kaiser commission on medicaid and the uninsured

Beyond Cash and Counseling:

The Second Generation of Individual Budget-based Community Long Term Care Programs for the Elderly

Prepared by

Brenda C. Spillman, Kirsten J. Black, and Barbara A. Ormond
The Urban Institute

January 2007

THE HENRY J. KAISER FAMILY FOUNDATION

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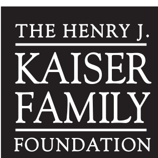

EXECUTIVE SUMMARY

States are increasingly interested in the individual budget model for older Medicaid beneficiaries as a mechanism to improve responsiveness of benefits to beneficiaries' needs and preferences and to increase their ability to remain outside or leave nursing homes. The "individual budget" model is a service option that offers beneficiaries an individual budget that they manage to obtain services they need, in place of the traditional package of Medicaid supports and agency-provided services. It originated in the Cash and Counseling Demonstration in three states in the late 1990s, and as of January 2006, the model had been implemented in some form by an additional seven states. Twelve other states were in the process of implementing the option. Beginning in January 2007, a new provision in the Deficit Reduction Act of 2005 (DRA) will allow states to offer an individual budget option for an expanded range of home and community-based services in their Medicaid state plans without having to obtain a waiver from the Centers for Medicare and Medicaid Services (CMS).

This report describes 10 operating individual budget model programs serving older persons, identifies four areas of program design that are of particular importance to the success of the individual budget model, and discusses how the states have addressed them. Based upon examination of existing information, this report draws the following key findings and implications:

Level and Adequacy of Benefits. The adequacy of individual budgets to meet participant needs depends on how the initial amount is set and on mechanisms to adjust for changing needs over time. A number of factors may affect the adequacy of resources actually available to beneficiaries to purchase supports. All states with operating waiver programs rely on the assessment process used for beneficiaries receiving traditional benefits as a basis for determining the individual budget for persons choosing the option. The budget amount is based on the dollar value of traditional benefits they would receive. Average individual budgets vary dramatically across the states with active programs, from about $400 in Arkansas to $4,000 in Colorado, reflecting differences in benefits available in the states' traditional programs, as well as differences in case mix. Reassessments occur at least as frequently as in traditional benefit programs and at any point when a participant's functional status or situation has changed.

States may also choose to reduce budget amounts to cover costs for financial and counseling services, affecting the amount of the money actually available to the participant. For example, in Florida, counseling services are covered as a waiver benefit outside the individual budget, but individual budget funds are used to pay for fiscal services through a monthly user charge and a fee for each payment processed. States also decide whether and how participants will be allowed to accumulate budget funds for larger purchases such as bathroom modifications.

Participant Choice. Choice of whether to participate is an important design feature for both states and beneficiaries. Consumer direction is not preferred by all long term care recipients and may not be appropriate for some. In all states operating waiver programs, the individual budget model is available as a voluntary alternative service delivery option with traditional services remaining as the default delivery system for persons who do not wish to manage a budget. All the states allow participants to select, hire, and supervise paid workers, including family members or friends, and to negotiate wage rates. With these expanded choices and opportunities for greater control over their own care, however, beneficiaries must be willing to

assume some of the management and fiscal responsibilities traditionally borne by agencies. All states exercise discretion in deciding whether an applicant is able to handle management responsibilities or has a suitable representative willing and able to take on these responsibilities. Training in employer and financial responsibilities commonly is required before participants can receive an allowance and direct their services.

The extent of beneficiary choice with respect to the range of services and supports they are allowed to direct may affect both willingness and ability to participate. Section 1915(c) waivers require states to specify all services included and which waiver services may and may not be consumer-directed. While these features have the potential to limit choice depending on the flexibility states build into waiver services, they also allow participants to choose to manage only those types of services they prefer and feel able to direct. In all states, personal assistance represents the largest expense in individual budgets for the typical participant.

Participant Support Systems. CMS requires state programs to include systems for supporting beneficiaries in developing and managing their budgets and obtaining needed services. Assistance with hiring, training, and supervising workers and managing the financial responsibilities associated with paying a worker have been found to be key program elements affecting elderly participants' continued involvement. The states with operating waiver programs differ in the level of support offered and in the level of support typically used. Participant supports typically are divided into counseling to help participants develop plans of care and manage budgets, and financial support services for payments to providers and payroll functions for workers. As of January 2006, one state, Arkansas, had the same contractor provide both services. Both the level of support available and the mechanism by which it is funded (e.g., by deductions from the participant allowance or by fees paid by participants) can affect whether participants, especially participants with greater needs, can be successful. Support services also serve a monitoring function to assure that services and other supports are within the plan of care, that participants do not overspend their budgets or underuse needed services, and that care plans and spending plans are revised as participant needs change.

Quality of care monitoring. States retain ultimate responsibility for assuring that individuals are receiving adequate care. A beneficiary's decision to direct his or her own care, however, entails an assumption of some risk in exchange for greater self-determination. For that reason, evaluations of individual budget programs have focused primarily on participant assessments of their care. In all states with operating programs, counselors are the first-line quality monitors, usually having the most frequent and consistent contact with both participants and financial management entities. Depending on the program, counselors visit participants as often as monthly, but typically quarterly or semi-annually, to monitor for service problems, abuse, neglect, or any changes in the participant's condition. In addition to qualitative indicators such as consumer satisfaction, several of the states have developed methods for gathering quantitative measures through participant surveys and/or toll-free numbers or hotlines to report problems.

Key Implications:

Careful attention is warranted to the interdependence of budget adequacy, quality of care, and choices and management supports available to participants. A willingness to revisit and calibrate program design based on experience is important for states. Successful participation is dependent upon a budget determination methodology that results in budgets sufficient to cover allowed services. Budgets may not be adequate if the discounts many states apply lock in traditional program problems with underuse of services stemming from an insufficient supply of agency workers or because services are not provided at the time or in the way needed. Successful participation also is affected by the extent to which budgets are adjusted to cover costs shifted from the state to participants, including the costs of planning, management, and fiscal services support, and by the amount of flexibility participants have in choosing the level of support they need.

Longer experience, larger enrollments, and evaluation evidence are needed to reveal how different program designs perform in attracting older participants and achieving better outcomes for them, as well as the implications for state spending. In most states, enrollments among older beneficiaries remain low, and long term impacts on their use of nursing homes, participant outcomes, and cost savings relative to standard benefits remain to be demonstrated empirically.

Newer designs that allow older beneficiaries to choose whether to manage a budget for all home and community-based services or only some services may increase participation. These designs differ fundamentally from "all or none" programs, so states should be cautious about relying too heavily on evaluation results from programs using the original Cash and Counseling design. Programs in North Carolina, South Carolina, and Wisconsin that allow participants the choice of receiving a budget for and directing only part of their service package have the potential to answer additional questions about what works best for older beneficiaries and the benefits of offering a more complete continuum of choices. Evaluation results from such programs may be particularly valuable for states considering an individual budget option for older beneficiaries but wanting to take smaller steps and not incur the costs of implementing a more comprehensive model. These programs also present a less straightforward evaluation platform and so present additional challenges for designing state evaluations.

It is important to continue to monitor the evolution of the individual budget model and variants on it, as well as other innovations in the organization and delivery of public long term care services for the older population and others. It remains to be seen how many states will choose to take advantage of the new DRA provisions for their older beneficiaries or others, and how many additional states will choose to pursue waivers for individual budget programs. In either case, up-to-date information on design choices made in existing waiver programs and new ones nearing implementation, as well as evaluation of their impact on beneficiaries and costs, can provide valuable guidance to states in adapting this model to their particular fiscal and political situations.

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BACKGROUND

The individual budget model originated in the Cash and Counseling Demonstration sponsored by the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services in three states in the late 1990s. In concept, the individual budget model is perhaps the most complete expression of the longstanding movement for consumer direction in public long term care benefits. The movement seeks increased beneficiary input into the configuration of public services and supports for persons with disability. The original constituency for consumer direction was younger persons with disability and their advocates. States increasingly are embracing consumer direction for a broader range of beneficiaries, including the frail elderly, however, as they attempt to reorient their Medicaid long term care systems away from costly nursing home care. Consumer direction may be as modest as increased beneficiary involvement in the care planning process but also may include allowing beneficiaries to choose, hire, and supervise their own workers. With one exception, all states offer some degree of consumer direction to at least some Medicaid beneficiaries.

What is new in the individual budget model is a broader range of beneficiary control, choice, and flexibility, and increased state activity in introducing the model for older beneficiaries. The increased activity has been fostered by CMS support through its Independence Plus waiver initiative, which began in 2002, augmented in some states by other federal support such as Real Choice Systems Change planning grants, and by a new round of RWJF grants in 2004.

The defining features of individual budget model programs identified by both RWJ and by CMS in its Independence Plus Initiative are the following:

- Conversion of traditionally delivered long term care services to a dollar value as the basis of a budget that beneficiaries can use to purchase services and supports tailored to individual needs;

- Increased beneficiary control in care planning and greater discretion to shift budget dollars among types of supports—especially between types of personal assistance and between personal assistance and other disability-related goods or services;

- Independent professional support (counseling) to assist with—but not direct—development of a flexible care plan and associated spending plan, obtaining services, and managing the budget;

- Beneficiary discretion in hiring and managing workers including, at state option, hiring a family member or friend; and

- Availability of fiscal services and support, such as issuing checks and withholding taxes for workers.

The hope and rationale for the individual budget model, generally supported by results of the Cash and Counseling Demonstration (Foster, Brown, Phillips, et al. 2003; Dale, Brown, Phillips, et al. 2003), is that it will promote greater beneficiary satisfaction and more efficient use of public dollars, while allowing persons with disability to remain outside of institutions. The

premise is that with more flexible benefits and increased control over how services are delivered, beneficiaries will be able to be wiser buyers than the state—to get "more" for a given level of state spending by better matching the service mix to their needs. Allowing beneficiaries to hire relatives, friends, or other nontraditional providers also has the potential to increase the supply and reliability of personal care workers, especially in rural areas where agencies may find it less profitable to operate.

Administrative Setting of Individual Budget Model Programs

The individual budget model is primarily an option for Medicaid long term care, although states also may offer it in state-funded programs or other programs, such as caregiver respite through the Older Americans Act. Long term care in nursing homes is a mandatory state Medicaid plan benefit, but community-based long term care is not. States may choose to offer community-based services either as an optional state Medicaid plan personal care benefit available to all Medicaid eligibles who meet functional criteria,[1] or through CMS approved waivers of basic Medicaid rules requiring access to and comparability of benefits for all Medicaid eligibles.

Waivers allow states to offer a broader range of benefits than are included in the state plan and to limit access to selected populations (e.g., the elderly) or geographic areas or by imposing explicit enrollment caps. Until the passage of the DRA, states implementing an individual budget program had to obtain either a research and demonstration waiver under Section 1115 of the Social Security Act or a home and community based services (HCBS) waiver under Section 1915(c). Both waiver authorities limit federal liability for waiver spending, although in different ways, by imposing limits on spending for enrollees in waiver programs relative to spending for similar persons without the waivers—through "budget neutrality" under Section 1115 waiver programs and "cost neutrality" under Section 1915(c) waiver programs.

States must use Section 1115 waivers if they want to combine different disability populations, include persons who do not meet functional requirements for institutional care, provide an actual cash allowance directly to beneficiaries, or make any other advance payments rather than reimbursements. "Advance pay" authority is necessary, for example, if states want to let participants receive discretionary amounts for allowed incidental expenses. The 1115 waiver mechanism generally gives states more flexibility in covering nontraditional supports and services than is available under Section 1915(c) HCBS waivers. States using 1115 waivers must demonstrate "budget neutrality," which means that the waiver program costs the federal government no more than it would spend for services without the waiver. The original three Cash and Counseling Demonstration states all used 1115 waivers.

Five of the seven states that have implemented individual budget programs for the elderly since the Cash and Counseling Demonstration have used 1915(c) waivers or plan to do so. Of the 12 additional states that are in the process of implementation, all but two also are using or

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[1] States also may cover some long term care through a combination of mandatory benefits, such as rehabilitation and home health, instead of or in combination with optional personal care benefits.

intend to use 1915(c) waivers. Under Section 1915(c) waivers, only persons who have disability severe enough to meet a state's functional criteria for nursing home admission are eligible for HCBS benefits. Payments must be reimbursements for expenses incurred. States must demonstrate "cost neutrality"—that it costs the federal government no more to care for beneficiaries in the community than to care for them in nursing homes.

Whereas 1115 waivers were designed to allow states to try innovative models, 1915(c) waivers originally were designed with traditional agency-provided services in mind. Requirements of 1915(c) waivers tend to be more restrictive for the purpose of implementing individual budget model programs. For example, states must specify each service to be covered, specify qualifications for each type of provider, and execute Medicaid provider agreements with each individual provider, including nontraditional providers, such as relatives and friends hired to provide personal care and discount vendors for disability-related purchases.

When the Independence Plus Initiative began in 2002, CMS developed special templates for both Section 1115 and 1915(c) waiver applications and encouraged states to use them in designing individual budget models. Based on early state experiences using the new templates, CMS issued a revised 1915(c) waiver application template and guidance in late 2005. The new template covers a continuum of program design options from entirely traditional benefit programs to individual budget programs. The new materials are intended to address difficulties states encountered in developing individual budget programs using 1915(c) waiver authority. For example, the states may execute Medicaid provider agreements with agencies that then assume responsibility for the qualifications of individual providers and for making payments to them. The revised application also incorporates the CMS quality framework, which was developed in response to congressional concerns about the quality of home and community based services and provides additional guidance on the quality framework to states seeking either type of waiver.

Under either waiver type, states may grant participants authority to manage an individual budget, including authorizing spending and moving resources between services or items contained in their plan of care. Participants may also have "employer authority," which allows them to recruit, hire, train, and direct workers, including, with some qualifications in 1915(c) programs, legally responsible and other relatives. Under either waiver authority, individual budget model programs must provide for support services to help participants plan and manage budgets and the financial responsibilities associated with the model (CMS 2005c).

States also may develop individual budget model programs through a combined 1915(b)/(c) waiver. This type of combined waiver allows states to design managed care programs under Section 1915(b) freedom of choice waivers that include 1915(c) HCBS care services.

Under the DRA, states will be able to offer the individual budget model as an option for long term care benefits in their state Medicaid plans, beginning January 1, 2007. The model could be made available in both the existing optional personal care benefit and in a new optional HCBS benefit through which states may offer the services included in Section 1915(c) in their state plans. The DRA also will allow states for the first time to limit access to state plan benefits by eligibility group, geography, or by using explicit enrollment caps, and will remove the requirement that states demonstrate budget or cost neutrality. Previously, states were required to

make all state plan benefits available statewide and to all Medicaid eligible persons meeting the state's functional criteria for the benefits. The DRA allows states wanting to limit access to the new optional HCBS benefit or the individual budget option in the personal care benefit—most often as a way of controlling costs—to do so without waivers.

Key Design Features

In exchange for greater control and flexibility in choosing a preferred package of services and supports, beneficiaries must be willing to take on greater responsibility for managing their care and greater risks associated with their ability to identify and obtain needed supports within a budget. States also face different challenges than under traditional program benefits directed and administered by home care agencies and other Medicaid providers. Under the individual budget model, states continue to have ultimate responsibility for the health and safety of participants and for ensuring quality and fiscal integrity of their Medicaid programs, but must design new systems and procedures or adapt existing ones to accommodate the individual budget model.

Four fundamental design issues states must consider are:

- how budget levels will be determined within program constraints,
- the range of choices available to participants,
- the support systems provided to help participants develop plans of care and manage fiscal responsibilities, and
- how the quality of participant-directed services can be monitored without undercutting participant autonomy.

Clearly, although these four design features may be considered discretely, they are interdependent. For example, the adequacy of benefits depends in part on the range of choices available to participants and on the supports provided to help participants accomplish their goals, and all three affect both the quality of HCBS and the systems for monitoring it.

