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Beyond Cash and Counseling:

An Inventory of Individual Budget-based Community Long Term Care Programs for the Elderly

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OVERVIEW

In recent years, several initiatives in publicly financed services for older persons with disabilities have focused on supporting community residence through greater beneficiary control and flexibility in choosing the services and supports that best meet their needs. This movement has gained strength from state efforts to control rising Medicaid long term care costs by "rebalancing" public long term care spending from institutional care to community-based alternatives. State innovations in Medicaid-financed community based long term care have tended to move programs along a continuum from the traditional set of Medicaid service benefits toward the ultimate flexibility that may be achieved with a beneficiary-managed individual budget that participants use for a preferred menu of services and supports.

The beneficiary-managed individual budget model had its origins in the Cash and Counseling Demonstration. This brief describes the evolution of the model since the original demonstration and provides an overview of state activity as of January 2006 in developing individual budget model programs for elderly beneficiaries. Although Medicaid waivers have been required for individual budget model programs to date, the Deficit Reduction Act that was signed on February 8, 2006, gives states the option to use this model for an expanded range of home and community based services in their state Medicaid plans without having to obtain a waiver.

Findings:

- **Nearly half the states (22) have or are actively planning programs for the frail elderly using the individual budget model.** Ten states have active programs or pilot programs. Of these ten, Arkansas, Florida, and New Jersey are the three original Cash and Counseling demonstration states. Twelve states have individual budget programs in various stages of development, 11 of which are recognized as having program designs consistent with Cash and Counseling.
- **Fourteen states and the District of Columbia have or are planning programs with some degree of participant direction that include the elderly, although these programs are generally limited to personal assistance services and only in some cases include a budget for even those services.** For example, Delaware, Georgia, Ohio, Oklahoma, and Texas allow a beneficiary budget or allowance, but the budget authority applies only to personal care services. Maine, New Hampshire, New York, Nebraska, Kansas, and Virginia allow elderly participants to hire their workers and use a fiscal agent to handle payments, but there is no individual budget.
- **Thirteen states have active programs or are planning programs that incorporate some degree of participant direction but do not include the frail elderly.** Some of these states have programs that allow individual budgets for other populations, most often only for personal care services. Two states, Connecticut and Louisiana, expressed the intent to extend existing individual budget programs for their MR/DD population to include the elderly.

INTRODUCTION

In recent years, several initiatives in publicly financed services for older persons with disabilities have focused on supporting community residence through greater beneficiary control and flexibility in choosing the services and supports that best meet their needs. The initial movement toward greater beneficiary input and more community-based options for long term disability care grew out of advocacy, particularly from younger persons with disabilities. It has gained strength from state efforts to control rising Medicaid long term care costs by "rebalancing" public long term care spending from expensive institutional care to community-based alternatives. State innovations in Medicaid-financed community based long term care have tended to move programs along a continuum from the traditional set of Medicaid service benefits toward the ultimate flexibility that may be achieved with a beneficiary-managed individual budget that participants use for a preferred menu of services and supports.

In this brief, we discuss the background for the most flexible service delivery model and examine the extent to which states are adopting it for their older Medicaid long term care beneficiaries. The model has its origins in the Cash and Counseling Demonstration. Initiated as a demonstration jointly sponsored by the Robert Wood Johnson Foundation (RWJF) and the Department of Health and Human Services in the late 1990s, Cash and Counseling continues with a new round of RWJF grants awarded in 2004 for design and implementation of new or expanded state programs.[1]

In the wake of generally positive evaluation results from the Demonstration (Foster et al. 2003, Dale et al. 2003), Real Choice Systems Change planning grants offered by the Centers for Medicare and Medicaid Services (CMS) beginning in 2001 have provided incentives for states to design and implement new models of community-based long term care, frequently in ways that enhance participant choice. Under the New Freedom Initiative the Bush administration has continued the trend toward expanding such opportunities, in particular through the Independence Plus Medicaid waiver initiative first announced in May of 2002. The Independence Plus initiative seeks to encourage states to introduce a range of participant-directed options into their community-based long term care programs and specifically to implement programs following the individual budget model.

The Independence Plus initiative is intended to give states tools and incentives to adopt some or all of the features of this model through streamlined waiver application processes, which have continued to evolve based on CMS and state experience since the initiative's inception. In late 2005, CMS released a revised 1915(c) Home and Community Based Waiver application with the dual aims of making it easier for states to incorporate some elements of participant direction in their programs and providing specific guidance on how states may use the 1915(c) waiver mechanism to accomplish a service delivery model consistent with the tenets of Cash and Counseling (CMS 2005a, 2005b). Moreover, the Deficit Reduction Act of 2005 provides the option for states to use this model for an expanded range of home and community based services in their state Medicaid plan without having to obtain a waiver.

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[1] Arkansas, Florida, and New Jersey were the original three Cash and Counseling Demonstration States. Eleven additional states, Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia have received RWJF grants to develop their programs, and Illinois has adopted the RWJF model with grant funding from the Retirement Research Foundation.

With these indications of growing state interest in using the individual budget model for elderly Medicaid beneficiaries and CMS commitment to helping them do so, we have undertaken to identify all states operating or planning such programs for older persons. The catalog of state activity we have compiled will serve as a foundation for subsequent research into particular aspects of this model that bear watching as more states gain experience with it.

