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Long-Term Care: Consumer-Directed Services Under Medicaid

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August 31, 2006

Abstract. This report discusses options for consumer-directed services under Medicaid; factors states need to take into account in developing consumer-directed programs; and considerations for future policy development.

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Long-Term Care: Consumer-Directed Services Under Medicaid

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Long-Term Care: Consumer-Directed Services Under Medicaid

Summary

Medicaid is a health insurance program jointly funded by the federal and state governments that pays for health care services for certain low-income individuals. Since the program's inception in 1965, Medicaid has played a vital role in providing long-term care services to individuals with a disability or long-term illness. "Long-term care services" refer to a wide range of supportive and health services for individuals with a disability or chronic illness. Medicaid primarily finances long-term care services and supports in institutions but has increasingly supported care in home and community-based settings under an optional program benefit.

States have been developing options for Medicaid beneficiaries with a disability (consumers) to manage and direct their home and community-based services including hiring their own providers, as an alternative to a traditional model of using agency-based providers. These options for consumer direction have most often included personal care services and other home and community-based services authorized under Section 1915(c) of the Social Security Act. The premise underlying consumer-direction is that the individual receiving the service is able to determine what he or she requires and can use good judgment in purchasing those services and overseeing their delivery.

The recently enacted Deficit Reduction Act of 2005 (P.L. 109-171) added a provision to Medicaid law that gives states the option of covering consumer-directed personal care services (other than room and board). Services must be based on a written plan of care, and the state's program must meet certain other criteria such as notification, assessment, and counseling of beneficiaries. This provision becomes effective January 1, 2007.

As states pursue options for consumer-direction, important questions remain: What beneficiary protections need to be built into these programs? How does one ensure the quality of consumer-directed services, and what types of services are most compatible with consumer-directed service options?

This report discusses options for consumer-directed services under Medicaid; factors states need to take into account in developing consumer-directed programs; and considerations for future policy development. This report will be updated as necessary to reflect any substantive program or policy changes.

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Long-Term Care: Consumer-Directed Services Under Medicaid

Introduction

Medicaid is a health insurance program jointly funded by the federal and state governments that serves low-income individuals including the elderly, persons with a disability, children, pregnant women, and members of families with dependent children. Eligibility requirements are based on age, income, family structure, and disability, and are determined by the states within broad federal guidelines.

Long-term care services refer to a wide range of supportive and health services generally provided on an ongoing basis for persons who have limitations in functioning because of a disability or chronic condition. Since its inception in 1965, Medicaid has played a vital role in providing long-term care services especially nursing facility care which all states must cover for individuals over age 21. Other examples of long-term care services which may be available under Medicaid include a range of home care services including personal care services or ongoing nursing care.[1] Personal care services include assisting an individual who has limitations in activities of daily living (ADLs) such as bathing, eating, dressing, and cooking.

Medicaid long-term care services are generally offered through the Medicaid state plan and/or a home and community-based (HCBS) waiver. The Medicaid state plan is the document that states submit to the federal government for approval which describes the eligibility groups and covered services. State plan services must be available statewide and must be available to all Medicaid enrollees who qualify for the service.

Under the state plan, states must provide two long-term care services: nursing facility services for individuals over age 21 and home health services for individuals who meet certain criteria. States have the option of providing several other types of long-term care services, including nursing facility services for individuals under age 21, intermediate care facility services for individuals with mental retardation (ICF/MR) (which all states have opted to provide), personal care services,[2] private duty nursing, hospice, clinic services, rehabilitation, and the recently enacted home and community-based services state plan option.[3,4] Of the services listed above,

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[1] Ongoing nursing care may be required for someone with a very significant disability, for example, an individual who requires a ventilator to breathe.

[2] Personal care services are also referred to as "personal assistance services" or "personal attendant services."

[3] Some states provide long-term care services such as adult day treatment and ongoing (continued...)

nursing facility and ICF/MR services are generally categorized as "institutional" services because individuals reside in and receive health care services in a specific type of certified facility. Those facilities are paid a rate that covers the individual's room, board and services. The other Medicaid services listed above are categorized as "home and community-based" services. The individual generally lives in the community (e.g., home or apartment). Medicaid pays only for that specific type of service (e.g., an hour of personal care), and does not pay for the room and board of that individual.

States also have the option of requesting permission from the federal government to provide additional home and community-based services for individuals who would otherwise be in an institution. These other services may be offered as a supplement to, or instead of, those optional services available through the state plan. This option is referred to as a "Home and Community-Based (HCBS) waiver" which is authorized under Section 1915(c) of the Social Security Act. Unlike most services offered as part of the Medicaid state plan, the HCBS waiver allows states to limit the number of individuals served and to offer the services on a less-than-statewide basis. In July 2003, there were 275 such waivers in operation in all states except Arizona.[5] These waivers include a broad range of services such as case management services, homemaker/home health aide services, personal care services, adult day health services, habilitation services, respite care, home modifications, and home-delivered meals.[6]

Based on FY2004 data, total Medicaid expenditures for long-term care services were $98.0 billion ($63.4 billion for services in institutions and $34.6 billion for

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[3] (...continued)
mental health services under the categories of clinic and rehabilitation services under the Medicaid state plan.