Level of budgets. The adequacy of individual budgets to meet participant needs depends on how the initial budget amount is set and on mechanisms to adjust for changing needs over time. A number of factors may affect the adequacy of resources actually available to beneficiaries to purchase supports. Different aggregate constraints apply depending on the waiver authority under which a state chooses to establish the program. States must design methods for translating traditional service packages into a monetary allowance. State approaches to covering the cost of financial and other counseling services for beneficiaries also affect the amount of the money available to the participant to pay for disability services and supports. Finally, states must decide whether and how participants will be allowed to accumulate budget funds for larger purchases.

Participant choice. Choice of whether to participate—and whether to continue participating—is an important design feature for both states and beneficiaries. Consumer direction is not preferred by all long term care recipients and may not be appropriate for some.

For example, there is evidence that a smaller proportion of elders than younger persons with disability historically and in the Cash and Counseling Demonstration have been interested in the risks and responsibilities of managing an individual budget, and officials in some states have expressed doubt about the appropriateness of the model for older beneficiaries (Phillips, Mahoney, Simon-Rusinowitz, et al. 2003, Coleman 2003, Tilly and Wiener 2001). On the other hand, some persons whom the state might consider unlikely to succeed may nevertheless wish to try managing an individual budget. Participants also may find that they prefer to return to traditional benefits, and changes in physical or cognitive status may make the model less manageable for some participants over time. In addition, the extent of beneficiary choice with respect to the range of services and supports they are allowed to direct may affect both willingness and ability to participate.

Participant-support systems. State program designs must include systems for supporting beneficiaries in developing and managing their budgets and obtaining needed services. Assistance with hiring, training, and supervising workers and managing the financial responsibilities associated with paying a worker have been found to be key program elements affecting elderly participants' continued involvement. Participant supports typically are divided into counseling to help participants develop plans of care and manage budgets, and financial support services for payments to providers and payroll functions for workers. In some programs, the same contractor or agency may provide both services. Both the level of support available and the mechanism by which it is funded (e.g., by deductions from the participant allowance or by fees paid by participants) can affect whether participants, especially participants with greater needs, can be successful. Support services also serve a monitoring function to assure that services and supports are within the plan of care, that participants do not overspend their budgets or underuse needed services, and that care plans and spending plans are revised as participant needs change.

Quality of care monitoring. The state retains ultimate responsibility to assure that individuals are receiving adequate care. A beneficiary's decision to direct his or her own care, however, entails an assumption of some risk in exchange for greater self-determination. For that reason, evaluations of individual budget programs have focused primarily on participant assessments of their care. In addition to qualitative indicators, such as consumer satisfaction, quality measures have included quantitative indicators, such as the frequency with which tasks were completed as assigned and the rate of measurable adverse outcomes, such as hospitalizations. The CMS quality framework incorporated into the new waiver templates and instructions includes increased beneficiary choice and control as explicit avenues to improved quality.

STUDY METHODS

To identify state individual budget programs serving the elderly, we reviewed the literature and conducted an internet search on participant-directed options in Medicaid state plan and waiver programs for all states and the District of Columbia. Using the information we gathered, we created an inventory of states with participant-directed programs of all types as of January 2006 in Spillman, Black, and Ormond 2006. We then developed tables with detailed program descriptions in uniform format for all states with active programs that both met the

criteria for individual budget programs and included the older population. The tables include a range of program characteristics including state goals in implementing the program, waiver authority used, enrollment targets, and eligibility criteria. We submitted draft tables to state officials and asked that they verify the information on their state programs, supply information we had not been able to find, and provide comments. The tables for the 10 states we identified as having an active program with an individual budget model that includes the elderly are provided in the Appendix.

The following sections rely on the information gathered from the 10 states. We describe their programs in brief and consider how they address the four fundamental design issues of adequacy of benefits, participant choice, support for participants, and quality monitoring. More detailed profiles of programs in South Carolina, Wisconsin, and Minnesota illustrate different approaches states are taking in implementing the second generation of individual budget model programs.

INDIVIDUAL BUDGET PROGRAMS FOR THE ELDERLY IN BRIEF: 10 STATES

In this section, we provide brief descriptions of the individual budget programs for the elderly in the 10 states that had implemented such programs by January 2006. Basic characteristics are summarized below in Table 1. States are ordered by implementation year and waiver authority.

Despite the individual budget model's origins in the "Cash and Counseling" Demonstration and the continued use of the label by RWJF and in the DRA, only Oregon allows participants to receive an actual cash budget payment into an individual bank account they control. In the remaining nine states, participants authorize spending from the budget or allowance, but the funds are held by the state or a contracted fiscal agent who makes payments on their behalf. All three of the original Cash and Counseling Demonstration states have discontinued cash payments, primarily because of lack of participant interest in the additional responsibilities associated with receiving cash. All 10 states allow the hiring of nontraditional workers, including family members. All states except Arkansas, South Carolina, and Wisconsinallow hiring of a legally responsible relative, such as a spouse. Some states explicitly distinguish between ordinary, expected familial assistance, and unusual amounts and types of assistance provided solely because of the participant's disability. Minnesota limits the number of hours of care for which a spouse may be paid to 40 per week.

Arkansas was the first of the three original Cash and Counseling states to implement its individual budget program, IndependentChoices, in 1998, and its program has been the subject of most of the evaluation studies that have come out of the demonstration to date. IndependentChoices is open to persons eligible to receive state Medicaid plan personal care benefits, and it is those benefits that are "cashed out" to arrive at the participant's budget amount. Participants may designate up to 10 percent of their budgets for discretionary spending, such as purchases of continence supplies. Participants also may save budget amounts for larger purchases approved in the plan of care. Between 10 and 13 percent of the 12,000 to 13,000 persons receiving personal care benefits in an average month choose to participate in IndependentChoices, well below the waiver enrollment cap of 3,500.

Table 1. Individual Budget Model Programs Serving the Elderly as of January 2006

	Arkansas	New Jersey	Florida	Oregon	Colorado
Year implemented	1998	1999	2000	2001	2002
Waiver type	1115	1115	1115	1115	1115
Program name	IndependentChoices	Personal Preference	Consumer-Directed Care Plus (CDC+)	Independent Choices	Consumer-Directed Attendant Support (CDAS)
Eligible population	Persons who are eligible for services under the state's Medicaid plan personal care benefit and have impairments in two or more Activities of Daily Living (ADLs)	Persons receiving or assessed for services under the state's Medicaid plan personal care benefit	Medicaid recipients enrolled in HCBS 1915(c) waivers	Adult Medicaid HCBS recipients who are able to plan for the adequate provision of services either independently or through a representative	Persons who have received Medicaid in-home attendant support services for the previous 12 months through the state plan home health benefit or personal care through an HCBS waiver
Basis of budget	State plan personal care benefits	State plan personal care benefits	HCBS waiver benefits	HCBS waiver benefits	State plan home health or HCBS waiver benefits
Budget period	Monthly	Monthly	Monthly	Monthly	Monthly
Participant directed services and supports	Personal care, homemaker services, home-delivered meals, adaptive equipment, home modifications, safety or communication devices, transportation, prescription drugs, co-pays for medical visits, durable medical equipment not covered by Medicaid, and discretionary spending	Personal assistance, assistive devices, other medical equipment and supplies, home modifications related to personal care needs	Personal care, homemaker services, home health services, respite care, durable medical equipment, non-emergency transportation, case management, mental health, adult day health services, and 24 other home and community-based services	Personal care, homemaker services, chore services, adult companion services, attendant care, respite care, transportation, personal emergency response systems, environmental accessibility adaptations, and other goods and services that enhance independence	Skilled nursing, personal care, home aide, homemaker services, and other goods and services that support healthcare needs
Accumulating of budget funds for larger approved purchases allowed?	Yes	Yes	Yes, up to $250 per month; more than $250 with approval	Yes	Yes, half of unspent amounts from monthly budget
Population eligible	12,000 to 13,000 per month	17,000	8,951 frail elders, 868 adults with physical disabilities, 276 adults with brain/spinal injuries, and more than 25,000 adults and children with developmental disabilities	11,000	4,000
Enrollment (as of *date*)	10 to 13 percent of eligibles (on average)	400 (Oct. 2005)	1095 (Sept. 2005)	300 (Nov. 2005)	148 (Oct. 2005)
Cap on enrollment	3,500	None	3,350	300	500

(continued)

Table 1. Individual Budget Model Programs Serving the Elderly (continued)

	Wisconsin	South Carolina	Minnesota	North Carolina	Massachusetts
Year implemented	2002	2003	2005	2005	2005
Waiver type	1915(b)/(c)	1915(c)	1915(c)	1915(c)	Pilot program
Program name	Family Care - Self Directed Supports (SDS)	South Carolina Choice (SC Choice)	Consumer Directed Community Supports	Community Alternatives Program (CAP) Choice	Real Choice Pilot Project
Eligible population	Medicaid recipients in five Family Care managed care organizations (CMOs) serving elders and people with developmental or physical disabilities who have long-term care needs	Medicaid recipients enrolled in the state's 1915(c) HCBS Aged and Disabled waiver and new waiver applicants meeting nursing home level of care and choosing community placement	Enrollees in any of five 1915(c) HCBS waiver programs or the state-funded Alternative Care program, and older persons receiving caregiver respite through the Older Americans Act (OAA).	Medicaid-eligible elderly and younger adults with disability who would otherwise require institutional care	Medicaid eligibles who require assistance with two or more "unmet needs" relating to ADLs or IADLs but are not eligible to receive state plan personal care benefits.
Basis of budget	Long term care related state plan and HCBS waiver benefits in a capitated managed long term care program	HCBS waiver benefits	HCBS waiver benefits, Alternative Care benefits, or OAA respite benefits	HCBS waiver benefits	Care plan services subject to grant funding limitations
Budget period	Annually or monthly depending on the CMO	6 months	Annual/paid monthly	Annual	Annual
Participant directed services and supports	Nursing services, home health, personal care, respite care, care/case management, medical supplies, home modifications, adaptive aids, transportation, home delivered meals, adult day care, and other care plan supports even if not part of the CMO benefit package	Personal assistance, respite services, home accessibility adaptations, appliances, and specialized medical equipment or supplies	Personal care, treatment and training, environmental modifications and provisions, and goods or services that augment state plan services or provide alternatives to waiver or state plan services	Personal assistant services; in-home respite; home mobility aids (e.g. ramps, railings); waiver-covered supplies, and consumer-designated items not covered by the waiver or state plan that enhance ADL/IADL performance or safety and reduce the need for other waiver or state plan services	Personal care, transportation, home modifications, equipment, medical and non-medical supplies, community integration activities, transition support
Accumulating of budget funds for larger approved purchases allowed?	Yes, and carryover from one year to the next is allowed	No, but participants may draw on 6-month budget as needed	No. Counties may approve a larger monthly payment subject to the annual budget limit but usually do not; participants may obtain loans for larger purchases and be reimbursed over time from monthly payments.	Participants may draw on annual budget as needed and may have the fiscal agent accumulate unspent amounts from the monthly budget for approved consumer-designated purchases.	Yes
Population eligible	9,725 persons (7,448 elderly) enrolled in Family Care	11,000	40,000 in all programs (9,135 Elderly Waiver, 5,264 Alternate Care, and 1,665 OAA-respite only).	About 13,600 persons if expanded statewide	n.a.[1]
Enrollment	23 percent of Family Care enrollees self-direct at least one service (on average)	184 (Oct. 2005)	22 Elderly Waiver, 12 Alternative Care, and 27 OAA-respite (Apr. 2006)	6 persons (4 elderly and 2 disabled) (Oct. 2005)	14 (duration of pilot)
Cap on enrollment	None	900	None	200	14

Source: See references by state and additional detail in the Appendix, "Active State Individual Budget Programs Including the Elderly as of January 2006."

[1] Pilot does not apply to a population currently eligible for Medicaid long term care benefits and is limited by grant funds available.

New Jersey implemented its Personal Preference program in 1999 for persons either receiving or assessed to receive traditional services under the state's Medicaid plan personal care benefit. As in Arkansas, the budget is based on the value of traditional services. The budget is made available monthly, and participants may set aside up to 10 percent of the monthly amount for discretionary spending. Participants may save budget funds for larger allowed purchases in the approved spending plan, but after 12 months, the state may recoup unspent amounts not linked to an allowed purchase. About 400 of the estimated 17,000 eligible persons were enrolled in Personal Preference in October 2005. The state has set no enrollment cap.

Florida's Consumer-Directed Care Plus (CDC+) program was implemented in 2000 for persons enrolled in 1915(c) waivers for the frail elderly, adults with physical disabilities, adults with brain or spinal cord injuries, and adults and children with developmental disabilities. Benefits are based on the value of traditional waiver services that participants would have received, and budget amounts are made available monthly. Participants may set aside up to $250 per month in a savings account for approved purchases and must make the purchase as soon as accumulated savings are sufficient. Unspent amounts not designated as savings may revert to the state. Savings above $250 per month may be approved in extraordinary circumstances. Approximately 35,000 persons are eligible to participate, most of them developmentally disabled (more than 25,000) or elderly (about 9,000). Enrollment in CDC+ was about 1,100 in September 2005, well below the enrollment cap of 3,350.

Oregon implemented its Independent Choices program as a pilot demonstration in 2001 under a Section 1115 waiver. The pilot is limited to persons eligible for 1915(c) waiver benefits and to three regions of the state. Participants receive a monthly budget and may receive the budget in cash if they or a representative acting for them undergo training and pass a financial skills assessment. Contrary to the experience in the three Cash and Counseling Demonstration states, nearly all participants choose to take the assessment and receive a cash benefit. Only participants who manage their own budget without a representative may save for approved expenses. Unspent funds not designated for approved spending revert to the state at the end of the demonstration. Enrollment as of November 2005 was 300, the enrollment cap set by the state.

Colorado's Consumer-Directed Attendant Support (CDAS) program was implemented in 2002 under a Section 1115 waiver. The individual budget option is open to persons who have received personal assistance for 12 months through the mandatory Medicaid home health benefit or through a 1915(c) HCBS waiver program. An important motivation behind the state's program was reducing the cost of attendant services. Participants receive a monthly budget based on average monthly spending for personal care services in the 12 months prior to enrollment. They may accumulate half of any unspent funds, with the other half reverting to the state. To use the savings, participants must submit a grant application to the state, specifying the services or other supports they intend to purchase. As of October 2005, 148 persons were enrolled out of an estimated 4,000 eligibles, well below the enrollment cap of 500 persons.

Wisconsin included a Self-directed Supports (SDS) option when it implemented its 1915(b)/(c) Family Care capitated managed long term care program in 2002, as a pilot in five areas of the state. An important motivation was to reduce long waiting lists for waiver services.

Following favorable evaluation results, legislation was passed in May 2006 to expand the program statewide within five years. Family Care is administered by local care management organizations (CMOs) in the five pilot areas and covers both community and institutional care. Persons in the five areas wanting access to Medicaid HCBS must enroll in a CMO. Once enrolled, Medicaid enrollees may choose to self-direct some or all of their services. The CMO determines the amount of the individual budget based on what the CMO would pay to provide the self-directed services, and can make it available monthly or annually. Participants are allowed to save for larger purchases, and these earmarked savings may be carried over from one year to the next. About 23 percent of the 9,725 persons (7,448 of them elderly) who were enrolled in Family Care at the end of March 2006 received a budget and self-directed at least one service.

South Carolina implemented its SC Choice program under a 1915(c) waiver in 2003. The program is open to persons enrolled in the state's existing 1915(c) Aged and Disabled waiver program and to new waiver applicants who choose community care. The budget amount is based on the value of authorized waiver services for persons already receiving traditional waiver services. For new applicants, the budget is based on the value of hypothetical services they would have received in the traditional waiver program. Participants have access to a six-month budget. The longer budget period provides some flexibility in allocating spending over time, but savings are not allowed. Carryover of unspent funds to the next six-month budget period is allowed only in an emergency. As of October 2005, 184 persons were enrolled in SC Choice out of about 11,000 persons eligible, well below the 900 person cap on enrollment the state set for the program's third year.