The specific features we looked for in identifying programs adopting the model are the following:

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

- Beneficiary participation in planning and discretion to shift budget dollars between types of supports—especially between types of personal assistance and between personal assistance and other disability-related goods or services;

- Independent professional support to assist in developing a flexible care 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 tax withholding for workers.

To compile an inventory of state programs with these features available to the frail elderly, we examined activities relating to community-based service options in all 50 states and the District of Columbia. We first reviewed the literature on participant-directed options in Medicaid state plan and waiver programs in published and on-line sources. We then contacted state officials and key program staff and asked that they verify the program information we had collected, supply information we had not been able to find, and provide comments. We also contacted officials and program staff in states for which we had not been able to identify a program using an individual budget model to ascertain whether the state had an active or planned program including the elderly population or another group (i.e., disabled adults or children, or mentally retarded or developmentally disabled individuals) and whether these active or planned programs met criteria for an individual budget program. As of January 24, 2006, we had received written or verbal comments on program descriptions from 22 states and had spoken with officials or staff in the remaining 28 states and the District of Columbia.

In our conversations with state officials and others, we found that the Cash and Counseling label, and particularly the word "cash," was not universally embraced by states using or considering similar service delivery options. In fact, only one state offers an explicit option for new beneficiaries to receive their allowance in cash. States with operating programs, including the original Demonstration states, found that almost all beneficiaries preferred to have an allowance managed by a fiscal agent rather than receiving cash and having the responsibilities, such as payroll functions and record keeping, associated with it. Some state officials also indicated that the idea of cash benefits was politically unpalatable. We have

therefore adopted the generic language "individual budget" model to differentiate this model from other traditional and "participant-directed" service options.

In this brief, we present an overview of our findings on state activity as of January 2006 in developing programs for elderly beneficiaries based on the individual budget model—which states have implemented a service delivery option for elderly beneficiaries in the spirit of the Cash and Counseling model, which are planning one, and which are not.

BACKGROUND

For many years states have been introducing aspects of participant direction into their Medicaid long term care benefits (Tritz 2005, Crowley 2003, Tilly and Wiener 2001). Although much of the impetus has come from younger persons with disabilities, participant-directed programs are increasingly being implemented for the low-income frail elderly as well. Participant direction encompasses features as modest as increased beneficiary involvement in the care planning process but also frequently includes allowing beneficiaries to choose, hire, and supervise their own workers, including family or friends.

The innovative feature of the individual budget model is the conversion of traditional Medicaid long term care benefits into a dollar value to establish a beneficiary-managed individual budget that may be used for a broad range of supports. Beneficiaries may then develop a spending plan, with the help of counselors. Depending on state design choices and the Medicaid waiver authority under which an individual budget program is implemented, counselors may have the authority to approve less conventional disability-related spending, which allows beneficiaries to use the budget to purchase the array of services and supports they believe best meets their needs.

In contrast to the traditional model in which personal assistance workers are provided and supervised by state-approved agencies that employ them, participants in individual budget model programs typically have the option to hire nontraditional providers, including (at state option) relatives or friends. From both the beneficiary and program perspective, this option has the potential to increase the supply and reliability of long-term care workers. A key feature of the budget model is the further flexibility the participant has to choose how the budget is allocated between personal care and other supports for community living. The rationale for the individual budget model is that it has the potential to 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 beneficiaries may be wiser buyers than the state and get "more" for the same level of state spending if they have the flexibility to tailor the service mix to their needs.

The responsibilities associated with a participant-directed individual budget may not be appropriate for all persons, and, although we found that a majority of states offer older beneficiaries some degree of consumer direction, concerns remain in some states about how well participant direction suits an older population. There is evidence that, historically, a smaller proportion of older persons than younger persons with disability has been interested in participant direction (AARP 2003, Tilly and Wiener 2001) and that government officials and key stakeholders often question the capacity of older persons to direct their care (Tilly and Wiener 2001). On the other hand, studies of older persons in participant-directed programs have found

evidence of increased levels of participant satisfaction from having more choice and control over their care, improved quality of life, and increased satisfaction with care related to hiring a family member as a worker (Doty et al. 1999, Foster et al. 2003, Benjamin 1998, Mathematica 2000). Assistance with hiring, training, and supervising workers as well as managing the financial responsibilities associated with paying a worker have been found to be key program elements in elderly participants' continued involvement. In Arkansas' Cash and Counseling program, a larger proportion of older than younger enrollees who voluntarily disenrolled reported problems with handling either management of workers or fiscal responsibilities (Schore and Phillips 2004).

In 2002, the CMS provided states with tailored Independence Plus application templates for the two waiver mechanisms through which states can implement an individual budget model (CMS 2002): Section 1115 Research and Demonstration waivers and 1915(c) Home and Community-based Services waivers for persons requiring a nursing home level of care.

