kaiser commission on medicaid and the uninsured

THE HENRY J. KAISER FAMILY FOUNDATION

ISSUE PAPER

November 2003

An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid

Prepared by Jeffrey S. Crowley, Health Policy Institute, Georgetown University

EXECUTIVE SUMMARY

The Independence Plus Initiative was established by the Department of Health and Human Services (HHS) to give states expanded opportunities within Medicaid to allow for consumer direction of long-term services and supports. A key element of consumer direction is the ability to hire, fire, train, and supervise personal assistance attendants, as well as the opportunity to directly purchase services. The Independence Plus Initiative provides participating beneficiaries with an individual budget (*i.e.* a voucher) to manage personal assistance attendants and a broad range of other services. The Initiative builds on the Cash and Counseling Demonstration program implemented in Arkansas, Florida, and New Jersey.

As of September 2003, 4 states (Florida, Louisiana, New Hampshire, and South Carolina) have had Independence Plus waivers approved. The approved waivers all target populations needing an institutional level of care, including frail elderly and adults with physical disabilities, and children and adults with mental retardation and developmental disabilities. The range of services included varies, but is quite broad, including personal care services, specialized and durable medical equipment, home health services, homemaker services, transportation, respite care services, mental health, case management, environmental adaptation services, and a number of other professional and home and community-based services. Independence Plus programs may be implemented using either the section 1115 or 1915(c) waiver authority.

The principles behind Independence Plus programs are the same as the Cash and Counseling Demonstrations, but these programs differ in several important ways that raise the following issues:

The range of services subject to consumer direction under Independence Plus may be too broad to handle under an individual budget. States that opt to use Section 1115 waiver authority to implement Independence Plus may allow consumer direction of any state plan or waiver service, while states using 1915(c) waivers may allow for consumer direction of only home and community-based waiver services. The Cash and Counseling Demonstration program was predicated on giving individuals

1330 G Street NW, Washington, DC 20005
Phone: 202-347-5270, Fax: 202-347-5274, Publications: 1-800-656-4533
Website: www.kff.org

greater control over personal assistance services. Barring injury or a change in health status, the need for these services is likely to remain fairly consistent from month to month. An individual budget may not work as well for services that are less predictable. For example, when medical equipment needs to be repaired or replaced, the cost for services could be significantly higher than usual. Or, when a physician orders a change in prescription medications or when the need for diagnostic and other services changes—as is often the case for older populations and persons with specific types of conditions—this could result in the beneficiary's individual budget being inadequate. In addition, the ability to leverage personal relationships to identify persons willing to provide personal assistance services does not necessarily translate into tangible benefits for managing other services. For example, using family members to provide services will not lower prescription drug costs or reduce the cost of primary medical care.

Federal requirements and guidance for states may be insufficient to ensure that individual budgets receive adequate funding. While the Independence Plus waiver templates require states to define a methodology for establishing the individual budgets and provide for re-determination of the budget, there do not appear to be any practical standards for ensuring that the budget is sufficient for the services included. In addition, CMS has not indicated minimal standards that would guarantee the adequacy of an individual budget or that would ensure that an individual budget increases at a rate comparable to increases in the cost of services purchased.

Sufficient state administrative resources are likely to be important for the ongoing success of Independence Plus programs. The Cash and Counseling experience highlights the important need for ongoing state support, including ensuring emergency back-up supports, adjusting the level of the individual budget when the need for services changes, and assisting individuals with financial management activities. Shifting control to the individual does not diminish the need for state administrative functions related to enrollment, financial management and program oversight.

Independence Plus and the consumer direction movement continue to evolve rapidly, and this calls for federal and state resources to evaluate new and changing programs. Federal resources should be devoted to evaluating Independence Plus programs. In addition to consumer satisfaction, information should be collected to assess the adequacy of individual budgets and the quality of services. Many people with disabilities have advocated for greater control over developing service and support plans that meet their needs and respond to their preferences, but consumer direction, coupled with an individual budget, should not be a condition of receiving home and community based services. Moreover, Independence Plus is not the only vehicle for promoting consumer direction. Many states have already integrated consumer direction, to some degree, in their Medicaid programs. Several states operate Medicaid consumer direction programs similar to Independence Plus, while others allow beneficiaries to direct their services without using an individual budget.

For the positive benefits of Independence Plus programs to be realized, it will be essential that careful attention be paid to assuring that the scope of services available for consumer direction under an individual budget includes only those services that can be appropriately managed under this arrangement. It will also be important to ensure that states are held accountable for providing adequate financing of individual plans of care, and that flexibility is appropriately balanced with reasonable beneficiary protections.

INTRODUCTION

In 2002, the Bush Administration announced a new Medicaid waiver initiative called Independence Plus. This initiative is intended to give states opportunities within Medicaid to allow people with disabilities and the elderly to have greater involvement, control, and choice in identifying, accessing and managing certain long-term services and supports. Independence Plus attempts to improve the quality and satisfaction with home- and community-based services by giving individuals an opportunity to direct their own services as an alternative to receiving professionally-managed long-term services. The initiative builds on and expands the Cash and Counseling Demonstration program. The Independence Plus Initiative allows participating beneficiaries to receive an individual budget (*i.e.* a voucher) that is tied to a plan of care developed with the beneficiary's input, and allows them to recruit and manage personal assistance attendants and other services. A notable feature of this program is that it allows states to permit individuals to hire family members to serve as personal assistance attendants.

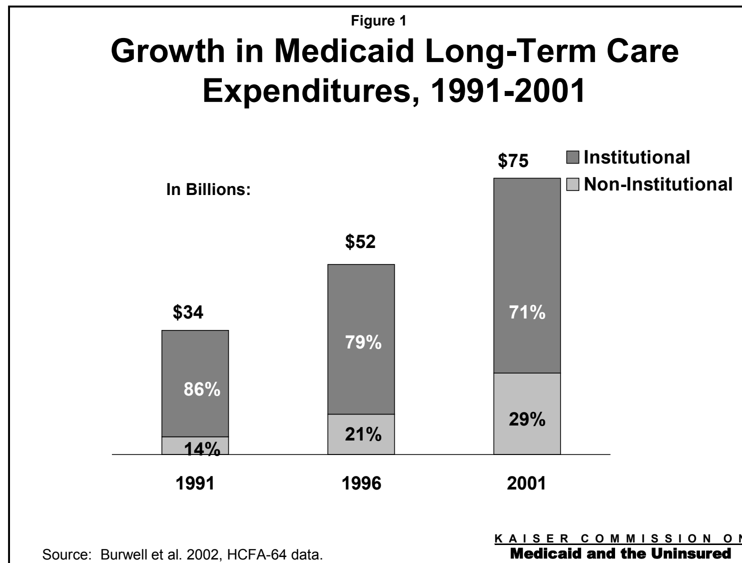
This issue brief provides an overview of the Independence Plus Initiative, compares core program features with the Cash and Counseling Demonstration program, and discusses several policy issues that arise in the implementation of this initiative.