Minnesota expanded a Consumer Directed Community Supports (CDCS) service delivery option in 2005 to include all persons eligible for benefits in its five 1915(c) waiver programs, a state-funded Alternative Care program for the elderly, and a caregiver respite program under the Older Americans Act. The program previously had been available only to persons in the state's Mental Retardation or Related Conditions (MR/RC) waiver. CDCS is a separate "grouped" waiver service category participants select as an alternative to traditional waiver services. The individual budget is based on the annual value of traditional benefits available in the appropriate program, but is paid monthly. Local lead agencies have the authority to approve larger monthly payments within the annual budget limit but usually do not. About 40,000 persons are potentially eligible for the CDCS option in all waiver programs, with about 9,135 in the Elderly Waiver, 5,234 in the Alternative Care program, and 1,665 in the caregiver respite program. At the end of April 2006, 61 persons eligible for the latter three programs for older Minnesotans were participating in CDCS. The state has set no cap on enrollment.

North Carolina's CAP Choice program was implemented in 2005 as a pilot program for adults and elders eligible for the state's Community Alternatives Program for Disabled Adults (CAP/DA) 1915(c) HCBS waiver program. The pilot operates in two counties, but pending a scheduled January 2006 evaluation, expansion statewide was expected in 2006. The annual individual budget is based on a maximum monthly payment for the participant's assessed level of care. Budget funds may be requested as often as preferred but must be received at least annually, and monthly spending is subject to the monthly maximum. Although participants are not allowed to save unspent funds, they are allowed to direct the fiscal agent to accumulate

budget amounts toward purchase of approved "consumer-designated goods and services." As of October 2005 six persons (four of them elderly) had enrolled. Enrollment is capped at 200 in the first year of theprogram.

Massachusetts implemented its individual budget pilot program in 2005, funded by a Real Choice Systems Change planning grant and administered by the University of Massachusetts Medical School Center for Health Policy and Research (UMMS/CHPR). It serves persons who are Medicaid eligible, are found in the assessment process to have two or more "unmet needs" relating to activities of daily living (ADLs) or instrumental activities of daily living (IADLs), and are not eligible for state plan personal care benefits. The goal of the pilot program is to identify and develop the systems and infrastructure required for broader implementation of an individual budget program through a 1915(c) waiver program. The individual budget is established based on aggregate grant funds available for services, the individual's level of need, and the amount requested in the spending plan. The annual budget is disbursed monthly. Participants may vary the monthly amount if needs change and may save for larger purchases. Pilot program enrollment was capped at 14 persons. The target population for an expanded waiver program has not been determined.

Level and Adequacy of Benefits

The fundamental constraint on the size of individual budgets for participants is the level of benefits states have chosen to provide in the programs for which the individual budget program is an alternative. Average individual budgets vary dramatically across states with active programs, from about $400 in Arkansas to about $4,000 in Colorado. The large range primarily reflects differences in benefits available in the states' traditional benefit programs, although it also may reflect differences in the case mix of participants. The more pertinent issues for potential individual budget program participants within a state, however, are how services they can obtain with their budgets compare with the traditional benefits they would receive if they did not participate and whether and how often care plans and budgets are revised.

All nine states with operating waiver programs rely on the assessment process used for beneficiaries receiving traditional benefits as a basis for determining the individual budget for persons choosing the option.[2] The budget amount is based on the dollar value of traditional benefits they would receive. Reassessments occur at least as frequently as in traditional benefit programs—at least annually, or, in four states, semiannually, and at any point when a participant's functional status or situation has changed. Spending in both traditional and individual budget programs is subject to overall budget or cost neutrality requirements imposed by the waiver.

In practice, the level of traditional waiver services *authorized* under care plans based on assessments is often higher than that *received* by beneficiaries. Therefore, some states discount individual budgets to bring them in line with the cost of services actually received by similar

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[2] We exclude Massachusetts' pilot program from this and the subsequent discussions of design features because it covers only persons not eligible for existing state Medicaid long term care benefits. The state has not determined the ultimate design of its planned waiver program.

persons receiving traditional services. Discounting budgets is one method states use to help meet budget neutrality requirements in Section 1115 waiver programs. Discounting also may reflect state desires to control costs, avoid high levels of induced demand by persons who would not apply for traditional benefits, or maintain equity between traditional service recipients and individual budget participants in traditional 1915(c) waiver programs.

States use a variety of discounting methodologies. Arkansas discounts the number of allowed *hours* of personal care between 9 and 30 percent in computing individual budget amounts, based on agency-specific ratios of hours of care provided to hours of care authorized for state plan personal care recipients. Florida discounts the *cash value* of traditional 1915(c) care plan services between 8 and 17 percent, depending on the waiver population (e.g., frail elderly or adult disabled). North Carolina discounts the *maximum hourly rate* paid for personal assistance hours between 10 and 20 percent, to adjust for the differences between hours authorized and hours received in its traditional waiver program and for agency overhead costs included in agency payment rates that do not apply to participant-directed care. After an initial period without discounting, South Carolina is implementing a discount of about 10 percent of the individual budget, based on observation that participants in its traditional 1915(c) waiver program received about 80 to 90 percent of approved services. Minnesota establishes an annual budget cap for individual budgets as 70 percent of the average cost for persons with similar functional status and situation who receive standard waiver services.

Although there are benign reasons why traditional program beneficiaries do not receive all allowed services, such as hospitalizations and travel, there is also the danger that discounted budgets will lock in difficulties traditional program beneficiaries have in obtaining all allowed services, particularly in areas with an inadequate supply of agency workers (Phillips, Mahoney, Simon-Rusinowitz, et al. 2003). Such difficulties have been cited as a rationale for allowing beneficiaries to use nontraditional providers such as family members or friends. In addition, some observers also have argued that pressures on state Medicaid budgets may lead to individual budgets that are inadequate to meet the needs of beneficiaries, particularly beneficiaries with more severe disability (Alliance for Health Reform 2006).

Inadequate budgets may reduce beneficiaries' willingness or ability to participate or continue to participate in individual budget programs. Under the Arkansas Cash and Counseling demonstration, one of the most common reasons given by enrollees for leaving the program voluntarily within the first nine months of enrollment was that the allowance was insufficient (Schore and Phillips 2004). On the other hand, evaluation of Arkansas' program also found substantially higher costs for personal care services for participants receiving a budget, relative to a control group receiving traditional benefits, primarily because budget recipients were far more likely to obtain all care hours allowed in their care plans, despite the discounts (Dale, Brown, and Phillips 2004).

States also may choose to reduce budget amounts in order to cover costs for fiscal and/or counseling services that would be included in rates paid to agencies or may require beneficiaries to pay all or part of the cost of these services out of their budgets. Arkansas sets aside one-third of the care plan value for counseling and fiscal services. In Florida, counseling services are covered as a waiver benefit outside the individual budget, but participants pay for fiscal services through a monthly user charge and a fee for each payment processed. New Jersey reserves 10

percent of the care plan value to cover the cost of counseling and part of the cost of fiscal services. The state also requires participants to use budget funds to pay fees for fiscal services, such as worker background checks and issuing payments to workers or vendors. In Minnesota, participants have a "required" case manager paid for outside the individual budget, but they must spend budget funds for a "flexible" case manager if they need more help than the required case manager provides. The entire cost of fiscal support services is included in the participant's spending plan and paid from participant budget funds. South Carolina participants pay a $15 per month flat fee for fiscal agency services based on average user costs. On the other hand, in Oregon participants choosing to manage their own cash budget rather than use a fiscal agent receive a higher budget amount to cover the employer share of payroll taxes.

In most 1915(c) waiver programs, states specify which services may be participant-directed and which must be agency-directed, and participants may choose a mix of HCBS waiver services and self-directed services. Budgets are based only on the services participants choose to direct. For example, in North Carolina participants may choose whether to direct in-home assistance, in-home respite services, home mobility aids, and supplies, or receive these services through an agency. They also may identify additional self-directed supports under a separate waiver service called "consumer-designated services and supports." Adult day health care, institutional respite care, home-delivered meals, and telephone alert systems must be agency-directed. If these services are included in the participant's care plan, they are not included in the individual budget.

Choice Available to Participants

By definition, the individual budget model allows choice in allocating budget resources between types of supports and control over by whom, when, and how care is provided. Thus, all nine programs allow participants some degree of choice in allocating budget resources between personal care services and other long term care services and supports they identify, but both program design and waiver authority create differences in the extent of flexibility across states. All the states also allow participants to select, hire, and supervise paid workers, including family members or friends, and to negotiate wage rates.

With these expanded choices and opportunities for greater control over their own care, however, beneficiaries must be willing to assume some of the management and fiscal responsibilities traditionally borne by agencies. Thus, the most fundamental choice for participants is whether to participate or to continue participating. This choice may be particularly important for older beneficiaries. Under Arkansas' Cash and Counseling demonstration, a larger proportion of older enrollees who voluntarily disenrolled reported problems handling either management of workers or fiscal responsibilities (Schore and Phillips 2004).

Choice of Participation. In all nine states operating waiver programs, the individual budget model is seen as a voluntary alternative service delivery option for persons eligible for state plan or waiver services and not living in residential care settings. Traditional services remain the default delivery system for persons who do not wish to manage a budget and those who no longer are willing or able to continue managing a budget. A minority of persons potentially eligible in each state has selected the option to date. In most states, to date, access

appears to be limited primarily by more general constraints, such as restrictions on groups eligible for long term care benefits or geographic limits on waiver programs, rather than caps on individual budget option enrollment. Although seven states report explicit caps on enrollment in the individual budget option, so far only the pilot program in Oregon reports being at its cap. New Jersey reports that its individual budget option has tended to attract a subset of clients dissatisfied with traditional agency services. They are typically less fragile clients with higher levels of function and less need for skilled services provided through agencies.

The voluntary nature of these programs and the relatively small enrollment to date complicate evaluation of program costs and benefits. In the original Cash and Counseling Demonstration, states were required to have an experimental design in which persons willing to manage a budget were eligible to enroll, but enrollees were randomly assigned to receive traditional benefits or an individual budget. The experimental design requirement has been dropped in renewals and is not required for new programs. As existing individual budget model programs mature and new ones are implemented, self-selection of participants for whom the model is most appropriate will need to be taken into account in evaluating program performance and costs relative to traditional benefits.

Although programs are voluntary, enrollment is not guaranteed. All states exercise discretion in deciding whether an applicant is able to handle management responsibilities or has a suitable representative willing and able to take on these responsibilities. Training in employer and financial responsibilities commonly is required before participants can receive an allowance and direct their services. Eight of the nine states with operating waiver programs allow a representative decision-maker, such as a spouse or guardian, to act on the participant's behalf if the participant prefers or if the state determines the participant is unable to manage their budget alone. As of January 2006, Colorado was the only state that did not allow a representative decision-maker but it was working with CMS to change the state's requirement that a physician certify a participant's ability to direct services.

Choice among Services. In its most straightforward form, the individual budget model is "all or none" in that participants receive *either* a budget covering all services *or* standard services. This is the design in the three Cash and Counseling Demonstration states and in the other two states using Section 1115 waiver authority, which requires less specification of covered services and allowed providers than required in Section 1915(c) waivers. It is also the design that has been evaluated in most detail.

Section 1915(c) waivers require states to specify all services included, provider qualifications for each service category, and which waiver services may and may not be consumer-directed. While these features have the potential to limit choice depending on the flexibility states build into waiver service categories, they also allow participants to choose to manage only those types of services they prefer and feel able to direct. Both North and South Carolina offer a set of services that may be self-directed and base budgets only on those services participants choose to self direct. In Wisconsin's capitated program, Medicaid enrollees may choose to self-direct some or all of their services. Minnesota appears to be the exception among states with operating programs using 1915(c) waiver authority. Beneficiaries choose between receiving a budget and managing all services through Consumer Directed Community Supports, a separate waiver service category, or receiving only standard waiver services.

In all states, personal assistance represents the largest expense in individual budgets for the typical participant. The opportunity to choose workers, negotiate pay rates, and control the work schedule, tasks to be performed, and how they are performed was found in the Cash and Counseling Demonstration to be an important factor in choosing to participate, in the ability of participants to obtain allowed hours of care, and in satisfaction with workers and performance. Participants also may be able to obtain the human assistance they need at a lower cost by negotiating lower wage rates than the maximum allowed by the state, using less skilled workers for some tasks, or substituting other supports that reduce the need for personal assistance. Commonly cited supports that increase independence or reduce the time it takes workers to complete tasks include bathroom modifications or devices that allow or increase independence in bathing, and microwave ovens or laundry appliances.

All nine states have a mechanism through which budget funds may be allocated to such supports—explicit provisions for accumulating any unspent funds from monthly budgets, longer budget periods, or, in Minnesota, recouping expenditures through monthly reimbursements. Depending on the waiver authority, purchases of such supports may be allowed only through savings from amounts allowed for personal assistance, as in the Section 1115 programs in Colorado and Oregon, or through specific 1915(c) HCBS waiver service categories included in budgets. North Carolina, for example, allows participants to make home modifications (e.g., adding grab-bars or hand-held showers), as a specific waiver service, which may be either participant or agency-directed, but also allows participants to direct the fiscal agent to accumulate unexpended amounts from their monthly budgets for "Consumer Designated Goods and Services." The latter service category is defined flexibly as supports not otherwise covered as a waiver service or in the state plan, provided they enhance independence or safety and reduce spending for other services.

Participant Support Systems

CMS requires states with individual budget programs to identify systems they will use to support participants with such tasks as developing care and spending plans consistent with participants' assessed needs, obtaining services, managing individual budgets, and other fiscal responsibilities. Whereas some beneficiaries are willing and able to handle responsibilities associated with an individual budget with a minimum of help, for others, the extent and quality of supportive systems may determine their success. Ideally, counseling and financial support services should be designed to provide the participant with the maximum desired level of autonomy consistent with meeting state fiscal and quality standards.

The nine states with operating waiver programs differ in the level of such support offered, participant choice with respect to the level of support used, whether systems have been developed for the individual budget program or use existing case management and/or fiscal systems, and whether the same entity is used for both counseling and fiscal functions. Typically, the counseling function includes providing participants with some level of orientation and training in their rights and responsibilities, assisting with the development of care and spending plans consistent with their budget, and helping participants monitor their budgets and the performance of the fiscal entity. Although counselors in individual budget programs also may be case managers for persons receiving traditional benefits and in all nine states are part of the quality monitoring process, both the philosophy and the responsibilities differ under individual

budget programs. The CMS quality initiative, with its increased focus on participant-centered planning in all HCBS programs, may blur the differences between case management and counseling to some degree in newer programs.

As of January 2006, Arkansas was the only state using the same contractor for both financial support and counseling services. New Jersey, however, was in the process of moving to a single contractor, citing the efficiency of dealing with one contractor and the overlap between the responsibilities of counselors and fiscal staff in monitoring spending. North Carolina uses the lead agencies for CAP/DA, the traditional waiver program, to provide both counseling and fiscal agency services for its CAP Choice program, in part because the agencies have experience with waiver participants and administrative processes but also to facilitate communication. These lead agencies employ and supervise care managers and provide all fiscal management services, including filing claims, reimbursing individual providers, handling payroll functions for participants' workers, and conducting background checks and verifying the age of personal assistants.

Most states build on the experience in traditional programs by using counselors drawn from existing case management systems, usually with specialized training. Colorado uses case managers from its Single Entry Point agencies for long term care services to assess eligibility for its CDAS program and for the counseling function. Case managers help participants develop their budget plans, conduct reassessments at least every six months, and provide mandatory participant training on managing workers and related fiscal responsibilities. A separate state-contracted fiscal agency, however, is the employer of record for workers and is responsible for performing background checks and all payroll and accounting functions. The fiscal agency pays workers based on timesheets submitted, works with case managers to address budget management problems, and provides monthly reports to participants and to the state.

Wisconsin and Oregon both give participants choice in how much fiscal responsibility they wish to assume but with very different results. In Wisconsin nearly all participants choose to use an agency with choice model. Rather than being the employer of record and receiving agency support only for payroll functions, the participant can rely on a "co-employer" agency to provide support for employer responsibilities. In Oregon, on the other hand, participants may choose to use a fiscal agency to manage their budgets—and must use one if they cannot pass mandatory training in management responsibilities—but nearly all have elected to receive an electronic transfer of their monthly budget funds into a dedicated bank account and manage all their own payroll and other fiscal functions. The state maintains a network of community resources to provide the mandatory management training and provide technical assistance with these duties free or at reduced cost. State personnel conduct random audits of participant accounts and may impose additional budget management training for participants who become overdrawn.