[4] For a description of the home and community-based services state plan option, see CRS Report RS22448, Medicaid's Home and Community-Based State Plan Option: Section 6086 of the Deficit Reduction Act, by K. Tritz.

[5] In a few cases, states have funded long-term services and supports through a Section 1115 (Social Security Act) research and demonstration waiver. For example, Arizona offers similar long-term care services under a Section 1115 research and demonstration waiver.

[6] *Adult day health services* refers to a type of service that provides assistance to multiple individuals with a disability in a group setting which generally operates during the daytime hours. Generally the individuals who receive services in this type of setting have a severe cognitive or physical disability. *Habilitation* services means those services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings. *Respite* services provide temporary services to an individual with a disability to give the normal caregiver a break from providing care. *Home modifications* refer to items such as a ramp to a home or bars installed in the shower that someone can hold onto while bathing.

services provided in home and community-based settings). Long-term care spending represents 37% of total Medicaid service expenditures.[7]

Many Medicaid beneficiaries (consumers) receive their long-term care services from agency-based providers that are certified to provide Medicaid services.[8] In some cases, there may also be a case manager who plays a role in coordinating and overseeing the consumer's long-term care services. Depending upon the structure of the state's program, the case manager or the agency-based provider may consult with the consumer, assess the consumer's needs, decide what services are needed, and monitor the care provided.

The agency-based provider is required to have an agreement with the state Medicaid agency and in the case of personal care services, workers are referred to as "direct care workers."[9] Depending upon the state's rules and the specific provider, the consumer may have varying degrees of ability to determine:

- who comes into the home to provide the service (e.g., is this someone they know and/or trust);
- what time of day the care is received;
- where that direct care worker can go with the individual (e.g., school, church, work, medical appointments);
- how much the worker is paid; and
- the process for getting a back-up worker when the regularly scheduled worker is unavailable.

Many consumers have expressed an interest in increasing their ability to direct and manage some of these key elements of the assistance they receive. State and federal policymakers have responded to this interest by developing opportunities for consumer-direction, starting with non-Medicaid programs such as state-funded long-term care programs and more recently in Medicaid long-term care programs, as described in this report.

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[7] CRS analysis of the Centers for Medicare and Medicaid Services, Form 64, FY2004 data. Institutional long-term care expenditures include nursing facilities, mental health facilities, and intermediate care facilities for individuals with mental retardation. Home and community-based long-term care expenditures include home health, home and community-based waivers under Section 1915(c) of the Social Security Act, personal care services, hospice, and home and community care for functionally disabled elderly individuals under Section 1929 of the Social Security Act.

[8] In this report, the term *agency-based providers* refers to health and/or social service agencies (both public and private) that provide long-term care services such as personal care to individuals with a disability or chronic illness.

[9] May also be referred to as a personal care attendant, attendant or aide.

Precedents for Consumer-Directed Programs

Although consumer-directed long-term care services under the Medicaid program have increased significantly over the last decade, it is not a new concept. Several programs both in the United States and other countries have preceded the current interest in Medicaid consumer-directed options and have served as models for comparison.

Examples in the United States

In the United States, consumer-direction began in long-term care programs other than Medicaid. Prominent examples have included programs in the Department of Veterans Affairs (VA) and some programs operated by states. For the past 30 years, the VA has operated the Housebound and Aid and Attendance programs which provide additional cash benefits to qualified veterans or their surviving spouses if they require ongoing personal care services, are housebound or require nursing home services.[10] This cash benefit provides the veteran with additional monthly income to purchase needed services and supports. There are no federal restrictions on how this additional cash benefit must be used. The veteran with a disability can determine how to spend the benefit; for example, he or she can hire friends or family members to provide personal care services.

In addition to the federal VA programs, several states, including California, Maine, Michigan, Oklahoma, Oregon, New York and Washington, have long histories operating state-funded, consumer-directed personal care services.[11] One of the more well known of these consumer-directed programs is California's In-Home Supportive Services (IHSS) program which has been in operation since 1979. IHSS did not include federal funding in its consumer-directed program until California adopted the Medicaid personal care option in the state plan in 1993. IHSS serves an estimated 200,000 consumers annually and provides up to 283 hours of service each month including personal care, household, paramedical, protective supervision and medical transportation.

