medicaid state-plan authority with no such requirement.

States can choose to offer home and community-based long-term care services under one or more of several Medicaid statutory authorities. The types of services (consumer-directed and other) that may be covered and the extent of consumer direction permitted vary (see Exhibit 1). Arkansas has always provided personal care services under the state plan as an entitlement to all who qualify, as legally required, and made the Cash and Counseling alternative similarly available.

However, many other states have elected to cover home and community-based services under Section 1915(c) home and community-based services waiver authority, subject to enrollment caps. Targeted exclusively to people who qualify for institutional care, such coverage typically consists of a professionally managed service plan that, on average, may cost as much but no more per person served than institutional care. Professionally managed and consumer-directed services may be covered, but until recently, coverage was often restricted to the former.

Use of enrollment caps to control costs often results in lengthy waiting lists. As the ranks of Medicaid recipients wait-listed for benefits grow, so does policymakers’ (especially elected officials’) awareness of the potential political costs of ignoring the plight of the wait-listed individuals and their family caregivers—and of the discontent of those who, having reached the head of the line, cannot obtain all authorized services because of shortages of traditionally authorized providers. The effectiveness of home and community-based alternatives to deter institutional placement is compromised when people with severe disabilities must wait for coverage (often for two years or more). It is further eroded if they subsequently have difficulty obtaining professionally managed services that are in short supply, especially when nursing home placement requires no wait.

Officials in these states are increasingly turning to consumer-directed budgets as the most cost-effective way to reduce and eventually eliminate waiting lists and assure access to services by allowing the use of nontraditional providers. In this respect, state officials (especially those in other poor, rural states) find Arkansas’s Cash and Counseling experience useful and encouraging. The lesson: People entitled to personal care
Kentucky decided to implement its Cash and Counseling program as a remedy for long waiting lists for home and community-based services programs with capped enrollment and inadequate traditional provider capacity in rural areas. Introduction of consumer-directed budgets was part of a broader strategy that included increased funding for home and community-based services to expand enrollment and reduce waiting times.

Yet in spite of the commitment of a newly elected governor, Ernie Fletcher, and other top officials to this strategy, the state experienced a “perfect storm” of adverse political and bureaucratic conditions. These included multiple reorganizations, in which lead responsibility for the new program shifted from the developmental disabilities agency to the Medicaid agency to the state unit on aging, and considerable turnover in both upper- and lower-echelon leadership within the various agencies (for example, four different Medicaid directors in four years). During the planning phase, the new program’s fate was hostage to that of other Medicaid policy reforms (such as plans for a comprehensive Medicaid reform Section 1115 research and demonstration waiver) that preoccupied top officials and took up much staff time, even though they eventually were abandoned.

Kentucky’s fledgling Cash and Counseling program prevailed against the odds, largely thanks to the political strength and sophistication of a coalition of consumer advocates representing the frail elderly, adults with physical disabilities, and people with developmental disabilities and their families. Immediately before the end of the Cash and Counseling grant period, a new governor, Steve Beshear, from a different political party, was elected. Aware of the program’s popularity, he took the unusual step of retaining a political appointee from the previous administration to ensure continuity of program leadership. The coalition’s triumph demonstrates that state officials are well advised to communicate and cultivate relationships of mutual trust with advocates.

Given adverse budgetary, organizational, and staffing conditions, states have to set realistic, achievable goals for implementing consumer-directed budgets. This is especially so when grant funding ends and grant-funded staff are let go because state budgetary constraints preclude putting them on the state payroll. The enrollment process for budget-authority programs necessitates intensive “up-front” counseling to ensure that enrollees fully understand their roles and responsibilities. In many states, a major reason for low or slow enrollment has been insufficient outreach and enrollment personnel.

Accordingly, state officials and support services providers have recommended turning necessity into virtue, by choosing to enroll participants slowly but steadily. West Virginia’s Personal Options program, launched in July 2007, got off to a very slow start. This could have easily been misinterpreted as a sign of lack of interest in consumer direction among potential enrollees, thanks to high satisfaction with traditional, agency-delivered aide services. However, within a little more than two years, the program had more than 500 participants, representing 10 percent of those eligible—an impressive result for a program that has relied almost entirely on word-of-mouth marketing.