Quality of Care Monitoring

States have responsibility for assuring that the quality monitoring procedures in place are appropriate for the individual budget model. On the one hand, states ultimately are responsible for the fiscal integrity of the program and for assuring that participants in individual budget

programs receive adequate and appropriate care. On the other hand, by choosing to participate, beneficiaries assume some of the risk and responsibility, formerly borne by agency providers, for the quality and adequacy of their care. They also have a larger role through the care planning process in defining quality for the services they direct and specifying desired outcomes.

Design features of quality management systems meeting the requirements of a consumer-directed program include providing participants with information about their rights and responsibilities, developing procedures to monitor fiscal agents and participant expenditures, developing emergency backup systems, establishing methods for participant feedback, and ensuring access to the desired level of support services (Nadash and Crisp 2005).

Typically, quality monitoring relies heavily on counselors and fiscal agents. Counselors are the most proximate monitors of participant health and welfare. Both counselors and fiscal agents monitor agreement between participant spending plans and purchases to ensure appropriate levels of service use and program compliance and to identify and address any fraud or abuse. State personnel monitor the performance of local lead agencies, counselors, and fiscal agencies through general contact and oversight, onsite visits and audits, reporting requirements, and in several states, participant surveys.

Not surprisingly, in all states with operating waiver programs, counselors are the first-line quality monitors, usually having the most frequent and consistent contact with both participants and financial management entities. Depending on the program, counselors visit participants as often as monthly, but typically quarterly or semi-annually, to monitor for service problems, abuse, neglect, or any changes in the participant's condition. They often have more frequent telephone contact. In addition to ongoing monitoring for overuse or underuse of services, which might indicate problems with the quality or adequacy of care or the need for remedial help with management responsibilities, counselors also are responsible for regular reassessments and spending plan reviews. Counselors typically also are responsible for assuring that participants have emergency backup services in place as part of the care planning process and may monitor how often backup is needed, as one indicator of service quality problems.

Quality indicators for individual budget programs rely heavily on beneficiary assessments of their care, but not necessarily purely on qualitative satisfaction. For example, quality indicators in the Arkansas Cash and Counseling demonstration included the frequency with which tasks were completed as assigned and dependability of workers in arriving on time. Several of the nine states have developed methods for participant feedback through surveys and/or toll-free numbers or hotlines to report service problems. In Wisconsin's capitated program, the CMOs are responsible for developing and implementing quality assurance and monitoring procedures, and an external quality review contractor conducts annual outcome interviews with participants.

THREE SECOND-GENERATION DESIGNS

In this section, we provide more detailed profiles of individual budget programs serving elderly beneficiaries in South Carolina, Minnesota, and Wisconsin. The programs illustrate three very different approaches to implementing this model. Two of the programs, South Carolina's

SC Choice and Wisconsin's Family Care – Self-Directed Supports (SDS), allow participants to choose from a continuum of benefit options ranging from traditional agency-directed waiver services only to an individual budget with which to purchase all services and supports. In between, recipients can select a mix of agency-supplied services, participant-directed services, and other purchased supports. In addition, Family Care is offered in a managed care framework that includes both institutional and home and community based services. The third state, Minnesota, offers an individual budget option more closely approximating the model used in the Cash and Counseling Demonstration states, in which participants choose between receiving traditional waiver services or a comprehensive individual budget. In each profile, we describe unique features of the programs and features relating to how each state addresses the four key design areas.

South Carolina: Building on Existing Infrastructure

South Carolina's SC Choice program was one of the first Independence Plus waiver programs approved by CMS. It represents an incremental approach, building on and adapting the case management and fiscal management infrastructure used in its traditional 1915(c) Aged and Disabled waiver program. SC Choice began as a pilot in only three counties but was expected to be available statewide by the end of January 2006. The state's explicit goals were to increase participant control, satisfaction, and quality of life by expanding the range of service options while reducing administrative expense and bureaucracy.

Participants work with a six-month budget based on the value of traditional waiver services the participant has been receiving or would be eligible for. The budget averages about $4,700, or nearly $800 per month. A local Care Advisor employed by one of 13 regional lead agency offices consults with the participant to help identify needs and develop a spending plan consistent with the care plan and budget. The Care Advisor provides training and orientation in directing services, information about obtaining services and goods, and assistance with paperwork and monitoring spending. The Care Advisor also has monitoring responsibilities, including responsibility for increased management assistance or monitoring if problems with services or management arise, or for recommending that the participant have a representative or return to the traditional program if problems cannot be resolved.

To increase choice of workers and types of assistance, the state added "personal assistance" as a separate participant-directed waiver service with more relaxed provider qualifications than the agency-directed "personal care" waiver service. "Personal assistance" includes assistance with daily activities, housework, yard work, chores, and transportation. Although personal assistance providers must become approved Medicaid providers, provider qualifications require only that they be at least 18 years of age, free of communicable diseases, capable of following the plan of care with minimal supervision, and able to demonstrate competence to the participant or representative. Participants also may choose to receive some of these services through the agency-directed personal care waiver service. In-home respite services also may be either participant- or agency-directed.

To facilitate participant choices of nonlabor supports, the state developed a new system for provider agreements. Such supports are available through two additional waiver services—

environmental accessibility adaptations and appliances, and specialized medical equipment or supplies—and may be either participant- or agency-directed. The service categories include, respectively, home modifications and appliances that can be demonstrated to increase independence or safety or reduce the amount of assistance required, such as wheelchair ramps, microwaves or washing machines, and supplies such as continence pads and nutritional supplements. Such supports in some cases might be more conveniently or economically purchased through vendors such as a local discount store that are not typically Medicaid providers, as is required under 1915(c) waivers. To facilitate participant access to a broader set of nontraditional vendors the state used a Real Choice Systems Change grant to develop a simplified provider agreement that reduces the bureaucratic requirements of becoming a Medicaid provider.

In designing its participant-support system, South Carolina drew on its existing waiver case management and fiscal management systems. The state considered that case managers already had detailed knowledge of the state's program, so that small marginal investment would be required for training them to become "care advisors" for SC Choice. Care advisors may be employees of the state or agency or individual contractors, but may not also be providers of other services. Small caseloads typically mean that there is a single care advisor for an area.

Fiscal support service is provided by the same state contractor used for South Carolina's traditional waiver program and is funded as an administrative expense, with a 50 percent federal match rather than the higher match that would be available if it were covered as a waiver service. Participants also pay a $15 monthly service charge from their budgets. The contractor provides an electronic monitoring system, Care Call, to verify services and submit claims for reimbursement to the state and makes payments to providers.

The participant is the employer of record for workers and is responsible for recruiting, hiring, setting schedules, and supervising workers, including verifying the hours they report. Participants also are responsible for obtaining the paper work necessary for workers to become Medicaid providers from the fiscal contractor and seeing that it is completed and submitted. The fiscal agency provides all employment-related financial services, such as payroll deductions and employer tax payments, as well as provider qualification checks, including criminal background checks. Workers log hours with Care Call by telephone upon arrival and departure. In addition to monthly reports, continuously updated summary reports on provider claims and remaining budget are available to participants and care advisors through the electronic system.

In its waiver renewal application submitted in March 2006, South Carolina proposes to combine SC Choice and its traditional 1915(c) waiver program into a single Community Choices program with the goal of providing "a true continuum of self-direction capable of meeting the needs of all waiver participants, from those choosing agency-directed services to those who desire to fully oversee their services." In addition to providing traditional waiver services to those who do not choose or are not able to direct their services, Community Choices expands services and supports available for participant direction. As in SC Choice, participants will be able to choose which services they direct, but also will be able to choose employer authority only, budget authority only, or a combination of the two. Community Choices also includes an

explicit Nursing Home Transition Service to cover initial costs for persons leaving nursing homes to return to the community.

Wisconsin: Managed Care with Choice

Wisconsin's Self-directed Supports (SDS) program is unique in that it was included as an option within the state's Family Care capitated managed long term care program. Family Care was implemented in five areas of the state under a 1915(b)/(c) waiver authority effective January 1, 2002, and is part of a larger long term care system reform (Justice 2003). The stated goals were improving cost effectiveness, choices available, access to services, and quality in the state's long term care system. It was also hoped that Family Care, which combines Medicaid community and institutional care benefits, would reduce the system's complexity and eliminate long waiting lists for services.

Persons seeking access to Medicaid long term care services in the areas where Family Care operates must enroll in one of the local care management organizations (CMOs) that administer the program. Initial assessment for Medicaid long term care benefit eligibility is done through the local Aging and Disability Resources Center, which serves as a community resource for social service information and assistance as well as a single point of entry for long term care. More comprehensive assessment is completed after CMO enrollment. Each CMO must offer an SDS option, in which participants may receive an individual budget to manage as many or as few services as desired. The SDS option is limited to persons not living in residential care facilities. More than 20 percent of Family Care enrollees in the five counties receive a budget and manage at least one service.

All Family Care enrollees work with an interdisciplinary CMO case management team to identify preferences and desired outcomes and translate them into an individual service plan. Persons choosing to participate in SDS then identify which services they wish to self-direct and which are to be managed by the CMO. The CMO determines the individual budget based on what it would spend to provide the services if they were not self-directed. The average monthly cost of participant-directed services is about $700, and there is no maximum amount or discounting. The full Family Care benefit package includes traditional HCBS waiver services (e.g., home modifications, supportive home care, and transportation), traditional state plan services related to long term care (e.g., nursing facilities, therapies, and home health), and additional services and supports outside the defined benefit package that are identified as both effective and cost-effective. In addition to community-based services in the CMO benefit package, an SDS participant's budget may include any other service or support to accomplish the participant outcomes specified in the individual service plan. The case management team reviews the plan and approves it unless it does not assure the participant's health and safety, exceeds the budget authority, or proposes to use the budget in a way that is not legal. The CMO team is responsible for monitoring participant spending and budget management.

CMOs, which receive their funding through capitation payments, also have fiscal responsibilities with regard to service plans. The care management team helps enrollees identify cost-effective ways of achieving their personal goals, and may choose a lower-cost option for providing a service if it still results in the desired outcome. Such decisions may affect the size of

the prospective budget for enrollees choosing to self-direct a service. If an enrollee and the CMO disagree, the CMO must document in writing that its decision takes into account both outcome and cost considerations and was made after working with the participant to explore other service solutions. Participants, in turn, may file a grievance or request a fair hearing to dispute the CMO's decision.

SDS participants employing workers have a choice in how they handle employment responsibilities. They may be the employer of record, assuming all employer responsibilities and hiring a fiscal agency to perform payroll functions only, or they may use an agency with choice model. In the agency with choice model, the participant is the managing employer and can choose workers but relies on a "co-employment agency" for all other employment responsibilities. CMOs are responsible for contracting with co-employment agencies. In addition to assuming payroll functions, the co-employment agency is the employer of record and provides additional support to participants, such as help with recruiting, training, supervising, and disciplining employees. The agency also is required to conduct criminal background checks on potential workers and provide emergency backup when the worker is not available. Nearly all participants have chosen the co-employment option. Reasons include more control over worker arrangements than traditional services, availability of emergency backup, and reduced fiscal responsibilities, and CMOs have reported that the co-employment option is no more expensive than traditional services (Medstat 2005).

CMOs are responsible for establishing systems to monitor and assure service quality, including the quality of co-employment and fiscal agency services. Systems include participant complaint procedures, participant interviews, surveys, and reviews of individual service plans, with case management teams having primary monitoring responsibility at the participant level. The state, in turn, monitors CMO performance, including quality of services and supports, adequacy of the support network, arrangements for 24-hour service availability, and health, safety, and welfare of participants. Family Care contracts with an external quality review organization to conduct annual participant outcome interviews.

Following Family Care evaluation reports indicating favorable cost results and improved access, including for elderly enrollees, new legislation was enacted in May 2006 to expand Family Care statewide. The evaluation results, however, were for the Family Care program relative to noncapitated programs in other areas. The evaluation did not address program design features affecting SDS participation of older or other beneficiaries or outcomes for SDS participants compared with enrollees receiving standard benefits.

Minnesota: A Program within a Program

Minnesota implemented its Consumer Directed Community Supports (CDCS) service delivery option in 2005 as a separate waiver service category available to persons eligible for any of its five 1915(c) HCBS waiver programs. The CDCS option previously had been available only to persons in the state's Mental Retardation or Related Conditions (MR/RC) waiver. The state's goal was to create statewide access to a participant-directed option for older adults, adults with disabilities, and their family caregivers. CDCS is available to persons eligible for waiver programs as well as to persons in a state-funded Alternative Care program for low income

elderly persons at risk for nursing home entry but not yet eligible for Medicaid and those in a caregiver respite program under the Older Americans Act. The basic design is the same across all waiver groups, but some features differ. The description here refers primarily to the population in the Elderly Waiver program.

Minnesota's program has two distinct features negotiated through its waiver approval process. First, CDCS is a separate "grouped" waiver service that Medicaid beneficiaries may choose *in lieu of* traditional waiver services. Second, the fiscal entity used by participants is the Medicaid provider for CDCS and at a minimum acts as a fiscal conduit, billing the state for CDCS services and disbursing payments to the participant. This arrangement avoids the need for individual Medicaid provider agreements with each CDCS worker or vendor a participant uses, as otherwise required in 1915(c) HCBS waiver programs.

In approving the waiver amendment that added CDCS, CMS required the state to better specify the CDCS waiver service. Ultimately four service subcategories were defined: 1) personal assistance, 2) treatment and training, 3) environmental modification (which includes "environmental supports," such as help with cleaning and chore services), and 4) self-directed support activities (including fiscal services). In order to be authorized, all participant-directed services must be claimed within one of these categories. If CDCS participants choose to include any traditional waiver or state plan home care services in their support plans, they must pay for them from budget funds. The support plan also may include other state Medicaid plan acute and primary care services, such as physical therapy or respiratory therapy, but these are covered outside the participant's CDCS budget.

CDCS is administered by lead agencies, which may be counties, tribal agencies or Medicaid managed care plans. "Required" case managers for these lead agencies conduct assessments and provide basic counseling functions. These functions include providing information on service alternatives, the budget amount that would be available if a beneficiary chooses CDCS, and other resources available to help participants developing the support plan and directing care. The annual budget cap for participants is determined by the state annually as 70 percent of retrospective costs among Elderly Waiver enrollees in 11 case-mix categories. The range for fiscal year 2005 was from about $8,300 to about $35,000—about $700 to $3,000 monthly. Although counties may allow a higher monthly amount for larger approved purchases within the individual's annual budget (e.g., home modifications), they typically do not, according to state contacts. Participants may need to borrow to make a purchase and pay off the loan from monthly budget amounts.

Required case managers are responsible for reviewing the participant-developed support plan for how well it meets participant needs and for technical issues, such as whether services are among those allowed, provider qualifications, and whether pay rates are appropriate as part of the approval process. Participants develop their support plans alone or with the help of family or friends, and also may choose to use part of their budget to pay for the services of a "flexible" case manager to help develop the plan. A required case manager also may recommend use of a flexible case manager. Participants may continue to use a flexible case manager to provide additional ongoing assistance, such as monitoring of the adequacy of the support plan and helping with recruiting, screening, and other duties associated with participant-directed workers.

Family members, including spouses, may be paid workers, but care received from a spouse must be "extraordinary," according to a screen that takes into account whether similar persons without disability would perform the service for themselves and whether duties are beyond normal responsibilities of a spouse. Spouses may be paid for no more than 40 hours per week, and required cases managers must increase monitoring if a spouse is a paid worker.

CDCS participants also must use a fiscal support entity (FSE) under contract to the lead agency and pay for services out of their budgets. Participants may choose their FSE and also may choose to pay for two higher levels of FSE support beyond the basic conduit model. In the conduit model, the FSE bills the state for participant expenses and disburses payments to the participant, who pays providers. Under the payroll model, the FSE pays providers as directed by the consumer and handles all payroll functions for workers. Under the agency with choice model, the FSE also pays an agency to be the employer of record and provide employee management services designated by the participant, while the participant is the managing employer only. The state and lead agencies provide participants with information on available FSE contractors and flexible case managers and the rates and fees they charge. FSEs may offer both flexible case management and fiscal support services, but may not provide both services to the same participant. Other conflict of interest protections preclude FSEs from having an interest in direct services and supports in the participant's plan.