MEDICAID COVERAGE FOR HOME AND COMMUNITY-BASED LONG-TERM SERVICES AND SUPPORTS

Ten million children and adults in the United States need access to long-term services and supports.[1] Long-term services and supports assist people in performing routine activities of everyday life, such as getting out of bed, preparing food and eating, taking medication, or managing a home. Medicaid programs spent $75.3 billion on long-term services in 2001, accounting for 44% of our nation's long-term services spending.[2] Long-term services spending represents a projected 35% of Medicaid benefits spending in 2003.[3]

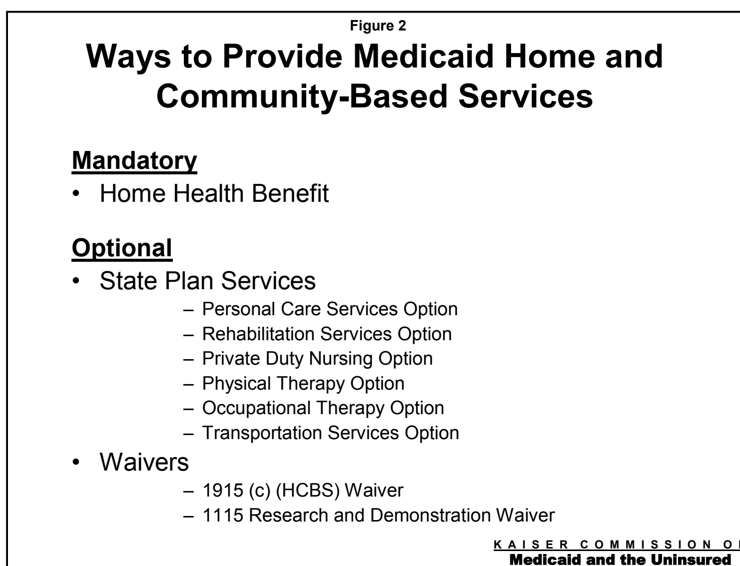
For people with disabilities and the elderly who need long-term services, how and where they receive such services is a major issue of concern. Although most people receiving Medicaid long-term services receive them in the community, the majority of Medicaid long-term service spending is for institutional care **(Figure 1)**. In 2001, only 29% of Medicaid long-term services spending was for home- and community based services.[4] As people with disabilities have become more integrated in public life, there has been increasing pressure to improve access to Medicaid home and community-based

services. Further, greater integration of people with disabilities in society has also changed longstanding perceptions that people with disabilities are simply passive recipients of services. Not content to be isolated in institutions and wanting to assert greater control over their own lives, individuals and their families are demanding greater access to community long-term services—and increased control over the services they receive.



The U.S. Supreme Court gave advocates for increased access to Medicaid home- and community-based services a considerable boost in 1999. In deciding the case, *Olmstead v. L.C.*, the court held that, "unjustified institutional isolation of persons with disabilities is a form of discrimination," that violates the Americans with Disabilities Act.[5, 6] The Olmstead decision should have the effect of encouraging states to more carefully consider ways to provide more long-term services and supports in the community, but it does not require states to immediately provide home- and community-based services to all Medicaid beneficiaries who need long-term services.

There are three main ways through which state Medicaid programs provide home- and community-based services: 1) through the home health benefit; 2) through one of several optional state plan services; and 3) through waivers **(Figure 2)**.



Home health is a mandatory benefit under Medicaid. While this benefit historically has not been seen as a home- and community-based service, because of its emphasis on providing skilled, medically-oriented services in the home, as opposed to providing personal assistance services, states have the discretion to cover a number of therapeutic services under this benefit. In any event, this benefit does provide important services that can be critical to assisting people in living at home or in the community. Access to this benefit is restricted, however, to persons who meet certain "level of care" criteria and therefore, is not available to all beneficiaries who need home- and community-based services.

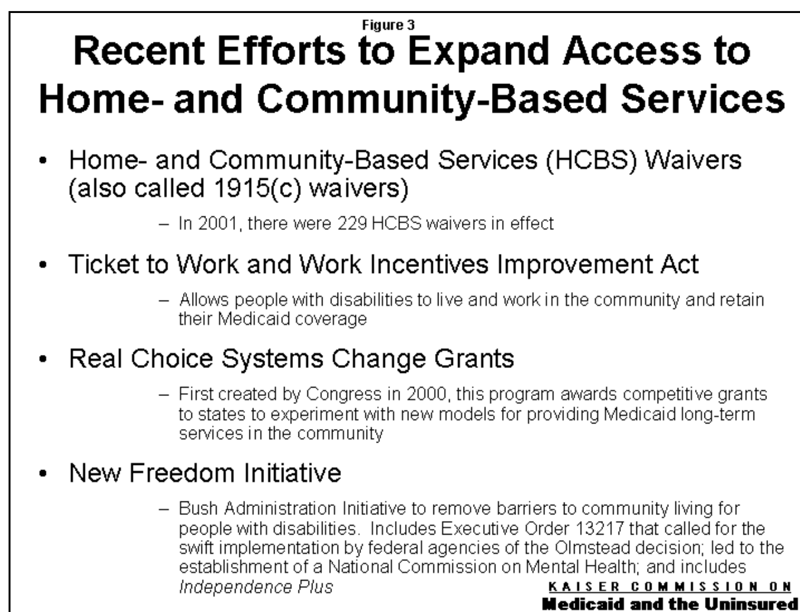
States can cover a number of "optional" services and receive a federal match. To do so, states either elect to provide optional services as part of their state plan or they apply for a waiver. A state plan is a publicly available, written document that describes the eligibility standards, covered benefits, and program components of a state's Medicaid program. State plan services, whether they are "mandatory" or "optional", must be provided, when they are medically necessary, to all Medicaid beneficiaries in a state, with the possible exception of the "medically needy".[7] A number of optional state plan services can be provided in home and community settings. These include: personal care services, rehabilitation services, private duty nursing, physical and occupational therapy, and transportation services.