Proceeding slowly may also be necessary to build consensus and achieve coordination across separate state agencies (for example, Medicaid, the state unit on aging, the developmental disabilities agency) and to gain the cooperation of powerful, semiautonomous local or regional agencies (for example, county social services agencies or area agencies on aging). Gradual enrollment and statewide phase-in strategies have the added advantage of giving state officials ample time to work out kinks in program infrastructure.

**NEW INFRASTRUCTURE REQUIRED** States seeking to implement new consumer-directed service programs—especially of the budget-authority type—benefit from specialized technical assistance to develop the necessary infrastructure. Indeed, they may suffer serious setbacks without this support. States that received Cash and Counseling grants used most of their grant funds to hire administrative and outreach/enrollment personnel, and they received considerable technical assistance related to infrastructure development directly from the Cash and Counseling National Program Office. Here we touch on three key elements of infrastructure: individual budget-setting methodologies, financial management services, and counseling.

▽ **INDIVIDUAL BUDGET-SETTING METHODOLOGIES:** The CMS requires that benefit allocations be based on a professional assessment of needs. Thus, an individualized consumer-directed budget must be based on a formula that ensures that funding can cover the cost of meeting assessed need. Fairness dictates parity of purchasing power vis-à-vis the standard personal care services or other home and community-based services that would be authorized as necessary and reimbursable for the same person if enrolled in a traditional program.

Depending on what the standard services would otherwise be, the formula for developing an individualized budget could be simple or complex. As Minnesota officials discovered, complex
methods (algorithms that use several years of Medicaid claims data to calculate average costs for people with similar disability profiles) can be difficult to explain in simple terms to Medicaid recipients, consumer advocacy groups, and service providers. Nevertheless, officials in Minnesota and elsewhere agree that transparency is essential and that investing the time and effort necessary to explain the methodology to stakeholders prevents misconceptions. There is also widespread agreement that by standardizing assessment tools and processes and developing budgets accordingly, for both consumer-directed and traditional services, states can better control costs and ensure fairness in resource allocation.

**Financial Management Services:** Financial management entities, which program participants may refer to as their “bookkeeper” or “accountant,” help program participants manage their budgets by performing payroll agent and accounting functions. In both employer- and budget-authority models, such services enable public program participants to fulfill their responsibilities as employers by filing and paying their share of payroll taxes on behalf of their assistance workers. These services also ensure that participants with budget authority do not exceed their budgets.

Financial management services entities provide the Medicaid program with financial accountability and protection against misuse of budgets by participants and representatives. Yet nearly all Cash and Counseling grantees report having experienced difficulties with financial management services. Hence, state officials agree that it is critical to develop strong oversight capability to detect and resolve these difficulties in a timely fashion. Minnesota and Pennsylvania initially qualified numerous such entities and had to prune those that proved insufficiently knowledgeable about key tasks such as payroll processing and tax filing. Arkansas had to decertify and replace a financial management service entity that engaged in questionable financial dealings. Florida had to redo its approach to financial management services four times but is pleased with its current arrangements, especially after substantial savings were recouped.  

State officials have learned valuable lessons from dealing with problems in this area but, in the process, have paid a price—chiefly in the form of delays getting under way, slower-than-expected growth, and, in some cases, having to suspend new enrollments while making the transition to new providers of financial management services. State officials frequently cite financial management services as the area where they most need external technical assistance.

**Counseling:** The key issue for states is to define the content of the counseling (some states prefer the terms “consultant” or “support broker”) role and differentiate it from traditional case management. Traditional case managers make recommendations to or decisions on behalf of the state, whereas counselors advise program participants. States must develop recruitment strategies and training for counselors or, in some cases, retrain traditional case managers so that they can adopt a new role, working with program participants who choose to direct their own services.

Counselors must explain to participants the state’s guidelines regarding permissible and impermissible use of their budgets. If there is uncertainty about whether a participant’s proposed purchase is or is not allowable, the state decides. Rhode Island has had considerable success using information technology (IT) to facilitate three-way communication among program participants, counselors, and state officials. State officials there report being able to obtain the necessary information to make case-by-case budget decisions rapidly and without undue burden on them. They also report that even when program participants are unhappy with the state’s final ruling, the quick response is appreciated.