Waivers authorized under Section 1115 of the Social Security Act provide the greatest flexibility in program design and were used in the original Cash and Counseling Demonstrations. These waivers generally are considered to be a research platform for testing innovations or issues of interest to CMS. They are initially limited to five years in duration, but states may apply for renewal for subsequent three-year periods. States wishing to combine different disability populations, include individuals who do not meet functional requirements for institutional care, or provide a cash allowance directly to beneficiaries must use Section 1115 waivers (CMS 2005c). Section 1115 waivers also are required if states wish to make budget resources available other than as reimbursement. Such "advance pay" authority is necessary if states want to include program features such as discretionary allowances for allowed incidental expenses or "saving" from the budget for larger purchases. States implementing broader health care reform also have included participant directed options within Section 1115 waiver applications.

Waivers under Section 1915(c) of the Social Security Act are applicable only to programs for persons eligible to receive Medicaid-financed nursing home care under the state's criteria. For the purposes of implementing individual budget model programs, requirements of 1915(c) waivers tend to be more restrictive. Section 1115 waivers require much less specification of services included and allow states to waive both comparability of services with those available to other Medicaid beneficiaries (which also may be waived in a 1915(c) program) and the requirement that each provider execute a provider agreement with the state. Under 1915(c) waivers, states must specify all services that will be subject to participant direction, define provider qualifications, and execute provider agreements with each individual provider. The more restrictive requirements of 1915(c) waivers have in some cases resulted in less flexibility than envisioned in the Cash and Counseling prototype, and at least two states currently are in the process of amending their 1915(c) waivers to incorporate additional features. The new 1915(c) application and guidance issued by CMS in late 2005 is intended to address some of the difficulties states have encountered to date, for example, by permitting states to execute provider agreements with a provider agency that assumes responsibility for individual provider qualifications and for making payments.

The two waiver types also differ with respect to the restrictions imposed on program spending. Section 1115 waiver programs must be "budget neutral," which is defined as costing the federal government no more than it would spend for services without the waiver. Under 1915(c) waivers, states must demonstrate "cost neutrality," which requires that federal spending

for community-based care not exceed what federal spending would have been had waiver participants instead received institutional care.

Both waivers allow states to grant "budget authority" to participants so they can manage their individual budgets, including the ability to authorize spending and to move resources between services or items contained in their plan of care. Participants may also have "employer authority" in 1115 and 1915(c) waivers, which allows them the opportunity to recruit, hire, train, and direct workers, including legally responsible and other relatives, at state option. Individual budget model programs designed under either waiver authority must provide for assistance with managing services and with the financial responsibilities associated with the model (CMS 2005d). States also may accomplish individual budget model programs through a combined 1915(b)/(c) waiver. This type of waiver allows states to design managed care waiver programs under Section 1915(b) that include 1915(c) long term care services and may incorporate an individual budget model.

OVERVIEW OF STATE PROGRAMS

Our results confirm the high level of state interest specifically in the individual budget model for older beneficiaries, but also more generally in offering older beneficiaries and others access to some participant-directed features. Nearly half the states have or are actively planning programs for the frail elderly using the individual budget model, and all but one state reported at least one program with some elements of participant direction for some groups of beneficiaries.

We summarize state activity relating to individual budget models in Table 1 and provide more detailed descriptions in the Appendix. The first section of Table 1 lists states that have an active individual budget program that includes elderly beneficiaries; the second lists states in the process of developing a program using this model; the third lists states with programs that offer elderly beneficiaries some degree of participant direction short of an individual budget model; and the fourth section lists state programs that include individual budget models or other participant-directed elements but for groups of beneficiaries other than the elderly.