IHSS allows the consumer to choose his or her direct care worker including a family member. The state then contracts with this direct care worker as an independent Medicaid provider (described in more detail later in this report). IHSS

[10] The amount of the VA cash benefit follows different rules depending on whether or not the disability is service-related. For service-related disability (compensation), the amount is set according to the living situation and degree of disability. For non-service related disability (pension), the amount is equal to the difference between the individual's countable income and a yearly standard set by law. Effective Dec. 1, 2005, the annual standard for a housebound veteran with no dependents was $12,929, and $17,651 for a veteran who required special in-home care.

[11] U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Oct. 2000. (Hereafter cited as *HHS-ASPE, Primer*). See also L. Williams and V. Dize, *Consumer-Directed Home and Community Based Services for Older People: An Overview of State Programs,* National Association of State Units on Aging, Apr. 2001

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is administered by county-based public authorities which provide support to both consumers and the large number of independent Medicaid providers by: (1) establishing a registry and referral system for consumers, (2) training both providers and consumers, and (3) serving as the employer of record for the independent providers for purposes of collective bargaining. Under IHSS, the consumer is still able to select, hire, direct and fire his or her worker.[12] Within IHSS, California also allows counties the option of contracting with an agency to provide personal care services under an agency-based model for individuals who are deemed unable to participate in consumer-direction. Twelve counties exercise this option. A 1996-1997 telephone survey of IHSS participants compared individuals who directed their long-term care services versus those who received agency-based services and found that individuals who participated in consumer-directed models reported more positive outcomes in the areas of safety, unmet needs and service satisfaction.[13]

Examples from Other Countries

Several European countries, including Germany and England, have developed programs that provide cash allowances to individuals based on their level of need to allow them to purchase long-term services and supports.[14] For illustrative purposes, key features of the consumer-directed, long-term care programs operating in Germany and England are described below.

Germany. In 1995, Germany established a universal, social insurance program for long-term care financed by mandatory employer and employee contributions. Eligibility for the program is not contingent on the individual having a certain level of income or assets. However, there is a maximum per-person benefit based on the individual's need. Individuals who require long-term care can choose between institutional care, home care, a cash benefit (which is about one-half the value of the home care benefit), or a combination of home care services and a cash benefit. In 1998, 76% of beneficiaries chose a cash benefit. The cash benefit option is not

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[12] P. Kumar, *California's Public Authorities: An Emerging Model for Consumer-Directed Personal Assistance Services Comes of Age*, American Rehabilitation, vol. 24, issue 4, winter 1998, p. 15.

[13] A.E. Benjamin, et al., *Comparing Consumer-directed and Agency Models for Providing Supportive Services at Home*, HSR: Health Services Research 35:1, Part II, Apr. 2000, pp. 351-366. In August 2004, California received approval for an *Independence Plus* Section 1115 waiver to provide self-directed personal care assistance for individuals who are elderly or have blindness or a disability. The waiver is statewide, and includes approximately 66,000 Medicaid beneficiaries who need personal care or other supports and who select a spouse or parent to provide those services to them. This program was previously operating through a state-funded portion of the In-Home Supportive Services (IHSS) program known as the "Residual Program." The Residual Program was to be eliminated from the state's budget. The approval of the Section 1115 waiver preserved these services for Medicaid beneficiaries.

[14] For a comparative summary of long-term care models in Europe compiled by the European Union, see *Social Protection in the Member States in the EU Member States and the European Economic Area Situation on January 1st 2002 and Evolution* at [http://europa.eu.int/comm/employment_social/missoc/2002/index_chapitre12_en.htm].

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restricted in its use of funds and has minimal federal monitoring.[15] Persons choosing the cash benefit choose how to direct and organize their care using the cash they receive.

England. Since 1996, England has offered cash payments to consumers as an option to direct the community-based services they need. The cash payment option is one type of program within a larger social services grant provided to localities referred to as "Community Care." In the cash payment option, the localities have a significant amount of decision-making to establish the eligibility criteria, make consumers aware of the program, and establish the amount given to the individual within broad national guidelines. There is no minimum or maximum on the amount paid to the individual, but it must be less than placing that particular individual in a residential facility. There are also restrictions on hiring close family members to provide care.[16]

An Overview of Consumer-Directed Medicaid Services

The underlying premise of consumer-direction is that the individual receiving the service knows what he or she requires and will use good judgment to purchase those services and oversee their delivery. In a 2001 *Health Affairs* article, A.E. Benjamin listed five factors that have influenced policymaker interest in developing options for consumer-directed services.[17]

- **Advocacy.** For decades, adults, primarily those with physical disabilities and under 65 have been strong advocates of increasing their ability to manage and direct their own services.