Local lead agencies are responsible for developing and implementing a plan for quality assurance and improvement and submitting the plan biannually to the state. The plan must demonstrate that the agency is implementing programs according to statute; is carrying out delegated quality assurance, monitoring, and assessment activities necessary to achieve desired program outcomes; and has policies and practices in place to ensure the health and safety, participation, and choice-making by participants. Required case managers have a broad range of monitoring duties with respect to participant health, safety, and satisfaction; adequacy of the plan as implemented and need for revisions; and budget and spending. Required case managers also must have a system by which participants have 24-hour access to the local agency in case of a service emergency or crisis.

DISCUSSION AND IMPLICATIONS

States have shown increased interest in the individual budget model as an option for the elderly in their long term care programs. They also have shown considerable creativity in designing programs. Nearly half the states and CMS believe that the model has the potential to improve satisfaction with and access to needed care among at least some older Medicaid beneficiaries and to allow more of them to remain in the community. In addition to the 10 states with operating programs discussed in this report, another 12 were actively planning or close to implementing programs for older beneficiaries, as of January 2006 (Spillman, Black, and Ormond 2006).

CMS has increased its support and technical assistance for states wanting to implement such programs. The DRA will allow states to include the individual budget model without waivers in both their state Medicaid plan personal care benefits and a new optional HCBS

benefit, beginning January 1, 2007. Thus, it is clear that the model has evolved from a promising experiment to a mainstream service delivery option. Nevertheless, it is also clear that the ultimate reach and impact of this model and optimal designs for the older population remains uncertain. Participation to date remains small, even in established programs, and few evaluation results are yet available beyond those from the Cash and Counseling Demonstration.

In this report we have compiled a baseline description of operating programs including the individual budget option for older beneficiaries, focusing primarily on the nine states operating programs under Medicaid waivers. The final design of the Medicaid program that will emerge from Massachusetts' grant-funded Real Choice pilot project has not been determined. We found a great deal of diversity in how states have chosen to implement their programs, and how they have worked within fiscal and waiver constraints to determine the level of budgets, provide for a range of participant choice, establish systems of support for participants, and monitor and assure quality. Finally, we looked more closely at three states that appear to exemplify the range of second-generation designs, from taking incremental steps within the conventional 1915(c) waiver framework to incorporating the model in a capitated long term care system redesign.

Our description relies, however, primarily on interpretation of publicly available materials, with review of basic program characteristics by representatives from each state. Such an overview cannot capture nuances or even larger issues arising in actual practice for older Medicaid beneficiaries. Deeper understanding of how the various design features actually work in improving outcomes for elderly Medicaid beneficiaries and for state spending will require case studies involving a wide range of stakeholders and results from evaluations, which are not yet available. Nevertheless, we draw the following implications from our examination of existing information:

Careful attention is warranted to the interdependence of budget adequacy, choices and management supports available to participants, and quality of care. A willingness to revisit and calibrate program design based on experience is important for states. Successful participation is dependent upon a budget determination methodology that results in budgets sufficient to cover allowed services. Budgets may not be adequate if the discounts many states apply lock in traditional program problems with underuse of services because of inadequate supply of agency workers or because services are not provided at the time or in the way needed. The practice of discounting arose in the original Cash and Counseling Demonstration because of Section 1115 waiver requirements that spending with the demonstration not exceed spending without it, based on actual spending experience for nonparticipants. This requirement does not apply to Section 1915(c) waiver programs, which must demonstrate only that costs do not exceed the cost to provide care in nursing homes, although several states with 1915(c) programs use discounting, and neither requirement will apply to new programs established under the DRA.

Successful participation also is affected by the extent to which budgets are adjusted to cover costs shifted from the state to participants, including the costs of planning, management, and fiscal services support, and by the amount of flexibility participants have in choosing the level of such support they need. The lack of interest in managing a cash benefit in the three Demonstration states contrasted with the almost universal choice to do so in Oregon and the

almost universal selection of the agency with choice model in Wisconsin illustrates that more needs to be known about how different participant groups, different state environments, and perhaps different benefit levels affect these participant choices and outcomes from them.

Longer experience, larger enrollments, and evaluation evidence are needed to reveal how different program designs perform in attracting older participants and achieving better outcomes for them, as well as the implications for state spending. In most states, enrollments among older beneficiaries remain low, and long term impacts on their use of nursing homes and cost savings relative to standard benefits remain to be demonstrated empirically. Final reports from evaluations commissioned by at least two of the states implementing programs for elderly beneficiaries since the Cash and Counseling Demonstration—Oregon and Minnesota—have been completed and presumably will be available soon. Both of these states use the "all or none" approach taken in the Cash and Counseling Demonstration states, in which beneficiaries choose between a package of traditional benefits and a comprehensive budget for all services. It will be particularly interesting to compare evaluation findings from these newer programs with findings from the Demonstration. Participation has been very low among the older population in the Minnesota program's first year of operation, however. Thus, it is not clear whether early results will shed much additional light on the appeal and performance of the model for elderly beneficiaries beyond what is known from the Demonstration.

Newer designs that allow older beneficiaries to choose whether to manage a budget for all home and community based services or only some services may increase participation. These designs differ fundamentally from "all or none" programs, so states should be cautious about relying too heavily on evaluation results from programs using the original Cash and Counseling design. Programs in North Carolina, South Carolina, and Wisconsin that allow participants the choice of receiving a budget for and directing only part of their service package have the potential to answer additional questions about what works best for older beneficiaries and the benefits of offering a more complete continuum of choices. This variation on the individual budget model is not the model tested, however, in the Cash and Counseling Demonstration. These programs present a less straightforward evaluation platform and so present additional challenges for designing state evaluations.

In these three states—and in other states that will soon be implementing programs under 1915(c) waivers—participants have the *opportunity* to manage a comprehensive budget for all home and community based services as in the Demonstration, but also may choose where they want to be along a continuum of individual budget options. For example, participants may choose to receive a budget to pay for a single personal care worker and use traditional services for all other supports. This additional dimension of participant choice may make an individual budget more manageable for a larger and more diverse population, and perhaps more appealing for older beneficiaries. Evaluation results from such programs may be particularly valuable for some states considering an individual budget option for older beneficiaries but wanting to take smaller steps and not incur the costs of implementing a more comprehensive model.

CONCLUSIONS

It is important for studies to continue to monitor the evolution of the individual budget model and variants on it, as well as other innovations in the organization and delivery of public long term care services for the older population and others. Under the DRA, states will be able to offer a wider range of HCBS services through their state Medicaid plans and will have the ability to limit both eligibility and enrollment in ways not previously allowed. They also will be free from cost or budget neutrality requirements that have affected how states using waivers have determined the size of the individual budgets participants have to work with. Other motivations that have affected state design decisions in existing programs, however, will persist, such as the desire to maintain equity across traditional and individual budget benefits or avoid inducing high levels of new enrollments among persons who would not enroll for traditional benefits.

It remains to be seen how many states will choose to take advantage of the new DRA provisions for their older beneficiaries or others, and how many additional states will choose to pursue waivers for individual budget programs. In either case, up to date information on design choices made in existing waiver programs and new ones nearing implementation, as well as evaluation of their impact on beneficiaries and costs, can provide valuable guidance to states in adapting this model to their particular fiscal and political situations.

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BEYOND CASH AND COUNSELING:

The Second Generation of Individual Budget-based Community Long Term Care Programs for the Elderly

APPENDIX:

Active State Individual Budget Programs Including the Elderly as of January 2006

ARKANSAS

Program Name	IndependentChoices
Lead Agency and Contact	Arkansas Division of Aging and Adult Services (DAAS) Debby Ellis: debby.ellis@medicaid.state.ar.us
Overview	Begun under the Cash and Counseling demonstration project, IndependentChoices allows elderly and disabled adult recipients eligible for the state's Medicaid optional plan service for Personal Care the choice of receiving a monthly allowance to purchase personal care and other related long term care services and supports instead of traditional service benefits.
Program Goals	The goal of the program is to provide people with disabilities more options and greater personal autonomy in determining how to meet their personal care needs in a cost effective manner.
Authority	1115 Medicaid Waiver
Implementation Date	December 1998
Funding Sources	Federal: Medicaid State: Medicaid Grants: Funding from RWJF and DHHS/ASPE for implementation and evaluation of the Cash and Counseling Demonstration Project
Population Eligible	Target population: Medicaid recipients age 18 and over who are eligible for services under the state's Medicaid plan personal care benefit and have impairments in two or more Activities of Daily Living (ADLs) Geographic coverage: Statewide Estimated number of eligibles: 12,000 to 13,000 individuals on average per month who receive agency personal care services
Population Enrolled	Enrolled: 10 to 13 percent of persons receiving personal care Cap on enrollment: 3,500 Enrollment is voluntary.
Program Description	DAAS refers persons eligible for personal care benefits who select IndependentChoices to the Counseling/Fiscal Agency (C/FA) serving the county in which the person lives. Participants (or a representative, if desired or required by the state) work with a counselor to determine the amount of personal care and other supports that best meet their needs and to develop their spending plans. Participants may receive their allowance as a cash benefit, but almost all choose to use a fiscal agency, and the state is discontinuing the cash option.[1]

[1] As of October 2005, three individuals were receiving a cash benefit and will continue to do so under a "grandfather" clause.

ARKANSAS

Assessment of Needs	Nurses hired by the state develop care plans as part of the assessment process for determining eligibility to receive state plan personal care services. Reassessment must occur every six months, but may also be triggered by any significant change in the recipient's condition.
Benefit Determination	The monthly allowance is based on the number of personal care hours allowed in a participant's care plan, discounted to reflect that, on average, the number of hours actually received by personal care recipients is less than allowed in the care plan. The discount is between 9 and 30 percent, based on agency-specific differences in the ratio of hours received to hours authorized. The discounted number of personal care hours is multiplied by the rates paid to providers of traditional services to determine the monthly allowance amount. The state also sets aside one-third of the allowance to fund counseling and fiscal services. The average benefit is around $430 per month, and the maximum benefit, $1,570 per month.
Development of a Spending Plan	The participant and the participant's counselor develop a spending plan or personal budget based on the monthly allowance. Counselors may approve almost any expenditure that is associated with the performance of an ADL or instrumental activity of daily living (IADL).
Services Covered	Personal care, homemaker services, home-delivered meals, adaptive equipment, home modifications, safety and communication devices, transportation, prescription drugs, co-pays for medical visits or prescription drugs, durable medical equipment not covered by Medicaid, and discretionary spending
Benefit Flexibility	Participants may spend up to 10 percent of their monthly allowance on discretionary items. They may also save money from their allowance toward the purchase of approved higher cost items or services that have been identified in their spending plan. There is no time limit for accumulating such savings, but if the allowance accumulates as a result of deviating from the spending plan then the savings must be returned to the state after 45 days.
Participant Choice and Control	Participants may choose their personal attendants, but cannot hire legally liable relatives, such as a spouse or parent. Participants can choose to appoint a representative decision-maker, who may be a family member, a friend, a legal guardian, or other legally appointed representative. The same individual may not serve as both representative and paid worker.
Participant Support Services	The state contracts with a regional C/FA to provide fiscal and support services for beneficiaries. Counselors employed by the C/FA provide training to help participants develop and revise individual spending plans and hire, train, and manage paid caregivers.

ARKANSAS

Fiscal Assistance and Monitoring	**Fiscal assistance**: The participant is the employer of record and is responsible for hiring and managing paid workers. The C/FA is responsible for withholding and paying of all state and federal taxes, paying for all goods and services specified in the spending plan. The C/FA distributes funds twice monthly. **Fiscal monitoring**: For participants who use the C/FA, counselors must verify worker time sheets and check spending requests against the spending plan before funds are disbursed. For the few respondents who receive a cash benefit, monthly documentation of expenditures is required to verify that money is spent on items identified in the spending plan or, in the case of discretionary funds, is used for items related to personal care needs.
Quality Assurance Monitoring	**Responsibilities**: DAAS has primary responsibility for quality and monitoring of the IndependentChoices program, including performance of the contract agencies. The C/FA counselor provides ongoing quality monitoring to ensure the health and safety of individual participants. **Areas monitored**: The counselor monitors whether change in the participant's condition necessitates a reassessment, the quality of the self-directed care, whether the care plan appropriately meets identified needs, the emergency backup plan, and, overspending or under-utilization. DAAS monitors C/FA performance according to standards identified in the C/FA contract. **Monitoring procedures**: Counselors may contact participants via telephone in the first six months, but thereafter are required to conduct face-to-face visits at least once each six months. Upon the participant's request, the state will run background checks on a potential employee. DAAS makes quarterly monitoring visits to C/FAs and conducts telephone surveys of participants. Participants may call a toll-free number to discuss a service problem. Participants can appeal any adverse decision to the Department of Health and Human Services Fair Hearings and Appeal process. Reports of abuse, neglect, or exploitation are referred to the Arkansas Adult Protective Services. **Reporting requirements**: The Counselor must document all contact and activity related to the participant in the participant's case file. Monthly monitoring activities and the corrective action taken are submitted in the C/FAs quarterly report to DAAS. DAAS submits annual quality assurance reports to CMS.

COLORADO

Program Name	Consumer-Directed Attendant Support (CDAS)
Lead Agency and Contact(s)	Colorado Department of Health Care Policy and Financing (HCPF) Aggie Berens: Aggie.Berens@state.co.us
Overview	Designed to combine home health aide and personal care funding into one funding stream, the CDAS program allows recipients of these Medicaid plan in-home support services the option of receiving a monthly budget with which to hire attendants. Beneficiaries may use part of any unspent amounts to purchase additional goods and services to support their healthcare needs.
Program Goals	The goals of the program are to increase participant independence, improve the quality of attendant support, and reduce the cost of providing attendant services.
Authority	1115 Medicaid Waiver
Implementation Date	December 2002
Funding Sources	Federal: Medicaid State: Medicaid Grants: HCPF received a Colorado Community Personal Assistance Supports and Services (COmPASS) grant to support program training and administrative activities; the grant has been extended through September 2006.
Population Eligible	Target population: Persons who have received Medicaid in-home attendant support services for the past 12 months through the state plan home health benefit or personal care under a HCBS waiver[2] Geographic coverage: Statewide Estimated number of eligibles: 4,000
Population Enrolled	Enrolled: 148 persons as of October 1, 2005 Cap on enrollment: 500 Enrollment is voluntary, but applicants are accepted only if they complete attendant support management training and pass a proficiency test.
Program Description	CDAS participants work within a care plan and monthly budget to purchase in-home services from attendants they personally select, train, and supervise. Participants receive training and assistance in managing their budget from a case manager and a fiscal agency.

[2] Colorado also provides a monthly cash payment for personal attendant services to additional persons through its state-funded Home Care Allowance (HCA) program. The program serves approximately 5,800 low-income, frail elderly or disabled clients. The maximum payment is $396 a month.

COLORADO

Assessment of Needs	Case managers from one of Colorado's Single Entry Point agencies conduct an eligibility assessment for state long term care services using a standardized assessment tool. Applicants must have a 12-month utilization history of Medicaid funded attendant support which means nursing, home health aide, personal care or homemaker services. Case managers reassess participant needs at least every six months.
Benefit Determination	The monthly allowance is the average monthly expenditure for Medicaid home health aide and personal care services for the previous 12 months according to paid claims in the Medicaid Management Information System. Twelve percent of each participant's monthly allocation goes to pay for fiscal services. The average benefit is about $4,000 per month. There is no maximum benefit amount.
Development of a Spending Plan	Each participant must complete an attendant support management plan before being approved for enrollment in the program. The plan identifies services needed and provides a detailed budget including number of attendants, wage rates, cost of taxes, and plans for emergency backup The plan also describes the participant's current situation and establishes individual goals and outcomes.
Services Covered	Skilled nursing, personal care, home aide, homemaker services, and other goods and services that support healthcare needs
Benefit Flexibility	Participants may accumulate half of any unspent amounts from their monthly budgets in a Fund for Additional Services (FAS). The state retains the remaining half. In order to use their savings, participants must submit a grant application to the HCPF specifying the approved services or equipment they wish to purchase. Savings do not have to be spent within a certain time period, but HCPF considers FAS grant applications only twice a year.
Participant Choice and Control	Participants may choose their own attendants, including a spouse or other legally liable relative. Participants receive assistance with the financial parts of the program, but a physician must certify that they are able to manage and direct their care. As of early 2006, the program did not allow for authorized representatives, but the state was working with CMS to change this restriction.
Participant Support Services	Case managers help participants develop their management plans and provide mandatory training on attendant support management and related fiscal management.