States also can provide home- and community-based services through more than one type of waiver. Waivers are programs authorized by law that allow the Secretary of Health and Human Services to waive compliance with specific provisions of Medicaid. Unlike state plan services, waiver services can be provided to specific targeted populations or to persons in limited parts of a state. The Independence Plus Initiative permits states to provide for consumer direction of services through both 1915(c) waivers and 1115 demonstration waivers.

1915(c) waivers, also called Home and Community-Based Services (HCBS) waivers, are the most frequently used waiver for providing services in the community. These waivers are available to certain groups who would be eligible for Medicaid if institutionalized, and without the waiver services, would be institutionalized in a hospital or nursing facility. This type of waiver allows the Secretary to waive certain financial eligibility requirements, the Medicaid requirements that services must be "comparable" among beneficiaries, and that services must be provided statewide.[8]

1115 demonstration waivers give the Secretary the broadest authority to waive compliance with Medicaid rules. While Congress has proscribed the waiving of certain parts of the Medicaid law, the 1115 demonstration authority gives the Secretary broad discretion to approve waiver programs that are, "likely to assist in promoting the objectives" of the Medicaid law.[9] 1115 demonstrations have been used by states to make changes to Medicaid that affect the entire Medicaid program. For example, Arizona and Tennessee are permitted to require virtually all of their Medicaid beneficiaries to enroll in managed care pursuant to an 1115 demonstration. This type of waiver can also be used to waive Medicaid rules that cannot be waived under the 1915(c) waiver program.

States generally make use of a combination of state plan services and multiple waivers to provide a range of services: some that are available to all Medicaid beneficiaries who need them, some that are targeted to specific populations, or some that are available in only certain parts of a state. Recently, policy makers also have responded to the demand for greater access to home and community-based services through a number of special initiatives **(Figure 3)**. (See the Appendix for additional background information related to Medicaid coverage for home and community-based services.)

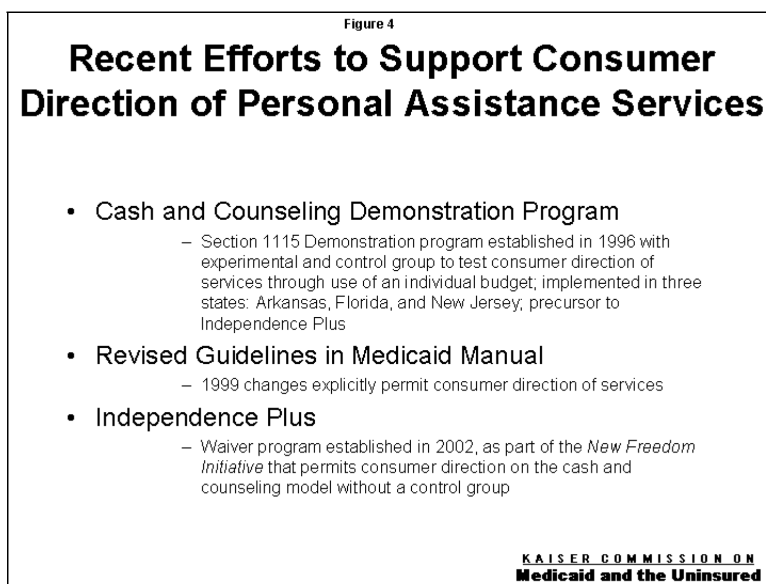


CONSUMER DIRECTION OF SERVICES IN MEDICAID

Medicaid programs have been criticized not only for the limited access to home- and community-based services, but also for providing these services using a professionally-managed service delivery model. Many people with disabilities have argued that this model is not responsive to their needs, and they have advocated for greater control over developing service and support plans that meet their needs and respond to their preferences.

Key elements of consumer direction are the ability to hire, fire, train, and supervise personal assistance attendants. Consumer direction also involves the opportunity to directly purchase services, and within certain constraints, to direct the payment of certain services. Consumer direction initiatives exist on a spectrum. At one extreme, all recruitment, hiring, firing, and supervising responsibility is vested in the individual—a level of responsibility that may not be desirable to many people. Other forms of consumer direction allow for support services to assist the individual in handling these responsibilities. For example, individuals may desire financial management services or they may seek assistance from independent support brokers that assist with functions such as recruitment and hiring of personal assistance attendants.[10]

Some people erroneously believe that Medicaid cannot accommodate consumer direction of services. While the rules for the home health benefit require services to be provided by Medicare/Medicaid certified home health agencies, this does not prevent these services from being directed by consumers. Persons who receive personal care services, which are not required to be provided by a home health agency, also use consumer direction. A study conducted in 2000 found that half of the 26 states with the optional personal care services benefit and 60% of HCBS waivers in 45 states provided for consumer direction of personal assistance attendants.[11] During the last decade, federal policy makers have also focused increasing attention on promoting consumer direction of personal assistance services **(Figure 4)**.



THE CASH AND COUNSELING DEMONSTRATION PROGRAM

The Independence Plus Initiative is an expansion and modification of previously approved Cash and Counseling Demonstrations. To understand the Independence Plus Initiative, it is necessary to understand the basic features of the Cash and Counseling program.

The Cash and Counseling Demonstration Program was established by the Department of Health and Human Services in 1996, with financial support from the Robert Wood Johnson Foundation. Three states implemented Cash and Counseling Demonstration programs: Arkansas, Florida, and New Jersey. The Robert Wood Johnson Foundation also established a related program in 1997, the Self-Determination Initiative for People with Developmental Disabilities. This initiative funded 19 programs aimed at exploring ways that people with developmental disabilities could influence the personal assistance services they receive through consumer direction, and involved the use of individual budgets and other core features of the Cash and Counseling Demonstration program.

Under the Cash and Counseling Demonstration Program, people with disabilities and the elderly received a monthly cash allowance (also called an individual budget) to purchase personal assistance and related services and goods. The program allowed individuals to purchase services from Medicaid agency providers and from other sources, such as family members and friends. The goals of the demonstrations were to increase consumer control over the personal assistance services they receive and increase their satisfaction with the services without increasing public costs.