- **Olmstead decision.** In 1999, the U.S. Supreme Court, in *Olmstead v. L.C.* (527 U.S. 581) held that states had a legal obligation (within certain specified limits) to serve individuals with a disability in a setting that reflected the individuals' preferences.[18] States' responses

[15] R. Stone, *Providing long-term care benefits in cash: Moving to a disability model*, Health Affairs, Nov/Dec 2001 and CRS Report RL30549, *Long-Term Care for the Elderly: The Experience of Four Nations* by Mayra De La Garza and Carol O'Shaughnessy.

[16] J. Wiener, et al., *Consumer-Directed Home Care in the Netherlands, England, and Germany*, Public Policy Institute, AARP, Oct. 2003.

[17] A.E. Benjamin, *Consumer-Directed Services at Home: A New Model for Persons with Disabilities*, Health Affairs, Nov./Dec. 2001, pp. 80-95.

[18] The case involved two women both with a cognitive and psychiatric disability who were residing in a psychiatric unit of a hospital. Although the womens' doctors stated that they could be served in a community-based setting, they remained institutionalized. The women sued the state alleging that the state violated Title II of the Americans with Disabilities Act. The Supreme Court found that states are required to provide community-based treatment for persons with a disability when the state's treatment professionals determine that such placement is appropriate, the affected individual does not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to

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to the *Olmstead* decision have focused attention on increasing the capacity of Medicaid home and community-based services as an alternative to institutions, such as nursing homes, and developing options that respond to consumer preferences.

- **Cost.** Both federal and state governments face increasing Medicaid long-term care costs. These growing expenditures have created a willingness by some policymakers to test alternative approaches which change how Medicaid services are delivered and provide better services at a lower or equal cost to the Medicaid program.

- **Workforce shortage.** Many states are facing critical shortages in the direct long-term care workforce. Some consumers do not receive the number of service hours they are assessed to need because the provider agency cannot find staff to deliver the service. This is a particular challenge in rural areas. Consumer-directed models of delivering services may expand the labor pool by allowing a consumer to select and/or hire a friend, family member or neighbor to provide direct care services. Such persons may not have otherwise been employed by a traditional home care agency.[19]

- **Changing perceptions.** Many believe that providing care to persons with a disability and to frail older persons should move from a purely medical model of care to one that considers other factors (i.e., a social model of care) such as the individual's involvement in the community or his or her interest in entering the workforce. Consumer-directed models can create a flexible array of services that can be responsive to these other factors, in addition to providing necessary medical and social services in the home.

Consumer-direction is not one model of service delivery but a variety of approaches with a common goal of moving the decision-making authority for services closer to the consumer who receives those services.[20] Consumer-directed

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[18] (...continued)
the state and the needs of others with a disability.

For additional information, see the following reports: National Conference of State Legislatures, *The States' Response to the Olmstead Decision: How are States Complying?* at [http://www.ncsl.org/programs/health/forum/olmsreport2003.pdf] and CRS Report RL31401, *The Americans with Disabilities Act: Supreme Court Decisions*, by Nancy Jones.

[19] For additional information on the supply and demand for long-term care workers see HHS, Assistant Secretary for Planning and Evaluation (ASPE) *The Future Supply of Long-term Care Workers in Relation to the Aging Baby Boom Generation: Report to Congress*, May 14, 2003 at [aspe.hhs.gov/daltcp/reports/ltcwork.pdf].

[20] This report does not discuss "consumer participation" in Medicaid long-term care services. Consumer participation may include consumer representation on the provider agency's board of directors, consumer surveys to evaluate the quality of the services, or
(continued...)

Medicaid long-term care programs have most often included personal care services, but some programs have included other categories of services (e.g., adult day health, respite) particularly for individuals with a developmental disability.[21]

Two of the more common types of consumer-directed approaches are described below. This description does not thoroughly discuss each approach, but provides a general overview of how many consumer-directed programs have been structured.

- **Individualized budget.** In an individualized budget, the state establishes a total dollar value for the services needed by the individual. The state contracts with an organization, such as a Medicaid provider, to track the individual's budget and, in some cases, to employ the direct care workers who are selected by the consumers. However, within the amount of the individual's budget, the consumer has discretion over what services he or she will receive (generally within broad state guidelines), who will provide those services, and how much that direct care worker will be paid.

- **Direct cash.** In the direct cash approach, the state also establishes a total dollar value for the services needed by the individual; however, the cash allotment is provided directly to the consumer rather than the provider. The consumer recruits, hires and manages the direct care worker. The direct care worker is employed by the consumer, does not have to be a certified Medicaid provider and is not required to have a written contract with the state. The state oversees the program but takes on a very different role as described later in this report.

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Agency-Based vs. Consumer-Directed Long-Term Care Programs

Consumer-directed long-term care models differ significantly from an agency-based approach in a number of areas, including program structure and policies. These differences are summarized in **Table 1**.

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[20] (...continued)
peer-delivered services.