COLORADO

Fiscal Assistance and Monitoring	**Fiscal assistance**: The state contracts with a fiscal agency to provide financial and personnel administration services for participants. The fiscal agency is the employer of record for attendants and handles taxes, withholding, benefits, payroll, other personnel and accounting activities; it also performs background checks on attendants. **Fiscal monitoring**: HCPF sends monthly payment authorization to the fiscal agency, which pays workers upon receipt of timesheets. The fiscal agency monitors information submitted by participant, works with case managers to address any performance problems, and provides monthly reports to participants and the state. HCPF oversees the fiscal agency's activities through ongoing communications and meetings, as well as feedback from CDAS participant surveys.
Quality Assurance Monitoring	**Responsibilities**: HCPF has primary responsibility for organizing and administering the CDAS program and assuring quality of service. Case managers assist the state with quality assurance and service monitoring. **Areas monitored**: Case managers monitor participant use of and spending on attendant support services for potential self-neglect (underutilization), overspending or underspending, and potential financial exploitation. The state monitors program eligibility, participant complaints and satisfaction, payments, and service utilization. **Monitoring procedures**: Case managers contact participants at least quarterly to discuss their service plans, budget, attendant management, and program satisfaction, and conduct face-to-face reassessments annually or sooner, if participant needs change. HCPF monitors quality through monthly participant surveys and uses a participant complaint and appeals system to track participant grievances and reports of abuse or neglect. HCPF also provides a complaint hotline for participants. Nurses or case managers under contract to HCPF assess participants every six months to evaluate quality of care and ensure that participants are receiving the appropriate service level. **Reporting requirements**: Case managers report to HCPF on the client's condition, ability to self direct, and self assessment. HCPF submits quality assurance reports to CMS.

FLORIDA

Program Name	Consumer-Directed Care Plus (CDC+)
Lead Agency and Contact(s)	Florida Department of Elder Affairs (DOEA) Ronald Taylor: Taylorrs@elderaffairs.org
Overview	Begun under the Cash and Counseling demonstration project as the CDC program, CDC+ allows elderly and disabled Medicaid recipients in Florida's HCBS waiver programs the option of receiving a monthly budget to purchase personal care and other long term care services and supports instead of traditional waiver benefits.
Program Goals	Program goals are to demonstrate that some participants can make more appropriate use of Medicaid resources with greater control over choice and delivery of services and related purchases, to improve access to services, and to improve participant satisfaction with their services.
Authority	1115 Medicaid Waiver
Implementation Date	June 2000
Funding Sources	Federal: Medicaid State: Medicaid Grants: Funding from RWJF and DHHS/ASPE for implementation and evaluation of the Cash and Counseling Demonstration Project
Population Eligible	Target population: Medicaid recipients enrolled in HCBS 1915(c) waivers for four groups 1) the frail elderly; 2) adults with physical disabilities, 3) adults with brain/spinal cord injuries, and 4) adults and children with developmental disabilities. All participants must require assistance with daily living. Geographic coverage: Statewide Estimated number of eligibles: 8,951 frail elders, 868 adults with physical disabilities, 276 adults with brain/spinal injuries, and more than 25,000 adults and children with developmental disabilities
Population Enrolled	Enrolled: 1,095 persons as of September 1, 2005 Cap on enrollment: 3,350 Enrollment is voluntary.
Program Description	CDC+ participants receive a monthly budget based on the participant's care plan or on the participant's Medicaid expenditure history if it is stable and consistent with the care plan. CDC+ trained consultants work with participants to determine the type and amount of personal care services they need. A fiscal agent assists participants with financial responsibilities.

FLORIDA

Assessment of Needs	A CDC+ trained consultant conducts an assessment to determine functional eligibility for the 1915(c) HCBS waiver program. Participants work with the consultant to develop a support plan identifying each necessary service and the frequency, duration, and unit cost of the service. Reassessments are conducted annually.
Benefit Determination	The value of the participant's budget is based on the discounted value of the services authorized in the care plan. The discounting, which is between 8 and 17 percent, depending on the waiver population, ensures budget neutrality by adjusting the allowance to take into account that the cost of waiver services actually received by persons not participating in CDC+ is less than the cost of services allowed in the care plan. The discounted amount is the annual budget available to each participant. The average benefit for elderly adults and adults with physical disabilities is about $975 per month. There is no maximum benefit.
Development of a Spending Plan	Participants develop a monthly purchasing plan with help from their consultants. The plan identifies services or purchases, number of workers, and associated costs. Only goods or services shown in the approved purchasing plan can be purchased, but participants may update their purchasing plans if a new service or support is identified.
Services Covered	Personal care, homemaker services, home health services, respite care, durable medical equipment, non-emergency transportation, case management, mental health, adult day health services, and 24 other home and community-based services requested by the state and approved by CMS.
Benefit Flexibility	Participants may receive a limited amount of cash for discretionary spending identified in their spending plan. They may also invest up to $250 of their monthly budget in a special "savings" account for approved purchases. These savings must be spent as soon as they are sufficient to cover the approved item. Funds that are not designated as savings for approved purchases may revert to the state. In extraordinary circumstances, if larger amounts are necessary, individuals may request to save more than the $250 limit.
Participant Choice and Control	Participants may hire their own workers, including spouses or parents of minor children or may choose to appoint a representative decision-maker to act for them. A representative may be a family member, a friend, a guardian or another legally appointed representative, but cannot be a paid worker or be paid to be the representative. Consultants may recommend the appointment or replacement of a representative.
Participant Support Services	Consultants assist participants in developing and revising their individual spending plans. Consultants provide training and assistance on hiring and managing paid workers and allowed uses for budget funds. Consultant services are funded through the existing HCBS waivers and are not deducted from the monthly budget.

FLORIDA

Fiscal Assistance and Monitoring	**Fiscal assistance**: The fiscal agency assists participants with processing employment information, handling payroll and provider payments, and employment related taxes. Under this arrangement, the participant is the employer of record. The state makes funds available to participants on a monthly basis through an account set-up with the fiscal agency. Participants pay for fiscal agency services through a monthly user charge and a user fee for each payment processed. **Fiscal monitoring**: The fiscal agency verifies worker time sheets and checks purchase requests against spending plans before funds are disbursed, and receipts are required for all purchases. The state monitors the fiscal agency for programmatic and financial performance as well as quality management and participant complaints with quarterly site visits and an annual formal monitoring visit and audit.
Quality Assurance Monitoring	**Responsibilities**: The DOEA and partner agencies responsible for each waiver population are responsible for quality management of both CDC+ and the 1915(c) waiver programs from which CDC+ participants are drawn. Consultants also play a role in monitoring. **Areas monitored**: Monitoring includes an evaluation of four quality indicators: 1) care management; 2) financial management; 3) abuse, neglect and exploitation; and 4) use of community resources to obtain long term care services and supports before using the budget. **Monitoring procedures**: Consultants visit participants in their homes in the 2nd and 12th month after enrollment, and annually thereafter, to monitor the participant's condition and assess potential risk for abuse, neglect, or exploitation. Consultants contact participants at least monthly, review spending patterns, compare spending to the purchasing plan, and review all cash receipts. Fiscal agency reports provided to the state are also used to monitor program quality. Participants may submit complaints, including problems with either consultants or fiscal agency services, and also have the right to a Medicaid hearing or appeal. **Reporting requirements**: Consultants are required to ensure that participant information is updated as needed. The state submits quality assurance reports to CMS with individual and aggregate level data for all participants.

MASSACHUSETTS

Program Name	Real Choice Pilot Project
Lead Agency and Contact(s)	University of Massachusetts Medical School Center for Health Policy and Research (UMMS/CHPR) Erin Barrett: Erin.barrett@umassmed.edu
Overview	UMMS/CHPR is administering a small grant-funded pilot program based on the individual budget model on behalf of the state. The program allows persons with disabilities, including the elderly, to receive an individual budget for personal care and other related purchases.
Program Goals	The goals of the pilot project are to increase participant's quality of life and independence though a flexible service model appropriate for persons with all types of disabilities, and develop the infrastructure required for larger program implementation.
Authority	Not applicable[3]
Implementation Date	January 2005
Funding Sources	Federal: Medicaid State: Medicaid Grants: The state received a 2001 Real Choice Systems Change Grant from CMS, which it is using to fund the pilot.
Population Eligible	Target population: Participants are Medicaid-eligible and identified in the assessment process as having two or more "unmet needs" relating to ADLs or IADLs. Participation in the pilot program is limited to persons who are not eligible to participate in Massachusetts' Personal Care Attendant (PCA) program.[4] Geographic coverage: Two regions–the Worcester area and Southeastern Massachusetts Estimated number of eligibles: Not applicable
Population Enrolled	Enrolled: 14 persons Cap on enrollment: 14 persons Enrollment is voluntary.
Program Description	Pilot participants receive an annual budget and support brokerage services, known as Community Liaison support, through the Consumer-Directed Agency for each of the two pilot regions. The Community Liaison helps participants develop and monitor their spending plan. Participants receive fiscal assistance from a fiscal agency.

[3] Massachusetts ultimately plans to continue the model either by modifying existing 1915(c) HCBS waiver(s) or seeking a new HCBS waiver.

[4] The PCA program is limited to persons who require hands on assistance with at least two ADLs. Participants may hire, fire, and train their workers, but the program does not include other consumer-directed supports.

MASSACHUSETTS

Assessment of Needs	Individuals are assessed using a functional assessment tool developed through the Real Choice Systems Change grant to provide a uniform functional assessment for individuals with diverse disabilities in a variety of settings. The new tool is designed to be more participant-driven and less medically driven than traditional tools, and is being piloted within the grant. Reassessments are required if there is a change in unmet need.
Benefit Determination	Pilot participants receive an annual budget based on the requests in the spending plan, the individual's level of functioning, and available funds. The program uses a formula that distributes funds across recipients based on the level of need and the budget request. The Commonwealth has not yet determined the approach that will be adopted for the waiver program.
Development of a Spending Plan	Participants work with the Community Liaison to develop their spending plans for monthly disbursements from the annual budget. All services in the spending plan should address an unmet need identified during the assessment phase. The spending plan documents any hired workers, agency support, home modifications, equipment, and emergency backup support.
Services Covered	Personal care, transportation, home modifications, equipment, medical and non-medical supplies, community integration activities, transition support (under the pilot)
Benefit Flexibility	The annual budget allows participants some flexibility to vary monthly payments if needs change or to save for one-time purchases or larger purchases.
Participant Choice and Control	The pilot participant is responsible for hiring, training, and supervising their workers. Participants can appoint a representative decision-maker, but a representative cannot be a worker or a Community Liaison. There are no other restrictions on who can be a worker. The state has yet to determine the standards for the waiver program.
Participant Support Services	The Community Liaison is responsible for training the participant and their representative, if applicable, on their employer-related responsibilities as well as assisting participants to develop and monitor their spending plan. Community Liaisons are also available to provide training on how to employ workers. The Consumer-Directed Agencies provide background checks, although not mandated for workers, and pay Community Liaisons through the Real Choice grant.

MASSACHUSETTS

Fiscal Assistance and Monitoring	**Fiscal assistance**: The fiscal service agency is responsible for all required employer forms and paperwork and for ensuring the payment of workers, workers' compensation, employee taxes, as well as payments for purchases outlined in the spending plan. Fiscal support is provided through a contractor serving as fiscal agency for the Massachusetts' PCA Program. The fiscal service agency is the employer of record while the participant is the managing employer. **Fiscal monitoring**: The state monitors fiscal support services through its current contract for PCA Program services. Monthly account statements also are provided to the Community Liaison and the participant for monitoring. The fiscal agency pays for services and purchases once a timesheet or invoice is received. Participants do not receive cash.
Quality Assurance Monitoring	**Responsibilities**: The UMass Medical School, in conjunction with the subcontractors, is responsible for monitoring program quality. **Areas monitored**: Consumer-Directed Agencies, through their Community Liaisons, monitor spending. The medical school is monitoring and testing procedures for the supports brokerage services, fiscal agency services, appeals and grievance procedures, as well as individual and secondary emergency backup systems. **Monitoring procedures**: Community Liaisons are required to meet with participants monthly, during which the participant and the Community Liaison discuss unmet needs, change in status, the spending plan, and paid workers. In addition, a research group is conducting 2 and 9-month individual interviews with pilot participants. The Consumer-Directed Agencies provide worker background checks, although they are not required. Also, one region is piloting a second tier emergency backup system in which home health aides are on call if a worker is not available. **Reporting requirements**: The Community Liaison provides monthly documentation of meetings with participants. As part of the evaluation, UMass is developing a multi-phased evaluation report that will include summaries and findings on several features of the pilot program including outreach and enrollment, assessment, use of support brokerage, spending plans, and fiscal agency support.

MINNESOTA

Program Name	Consumer Directed Community Supports (CDCS)
Lead Agency and Contact(s)	Minnesota Department of Human Services (DHS) Lisa Rotegard: lisa.rotegard@state.mn.us; Kathy Kelly: kathy.kelly@state.mn.us; Jane Vujovich: jane.vujovich@state.mn.us
Overview	Under Minnesota's CDCS program, eligible elderly and disabled participants in any of five Medicaid HCBS waiver programs and certain other community care programs and living outside residential care can choose to receive an individual budget to purchase personal care and other services and supports.
Program Goals	The goal is to create permanent, multi-point, statewide access to a participant-directed option for older adults, adults with disabilities, and their family caregivers.
Authority	1915 (c) Medicaid HCBS waivers
Implementation Date	April 2005 (Prior to 2005, CDCS was available only for persons in the state's waiver program for persons with mental retardation or related conditions.)
Funding Sources	Federal: Medicaid State: Medicaid Grants: The state received a Cash and Counseling Grant from RWJF for program implementation and data collection to monitor program effectiveness.
Population Eligible	Target population: Enrollees in any of five 1915(c) HCBS waiver programs [Elderly Waiver (EW), Community Alternative Care (CAC), Community Alternatives for Disabled Individuals (CADI), Traumatic Brain Injury (TBI), Mental Retardation or Related Conditions (MR/RC)] or the state-funded Alternative Care (AC) program, and older persons receiving caregiver respite through the Older Americans Act (OAA) Geographic coverage: Statewide Estimated number of eligibles: 40,000 in all programs (9,135 EW, 5,264 AC, and 1,665 OAA respite only)
Population Enrolled	Enrolled: 61 (22 EW, 12 AC, and 27 OAA respite) as of April 30, 2006 Cap on enrollment: None Enrollment is voluntary.
Program Description	CDCS is administered by lead agencies that may be counties, a tribal agency, or Medicaid managed care health plans. Participants receive an annual budget, paid monthly, based on assessed needs, and work alone or with the help of friends, family, or an optional flexible case manager to develop a Community Support Plan. Participants choose one of three fiscal management options with varying degrees of participant responsibility. A participant-directed supports database provides participants with information about Fiscal Support Entities and Flexible Case Management/Support Broker services through the Internet.