Table 1. Summary of State Activity Relating to Individual Budget Models of Long Term Care for the Elderly, as of January 2006		
State	**Program Name**	**CMS Waiver Authority**
Active Individual Budget Programs Including the Elderly		
ORIGINAL CASH AND COUNSELING DEMONSTRATION STATES		
Arkansas	IndependentChoices	1115
Florida	Consumer-Directed Care Plus (CDC+)	1115
New Jersey	Personal Preference	1115
OTHER STATES		
Colorado	Consumer-Directed Attendant Support (CDAS)	1115
Minnesota	Consumer Directed Community Supports (CDCS)	1915(c)
North Carolina	Community Alternatives Program (CAP) Choice	1915(c)
Oregon	Independent Choices	1115
South Carolina	SC Choice	1915(c)
Wisconsin	Wisconsin Family Care - Self Directed Supports (SDS)	1915(b)/(c)
Massachusetts	Real Choice Pilot Project	--[1]
Planned Individual Budget Programs Including the Elderly		
Alabama	Alabama's Cash and Counseling Program	1115
Illinois	My Choices	1915(c)
Iowa	Developing Choices - Empowering Iowans	1915(c)
Kentucky	Consumer Directed Option	1915(c)
Michigan	Self-Determination in Long-Term Care	1915(c)
Montana	Big Sky Bonanza	1915(c)
New Mexico	Mi Via (My Way)	1915(c)
Pennsylvania	Cash and Counseling Program	1915(c)
Rhode Island	Personal Choice	1915(c)
Vermont	Cash and Counseling Pilot Program	1115
Washington	New Freedom Participant Directed Services	1915(c)
West Virginia	Personal Options	1915(c)
Other Active or Planned Programs with Participant-directed Features Including the Elderly		
Alaska	(Planning stage)	--[1]
California	In-Home Supportive Services Plus (IHSS+)	1115
Delaware	Independence Plus Attendant Services Waiver Program	1915(c)
District of Columbia	(Planning stage)	--[1]
Georgia	Community Care Services Program	1915(c)
Indiana	(Planning stage)	--[1]
Kansas	Frail and Elderly Waiver Program and Physical Disabilities Waiver Program	1915(c)
Maine	MaineCare, Consumer-Directed Personal Assistance Services (CD-PAS) Waiver Program, and Home Based Care Program	Medicaid State Plan, 1915(c), and State funded
Nebraska	(Planning stage)	Medicaid State Plan
New Hampshire	Home and Community-Based Care for the Elderly and Chronically ill (HCBC-ECI) Program	1915(c)
New York	Consumer Directed Personal Assistance Program (CDPAP)	Medicaid State Plan
Ohio	Choices	1915(c)
Oklahoma	ADvantage	1915(c)
Texas	Consumer Directed Services (CDS)	1915(c)
Virginia	Consumer Directed Personal Assistance Services (CDPAS)	1915(c)
Other Active or Planned Programs not Including the Elderly		
Arizona	Human Services Cooperative of Northern Arizona	1115
Connecticut	Individual and Family Supports Waiver Program	1915(c)
Hawaii	MR/DD Waiver Program	1915(c)
Idaho	DD Waiver Program	1915(c)
Louisiana	New Opportunities Waiver (NOW) Program	1915(c)
Maryland	New Directions	1915(c)/ 1115
Missouri	MR/DD Waiver Program	1915(c)
Nevada	(Planning stage)	1915(c)
North Dakota	Independence Plus Waiver Program	1915(c)
South Dakota	MR/DD Waiver Program	1915(c)
Tennessee	Self-Determination Waiver Program	1915(c)
Utah	MR/DD, ABI, and Individuals with Physical Disabilities Waiver Programs	1915(c)
Wyoming	Wyoming's Individual Budget Amounts/ DOORS model	1915(c)
No Individual Budget Programs or Initiatives Identified		
Mississippi	The state does not have a named active or planned program	--[1]

[1] Not applicable to the state's current situation.

Key to acronyms: CMS = Centers for Medicare and Medicaid Services; DD = Developmentally Disabled; MR = Mental Retardation

Active or Planned Individual Budget Programs for the Frail Elderly

Twenty-two states had an active or planned program meeting the individual budget model criteria and including the elderly. Ten states have active programs or pilot programs. Of these ten, Arkansas, Florida, and New Jersey are the three original Cash and Counseling demonstration states, and all used Section 1115 waiver authority. Colorado and Oregon, the latter of which is the only state to allow participants to receive a cash benefit, also used Section 1115 waiver authority. Minnesota, one of the states receiving funding in the 2004 round of RWJF Cash and Counseling grants; North Carolina; and South Carolina, all used new 1915(c) waivers or amended existing ones. Massachusetts is operating a pilot program, supported by a Real Choice grant received in 2001, and plans to implement a statewide program. The state has not yet decided whether it will modify an existing 1915(c) waiver or seek a new waiver. Wisconsin is unique in having implemented its program under a combination 1915(b)/1915(c) managed care waiver including both institutional and community-based long term care.

Of the 12 states with individual budget programs in various stages of development, 11 are recognized by RWJF as having program designs consistent with Cash and Counseling. Montana is the only one of the 12 states not officially considered an RWJF "Cash and Counseling" state. Most are using or intend to use 1915(c) waiver authority. Rhode Island and Montana submitted 1915(c) waiver applications in September and October of 2005, respectively, and are awaiting CMS approval. Six states (Iowa, Illinois, Michigan, New Mexico, Pennsylvania, and Washington) are drafting new or amended 1915(c) waiver applications. Vermont has received CMS approval of an 1115 waiver and expects to implement its program in winter 2006. Alabama has delayed submission of a Section 1115 waiver because of difficulty demonstrating budget neutrality and is working with CMS to resolve the issue. Two RWJF grantee states, Kentucky and West Virginia, originally submitted 1915(c) waiver applications with the intention of implementing programs consistent with the Cash and Counseling model, but in the approved waivers budget authority was limited to in-home services. Both states plan to expand budget authority so that participants may purchase other goods and items that will enhance independence in the home. To accomplish this, Kentucky is drafting a new waiver using Section 1115 authority, and West Virginia plans to amend its 1915(c) waiver.

Other Programs and Activities Relating to Participant Direction

Another 14 states and the District of Columbia have or are planning programs with some degree of participant direction that include the elderly but which generally are limited to personal assistance services and only in some cases include a budget for even those services. Delaware, Georgia, Ohio, Oklahoma, and Texas allow a beneficiary budget or allowance, but the budget authority applies only to personal care services. Maine, New Hampshire, New York, Nebraska, Kansas, and Virginia allow elderly participants to hire their workers and use a fiscal agent to handle payments, but there is no individual budget. Indiana also allows elderly participants to direct personal assistance services and is developing a financial management system under a grant from CMS, which it may add as a service under its 1915(c) waiver. The District of Columbia is using a CMS grant to develop a pilot program with a participant-directed budget for personal care services with the intent of introducing this feature into its 1915(c) waiver program for the elderly and disabled. California, which brought most of an existing participant-directed personal attendant program into its Medicaid program in 1993, received a Section 1115

Independence Plus waiver to bring additional persons from the state's In-Home Supportive Services (IHSS) Residual Program into its Medicaid program. California's program is one of the largest and oldest personal care programs allowing participant direction, but there is no individualized budget, participant direction is limited to personal care services, and advance payments are allowed only under limited special circumstances.