[21] In general, *developmental disability* refers to conditions that occurred before the age of 22 that impair cognition and functioning. Some examples of developmental disabilities include mental retardation, autism, Downs Syndrome, fetal alcohol syndrome or head injury.

Table 1. Comparison of Agency and Consumer-Directed Personal Care Models

Feature	Agency-based provider model	Consumer-directed model
Services provided	A prescribed number of service hours are authorized by the state or agency.	Variable. Some programs use an authorized number of service hours. Other programs provide cash to purchase goods and services, with the amounts of services and number of hours available dependent on the prices paid for services.
Consumer screening	None.	Variable. Some programs have no screening. Others may screen the consumer for his or her financial competency in managing an individualized budget or the direct cash option.
Hiring legally responsible family members as a provider[a]	Generally not permitted.	Variable. In some states it is not permitted. Other states permit this but use state-only funds to pay for these services. Other programs have received approval through a Medicaid waiver to use Medicaid funds to hire a legally responsible family member. Starting in January 2007, states that choose to offer a consumer-directed model under Section 1915(j) of the Social Security Act may pay legally responsible family members as providers.
Role of case manager (service consultant)	Variable. Some states have no case managers as part of personal care programs. When there is a case manager, the duties often include assessing the need for services and locating, managing, coordinating and monitoring those services.	Variable depending on the type of program. Generally, the consumer has more independence and responsibility and assumes many of the functions of the case manager. The case manager (sometimes referred to as a "service consultant") may take on other functions such as education, guidance, and reviewing a consumer's expenditure plan and receipts for purchased goods and services.
Supervision of direct care worker	Agency	Consumer; or in some programs the consumer receives support from a service consultant.
Fiscal responsibilities	Agency	Variable. May be handled by the county, state, a contracted intermediary, or the consumer.
Degree of consumer choice	Variable	In most cases there is a high degree of consumer choice.[b]

a. A legally responsible relative is generally a spouse or the parent of a dependent child, but may include others depending on state law.

b. In California, most Medicaid beneficiaries are automatically assigned to a consumer-directed model of services.

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Scope of Consumer-Directed Long-Term Care Initiatives

It has generally been difficult to get a comprehensive list of all consumer-directed programs because the definition of consumer-direction is not consistent, and there are many different program authorities. There have been some attempts to get general information about the size and scope of consumer-directed programs. A recent inventory (released in April 2006) reported that all states except Mississippi had either operational or planned consumer-directed Medicaid long-term care programs. These programs vary in the size of the project (ranging from a pilot project to a statewide program) and in the specific disability group covered (some focus only on individuals with developmental disabilities; others serve all disability groups).[22]

Experience of Different Disability Groups

The consumer-direction principles are the same across types of disabilities. However, different groups of individuals with a disability have developed different initiatives to fit their specific needs and the services they receive. For individuals with a physical disability and the elderly, consumer-directed programs have generally focused on personal care services. For individuals with a developmental disability, consumer-direction has been referred to as "self-determination" and has often included other long-term care services in addition to personal care services such as respite and adult day health. For some individuals with a developmental disability, family members may also have a role directing services. For individuals with a serious and persistent mental illness, opportunities for consumers to direct their own services have not been as prevalent. There is a significant and growing interest in consumer-empowerment, peer-support services, and peer participation on the treatment team,[23] but programs for consumers with a mental illness to manage their services or receive a flexible array of services through an individualized budget are not as widespread or well-developed as programs for other disability groups.

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[22] B. Spillman, et al., *Beyond Cash and Counseling: An Inventory of Individual Budget-based Community Long-term Care Programs for the Elderly*, Kaiser Commission on Medicaid and the Uninsured, Apr. 2006.

[23] Peer-support services is a model of providing mental health services where individuals who also have a psychiatric disability and are in recovery are trained to assist other consumers in skill building, goal setting, problem solving. They also serve as a role model for the consumers they work with. The goals of peer participation on a treatment team are similar to peer support services but may involve a peer working jointly with other mental health professionals to provide services to a consumer.

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Relevant Medicaid Options

Current law permits many forms of consumer-direction in Medicaid home and community-based long-term care services. States may offer consumer-direction as part of certain Medicaid state plan services, managed care programs, home and community-based waivers, and research and demonstration waivers. The specific features of the consumer-directed program govern whether the state is able to implement consumer-direction through its existing Medicaid state plan or by requesting permission from the federal government through a waiver.

There is relatively little data available on the number of states that are operating consumer-directed programs under Medicaid. As described earlier, one study found consumer-directed programs in operation or planned in all states except Mississippi. CMS does not collect data about specific consumer-direction policies on Medicaid state plan services or the 275 home and community-based waivers in operation as of July 2003. In addition, the definition of consumer-direction varies widely so that independent surveys of states' consumer-direction programs yield different results. States' options for consumer-direction programs under the Medicaid state plan and waivers are discussed in more detail below.