MINNESOTA

Assessment of Needs	County long term care consultants conduct a needs assessment to determine 1915(c) HCBS waiver program eligibility using a standard assessment tool for the state's long term waiver programs. Recipients can have a needs reassessment when there is a change in condition, hospitalization or nursing home stay, or loss of family caregiver. Reassessments are conducted at least annually.
Benefit Determination	DHS determines the amount of the participant's annual budget by applying a state formula to the assessment. For EW and AC, the budget amount is capped at 70 percent of the average cost for similar persons receiving standard services, based upon aggregate service utilization by case mix category determined in the functional needs assessment. Annual budgets range from about $8,000 to $35,000 annually for EW participants and slightly less for AC participants.
Development of a Spending Plan	Participants develop a Community Support Plan that identifies the services and supports they intend to purchase with their budget. This may be done independently or with the help of friends, family, or an optional flexible case manager. The plan includes a description of the participant's wants, environmental modification needs, participant-directed support activities (e.g., flexible case management costs, payroll services), a plan for monitoring the participant's health and safety (including an emergency backup plan), and a budget.
Services Covered	CDCS are divided into four allowed subcategories: personal care, treatment and training, environmental modifications and provisions, and self direction support activities. Services in the budget may include waiver services and state plan home care services, as well as consumer-directed services and other consumer designated supports.
Benefit Flexibility	Under the EW and the AC programs, participants receive an annual budget in monthly installments and may apply only the amount available in their monthly budget toward payment for larger expenses. Counties may agree to a larger amount, but usually do not. Participants may need to obtain a loan for such purchases and pay it off from monthly CDCS payments. Under CADI, participants receive an annual budget and can use up to three months of money to purchase more expensive items.
Participant Choice and Control	Participants can hire their own workers including a spouse or parent (limited to 40 hours per week), and other family, friends, or neighbors. Participants have the option of appointing a representative decision-maker, which may be a family member, a friend, a legal guardian or another legally appointed representative.
Participant Support Services	Participants must have "required case management" services through the county or health plan, but have the option of using some of their budget to pay a flexible case manager, who can be a professional, a family member, or a friend, to assist in developing the Community Support Plan. A flexible case manager may be recommended if a participant's support needs exceed what the required case manager can provide. Participants also pay for fiscal services out of their budgets. Required case management costs are not taken from the individual budget amount.

MINNESOTA

Fiscal Assistance and Monitoring	**Fiscal assistance**: Participants may choose one of three fiscal management options which offer varying amounts of participant control: 1) The participant performs all employer functions, including withholding taxes and paying employment taxes, and hires a fiscal agency to submit claims and disburse payments; 2) The participant is the common law and managing employer, but hires a fiscal agency to perform additional duties, such as managing worker taxes, payroll, and insurance; 3) The participant acts as managing employer only, hiring and supervising workers, but hires a fiscal agency to perform all employer-related financial functions. Regardless of which option a participant chooses, all payments for fiscal services come from the participant's individual budget. **Fiscal monitoring**: The lead agency is responsible for monitoring the fiscal agent as outlined in the county's quality assurance plan. At a minimum, the required case manager must review the participant's budget and spending before the third, sixth, and twelfth month of the first year of CDCS services and at least annually thereafter. The fiscal agency conducts monthly reviews of hours billed for family provided care and the total amounts billed for all goods and services during the month, and must maintain records to track all CDCS expenditures.
Quality Assurance Monitoring	**Responsibilities**: Each county, tribal agency, or health plan administering a CDCS program must develop and implement a plan for quality assurance. The plan is forwarded to DHS bi-annually to assure the state that the local county agency is carrying out delegated quality assurance, monitoring, and assessment activities. **Areas monitored**: Implementation of the community support plan; participant satisfaction; adequacy of participant's current supports plan; abuse, neglect, or exploitation; and policies and practices in place to ensure the health, safety, participation, and choice-making of participants. **Monitoring procedures**: At a minimum, the required case manager conducts quarterly reviews of the expenditures and the health, safety, and welfare status of the individual recipient and conducts face-to-face visits with the recipient by the county on at least a semi annual basis. The county is responsible for monitoring contractor's performance and maintenance of financial records and management of the budget and services. The county must assist participants with monitoring and revising their support plan and monitoring paid workers. **Reporting requirements**: An independent evaluation will assess the first-year implementation of CDCS through interviews, telephone surveys and policy review. Findings from the evaluation will be used to make quality improvements to CDCS policies and procedures. The evaluation will be completed in January 2006. The state will submit a summary of its program monitoring and waiver operations annually to CMS.

NEW JERSEY

Program Name	Personal Preference
Lead Agency and Contact(s)	New Jersey Department of Human Services, Division of Disability Services (DDS) William Ditto: William.Ditto@dhs.state.nj.us
Overview	Begun under the RWJF Cash and Counseling demonstration project, the Personal Preference program allows elderly and adult persons with disability who qualify for state Medicaid plan optional Personal Care Assistant (PCA) benefits the choice of receiving a cash allowance to purchase long term care services and supports instead of traditional service benefits.
Program Goals	The goals of the program are to provide people with disabilities greater personal autonomy in determining how best to meet their long term needs in a cost effective manner, and to account for demographic changes related to population aging and a projected shortage of agency workers.
Authority	1115 Medicaid Waiver
Implementation Date	November 1999
Funding Sources	Federal: Medicaid State: Medicaid Grants: Initially the state received grant funding from RWJF and DHHS/ASPE for implementation and evaluation of the Cash and Counseling Demonstration Project.
Population Eligible	Target population: Medicaid beneficiaries age 18 or older currently receiving or qualified to receive Medicaid state plan PCA services. Geographic coverage: Statewide Estimated number of eligibles: 17,000
Population Enrolled	Enrolled: 400 persons as of October 2005 Cap on enrollment: None Enrollment is voluntary.
Program Description	Medicaid plan personal care beneficiaries may choose to receive a monthly budget instead of their current agency-directed services. Participants may use their budgets to hire their own workers and purchase other long term care services and supports, such as assistive devices or home modifications. Consultants work with participants to develop and revise individual budgets. A fiscal agency assists participants with financial responsibilities.

NEW JERSEY

Assessment of Needs	A registered nurse conducts an assessment of the need for personal care assistant services using a standardized instrument developed by the state. After recipients begin receiving traditional services, they are given the option of receiving a budget and directing their own personal care services. Participants are reassessed every six months or sooner if their condition changes to confirm eligibility and make any needed adjustments to the care plan.
Benefit Determination	The monthly budget amount is based on the hours of personal care allowed in a participant's care plan, using a formula that takes into account the costs of consulting and fiscal services. The state reserves 10 percent of the cashed-out value of participants' care plans to pay for counseling and part of the cost of fiscal agency services. The average benefit is about $1,300 per month, with amounts ranging from $262 to $2,630 per month.
Development of a Spending Plan	The participant develops a spending plan with the assistance of a Consultant. The spending plan must account for all anticipated expenditures, including arrangement for emergency backup support.
Services Covered	Personal assistance, assistive devices, other medical equipment and supplies, home modifications related to personal care needs
Benefit Flexibility	Participants may allocate up to 10 percent of the monthly budget for discretionary spending for allowed items and also may build savings for larger purchases into their spending plan. Savings may accrue for as long as necessary, but after 12 months, the state may recoup unspent funds not linked to an allowed spending plan purpose.
Participant Choice and Control	Participants may hire their own workers, including spouses, and also may choose to appoint a representative decision-maker. The state may require a representative if, for example, a participant has misspent funds or their functioning has deteriorated. A representative may be a family member, friend, guardian or another legally appointed representative, but the same individual may not serve as both representative and paid worker.
Participant Support Services	Participants work with Consultants to formulate their spending plans. Consultants receive a lump-sum payment for the development of the spending plan and hourly reimbursement for counseling services. Consultant fees are paid from the 10 percent of the plan value set aside for counseling and fiscal assistance.

NEW JERSEY

Fiscal Assistance and Monitoring	**Fiscal assistance**: The fiscal agency assists participants with financial responsibilities.[5] The participant is the employer of record, but the fiscal agency is responsible for payments to providers, verifying time sheets, and checking payment requests against spending plans. Fiscal agencies are paid in part from the 10 percent of the participant budget withheld by the state for the purpose and in part from fees paid from participant budgets for services used, such as issuing checks or conducting background checks on workers. **Fiscal monitoring**: A monthly financial statement is sent to each participant with a copy to the state. Any problems such as misuse of funds, failure to pay assistants, failure to comply with employment laws or submit required documented expenditures, must be reported to the state. The state monitors fiscal agency services according to established monitoring schedules and requirements and conducts on-site quality assurance audits. The fiscal agency is required to submit reports of its activities to the state.
Quality Assurance Monitoring	**Responsibilities**: DDS is primarily responsible for monitoring program quality with assistance from Consultants. **Areas monitored**: The state, in coordination with the Consultants, monitors participant satisfaction, the participant's physical environment, changes in the participant's condition, and the quality of self-directed care to assure that the health and well-being of the participant are not compromised and that needs identified in the participant's plan are being met. **Monitoring procedures**: Consultants contact participants at least monthly by telephone and make quarterly in-person visits. Agency nurses monitor the participant's condition when they visit for the six-month reassessment. The fiscal agency, along with Consultants, monitors monthly spending. DDS staff review documentation on individual participants and conduct participant satisfaction surveys. Participants may use a toll-free number to report difficulties with the program. Consultants may make unannounced home visits if a quality of care problem is reported, and, if necessary, the state will make referrals to adult protective services. **Reporting requirements**: Consultants document any contact with participants and provide the state with reports of any problems, abuse, neglect, program non-compliance, or other significant occurrences. Consultants provide monthly reports on the number of participants served, hours of training and consulting provided, and any problems or issues. DDS submits annual quality assurance reports to CMS.

[5]As of early 2006, separate organizations provided counseling and fiscal services, but the state was in the process of contracting with a single organization to provide both services throughout the state.

NORTH CAROLINA

Program Name	Community Alternatives Program (CAP) Choice
Lead Agency and Contact(s)	North Carolina Department of Health and Human Services Tracy Colvard: tracy.colvard@ncmail.net
Overview	CAP Choice, a 1915(c) Independence Plus waiver for the elderly and disabled, provides Medicaid eligible elderly and persons with disability an alternative to the state's traditional 1915(c) HCBS waiver program, Community Alternatives Program for Disabled Adults (CAP/DA). CAP Choice participants have the option of receiving an individual budget to purchase of personal care and other supports and may set aside a portion of their budget for nontraditional long term care services and supplies.
Program Goals	The goals of the program are to increase choice and independence in meeting home care needs, to increase satisfaction, to develop a system that supports responsible stewardship of public dollars and provides safeguards for participant's security and well-being, and to reduce unnecessary bureaucratic intervention and expense.
Authority	1915(c) Medicaid Waiver
Implementation Date	January 2005
Funding Sources	Federal: Medicaid State: Medicaid Grants: The state received a 2001 Real Choice Systems Change Grant from CMS for program start-up costs.
Population Eligible	Target population: Elderly and younger adults eligible for traditional benefits under the CAP/DA waiver program Geographic coverage: Two counties -- Cabarrus and Dublin. Statewide expansion may occur by the end of 2006, following an evaluation scheduled for January 2006. Estimated number of eligibles: About 13,600 persons if expanded statewide
Population Enrolled	Enrolled: 6 persons (4 elderly and 2 disabled) as of October 13, 2005 Cap on enrollment: 200 participants in the first year, 400 in the second year, and 600 in the third and final year of the waiver Enrollment is voluntary.
Program Description	CAP Choice is coordinated through local agencies that function as the entry point to the CAP/DA and CAP Choice waiver programs. These agencies provide specialized case managers, called Care Advisors, and oversee fiscal management services. Participants receive a monthly allowance developed from their care plans and work with Care Advisors to develop and revise their spending plans. Participants can use the funds to hire personal assistants and purchase goods or other services that increase their independence.

NORTH CAROLINA

Assessment of Needs	After physician certification that an applicant requires a nursing home level of care, the applicant is advised of available options, including nursing facility and community alternatives. Care Advisors conduct needs assessments for persons choosing community care using the CAP/DA assessment tool. Reassessments occur annually or sooner if needs change.
Benefit Determination	Individual budgets are based on the needs assessment and level of care methodology in place for the CAP/DA waiver and include only the services the participant elects to self-direct. The state discounts the share of the budget used for personal assistance by discounting the maximum hourly rate for such services used in determining the budget. The rationales given for discounting are that evidence from the Cash and Counseling Demonstration indicate that persons using traditional services received 10 to 20 percent fewer hours than authorized in care plans and that overhead charges included in agency rates do not apply for consumer-directed services. The maximum benefit is $2,680 per month for intermediate level of care, $3,487 per month for skilled level of care.
Development of a Spending Plan	Participants work with a Care Advisor to develop a care plan and budget. The care plan describes services and supports, type of provider, family support, and emergency backup. If participants can negotiate a lower rate for services, they may set aside any savings for "consumer-designated" goods and services identified in the care plan.
Services Covered	Participants may direct personal assistant services; in-home respite; home mobility aids, such as ramps or railings; supplies covered as a waiver service; and consumer-designated goods or supplies not otherwise covered by the waiver or the state Medicaid plan, provided they enhance ADL or IADL performance or safety and reduce the need for waiver or plan services. Participants also may use agency-directed in-home aides, home mobility aids, home delivered meals, in-home or institutional respite care, personal alert system, and other supplies covered under the waiver. Home mobility aids and consumer-designated items are limited to $1,500 and $600 per year, respectively.
Benefit Flexibility	Participants receive an annual budget and draw on funds as needed. Excess funds, which may include savings from unexpected absences of personal assistants or supplies purchased at a lower rate or quantity than anticipated, remain in the account for the participant's use until the annual review, when any unspent funds are returned to the state. Although savings are not allowed, participants may have the fiscal agent accumulate funds for approved "consumer-designated" goods and services up to a total of $600 per year.
Participant Choice and Control	Participants can hire their own workers, including spouses. Participants may choose to designate a representative decision-maker. The state may require a representative if it is deemed necessary. A representative may be a family member, a friend, a guardian, or another legally appointed representative and cannot be paid.
Participant Support Services	The Care Advisor assists participants in assessing needs and developing a care plan, budget, and emergency backup plan. The Care Advisor also provides orientation and training on participant-directed care and guidance on recruiting workers. Care advice is provided as a waiver service not included in the individual budget.

NORTH CAROLINA

Fiscal Assistance and Monitoring	**<u>Fiscal assistance</u>**: The participant is the employer of record and is required to use the services of a fiscal agency to handle all employee payroll tasks, including employment taxes and other benefits, account management, and payments to providers. The fiscal agent is an enrolled Medicaid CAP Choice provider. Fiscal services are provided as a waiver service to participants outside the individual budget. **<u>Fiscal monitoring</u>**: Payment for all participant-directed services requires documentation such as a time sheet or invoice, and participants are required to provide receipts for any consumer designated items purchased. The fiscal agency will alert the Care Advisor to any participant overspending. Program consultants conduct annual on-site reviews of fiscal agent services.
Quality Assurance Monitoring	**<u>Responsibilities</u>**: North Carolina's Division of Medical Assistance is accountable for the program administration and daily operations. Quality assurance and monitoring begins at the local level with the recipient, the Care Advisor, and the local lead agency. **<u>Areas monitored</u>**: Plans of care, quality of care advice services, financial management, performance of personal assistants, unmet needs, expenditures, and feedback on overall program operation **<u>Monitoring procedures</u>**: The Care Advisor monitors the plan of care, the provision of care, and expenditures, and maintains contact with participants by telephone on a monthly basis. The Care Advisor also makes quarterly home visits to assure that the needed care is being provided. CAP/DA State Medicaid waiver program consultants oversee the lead agencies and CAP Choice waiver program activities. Program consultants review plans of care retroactively and conduct annual on-site reviews of Care Advisor services. DMA and the local lead agencies work together to develop and administer recipient surveys. Under the program's incident management system, the Care Advisor will address critical incidents involving the plan of care. Problems that are non-plan of care related such as neglect and abuse will be referred to Adult Protective Services for investigation. **<u>Reporting requirements</u>**: DMA CAP Choice Consultants generate a written report to the CAP Choice local lead agency from annual on-site reviews, including corrective actions for any problems that are identified. The state submits a summary report of findings and corrective actions to CMS annually.