The basic design of the demonstrations was the same in each state. Participation was voluntary, and individuals who volunteered for the demonstration were randomly assigned to receive personal assistance services through either a “treatment group” that received an individual budget with which to recruit, hire, or arrange for personal assistance services or a “control group” that received traditional agency-delivered services. All persons receiving an individual budget had access to a wide range of counseling services and assistance with fiscal tasks and bookkeeping. Counselors were available to help individuals develop a cash plan, recruit, train, and manage workers, gain access to community services, and develop a backup plan.[12]

The look and feel of the demonstration programs in the three states was different. States made different choices regarding which populations to enroll in the Cash and Counseling programs and they covered different packages of services. Arkansas and New Jersey used their programs to “cash out” services that were previously provided through the state plan personal care option. Florida chose to “cash out” services previously provided through an HCBS waiver. These program decisions and variations in state payment practices have led to significant variation in the size of the individual budget **(Table 1)**. In Arkansas, at the final evaluation, the average monthly individual budget was $350.[13] In New Jersey, it was $1,400.[14] In Florida, the average individual budget for elderly adults and adults with physical disabilities was $975, and the average individual budget for children with developmental disabilities was $1,825.[15]

Table 1: Core Features of the Cash and Counseling Demonstrations

	Services "Cashed Out"	Populations Served	Total Enrollment (As of June 2002)	Average Monthly Budget
Arkansas	Personal Care	Elderly Adults	1,452	$350
		Adults with Physical Disabilities	556	
Florida	Waiver	Elderly Adults	814	$975
		Adults with Physical Disabilities	1,002	
		Children with Developmental Disabilities	1,004	$1,825
New Jersey	Personal Care	Elderly Adults	941	$1,400
		Adults with Physical Disabilities	821	

Sources: Phillips, B. et. al., Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report, Mathematica Policy Research, Inc., June 2003 and Cash and Counseling At a Glance, June 30, 2002, University of Maryland Center on Aging.

Determining how to evaluate these programs and identifying the best evaluation measures is challenging. The Cash and Counseling Demonstration program used consumer satisfaction as one of its key evaluation criteria. Generally, participants in these demonstrations were highly satisfied with their ability to direct their own personal assistance services. An evaluation of Florida's demonstration program conducted nine-months after implementation found that 97% of participants who used the monthly budget would recommend the program to others wanting more control over the personal assistance services they receive.[16] A similar level of satisfaction was found during a nine-month evaluation of New Jersey's program and in an early evaluation of Arkansas' program, 93% of participants would recommend the program to others.[17, 18] While these finding are encouraging, it is important to note that satisfaction, alone, may not be sufficient to consider this type of initiative successful. High satisfaction may result from the new ability to have greater control over services, but it could also mask continuing deficiencies related to the level of resources available to purchase services, or deficiencies in the availability or quality of personal assistance services.

THE INDEPENDENCE PLUS INITIATIVE

The purpose of the Independence Plus Initiative is to provide assistance to individuals and families so that persons who need long-term services and supports can remain in their own home. The movement toward consumer direction is much more broad than the Cash and Counseling Demonstrations and the Independence Plus Initiative. Many states have already integrated consumer direction, to some degree, in their Medicaid programs. Some of these state initiatives share similar features as Independence Plus,

while others allow beneficiaries to direct their own services without using an individual budget.

There are two basic types of Independence Plus programs, 1115 demonstrations and HCBS waivers. The basic principles behind Independence Plus programs are the same as the Cash and Counseling Demonstrations, although these programs differ in important ways. The Independence Plus waivers do not include a control group, they do not undergo the same level of intensive monitoring and evaluation as the Cash and Counseling program, and they create the opportunity for states to permit self direction of any Medicaid service, not a defined list of HCBS waiver services. The policies and contours of a state's Independence Plus program can look very different depending on whether the state implements its program through an 1115 demonstration or through an HCBS waiver **(Table 2)**.

Table 2: Comparison of Cash and Counseling and Independence Plus

	Cash & Counseling	Independence Plus	
Waiver Type	1115 Demonstration	1115 Demonstration	HCBS/1915(c)
Eligible Populations	People with disabilities and the elderly	People with disabilities and the elderly	People with disabilities and the elderly
Voluntary	Yes	Yes	No
Services available for consumer direction	HCBS Services	Any State Plan/ Waiver Service	HCBS Services
Use Individual Budgets	Yes	Yes	Yes
States can permit direct cash management	Yes	Yes	No
States can permit hiring of family members (legally responsible relatives)	Yes	Yes	No

Source: Georgetown University Health Policy Institute Analysis of CMS Independence Plus waiver templates and University of Maryland Center on Aging Cash & Counseling background materials.

Independence Plus and the 1115 Demonstrations

The 1115 demonstration authority gives states broader discretion in designing programs than the HCBS waiver authority. Through the 1115 demonstration program, states can enroll all persons needing personal assistance, without requiring them to meet a specific level of care standard. These waivers also allow for consumer direction of any state plan or waiver service. Further, states determine whether or not individuals directly

receive cash with which to purchase services or whether they are required to use financial management services to handle the payment for services received.

Independence Plus programs operated as 1115 demonstrations must be voluntary for program participants. The state must assure that a fiscal agent or employer agent will be available to participants who request these services or are determined to need them based on a skills test. States are permitted to determine whether the program will operate statewide, what the enrollment cap will be, whether legally responsible family members (such as spouses or parents of minors) may qualify as providers, and whether to allow beneficiaries to save resources in an account for approved special purchases such as adaptive equipment or to pay for environmental modifications. While the waiver guidance indicates that any state plan or waiver service can be included in the demonstration, the waiver template provides a checklist of the following state plan services which are anticipated to be most commonly included: personal care services, durable medical equipment, home health services, and non-emergency transportation. The checklist also permits states to include "other" services in the waiver.

1115 demonstrations must meet budget neutrality requirements. This is an administratively imposed requirement that means that the state must show that the program does not cost more than providing state plan services (such as nursing home care) to the same population. States must also use the same procedures for determining the personal care services an individual is eligible to receive without regard to whether an individual elects to participate in the waiver.

States must submit an operational protocol for approval by the Centers for Medicare and Medicaid Services (CMS) that covers a broad range of administrative issues and describes procedures for determining the plan of care, the methodology for establishing the budget for the plan of care, procedures and mechanisms to review and adjust payments for the plan of care, services which will be cashed out, and alternative health related services which may be approved for participants. The operational protocol also addresses the enrollment cap, requirements for quality assurance monitoring, and procedures for ensuring sufficient availability of fiscal agent or employer agent services.

States must assure that there are adequate resources to support participants in directing their own care. The operational protocol requires states to assure that several beneficiary protections are in place. These include: procedures to ensure that families have the information needed to participate in a family-centered or person-centered planning process and procedures to work with individuals and families to monitor the ongoing expenditure of the individual budget. The state must also have a viable system for assuring emergency back-up or emergency response capability in the event that those providers or services and supports vital to the individual's health or welfare are not available. The state must also assist participants in complying with laws pertaining to employer responsibilities, providing for back-up attendants, as needed, and performing qualifications checks and criminal background checks on persons or organizations that the beneficiary is considering hiring. States must also assure that

individuals who are not capable of directing their own care will not be deliberately excluded from the demonstration.