**Resistance from Key Stakeholders** Traditional providers (such as home care agencies) seldom welcome perceived competition from consumer-directed alternatives. However, traditional providers are not uniformly opposed to consumer direction.

In some states, agencies recognize that they cannot recruit enough workers to meet demand and cannot afford to serve people living in rural or frontier areas. Some also recognize that their services might not be culturally attractive to some minority participants. Also, it can be to traditional providers’ advantage to refer so-called problem clients, who complain about and often ask to change workers, to consumer-directed services. New Jersey, among other states, reported successfully making the argument to agencies and their associations that “your least desirable clients can be our best customers.”

The most operationally problematic source of resistance to consumer direction is from case managers and service coordinators, who play a key role in traditional home and community-based waiver programs. States typically want or need these people to assume a counseling role, or at least inform eligible consumers about the consumer-directed service option. Two of the original Cash and Counseling states, Arkansas and New Jersey, were able to circumvent this problem; their programs were offered as alter-
natives to state-plan personal care services in which agency nurses supervised aides but participants had no case managers. Consequently, these states were able to recruit counselors who had no preconceptions based on prior experience as traditional system case managers and who were enthusiastic about facilitating consumer direction.

In contrast, Florida and all of the replication programs designed their programs to offer a consumer-directed budget alternative to a case-managed home and community-based services waiver care plan. Under these circumstances, it becomes crucial to obtain the buy-in of traditional system case managers, for several reasons. First, case managers who disapprove of consumer direction or do not consider it appropriate for most of their clients will discourage participation. Second, it is typically not practical, for cost reasons, for states to bypass the existing case management infrastructure to recruit and train a whole new cadre of counselors. Third, replacing case managers with newly recruited counselors is impractical. Case managers and their agencies could perceive such an act as a threat to their job security and business interests, and might therefore mobilize politically against consumer direction.

In states that plan to use case managers to provide counseling, training curricula for the counselors typically take the form of retraining programs that teach new roles and responsibilities for working with program participants who are directing their own care. Officials in Florida and Maine say that it often takes multiple training sessions for case managers to make the shift to the counselor role.

Case managers’ resistance to consumer direction is sometimes based on purely pragmatic considerations. It can be overcome if state officials understand and remove bureaucratic disincentives. For example, performance standards for case managers in Washington State required them to ensure service delivery startup within a stated time frame. However, by imposing a waiting period to ensure that participants fully understood what consumer direction entailed, the state made it more difficult to ensure their receipt of services by the deadline. Once the rules were amended to fix this problem, case managers were more willing to make referrals, and enrollment of Cash and Counseling participants increased.

However, case managers’ resistance to consumer direction is largely philosophical, rooted in adherence to a model in which service provision is professionally managed. Traditional case managers often express ambivalence about family caregivers who wish to become paid aides or wish to help a self-directing program participant decide how to spend his or her budget. State officials in Alabama and Iowa reported that their case managers were concerned that consumer direction would lead to fraud and abuse (even though this did not happen). In Minnesota, focus groups with case managers revealed that many thought that consumer direction was inappropriate for elderly people because it was too complex. They considered the budget amounts for participants with certain need profiles inadequate, even though those amounts accurately reflected the cost of services the same managers had previously authorized for participants in other types of programs at identical need levels.

Whether resistance is for pragmatic or philosophical reasons, state officials (especially in Minnesota, Rhode Island, and Michigan) report that one of their most effective strategies is to find a few champions among case managers who, well respected by their peers, help gradually win over the skeptics.

**Conclusion**

Despite having to contend with unusually adverse Medicaid budget conditions, resistance from traditional service system providers and case managers, and other serious implementation challenges that have delayed program startup and slowed enrollment, states have demonstrated that it is possible to implement and sustain successful new budget-authority consumer-directed service programs.19

Rhode Island’s Cash and Counseling grant report was emblematic in acknowledging the “very large issue” of “an extreme state budget deficit in state fiscal year 2008 [that was projected to last] at least through state fiscal year 2010,” yet at the same time expressing confidence that “the Personal Choice program is...a cost-effective alternative” and “will undoubtedly remain.” In New Mexico and Michigan, consumer-directed services were described as driving a “paradigm shift” in long-term care services. According to Michigan officials, the availability of person-centered planning and self-determination (Michigan’s preferred terms) had a major positive impact even on those who chose not to enroll in consumer-directed service options, by raising the quality bar and causing traditional providers to improve their services.