Two states that had planned to implement individual budget-type programs have changed course. Alaska had planned to apply for an Independence Plus waiver, but high program costs associated with the introduction of a participant direction option for personal care benefits under the state Medicaid plan led state officials to look at different ways to expand participant direction, such as amending current waiver programs. Alaska has contracted with a research organization to study the state's long-term care rate-setting structures and service delivery systems and to suggest improvements. Mississippi submitted a Cash and Counseling grant application to RWJF in 2004, but the grant was not approved. The state reports that it currently has no plans to pursue the matter further.

The remaining 13 states have active programs or are planning programs that incorporate some degree of participant direction but do not include the frail elderly. Some of these states have programs that allow individual budgets for other populations, most often only for personal care services. Two states expressed the intent to extend existing individual budget programs to include the elderly. Louisiana has an individual budget program for its mentally retarded or developmentally disabled (MR/DD) population as a first step, and state officials indicated that they intend to expand these initiatives to other waiver programs that include the elderly and physically disabled. Similarly, Connecticut has an Independence Plus waiver for its MR/DD population and is considering implementing a similar waiver program for the elderly. Maryland has received a 1915(c) Independence Plus waiver for the developmentally disabled and recently submitted an 1115 waiver application for a managed long-term care program that might include an individual budget component, but the specifics have yet to be determined.

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APPENDIX

APPENDIX: Overview of State Activity Relating to Individual Budget Models of Long Term Care for the Elderly			
State	**Program Name**	**CMS Waiver Authority**	**Status (as of January 2006)**
Active Individual Budget Programs Including the Elderly			
ORIGINAL CASH AND COUNSELING DEMONSTRATION STATES			
Arkansas	IndependentChoices	1115	Arkansas implemented its IndependentChoices program in December 1998. In 2002, CMS approved an extension of the 1115 waiver demonstration thru 2006 and an amendment to continue the program without the random assignment required for the original experimental design.
Florida	Consumer-Directed Care Plus (CDC+)	1115	Florida implemented its CDC program in 2000. In 2003, CMS approved a five-year extension of the 1115 waiver demonstration to expand the program statewide and an amendment to eliminate the requirement for random assignment. The expanded program is called CDC+.
New Jersey	Personal Preference	1115	New Jersey implemented its Personal Preference program in November 1999. In 2004, CMS approved an extension of the 1115 waiver demonstration thru 2008. The state also received approval to amend its 1115 waiver to continue the program without the random assignment required for the original experimental design.
OTHER STATES			
Colorado	Consumer-Directed Attendant Support (CDAS)	1115	Colorado has a Section 1115 waiver from CMS to implement CDAS, a five-year demonstration project that offers eligible participants the option of an individual budget. The program was implemented in December 2002.
Minnesota	Consumer Directed Community Supports (CDCS)	1915(c)	Minnesota received an RWJF grant to implement a Cash and Counseling model. The state amended five of its 1915(c) HCBS waiver programs to include participant direction. The program was implemented statewide in April 2005.
North Carolina	Community Alternatives Program (CAP) Choice	1915(c)	North Carolina implemented CAP Choice, a 1915(c) Independence Plus waiver program, on January 1, 2005. The program is operating in two pilot counties and will be evaluated in January 2006 for statewide expansion in 2006.
Oregon	Independent Choices	1115	Oregon secured a Section 1115 waiver from CMS to implement Independent Choices, a five-year demonstration program implemented in November 2001.

APPENDIX

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Active Individual Budget Programs Including the Elderly (continued)			
South Carolina	SC Choice	1915(c)	South Carolina implemented SC Choice, a 1915(c) Independence Plus waiver program, on July 1, 2003. SC Choice is available in all but six counties statewide. Participants in the state's 1915(c) Elderly and Disabled waiver are eligible.
Wisconsin	Wisconsin Family Care - Self Directed Supports (SDS)	1915(b)/(c)	Wisconsin's Family Care program, a managed care model for delivering Medicaid long-term care services operating in five counties across the state, offers optional participant-directed services that include an individual budget, called SDS. The program was implemented in February 2000 with participant direction phased in over the first three years.
Massachusetts	Real Choice Pilot Project	--[1]	Massachusetts is operating a small pilot program funded through a 2001 Real Choice Grant and based on a Cash and Counseling model. The program was implemented in summer/fall 2005. The state is working toward developing the infrastructure required for larger implementation through the modification of existing 1915(c) HCBS waiver programs and/or the creation of a new waiver program.
Planned Individual Budget Programs Including the Elderly			
Alabama	Alabama's Cash and Counseling Program	1115	Alabama received an RWJF grant to implement a Cash and Counseling model program. The state has delayed submission of its Section 1115 demonstration in order to resolve outstanding budget issues, but is continuing to move forward with plans for implementation.
Illinois	My Choices	1915(c)	Illinois is working with RWJF to implement a Cash and Counseling model program, using funding from the Retirement Research Foundation. The state is in the process of submitting a 1915(c) HCBS waiver to CMS.
Iowa	Developing Choices - Empowering Iowans	1915(c)	Iowa received an RWJF grant to implement a Cash and Counseling model program. The state is in the process of amending its current 1915(c) HCBS waivers to incorporate the Cash and Counseling model.
Kentucky	Consumer Directed Option	1915(c)	Kentucky received an RWJF grant to implement a Cash and Counseling model program. The state received approval from CMS for its HCBS and Supports for Community Living (SCL) 1915(c) waivers, but participant direction is limited to in-home, non-skilled services. The state currently is working on a 1115 waiver application and plans to expand the individual budget to cover additional goods and supplies.