Medicaid State Plan Services

States may opt to cover personal care services under their Medicaid state plans. In March 2005, 35 states and the District of Columbia offered the optional personal care benefit to at least some Medicaid beneficiaries.[24] Under this option, the Centers for Medicare and Medicaid Services (CMS) explicitly permits consumer-direction of personal care services. The CMS State Medicaid Manual specifies, "Medicaid beneficiaries may hire their own provider, train the provider according to their personal preferences, supervise and direct the provision of the personal care services and, if necessary, fire the provider." However, the state Medicaid agency maintains responsibility for monitoring service delivery and ensuring that qualified providers are delivering the personal care services.[25] The state is not permitted to provide Medicaid funds directly to a consumer to pay for the personal care services.

Some states permit friends and non-legally responsible family members[26] to become either employees of a Medicaid provider agency or become an independent Medicaid provider. If the friend or family member becomes an employee of the provider agency, he or she would have to take all of the training required by the agency and may be asked to provide services to other individuals who are not family members. Another option is for the friend or family member to become an independent Medicaid provider.

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[24] Centers for Medicare and Medicaid Services, *Medicaid at-a-Glance*, 2005, CMS-11024-05.

[25] Centers for Medicare and Medicaid Services, *State Medicaid Manual*, CMS-45 Section 4480.

[26] Generally, non-legally responsible family members include all individuals except spouses and parents.

An independent Medicaid provider is not tied to a specific agency or business, but is still permitted to receive reimbursement directly from Medicaid for providing services. To qualify as an independent Medicaid provider the individual must meet the state's licensure requirements (if any) or state-prescribed qualifications and have a contract with the state Medicaid agency to provide Medicaid services. States may allow a variety of professionals or paraprofessionals to become independent Medicaid providers including speech therapists, nurses, radiologists and — most relevant for this discussion — direct care workers. For example, in the Washington and Michigan personal care programs, about one-half of the independent Medicaid providers were family members.[27] In cases where a friend or family member is the independent Medicaid provider, the consumer may have a considerable amount of discretion over key elements of the services, but the state establishes the reimbursement rate and pays the family member directly. The consumer is generally not permitted to change the hourly rate paid to the direct care worker, manage a flexible array of services within a particular dollar level, or receive payment directly from the state to pay for his or her personal care services. These activities are done by the state or the Medicaid provider.

The home health benefit of the Medicaid state plan also provides personal care to Medicaid beneficiaries and is a mandatory state plan service for individuals who are entitled to nursing facility services. However, the prescriptiveness of the federal certification requirements for home health providers limits a state's flexibility to develop opportunities for individuals to direct their own care and hire non-traditional providers under the home health benefit.[28]

Starting in January 2007, states will also have the option of covering certain home and community-based services (including personal care and related services) under the Medicaid state plan under the authority of Section 1915(i) of the Social Security Act. Under this provision, states may give individuals the option of directing their services. Elements of this self-directed option must include an individualized assessment, a service plan, an individualized budget, and a process that assures service quality.

Medicaid Home and Community-Based Waivers

A more commonly-used method for providing consumer-directed long-term care services is under the home and community-based (HCBS) waiver authorized under Section 1915(c) of the Social Security Act. The HCBS waiver program provides a broad array of services to individuals who would otherwise be in an institution including homemaker/home health aide services, personal care services, respite care, adult day health and home-delivered meals. States have significant flexibility in identifying and defining services that will be covered under HCBS waivers. The state must identify the covered services in its waiver application to CMS including who the providers will be, and how the payment rates will be established.

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[27] J. Wiener et al., "Home and Community-Based Services in Seven States," *Health Care Financing Review,* Mar. 22, 2002.

[28] *HHS-ASPE, Primer.*

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Under the HCBS waivers, a state may provide significant flexibility allowing the consumer to select friends and non-legally responsible family members as independent Medicaid providers similar to the option described above in the Medicaid state plan section. The state may also establish an individualized budget and give the consumer significant flexibility with respect to the specific services covered and the rate to be paid to providers so long as these rates fall within the budgeted amount. Under an HCBS waiver, the state is not permitted to provide Medicaid funds to a consumer directly to pay for the personal care services. As discussed above, of the 275 waivers in operation as of July 2003 there was no data regarding the number that are providing consumer-directed programs.

Medicaid Managed Care

Consumer-directed programs have also been developed under Medicaid managed care although they occur less frequently than under the state plan option or under HCBS waivers. Under Medicaid managed care, the state contracts with a plan(s) to provide an agreed-upon set of benefits. Generally, the state establishes fixed, prospective, monthly, per-person payments rate(s) referred to as a "capitation" payment for the services identified in the managed care contract. The managed care organization is responsible for selecting and paying the service providers, and under some circumstances can use savings from the program to provide enhanced services to beneficiaries.[29] A few states provide Medicaid long-term care services to beneficiaries through a managed care program.