Independence Plus and HCBS Waivers

In many instances, the differences between HCBS Independence Plus programs and 1115 Independence Plus demonstrations result from limitations in the 1915(c) waiver authority that do not permit CMS to waive as many Medicaid provisions as allowed under the 1115 demonstration authority. HCBS waivers only enroll persons needing an institutional level of care and they allow for consumer direction of only HCBS waiver services. Waiver requirements mandate that when an individual is determined to need an institutional level of care, they must be informed of any feasible alternatives under the waiver, and they must be given a choice of receiving either institutional or community-based services. Unlike the 1115 Independence Plus programs, however, there is no requirement that participation in consumer direction is voluntary for HCBS waiver participants. States can require beneficiaries electing to receive community-based services to participate in consumer direction.

Individuals do not manage cash directly in HCBS Independence Plus programs. The individual arranges for services, but a third party (under contract with the state) provides financial management services and handles the actual payment. The 1915(c) waiver authority requires states to ensure budget neutrality. States are required to provide assurances that they have adequate standards for all providers that provide services under the waiver. They must also assure that all state licensure and certification standards are met. The waiver also requires that a written plan of care be developed for each individual using a family or person-centered planning process that reflects the needs and preferences of the individual and their family.

Individual budgets are developed for each participant. The amount of money designated in the budget is established by a methodology determined by the state and must be based on a plan of care that was developed through a family or person-centered planning process. States choose either to receive waiver approval to adopt a uniform methodology for calculating all budgets in the state or to receive waiver approval to establish a minimum set of criteria and an approval process for methodologies developed by subcontractors, counties, or other entities. Under the latter approach, the minimum requirements must include that the budget is built upon actual service utilization and cost data, the methodology must be described to the individual and their family, the methodology must be open for inspection by authorized public entities including CMS, and there must be a process for re-determination of the individual budget when there are changes in circumstances, such as a change in the level of need for services.

As with 1115 demonstrations, HCBS waivers require states to assure that several beneficiary protections are in place. These include: procedures to ensure that families have the information needed to participate in a family-centered or person-centered planning process; procedures for providing, at individual or family request, qualification

and criminal background checks of providers; procedures to promote individual or family preferences that are balanced with accepted standards of practice; and procedures to work with individuals and families to monitor the ongoing expenditure of the individual budget. The state must also have a viable system for assuring emergency back-up or emergency response capability in the event that those providers or services and supports vital to the individual's health or welfare are not available.

Approved Independence Plus Programs

As of September 2003, 4 states have had Independence Plus programs approved **(Table 3)**. Several other states operate Medicaid consumer direction programs that are similar to Independence Plus. In some cases, these are longstanding programs, and in other cases, states implemented consumer direction initiatives for very small numbers of beneficiaries. If state programs do not meet all of the Independence Plus requirements, then CMS does not consider them to be part of the Independence Plus Initiative.

Table 3: Approved Independence Plus Waivers

State	Waiver Authority	Target Population	Level of Care	Enrollment Cap	Consumer Directed Services
Florida Effective Date: 02/12/03	§ 1115	Frail elders, adults with physical disabilities, children and adults with developmental disabilities	Frail elders and adults with physical disabilities: nursing facility Children and adults with developmental disabilities: ICF/DD	6,000	Services provided through the personal care benefit that include durable medical equipment, home health services, non-emergency transportation, targeted case management, mental health, homemaker services, respite care services, transportation services, supported employment, and 34 other home- and community-based services
Louisiana Effective Date: 04/24/03	1915(c)/ HCBS	Persons with mental retardation and developmental disabilities	ICF/MR	Year 1 = 4,251 Year 2 = 4,576 Year 3 = 4,776 Self-directed portion of waiver has 3-year phase-in of up to 250 people. In year 4, all waiver participants will be eligible for self-direction	Respite services, habilitation (residential habilitation, day habilitation, supported employment, employment related training), environmental accessibility adaptations, skilled nursing, specialized medical equipment and supplies, personal emergency response systems, adult residential care, individualized and family support, community integration development, professional services, professional consultation, transition start-up expenses, and transitional professional support services
New Hampshire Effective Date: 01/01/03	1915(c)/ HCBS	Children with developmental disabilities	ICF/MR	Year 1 = 180 Year 2 = 190 Year 3 = 200	Family support/care coordination, enhanced personal care, consultative services, respite services, and home and vehicle modifications
South Carolina Effective Date: 03/22/03	1915(c)/ HCBS	Elderly, and people with disabilities 21 and over residing in Spartanburg, Cherokee and Union Counties	Nursing Facility	Year 1 = 300 Year 2 = 600 Year 3 = 900	Personal care, personal assistance, care advice, adult day health, respite services, environmental accessibility adaptations and appliances, specialized medical equipment and supplies, personal emergency response systems, adult day health care nursing, and home delivered meals

Source: CMS, 2003.

POLICY IMPLICATIONS

The Independence Plus Initiative provides important opportunities for improving the quality of and satisfaction with Medicaid home- and community-based services. Experience with the Cash and Counseling Demonstration program and broader efforts by the federal government and the states to adopt consumer direction in Medicaid all reinforce the basic rationale for the Independence Plus Initiative. Critical policy issues must be resolved, however, in order for this initiative to successfully meet the needs of the beneficiaries who wish to direct their own services. These issues include:

- **Independence Plus may be too broad and may inappropriately permit consumer direction of acute care and other services**

The Cash and Counseling Demonstrations and other initiatives to permit beneficiaries to direct their own services focused on consumer direction of personal assistance and related long-term services and supports. The policy of the Independence Plus Initiative that permits consumer direction of any state plan or waiver service in 1115 demonstration waivers could distort the program in ways that are harmful to beneficiaries.

<u>Consumer direction and an individual budget may not be appropriate for certain services.</u> The Cash and Counseling Demonstration waiver program was predicated on giving individuals greater control over a defined set of home- and community-based services. Indeed, the movement toward consumer direction resulted, in part, from the belief that the medical model of delivering health care was being inappropriately applied to long-term services and supports. A potential danger with Independence Plus is that it risks the reverse problem—inappropriately applying a consumer direction model to acute care medical services.