OREGON

Program Name	Independent Choices
Lead Agency and Contact(s)	Oregon Department of Human Services, Seniors and People with Disabilities Services Division (SPDS) Susan Stoner: Susan.K.Stoner@state.or.us
Overview	Under Independent Choices, individuals eligible for Medicaid HCBS waiver program services may elect to receive their benefit as either a monthly cash payment or an allowance to be used to purchase personal care and other related long term services and supports.
Program Goals	The goals of the program are to assess the benefits of allowing a select group of Medicaid participants to arrange and purchase their own long term care services and continue the state's tradition of innovation and responsiveness to participants.
Authority	1115 Medicaid Waiver
Implementation Date	November 2001
Funding Sources	Federal: Medicaid State: Medicaid Grants: Initially the state received a $300,000 grant from RWJF for implementation costs including training, technical assistance, and a formal evaluation.
Population Eligible	Target population: Adult Medicaid HCBS recipients who are able to plan for the adequate provision of services either independently or through a representative Geographic coverage: Three pilot areas, two in rural southwest Oregon (Jackson-Josephine Counties and Coos-Curry Counties) and a county just south of Portland (Clackamas County) Estimated number of eligibles: 11,000
Population Enrolled	Enrolled: 300 persons as of November 2005 Cap on enrollment: 300 persons (100 per pilot area) Enrollment is voluntary.
Program Description	Eligible Medicaid HCBS waiver program participants have the choice of receiving a monthly individual budget and managing their own personal care and related services. A case manager assists with the development of a care plan. Participants or a surrogate may receive the budget in cash but must pass a financial skills assessment in order to do so. Otherwise participants are required to use the services of a fiscal agency. Almost all participants choose to take the fiscal skills assessment and manage payments to providers.

OREGON

Assessment of Needs	Eligible participants receive a functional assessment completed by case management staff from SPDS using a standardized assessment tool for all long term care clients in both community and institutional settings. Case managers perform a reassessment every six months.
Benefit Determination	Based on the functional assessment, participants are assigned to one of three categories of need (minimal, substantial, or full) through an automated computer system. Project staff members use the assigned category of need to determine the individual's service hours within the state's maximum authorized hours for ADL and self-management tasks. The monthly budget is calculated by multiplying the number of hours by the service payment rate. For participants managing payments to providers, budgets are increased to include the employer share of FICA and unemployment tax. Benefit amounts range between $900 and $1,200 per month
Development of a Spending Plan	With the assistance of a case manager, participants develop a plan of care that identifies services and number of approved hours of care. Case managers re-evaluate the care plan every six months.
Services Covered	Personal care, homemaker services, chore services, adult companion services, attendant care, in-home services, respite care, transportation, personal emergency response systems, environmental accessibility adaptations, and other goods and services that support the individual's ability to remain as independent as possible
Benefit Flexibility	Cash accumulated in a participant's account may be held as contingency funds, as long as the participant designates the purpose for the funds. Savings may be accumulated to cover approved expenses that do not have another funding source. Savings can remain in the account until enough money has accumulated for the approved purpose. Any unspent funds not designated for approved purposes will be returned to the state at the end of the demonstration. Surrogates acting for the participant may not accumulate funds.
Participant Choice and Control	Participants may hire their own personal attendants, including spouses, and may designate a surrogate decision-maker. A surrogate may be a family member, a friend, a legal guardian or another appointed representative.
Participant Support Services	Participants receive mandatory training on issues such as finding, hiring, and supervising personal care attendants; state and federal tax responsibilities; applicable state law regarding providers; required documentation; development of a budget; and other accountability issues. Case managers help locate a provider, if necessary. The program has developed a network of community resources that provide training and technical assistance services *pro bono* or at reduced cost.

OREGON

Fiscal Assistance and Monitoring	**Fiscal assistance**: Participants or their surrogates may choose to use a fiscal agency to perform payroll functions or conduct these tasks on their own. Participants or surrogates must complete a ten-hour training session and pass an exam to be eligible to conduct payroll tasks. Currently, all participants in the program conduct these tasks. Cash payments are made prospectively as a monthly electronic deposit to the participant's Independent Choices checking account. Participants or surrogates pay providers directly and have the responsibility for employment tax deductions and remitting taxes to the state and federal government. **Fiscal monitoring**: Participants or surrogates must use a separate checking account for deposit of the Independent Choices service payment and for all associated provider and contingency fund payments. The state conducts random audits of these accounts to ensure compliance with the terms and conditions of the demonstration. Bank account statements are sent to Audit Unit staff for review on a monthly basis. Participants who become overdrawn must attend budget management training.
Quality Assurance Monitoring	**Responsibilities**: SPDS has program management, oversight, and monitoring responsibilities. **Areas monitored**: Participant compliance with fiscal and legal responsibilities; health and safety; complaints of non-payment; participant and provider satisfaction **Monitoring procedures**: Program staff members are responsible for monitoring the health and safety of participants. Case managers contact participants at least once every two months during the first year of enrollment and conduct semi-annual reassessments. Participants and providers are surveyed at enrollment, and then quarterly to determine satisfaction and identify potential or actual problems. If problems are identified, a corrective action plan is instituted. Any complaints of self-neglect or abuse are referred to the local office Protective Services unit. Substantiated complaints result in project disenrollment. Participants have the right to the same grievance and appeals procedures as any participant in a SPDS program. **Reporting requirements**: SPDS submits annual quality assurance reports to CMS.

SOUTH CAROLINA

Program Name	South Carolina Choice (SC Choice)
Lead Agency and Contact(s)	South Carolina Department of Health and Human Services, Bureau of Long Term Care Services Roy Smith: smithroy@dhhs.state.sc.us
Overview	SC Choice, a 1915(c) Independence Plus waiver for the elderly and disabled, provides an alternative to the state's traditional HCBS waiver program for Aged and Disabled. Participants choosing SC Choice receive an individual budget with which they can hire and manage their own direct care workers, and purchase supplies and equipment.
Program Goals	The goals of the program are to increase participants' control, empowerment, independence, satisfaction and quality of life; to provide greater flexibility in service delivery by making available a broad range of service options and services tailored to the participant's needs and preferences; and to reduce administrative expense and bureaucracy.
Authority	1915(c) Medicaid HCBS Waiver
Implementation Date	July 2003
Funding Sources	Federal: Medicaid State: Medicaid Grants: In 2001, the state received a Real Choice Systems Change grant from CMS to develop support coordination, fiscal intermediaries, and use of cash equivalencies.
Population Eligible	Target population: Medicaid recipients enrolled in the state's 1915(c) HCBS Aged and Disabled waiver and able to self-direct their waiver services, and all new Medicaid HCBS waiver applicants meeting a home level of care and choosing community placement Geographic coverage: All but six counties, but scheduled to expand statewide by the end of January 2006 Estimated number of eligibles: 11,000 in the two waivers statewide
Population Enrolled	Enrolled: 184 persons as of October 2005 Cap on enrollment: 300 persons in the first year, 600 in the second year, and 900 in the third and final year Enrollment is voluntary.
Program Description	SC Choice participants work with a 6-month budget allowance to hire their own workers and purchase other long term care goods and services. Participants receive training and assistance in developing their care plans from a Care Advisor. The state contracts with a fiscal agency to manage program finances.

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Assessment of Needs	Registered nurses conduct an assessment to assure participants meet the established level of care for nursing home placement required for waiver eligibility, using a standardized assessment instrument. Reassessments occur at least every 12 months.
Benefit Determination	The benefit amount for participants transferring from the Aged and Disabled waiver is based upon the value of their authorized waiver services. For new applicants to SC Choice, the benefit amount is based upon the hypothetical services they would have received in the Aged and Disabled waiver. The state is in the process of implementing a 10 percent discount to the SC Choice benefit based on empirical data indicating that persons receiving traditional waiver services typically receive only 80 to 90 percent of their allocated services. The average benefit is about $4,700 per six-months.
Development of a Spending Plan	Care Advisors consult with participants to assess needs, identify self-directed and other solutions to identified needs, and establish a spending plan and an emergency backup plan.
Services Covered	Participants may self-direct personal assistance, respite services, environmental accessibility adaptations, appliances, and specialized medical equipment or supplies and may also use agency-directed respite services, environmental accessibility adaptations and appliances, personal care (two payment levels, defined as predominantly ADL assistance under supervision of a registered nurse and predominantly IADL assistance), adult day health, personal emergency response systems, adult day health care nursing, and home delivered meals.
Benefit Flexibility	Participants have access to a six-month budget which provides some flexibility in allocating spending for services and purchases over time. Carryover of unspent funds to the next six month budget period is not allowed, except in an emergency. The participant has flexibility to allocate budget funds between services and goods, so long as purchases are authorized in the plan of care and spending plan.
Participant Choice and Control	Participants may hire their own workers, but cannot hire a legally responsible relative or guardian. Participants have the option of appointing a representative decision-maker. The state may require a representative if it determines one is needed. A representative may be a family member, a friend, a legal guardian or another legally appointed representative, but the same individual may not serve as both representative and paid worker.
Participant Support Services	Care Advisors conduct needs assessments and reassessments, assist participants with developing spending plans, provide program education, and training, and monitor the budget for over- or under-spending. Care advisor services are provided as a waiver service outside the individual budget.

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Fiscal Assistance and Monitoring	**Fiscal assistance**: The participant or designated representative is the employer of record. Fiscal assistance and monitoring is provided by Financial Management Services (FMS), a state contractor, which pays providers, prepares accounting and expenditure reports, and performs employer responsibilities, such as withholding and payroll taxes. Participants pay a $15 monthly fee for fiscal agency services based on an average monthly user cost. **Fiscal monitoring**: The state's Care Call system, set up by FMS for the traditional waiver program, electronically documents provider work hours, amounts spent, and amounts remaining in the participant's budget. FMS assists Care Advisors in monitoring service provision. Participants, Care Advisors, and the state can access real-time participant accounts and print out web-based reports, and monthly reports are provided to Care Advisors and participants. Performance standards are incorporated in the state's contract with FMS.
Quality Assurance Monitoring	**Responsibilities**: South Carolina's Department of Health and Human Services is responsible for administering the SC Choice waiver and monitors the fiscal and counseling agencies, while the Care Advisor monitors individual participants to ensure program quality. **Areas monitored**: Participant health and welfare, plan of care, budget underutilization or overutilization, care advisor and financial management services, and quality of services **Monitoring procedures**: The Care Advisor monitors the participant spending plan and the quality of self-directed care by conducting monthly visits with participants. The Care Advisor monitors whether the participant had to utilize his/her emergency backup plan and how often. The Area Administrator supervises the work of the Care Advisor and reviews incident data monthly to identify patterns or problems and make recommendations for changes. The Long Term Care Ombudsman or the Department of Social Services Adult Protective Services Program investigates complaints and critical incidents with findings forwarded to the Area Administrator for review and necessary action. As part of a Real Choice grant, the University of SC School of Public Health is conducting an evaluation of the waiver program. Quarterly results are reviewed by program staff members and used to implement program improvements. **Reporting requirements**: The state is responsible for annual reports to CMS on its monitoring of recipient health and welfare and improvements in waiver program operations.

WISCONSIN

Program Name	Family Care - Self Directed Supports (SDS)
Lead Agency and Contact(s)	Department of Health and Family Services Ann Sievart: sieveal@dhfs.state.wi.us
Overview	Wisconsin's Family Care, a managed care program for long term care services, including both nursing home and home care, is administered by Care Management Organizations (CMOs) in five counties and includes a Self Directed Supports (SDS) option. SDS participants work with the CMO to develop a care plan and may choose to receive an individual budget and self-direct all or part of their long term care supports.
Program Goals	The goals of the Family Care program are to give people better choices about the long term care services and supports available to meet their needs, to improve access to services, to improve the overall quality of the long term care system by focusing on achieving individual health and social outcomes, and to create a cost-effective long term care system. The SDS option is designed to allow enrollees more control over services and supports.
Authority	1915(b)/(c) Medicaid waiver
Implementation Date	Family Care began enrolling participants in February 2000. The 1915(b)/(c) implementation date was January 2002. CMOs were to phase in SDS in their first three contract years – starting with home care and personal care.
Funding Sources	Federal: Medicaid State: Medicaid Grants: None
Population Eligible	Target population: Medicaid recipients enrolled in five Family Care CMOs serving elders and people with developmental or physical disabilities who have long term care needs Geographic coverage: Five pilot counties (Milwaukee, LaCrosse, Fond du Lac, Richland, and Portage) Estimated number of eligibles: 9,725 persons (7,448 elderly) enrolled in Family Care at the end of March 2006
Population Enrolled	Enrolled: Approximately 23 percent of Family Care enrollees self-direct at least one service. Cap on enrollment: None Enrollment is voluntary.
Program Description	The CMO develops an individual budget for participants choosing SDS and establishes an account from which they can draw to pay for self-directed goods and services identified in their service plans. Participants may choose to be the employer of record or to use an agency with choice model in which a co-employment agency is the employer of record and the participant is the managing employer. Participants choosing co-employment have access to a wider range of self-direction support services. Persons choosing to be the employer of record must hire a fiscal agency to handle payroll functions. Nearly all participants to date have chosen the agency with choice model.

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Assessment of Needs	Eligible individuals are assessed by staff of Aging and Disability Resource Centers, which serve as a single point of entry for long term care services. The State's Long-Term Care Functional Screen is used to determine eligibility for home and community-based waivers for adults in Family Care pilot counties and other adult long term care services. Trained registered nurses or social workers administer the screen. A more comprehensive person-centered assessment is completed after a person enrolls in a CMO as part of the care planning process.
Benefit Determination	The individual budget is based on a plan of care for what the CMO would provide if the person had not chosen SDS using the CMO's estimate of number of units times the unit rate paid. The average benefit amount is about $700 per month.
Development of a Spending Plan	Participants work with a CMO interdisciplinary case management team to develop a care plan. The plan includes participant's preferences and desired outcomes that are then translated into a service plan. Participants may choose to self-direct all or only part of their services and are encouraged to include backup provisions in their plans. Once budget authority is established, the participant develops the spending plan for the use of their budget.
Services Covered	An SDS participant's budget may include most community services in the Family Care benefit package, including traditional waiver services, such as home modifications, supportive home care, and transportation, and additional services and supports that will meet the participant's personal outcomes as defined in the service plan, even if the service or provider is not part of the CMO's benefit package. Case management is provided outside the budget.
Benefit Flexibility	Budget allocation varies by CMO, with some CMOs budgeting annually and others monthly. Participants may save from their budget for purchases, and savings can be carried over from one year to the next.
Participant Choice and Control	Participants are responsible for hiring, training, and supervising their workers. Participants may choose to hire a friend or family member, but cannot hire a spouse or legal guardian. Participants determined by the CMO to be incapacitated or otherwise unable to be involved in the planning process must have a guardian or health care agent with power of attorney as a representative decision maker.
Participant Support Services	The counseling function is provided by the case management team. Participants using the co-employment option have access to additional services such as emergency backup assistance, management training, worker registries, and criminal background checks in addition to payroll functions. Participants who choose to be the employer of record do not have access to these services but must use a fiscal agent for payroll functions.

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Fiscal Assistance and Monitoring	**Fiscal assistance**: SDS participants choosing the co-employment option act as the managing employer and work with an agency that serves as the employer of record with responsibility for hiring workers, payroll, tax withholding, and providing other fiscal support services to participants. SDS participants who choose to be the employer of record must use a fiscal agency to ensure payment of workers and tax compliance. Fiscal agencies provide only payroll services **Fiscal monitoring**: The CMO monitors co-employment agency and fiscal agencies. The CMO must implement monitoring systems to evaluate the quality of services provided by these subcontracted providers.
Quality Assurance Monitoring	**Responsibilities**: The CMO has primary responsibility for quality assurance and monitoring of program participants, and the state in turn monitors CMO performance. **Areas monitored**: CMOs monitor SDS planning, individual budget and spending plans, use of the cash payment, and contracted vendors. The state monitors CMOs for quality of services and supports, adequacy of their support network, arrangements for 24-hour service availability, subcontracted providers, and health, safety, and welfare of participants. **Monitoring procedures**: The CMO must implement monitoring systems to evaluate the quality of services provided by subcontracted providers, member complaint procedures, and internal quality improvement programs. Monitoring activities on the individual member level include CMO member and family interviews, surveys, and individual service plan reviews. The state's monitoring activities include annual site reviews and CMO performance reports. Family Care contracts with an external quality review organization to conduct annual participant outcome interviews. **Reporting requirements**: CMO summary reports are submitted to the department's Quality Oversight Committee at the end of each quarter. The state submits annual reports to CMS on its monitoring of recipient health and welfare and impacts of the waiver on the type, amount, and cost of services provided.

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