Endorsements such as these, and the willingness of states that have effectively met challenges to share their insights, should serve as an encouragement to other states contemplating the creation or expansion of consumer-directed long-term care services programs.
The authors acknowledge the helpful comments of Janet O’Keeffe, Research Triangle Institute; Vidhya Alakeson, U.S. Department of Health and Human Services; Lori Simon-Rusinowitz, University of Maryland; and Suzanne Crisp, National Resource Center for Participant-Directed Services, Boston College. The contents of this paper are the responsibility of the authors and do not necessarily reflect the views or policies of the U.S. Department of Health and Human Services, Boston College, or Pennsylvania State University. A previous version of this paper was presented at the Health Affairs/SCAN Foundation conference: Long-Term Care in America, The Agenda for Health Reform, 7 May 2009, in Washington, D.C.

NOTES

4 For a comprehensive overview of evaluation results, see Benjamin AE, editor. Putting consumers first in long-term care: findings from the Cash and Counseling demonstration and evaluation. Health Serv Res. Special Issue. 2007;42(1).
5 Cash and Counseling reports as well as links to articles published in journals are available from http://www.cashandcounseling.org
6 Among states surveyed, twenty-five reported that Cash and Counseling was part of their strategy or planning for 2007; fifteen reported that such programs were under consideration for 2008 or later. Greene J. State approaches to consumer direction in Medicaid [Internet]. Hamilton (NJ): Center for Health Care Strategies Inc.; 2007 [cited 2009 Nov 23]. Available from: http://www.chcs.org/usr_doc/ State_Approaches_to_Consumer Direction.pdf
7 CMS officials Suzanne Bosstick and Mary Sowers report that they seldom review home and community-based services waiver applications (new or renewals/amendments) that do not include consumer direction. Five states have approved 1915(j) “cash and counseling” state-plan amendments, and CMS official Marguerite Schervish reported that three additional states had such amendments in process as of July 2009. Personal communication with the lead author; 21 October 2009.
8 A comprehensive inventory of publicly funded consumer-directed services is under way, but not yet completed, under the direction of Mark Sciegaj. Franke T. Home supportive services waiver applications [Internet]. Washington (DC): Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services; 2009 [cited 2009 Oct 21]. Available from: http://aspe.hhs.gov/daltcp/reports/hhs.htm
10 Calculating participation rates in consumer-directed services is difficult not only because some programs do not keep good statistics but also because sizable minorities of home and community-based services recipients live in group homes or assisted living, which makes them ineligible. Although total national enrollment is currently unknown, the numbers enrolled in long-standing employer-authority programs in a handful of populous states alone (such as California, Michigan, Massachusetts, and New York) exceed 500,000.
11 The National Center for Participant-Directed Services at Boston College, under the direction of Kevin Mahoney, updates Cash and Counseling program statistics quarterly.
17 The discussion of Arkansas’ cost experience and cost containment strategies is based primarily on numerous past and recent (2008–2009) personal communications (including data shared by e-mail) between current and former Arkansas state officials (including Debby Ellis, Suzanne Crisp, Sandra Barrett, and Herb Sanderson) and the authors. Marguerite Schervish, Arkansas’ CMS 1115 waiver project officer, confirmed the CMS’s acceptance of Arkansas’ closeout cost report and forwarded a copy to the lead author.
18 Personal communications by the lead author (most recent, June 2009) with Karen Huber, retired Florida Consumer Directed Care Program director; and Sherry Jackson, current program director.
19 Additional information on research and technical assistance (publications and other materials) related to consumer direction is available on two Web sites maintained by the Boston College National Resource Center for Participant Directed Services: http://www .cashandcounseling.org and http://www.bc.edu/schools/gsww/nrcpds/