The ability of the managed care organization to select and pay service providers and provide additional services from program savings creates opportunities for consumer-direction. For example, the managed care program could hire the direct care worker who is selected by the consumer, and permit the consumer to manage and train that worker. The managed care program could also use program savings to provide a flexible benefit to consumers for the purpose of increasing their independence. For example, one consumer could purchase an assistive device or piece of equipment while another could purchase transportation services. A survey of 45 Medicaid managed care plans that included long-term care services found that over half practiced some form of consumer-direction, and 32% of the programs surveyed allowed individuals to hire and fire their own workers.[30]

It is also possible for Medicaid managed care programs to provide a cash benefit to beneficiaries to pay for services. However, payments directly to beneficiaries may be counted as resources in determining eligibility for the Supplemental Security Income (SSI) program unless they received a waiver from the Social Security Administration using the authority of Section 1110(b) of the Social Security Act. Counting these payments as additional resources could affect their eligibility for both SSI and Medicaid because eligibility determinations for these two programs are often linked.

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[29] Savings can be used to provide additional services only if the state has received a waiver from CMS of Section 1915(b)(3) of the Social Security Act.

[30] M. Meiners, "Consumer-Direction in Managed Long-term Care: An Exploratory Survey of Practices and Perceptions," *The Gerontologist*, Feb. 2002.

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Section 1115 Waiver

Finally, a Section 1115 waiver offers states broad flexibility in the design of a consumer-directed long-term care program.[31] Under the state plan, and HCBS waiver provisions described above, states cannot directly pay beneficiaries or their representatives.[32] However, a state may get approval for these practices and a variety of other activities under a Section 1115 waiver, including (1) providing cash directly to individuals; (3) changing the Medicaid eligibility requirements (e.g., allowing an individual to have more income and still qualify for Medicaid); or (3) waiving the requirement that the state only pays those agencies that have provider agreements with the state.[33]

Independence Plus Initiative

Through the Medicaid state plan and waivers described above, states have been permitted to develop and implement many different consumer-directed programs. To assist states in further developing these programs and to streamline the waiver process, on May 9, 2002, the Bush Administration released the *Independence Plus template*. The Independence Plus template does not change current Medicaid law; it facilitates requests by states for waivers to develop consumer-directed programs by outlining the specific waiver application elements required of states and by providing technical assistance on key features of a consumer-directed program.

The Independence Plus template also established a minimum set of program design features that states must document in their waiver application for a consumer-directed program in order to receive approval from CMS. The six features comprise: a person-centered planning process, an individualized budget, fiscal intermediary services, a support broker who serves at the direction of the consumer, a quality assurance and quality improvement system, and consumer protections such as an emergency back-up system and an incident management system.

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[31] Authorized under Section 1115 of the Social Security Act, this research and demonstration waiver authority allows the Secretary of HHS to waive many provisions of Medicaid law. The waiver must be budget neutral over five years, meaning that it cannot cost the Medicaid program any more under the waiver than the state would have spent in the absence of the waiver.

[32] Section 1902(a)(32) of the Social Security Act and 42 CFR 447.10(d) specify who can receive payment for Medicaid services. An exception is allowed for certain beneficiaries to pay for physician or dentist services; see 42 CFR 447.25 for additional information.

[33] Some of the individuals who are receiving cash payments directly may also be receiving cash benefits through the Supplemental Security Income (SSI) program — a means-tested program for individuals with a disability who are low-income, but also have a small amount of assets/resources. Payments directly to individuals for long-term care services under Medicaid would not be considered income, but in some cases would be counted as a resource. For the consumer-direction programs in Arkansas, New Jersey, Florida, and Oregon, the Commissioner of the Social Security Administration has used the authority of Section 1110(b) of the Social Security Act to waive payments to Medicaid beneficiaries for consumer-directed services from being counted as resources for the purposes of SSI eligibility (63 Federal Register 59902 and 66 Federal Register 9406).

There are two ways to establish an Independence Plus Initiative depending on the state's objectives. Waiver templates have been developed for both the Section 1915(c) and 1115 waivers. The state must submit a Section 1915(c) waiver (HCBS) if it wants to provide services through an individualized budget, or have individuals manage some or all of their HCBS waiver services (e.g., respite, transportation, personal care services, or home modifications). The state *is required to* submit a Section 1115 waiver if it wants to (1) provide cash directly to individuals, (2) change the Medicaid eligibility requirements, or (3) waive the requirement for provider agreements (i.e., use non-Medicaid providers).