APPENDIX

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Planned Individual Budget Programs Including the Elderly (continued)			
Michigan	Self-Determination in Long-Term Care	1915(c)	Michigan received an RWJF grant to implement a Cash and Counseling model program. The state is in the process of amending its MI Choice 1915(c) HCBS waiver to include features of the Cash and Counseling model.
Montana	Big Sky Bonanza	1915(c)	In October 2005, Montana applied for 1915(c) Independence Plus waiver for seniors and adults with disabilities. The program offers participants an individual budget to purchase personal assistant services and other goods, services, and supplies.
New Mexico	Mi Via (My Way)	1915(c)	New Mexico received an RWJF grant to implement a Cash and Counseling model program and is in the process of submitting two new 1915(c) HCBS waivers for CMS approval.
Pennsylvania	Cash and Counseling Program	1915(c)	Pennsylvania received an RWJF grant to implement a Cash and Counseling model program. The state plans to amend seven of its existing 1915(c) HCBS waivers to include participant direction.
Rhode Island	Personal Choice	1915(c)	Rhode Island received an RWJF grant to implement a Cash and Counseling model program. In September 2005, the state submitted a 1915(c) HCBS waiver and is waiting for CMS approval.
Vermont	Cash and Counseling Pilot Program	1115	Vermont received an RWJF grant to implement a Cash and Counseling model program through a Section 1115 waiver. The Cash and Counseling option will be a small part of a larger initiative that makes home and community based care an entitlement for those who qualify for Medicaid long-term care. The expected enrollment date is winter 2006.
Washington	New Freedom Participant Directed Services	1915(c)	Washington received an RWJF grant to implement a Cash and Counseling model program. The state is in the process of designing a new 1915(c) HCBS waiver for CMS approval.
West Virginia	Personal Options	1915(c)	West Virginia received an RWJF grant to implement a Cash and Counseling model program. The state received approval from CMS for its 1915(c) HCBS waiver, which allows for participant direction of only homemaker, case management, nursing, and transportation services. The state is pursuing a waiver amendment to allow participants to purchase goods and supplies with their individual budgets.

APPENDIX

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Other Active or Planned Programs with Participant-directed Features Including the Elderly			
Alaska	--[2]	--[3]	Alaska has dropped for the present plans to develop an Independence Plus Waiver application for HCBS-eligible populations because of rapid growth in costs for optional personal care under the state's Medicaid plan, which allows participants to recruit, hire, and supervise workers. Officials are looking at different ways to further participant-directed services in the state, such as amending current waiver programs.
California	In-Home Supportive Services Plus (IHSS+)	1115	California received approval to implement a Section 1115 Independence Plus waiver in August 2004. Under the IHSS+ program, participants can direct only their personal care services, including hiring workers. Fiscal services are available from either the state, a contracting agency, or the county. A very small number of participants determined to be "high risk" are eligible to receive their benefit in cash and pay workers directly through an advance pay option.
Delaware	Independence Plus Attendant Services Waiver Program	1915(c)	Delaware is in the process of implementing a 1915(c) Independence Plus Attendant Services waiver program for older persons and adults with physical disabilities. Under this program, participants will receive an individual budget for their personal care services only. Participants will have the option to hire workers, work with a case manager and a fiscal agent. An implementation date for the program has not yet been set.
District of Columbia	--[2]	--[3]	The District of Columbia received a CMS CPASS grant in 2002, which it is using to implement a participant-directed pilot program for individuals eligible for the District's 1915(c) Elderly and Persons with Physical Disabilities waiver. Participants will be allowed to receive an individual budget, work with a case manager, hire and supervise workers, and use the services of a fiscal agent. The District expects to implement the pilot in early 2006, with full implementation in fall 2006. The District has not yet worked out all the program details.
Georgia	Community Care Services Program	1915(c)	Georgia is awaiting CMS approval for an amendment to add participant direction to its 1915(c) HCBS waiver program for elderly and adults with physical disabilities, and has already received approval for amendments to their Physically Disabled and MR waivers. Participants will receive an individual budget to purchase personal care services only, and will have the option to hire their own workers, receive assistance from a case manager, and use the services of a fiscal agent.