The high level of beneficiary satisfaction in the Cash and Counseling Demonstration program appears to result, in part, from the fact that individuals were permitted to manage services and benefits that have a predictable level of need. For many individuals, the need for personal assistance services, barring injury or an unusual event, remains fairly consistent from month to month. Consumer direction may not work effectively for other services for which the need is unpredictable. For example, when an individual needs to repair or replace a major piece of medical equipment, the costs for an individual's services would be significantly higher than usual. Or, when a physician orders a change in prescription medications or when the need for diagnostic and other acute care services changes—as is often the case for older populations and persons with specific types of conditions—this could result in the beneficiary being underfunded, depending on the individual's need for such services when the individual budget was established.

The benefits of hiring family members and friends do not extend to services unrelated to personal assistance. The ability to leverage personal relationships to identify persons willing to provide personal assistance services—a key positive aspect of Independence Plus—does not always translate into tangible benefits for managing other services. For example, using family members to provide services will not lower prescription drug costs or will not reduce the cost of primary medical care.

Federal policy makers should consider placing reasonable constraints on which services and supports are appropriate for consumer direction. The Cash and Counseling Demonstrations limited consumer direction to personal care services and HCBS waiver services. There may be reasons why 1115 demonstrations should permit consumer direction for a broader range of services than the Cash and Counseling Demonstrations. Nonetheless, policies should be developed that set clearly defined parameters on which services can be directed by consumers. This is necessary to ensure that consumer direction is not used to shift financial risk for the cost of medical care and supportive services to beneficiaries and to guard against shifting too much responsibility and burden on beneficiaries for arranging for the delivery of medical and health-related services.

- **Federal requirements and guidance for states may be insufficient to ensure that individual budgets receive adequate funding**

There do not appear to be adequate safeguards for ensuring that individual Medicaid beneficiaries will receive an individual budget that allows them to purchase the level and range of services that are subject to consumer direction. While Medicaid requires states to ensure that funding is adequate to protect the health and welfare of individual beneficiaries and the Independence Plus templates require states to define a methodology for establishing the individual budgets and provide for re-determination of the budget, there do not appear to be any practical standards for ensuring that the budget is sufficient for the services under consumer direction. There also do not appear to be objective standards for adequacy that a beneficiary could use to challenge the level of the individual budget, if they believed that the state was not providing sufficient funding for their individual budget.

CMS has not indicated minimal standards that would guarantee the adequacy of the individual budget or that would ensure that an individual budget increases over time at a comparable rate as increases in the costs of services purchased. It is possible that states could respond to pressure to balance the state budget by ratcheting down the level of the individual budget without regard for the cost of services to be purchased.

The individual entitlement to Medicaid protects access to all medically necessary, covered Medicaid services. When a person is given an individual budget, however, it could be difficult to enforce this important right. This is because it may be difficult to discern when a state's method of funding the individual budget is inadequate and thus denies Medicaid beneficiaries covered services to which they are entitled.

The practice of "discounting" when setting the individual budget may penalize beneficiaries and lead to inadequate resources. In the Cash and Counseling Demonstration program, Arkansas and Florida discounted the approved number of hours for services in a care plan before establishing a value for the plan of care at the rate paid to providers of traditional services. This means, for example, that if a plan of care would call for 100 hours of a service that is professionally managed, the state established an arbitrary discount of only paying for 90% (or some other percentage) of those hours when establishing the individual budget. Discounting is intended to reflect the fact that beneficiaries receive fewer hours of care than approved in their plan of care. This can be due to factors such as hospitalizations, times when a personal aide does not show up for work, or other situations in which an individual does not receive approved services. Consumer advocates have criticized the practice of discounting because it serves to penalize beneficiaries for not receiving services for reasons which may be beyond their control—and which increases the likelihood that they will not receive adequate funding through an individual budget to pay for all of the services they need.[19]

Budget neutrality requirements may lead to inadequate resources in states that have historically underfunded the services that are "cashed out". Longstanding federal waiver policy is to ensure that any approved programs must not cost the federal government more money than would be spent in the absence of the waiver (budget neutrality requirement). This has served as an important constraint on the cost and scope of waiver programs. The Independence Plus Initiative highlights one of the major shortcomings of this policy. Many states have historically underfunded their long-term services programs. This is well documented and can be observed by the large variation in the size of the individual budgets in Arkansas and New Jersey, both of which "cashed out" the personal care services benefit to finance their Cash and Counseling Demonstration programs. At the final evaluation of the Cash and Counseling Demonstrations, the average size of the individual budget was four times higher in New Jersey than in Arkansas for the same benefit. This disparity resulted, in part, from differences in historical spending for the personal care benefit.

The budget neutrality policy can serve to prevent a state with an Independence Plus waiver from ever addressing a past practice of underfunding long-term services and supports. If a state that has underfunded long-term services seeks a waiver, their historical spending results in a low base from which budget neutrality is calculated. Any efforts by a state to increase their financing for long-term services after receiving a waiver would be limited by the budget neutrality provisions of the waiver. Therefore, the Independence Plus Initiative that is intended to be part of the solution for improving the ways that states finance long-term services and supports could lock-in a state practice of providing inadequate funding for these services.

- **Sufficient state administrative resources are likely to be important for the ongoing success of Independence Plus programs**

Consumer direction may allow states to greatly increase beneficiary satisfaction, while decreasing the need to identify, recruit, and train sufficient numbers of personal assistance attendants. Clearly, properly implemented programs can provide benefits both for the beneficiaries and states. Nevertheless, the Cash and Counseling experience highlights the need for ongoing state support. This includes ensuring that back-up supports are provided in an emergency, monitoring and adjusting the level of the individual budget when the need for services changes, and assisting individuals with financial management activities. The final report on the Cash and Counseling program found that the cost of hiring enrollment staff is substantial and that administrative functions associated with financial management and program oversight are critical to the successful implementation of these programs and to prevent abuses.[20] States should not assume that through consumer direction programs the state can eliminate the administrative functions that currently serve to protect and support Medicaid beneficiaries with disabilities.

- **Independence Plus and the consumer direction movement continue to evolve rapidly, and this calls for federal and state resources to evaluate new and changing programs**

Representatives of people with disabilities, while supportive of the Cash and Counseling model, have questioned the appropriateness of consumer satisfaction as the primary evaluation criteria. They argue that satisfaction could reflect the fact that individuals are able to stretch limited resources further than an agency or reflect satisfaction with the person providing a service, without providing adequate information to assess the level of the individual budget or the quality of services provided.