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Other Active or Planned Programs with Participant-directed Features Including the Elderly (continued)			
Indiana	--[2]	--[3]	Indiana received a CMS CPASS grant in 2002, which it is using to develop a model for financial management services to assist beneficiaries who choose to direct their personal assistant services. The state is considering several models and is reviewing whether to amend its 1915(c) Aged and Disabled waiver to include financial management as a supports service.
Kansas	Frail and Elderly Waiver Program and Physical Disabilities Waiver Program	1915(c)	Kansas allows elderly beneficiaries in two of its 1915(c) HCBS waiver programs the option to direct attendant services. Under the 1915(c) Frail Elderly waiver, participants can choose agency-managed services or participant-directed personal assistance, or a combination of these service delivery options. Participants can hire their own workers and use the services of a case manager and fiscal agent, but there is no individual budget. Participants who have been enrolled in the state's 1915(c) HCBS waiver for physically disabled aged 19 to 64 can remain when they reach age 65. In this waiver program, participants can develop a plan of care that with a total allowance that participants may allocate across specified waiver services, but the state does not consider this amount to be a budget.
Maine	MaineCare, Consumer-Directed Personal Assistance Services (CD-PAS) Waiver Program, and Home Based Care Program	Medicaid State Plan, 1915(c), and State funded	Maine offers participant direction under three programs: MaineCare (the state's Medicaid plan, which includes a personal care benefit), a 1915(c) CD-PAS waiver for the elderly and adult disabled, and a state program called Home Based Care. Under all three programs the participant may either choose to hire workers and use the services of a fiscal agent or use agency managed workers.
Nebraska	--[2]	Medicaid State Plan	Nebraska received a CMS CPASS grant in 2003, which it is using to develop participant direction in the state's Medicaid optional plan for personal care services. Participants will have the opportunity to recruit, hire, and supervise workers, receive case management, and use the services of a fiscal agent.
New Hampshire	Home and Community-Based Care for the Elderly and Chronically ill (HCBC-ECI) Program	1915(c)	New Hampshire offers participant direction of personal assistance services only for the elderly and chronically ill through its 1915(c) HCBC-ECI waiver program. Participants recruit, hire, and supervise their own workers and use the services of a fiscal agent. The program was implemented statewide in 2002.

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Other Active or Planned Programs with Participant-directed Features Including the Elderly (continued)			
New York	Consumer Directed Personal Assistance Program (CDPAP)	Medicaid State Plan	New York's CDPAP program offers beneficiaries the option to direct personal assistance services only. Participants may recruit, hire, and supervise workers and have access to the services of a fiscal agent.
Ohio	Choices	1915(c)	Ohio's Choices program offers participant direction as an option to beneficiaries in the state's PASSPORT 1915(c) HCBS waiver program for the elderly. Like PASSPORT participants, participants in Choices are assigned a dollar amount for specified waiver services up to an $1,800 cap, but the state does not consider this amount to be a budget that participants may allocate across services. Participant direction applies only to the hiring and supervision of participant's own workers and the use of case manager and payroll agent services. The program was implemented as a demonstration in 2002 and currently is operating regionally in selected counties.
Oklahoma	ADvantage	1915(c)	Oklahoma received CMS approval for an amendment to implement participant direction in its 1915(c) ADvantage waiver for the elderly and physically disabled. Participants receive an individual budget to direct personal assistant services only. Participants can hire workers and use case management and fiscal agent services. The state is currently conducting outreach to begin a pilot program in Tulsa.
Texas	Consumer Directed Services (CDS)	1915(c)	Texas offers participant direction with an individual budget in its 1915(c) HCBS waiver programs for the aged and for disabled individuals of all ages. The budget includes attendant services only. Participants can hire workers and use the services of a case manager and fiscal agent. Over the next two years, the state plans to amend its 1915(c) HCBS waivers for individuals with MR to include participant direction.
Virginia	Consumer Directed Personal Assistance Services (CDPAS)	1915(c)	Virginia received CMS approval for an amendment to implement participant direction in its 1915(c) CDPAS waiver for the elderly and physically disabled in 2004. Participants can hire workers and work with a case manager. Currently fiscal services are provided by the state, but the state intends to move to an outside contractor.

APPENDIX

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Other Active or Planned Programs not Including the Elderly			
Arizona	Human Services Cooperative of Northern Arizona	1115	Arizona received a CPASS grant from CMS in 2003, which it is using to implement a participant-directed human services cooperative model for the DD participant's enrolled in the state's 1115 waiver program. The cooperative pools providers and information resources to contract with qualified vendors. Participants also have the option to recruit and hire their own workers, but providers must be independent Medicaid providers. The state provides fiscal intermediary services for these providers.
Connecticut	Individual and Family Supports Waiver Program	1915(c)	Connecticut has a 1915(c) Independence Plus waiver for the MR/DD population; program enrollment began in February 2005. Participants can choose to recruit, hire, and supervise workers and use the services of a fiscal intermediary. Participants may also use a case manager or hire their own individual support person to assist them with participant direction. The state is developing a waiver program for the elderly that will likely include the criteria for an individual budget, but has not worked out all the program details.
Hawaii	MR/DD Waiver Program	1915(c)	Hawaii is renewing an existing 1915(c) HCBS waiver for the MR/DD population that may include a participant-directed approach and emphasize participant direction and managed care. The state expects to complete its renewal waiver application in the fall of 2005. At this time it is not known whether the state plans to implement a program that includes an individual budget.
Idaho	DD Waiver Program	1915(c)	Idaho submitted an 1915(c) HCBS waiver amendment to include participant-directed services for the MR/DD population. Participants can hire and supervise their own workers with assistance from case managers. Participants will receive an annual individual budget and financial management services. The state expects to consider eventually giving all HCBS populations the option to use participant-directed services.
Louisiana	New Opportunities Waiver (NOW) Program	1915(c)	Louisiana implemented the 1915(c) Independence Plus NOW waiver program in 2003 for adults and children with MR/DD. Participants receive an individual budget and can direct specified waiver services, receive case management services, and have the right to hire and supervise workers. Participants use the services of a fiscal agent. The state anticipates implementing participant direction in two other waiver populations, one for children and another for the elderly and adult disabled within two years. State officials currently are drafting amendments to these 1915(c) HCBS waivers.

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Other Active or Planned Programs not Including the Elderly (continued)			
Maryland	New Directions	1915(c)/ 1115	Maryland has a 1915(c) Independence Plus waiver for the DD population with enrollment expected to begin in late fall 2005. Participants will have an individual budget to direct toward specified waiver services, with assistance from a fiscal management service and a case manager. Individuals will manage their budgets, hire and supervise their own workers, and make decisions about how their services are provided. The state also has submitted an 1115 waiver to CMS to develop a managed long term care program which may include an individual budget model program.
Missouri	MR/DD Waiver Program	1915(c)	Missouri received an Independence Plus grant from CMS in 2003, which it is using to develop and implement a participant-directed pilot program for the MR/DD population. Under the current 1915(c) program, participants receive an individual budget to direct specified waiver services and can hire workers. The pilot program will add case management and is testing the use of a different fiscal agent model. If the pilot is cost-effective the state plans to amend its 1915(c) HCBS waivers for the MR/DD population to incorporate these participant-directed components.
Nevada	--[2]	1915(c)	Nevada is drafting a new 1915(c) HCBS waiver for the MR/DD population, to replace an existing waiver, with the goal to increase participant-directed options for this population. The state is planning to allow participants the option of hiring their own workers. Participants will receive an individual budget for the purchase of direct care services only. Participants will use the assistance of a case manager and a fiscal agent.
North Dakota	Independence Plus Waiver Program	1915(c)	North Dakota submitted a 1915(c) Independence Plus waiver to implement participant-directed initiatives in two of its 1915(c) HCBS waiver programs for the MR/DD population in 2003. Participants will have an individual budget to direct the services and supports defined in their plan of care, hire workers, and use the services of a case manager and fiscal agent. The state is awaiting CMS approval of the waiver.
South Dakota	MR/DD Waiver Program	1915(c)	South Dakota has individual budgets for direct services only in its 1915(c) waiver for the MR/DD population. Participants can recruit, hire, and manager workers, but workers are employed through an agency. Through a state initiative called People Leading Accessible Networks of Support (PLANS), the state is meeting with stakeholders to discuss expansion of participant-directed services in all state programs.

APPENDIX

State	Program Name	CMS Waiver Authority	Status (as of January 2006)
Other Active or Planned Programs not Including the Elderly (continued)			
Tennessee	Self-Determination Waiver Program	1915(c)	Tennessee received a CMS CPASS grant in 2002, which it is using to implement a participant-directed pilot program for adults with physical disabilities. Participants have an individual budget to direct personal assistance services, receive assistance in recruiting and hiring workers, and use the services of a fiscal agent. The state also has a 1915(c) Self-Determination waiver program for the MR population, under which participants receive a budget and have the option of directing specified waiver services. The state is considering expanding participant direction to other disabled populations including the elderly.
Utah	MR/DD, ABI, and Individuals with Physical Disabilities Waiver Programs	1915(c)	Utah has individual budgets in its 1915(c) HCBS waivers for the MR/DD population, those with acquired brain injuries, and the physically disabled. The individual budget is for direct services only. Participants can hire their own workers and use a fiscal agent to assist with payment responsibilities.
Wyoming	Wyoming's Individual Budget Amounts/ DOORS model	1915(c)	Wyoming implemented individual budgets in its 1915(c) HCBS waiver programs for the MR/DD population in 1998. Participants receive an individual budget to direct waiver services, case management support, and have the option to hire workers. The state does not contract with a fiscal agent, providers must be enrolled as certified Medicaid providers.
No Individual Budget Programs or Initiatives Identified			
Mississippi	--[2]	n.a.	Mississippi submitted a Cash and Counseling grant proposal to RWJF in 2004, but the state did not receive the grant and currently is not pursuing any participant-directed initiatives.

[1] CMS waiver authority does not apply to the program's current status.

[2] The state does not have a named active or planned program.

[3] The state has not determined CMS waiver authority.

Key to acronyms:
CMS = Centers for Medicare and Medicaid Services
CPASS = Community-integrated Personal Assistance Services and Supports
DD = Developmentally Disabled
HCBS = Home and Community-based Services
MR = Mental Retardation
RWJF = Robert Wood Johnson Foundation

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