The final report on the Cash and Counseling program found that states benefit from technical assistance in implementing the Cash and Counseling program.[21] In the three states studied, program features and policy decisions differed in many areas. As this model is implemented nationally through the Independence Plus Initiative, the consequences of different policy decisions could become clearer—if systematic evaluations are conducted to ensure that lessons can be learned across states. Since this approach to providing long-term services is still new and may not be desirable to all beneficiaries, participation in consumer direction should remain voluntary, and should not be a condition for participating in an HCBS waiver.

Federal policy makers should allocate resources to evaluating Independence Plus programs using measures that include more than beneficiary satisfaction. Federal policy makers should also conduct comparative reviews and publish emerging findings and best practices as they become available. Additionally, consumer direction should become an opportunity, but not a requirement for Medicaid beneficiaries. Federal

policymakers should amend the Independence Plus requirements to restrict states from requiring consumer direction as a condition of participating in an HCBS waiver.

CONCLUSION

Medicaid long-term services programs are evolving to meet the increased demand for home- and community-based services. Nonetheless, continued changes are needed to respond to increasing need for services, to comply with the US Supreme Court's Olmstead ruling, and to respond to consumer demands for access to home- and community-based services that meet their needs.

Federal policy makers are encouraged to continue to create incentives and guidance on how to provide for consumer direction of home and community-based personal assistance services. Through the Independence Plus Initiative states have the means to significantly increase the satisfaction with and quality of home- and community-based services. For the positive benefits of these programs to be realized, however, it will be essential that careful attention be paid to limiting the scope of services available for consumer direction to only those services that can be appropriately managed by individuals, it will be important to ensure that states are held accountable for providing adequate financing of individual plans of care, and that state flexibility is appropriately balanced with reasonable beneficiary protections.

APPENDIX: MANDATORY AND OPTIONAL HOME AND COMMUNITY-BASED SERVICES

The following describes basic program rules and explains some state policy choices related to how states provide Medicaid coverage of home and community-based services:

MANDATORY HOME HEALTH BENEFIT

In 2001, 728,000 people received Medicaid home health services at a total cost of $2.8 billion.[22] Under federal regulations, home health services are specific services provided to a beneficiary at her or his home on a physician's orders as part of a written plan of care that is reviewed every 60 days (except for medical equipment). Mandatory home health services are nursing services, home health aides, medical supplies, medical equipment, and appliances suitable for use in the home. States also can choose to provide additional therapeutic services as part of the home health benefit, including physical therapy, occupational therapy, and speech pathology and audiology services.[23] Generally, federal regulations require these services to be provided by a home health agency, or depending on the particular service, a specific type of health professional. Coverage of medical equipment such as wheelchairs and lifts, and other devices are a particularly important aspect of this benefit.

Except for the medically needy, home health services are a mandatory Medicaid benefit for persons who are "entitled" to nursing facility care.[24] In states where Medicaid has chosen to extend nursing facility care to other populations such as the medically needy, these individuals also become "entitled" to care in nursing homes.[25]

This policy is somewhat confusing, as states can condition access to the home health benefit on meeting "level of care" criteria. This means that individuals may need to demonstrate that they need a level of care provided in a nursing home in order to receive home health services. States are only permitted to impose two types of criteria: medical necessity and utilization. In practice, this means that states can require preauthorization before a service is received, whereby a medical professional must authorize the service before it is provided and states can place limits on the number of times that a service may be provided or the period of time over which it can be provided, for a given condition.[26]

Medicare policy limits access to home health services to persons who are homebound. This is not Medicaid policy. Indeed, in July 2000, the Health Care Financing Administration issued a State Medicaid Directors letter to clarify that restricting access to home health services to persons who are homebound is a violation of the Medicaid law.[27]

OPTIONAL HOME- AND COMMUNITY-BASED SERVICES

States that want to provide home- and community-based services in addition to the home health benefit can do so in two ways: covering an optional service or requesting a waiver.

- **Optional state plan services**

State plan services must be provided, when they are medically necessary, to all Medicaid beneficiaries in a state, except for the medically needy. A number of optional state plan services can be provided in home and community settings. These include: rehabilitation services, private duty nursing, physical and occupational therapy, and transportation services.

The rehabilitation services option, in particular, gives states broad flexibility. Rehabilitation services are any medical or remedial services recommended by a physician or licensed practitioner for maximum reduction of physical or mental disability and restoration of a beneficiary to his or her best possible functional level.[28] Many states cover psychosocial rehabilitation services which, when combined with personal care and targeted case management services, can meet a wide range of service and support needs of persons with mental illness. The rehabilitation option, however, is generally not used to furnish long-term services and supports to people with disabilities other than mental illness.[29]

The personal care services option is a major route through which states provide home- and community-based services. In 2001, 557,000 people received Medicaid personal care services at a total cost of $5 billion.[30] Personal care services are (unless defined differently through a waiver) services furnished to an individual who does not reside in an institution [*i.e.* a hospital, nursing home, ICF/MR, or institution for mental disease (IMD)]. The services must be authorized by a physician (or at state option, otherwise authorized) and provided by a qualified individual who is not the individual's legally responsible relative (*i.e.* spouse or parent of a minor) in the individual's home (or at state option, in another location).[31] Generally, services provided through the personal care option assist individuals with activities of daily living (ADLs) such as bathing, dressing, eating, toileting, and transferring from a bed to a chair and instrumental activities of daily living (IADLs) such as personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. Skilled services that may only be performed by a health professional are not considered personal care services.[32]

The personal care services option was first made available to states in the mid-1970s through administrative action. In 1993, however, Congress formally added this option to the Medicaid statute and allowed personal care services to be provided outside the individual's home, thus enabling individuals to participate more fully in community activities.[33] In 2001, 28 states covered personal care services under their Medicaid state plans.[34]

- **Waiver services**

Waivers allow the Secretary of Health and Human Services to "waive" certain provisions of the Medicaid law. 1115 demonstrations allow states to test new ideas of policy merit. This type of waiver has been used by states to experiment with new ways of delivering health care, frequently on a statewide basis. Home- and community-based services can be a component of 1115 waivers. For example, the state of Arizona's entire Medicaid population is enrolled in managed care through its 1115 waiver, and this waiver provides for home- and community-based services.

Home- and community-based services (HCBS) waivers, also called "1915(c) waivers", however, are the major type of waiver for providing long-term services and supports at home or in the community. These waivers allow states to provide services in only limited parts of a state (waiving the requirement that services be provided statewide), allow states to provide services to certain beneficiaries without making them available to all Medicaid beneficiaries for whom they are medically necessary (waiving the requirement that benefits be comparable from one beneficiary to the next), and allow states to cover medically needy individuals using different income and resource standards than for other Medicaid beneficiaries receiving services in the community (waiving the income and resource rules applicable in the community).[35]

HCBS waivers are intended to give states flexibility to develop and implement community-based alternatives to providing services in institutions, as long as states can demonstrate that these programs would not cost the federal government more than it would spend to care for these individuals in an institution. Eight services are explicitly included in the HCBS waiver program, and states can choose to include or exclude these services:

1) case management;
2) homemaker services;
3) home health aide services;
4) personal care services;
5) adult day health services;
6) habilitation services;
7) respite care; and
8) day treatment and other partial hospitalization services, psychosocial rehabilitation services, and clinic services for individuals with chronic mental illness.[36]

States can also seek to cover, with federal approval, other services because they are needed to prevent waiver beneficiaries from needing to be placed in an institution, such as non-medical transportation, in-home support services, special communication services, minor home modifications, and adult day care. Except in limited circumstances, room and board cannot be covered.[37]

States can operate HCBS waivers to serve the elderly, persons with physical disabilities, developmental disabilities, mental retardation, or mental illness. States may also target these waiver programs by specific illness or condition, such as technology-dependent children or persons with AIDS.[38] All states, except Arizona, have at least one HCBS waiver. Arizona is a technical exception as its 1115 demonstration waiver provides an equivalent program. As of 2001, there were 229 HCBS waivers in effect across the country.[39]

[1] *Fact Sheet: Who needs long-term care?*, Long-Term Care Financing Project, Georgetown University, May 2003.
[2] *Fact Sheet: Who pays for long-term care?*, Long-Term Care Financing Project, Georgetown University, May 2003.
[3] Spending data excludes administrative expenses, Disproportionate Share Hospital expenses, and other miscellaneous expenses. Source: CBO Baseline, March 2003.
[4] *Fact Sheet: Who pays for long-term care?*, Long-Term Care Financing Project, Georgetown University, May 2003.
[5] *Olmstead v. L.C.*, 119 S. Ct. 212187 (1999).
[6] For additional information, see, *The Olmstead Decision: Implications for Medicaid*, Kaiser Commission on Medicaid and the Uninsured, March 2000.
[7] Medically needy is an optional Medicaid eligibility group for people who are not eligible for any other (categorically needy) eligibility group. States that elect to cover medically needy individuals can provide them with fewer services than they provide to categorically needy individuals, although there are specific minimum benefit standards for the medically needy. For more information, see KCMU publication, *Medicaid Medically Needy Programs: An Important Source of Medicaid Coverage*, January 2003.
[8] 42 USC § 1396(a)(10)(A)(ii)(VI)
[9] 42 USC § 1315(a)
[10] *Understanding Medicaid Home and Community Services: A Primer*, U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000.
[11] LeBlanc, A., Tonner, C.M., and Harrington, C., *State Medicaid programs offering personal care services*, University of California: San Francisco (2000).
[12] Mahoney, K.J., Simone, K., and Simon-Rusinowitz, L., "Early Lessons from the Cash and Counseling Demonstration and Evaluation", *Generations*, Fall 2000.
[13] Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., and Doty, P., *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, Inc., June 2003.
[14] Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., and Doty, P., *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, Inc., June 2003.
[15] Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., and Doty, P., *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, Inc., June 2003.
[16] Foster, L., Brown, R., Carlson, B., Phillips, B., and Jennifer Schore, "Interim Memo—Cash and Counseling: Consumer's Early Experiences in Florida, Part II: Uses of Cash and Satisfaction at Nine Months", Mathematica Policy Research, Inc., April 2002.
[17] Foster, L., Brown, R., Carlson, B., Phillips, B., and Jennifer Schore, "Interim Memo—Cash and Counseling: Consumer's Early Experiences in New Jersey, Part II: Uses of Cash and Satisfaction at Nine Months", Mathematica Policy Research, Inc., October 2002.
[18] *Issue Brief—Cash and Counseling: Early Experiences in Arkansas*, Mathematica Policy Research, December 2000.
[19] Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., and Doty, P., *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, Inc., June 2003.
[20] Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., and Doty, P., *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, Inc., June 2003.
[21] Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., and Doty, P., *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, Inc., June 2003.
[22] M. Kitchener, et al., *Medicaid Home and Community-Based Services, Program Data, 1992-2001*., Kaiser Commission on Medicaid and the Uninsured, Forthcoming, Fall 2003.
[23] 42 CFR § 440.70.
[24] The medically needy are persons whose income before counting medical expenses is above the maximum income standard for "categorical" Medicaid coverage. For additional information, see *Medicaid*

Medically Needy Programs: An Important Source of Medicaid Coverage, Kaiser Commission on Medicaid and the Uninsured, January 2003.
[25] *Understanding Medicaid Home and Community Services: A Primer*, US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000.
[26] *Understanding Medicaid Home and Community Services: A Primer*, US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000.
[27] July 25, 2000 State Medicaid Director Letter (Olmstead Update No: 3, see Attachment 3-g), Centers for Medicare and Medicaid Services.
[28] 42 CFR §440.130(d)
[29] *Understanding Medicaid Home and Community Services: A Primer*, US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000.
[30] M. Kitchener, et al., *Medicaid Home and Community-Based Services, Program Data, 1992-2001*., Kaiser Commission on Medicaid and the Uninsured, Forthcoming, Fall 2003.
[31] 42 CFR §440.167.
[32] *State Medicaid Manual*, § 4480, Centers for Medicare and Medicaid Services.
[33] Omnibus Budget Reconciliation Act of 1993 (OBRA 93) § 13601(a)(5) or Social Security Act § 1905(a)(24).
[34] M. Kitchener, et al., *Medicaid Home and Community-Based Services, Program Data, 1992-2001*., Kaiser Commission on Medicaid and the Uninsured, Forthcoming, Fall 2003.
[35] Social Security Act § 1915(c)(3).
[36] Social Security Act § 1915(c)(4)(B).
[37] Social Security Act § 1915(c)(1).
[38] 42 CFR §435.217.
[39] Centers for Medicare and Medicaid Services, July 16, 2002.

1330 G Street NW, Washington, DC 20005
Phone: (202) 347-5270, *Fax:* (202) 347-5274
Website: www.kff.org/KCMU

Additional copies of this report (#4151) are available
on the Kaiser Family Foundation's website at www.kff.org.

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.