Self-Directed Personal Care Services Option Enacted Under the Deficit Reduction Act of 2005

The recently enacted Deficit Reduction Act (P.L. 109-171) added a provision under Section 1915(j) of the Social Security Act to permit states to cover personal assistance services under a self-directed program. The self-directed program must allow beneficiaries to exercise "choice and control over the budget, planning, and purchase of self-directed personal assistance services." Other requirements include an assessment of the beneficiary's need, the availability of a support system to counsel beneficiaries, a written service plan, an individualized budget, and appropriate quality assurance and risk management techniques. Individuals may qualify for this self-directed program if they would require and receive personal care services under the Medicaid state plan or home and community-based waiver. The state may offer this self-directed personal assistance services program on a less than statewide basis, and can target the program to certain populations. In addition, beneficiaries may pay legally liable relatives to provide the services. This provision is effective on January 1, 2007.

Self-Directed Support Corporation

Another approach to consumer-directed services operating under current Medicaid law in a few states is known as the Self-Directed Support Corporation (SDSC).[34] The SDSC approach has generally been used by interested friends and family of a consumer with a significant cognitive disability as an alternative to the traditional agency-based system. The SDSC generally consists of a small group of individuals who know the consumer and establish a legally recognized organization to assist that consumer in coordinating and receiving his or her services. With the state's permission, the SDSC either becomes a licensed provider of Medicaid services for one individual with the ability to hire and supervise staff, or operates under the auspices of a third-party agency which is the employer and certified Medicaid provider but acts at the direction of the Self-Directed Support Corporation.[35]

[34] This approach for consumer-directed services originated in British Columbia, Canada, and is also referred to as a "Microboard ©".

[35] For additional information, with questions and answers and information about state projects, see the Inclusion Research Institute's website at [http://www.self-determined.org].

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Although SDSC programs are not widespread, interest and activity are growing. States active in this area include Maryland, Michigan, Missouri, Tennessee and Oregon. For example, Tennessee has formed The Tennessee Microboard Association to provide assistance and training for interested individuals and families.[36]

Recent Research and Development Initiatives

Highlighted below are several research and demonstration initiatives that demonstrate various approaches for consumer-directed long-term care services. These initiatives many of which started in the late 1990's expanded the options under a consumer-directed model by permitting consumers to pay workers directly and to manage a flexible benefit within a given dollar value. These initiatives have quickened the pace of development of Medicaid consumer-directed options by providing funding and technical assistance to states. Some of the initiatives described below have limited information about the extent of implementation, the numbers of individuals served and the findings or outcomes from the initiative; this information is provided or referenced whenever possible.

Cash and Counseling Demonstration

The Cash and Counseling Demonstration is one of the most well-known and largest demonstrations in consumer-directed long-term care under Medicaid. In 1996, the Robert Wood Johnson Foundation partnered with the Department of Health and Human Services, Assistant Secretary for Planning and Evaluation (HHS, ASPE) and CMS to conduct the demonstration in Arkansas, Florida and New Jersey.[37] The Robert Wood Johnson Foundation and ASPE provided funding to implement and evaluate the demonstration, and CMS granted Section 1115 waivers to permit these states to pay consumers directly and employ legally responsible relatives as direct care workers.

The purpose of the demonstration was to assess the impact of providing a cash allotment to an individual for managing and directing his or her own personal care services.[38] Participation in the demonstration was voluntary. Individuals were randomly assigned to either receive the cash allotment as part of a treatment group, or use a traditional agency-based provider as part of a control group. **Table 2** describes the primary features of each state's demonstration.[39]

[36] For additional information, see [http://www.tnmicroboards.org/].

[37] Oregon implemented a similar demonstration separate from the Cash and Counseling Demonstration in Dec. 2001.

[38] [http://www.hhp.umd.edu/AGING/CCDemo/].

[39] Ibid.

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Table 2. Overview of Cash and Counseling Demonstration

	Arkansas	New Jersey	Florida
State program name[a]	Independent Choices	Personal Preference	Consumer-Directed Care
Implementation date [b]	December 1998	November 1999	June 2000
Authority for personal assistance services [b]	Medicaid state plan: personal care option	Medicaid state plan: personal care option	Section 1915(c) Home and Community-Based Waiver services except case management/ support coordination
Populations served[a]	Elderly and adults with a physical disability	Elderly and adults with a physical disability	Elderly, adults with a physical disability and children with a developmental disability
Territory covered[a]	Statewide	Statewide	Central and South Florida: Elderly and adults with a physical disability Statewide: Children and adults with developmental disabilities
Median Monthly Allowance [b]	$313	$1,097	$829 (adults) and $768 (children)
Formula for determining cash allotment [b]	$8 per hour in care plan multiplied by provider-specific discount factor.	Value of care plan minus 10 percent set aside for fiscal agent and counseling services.	Claims history or discount factor multiplied by the value of care plan. Care plans were used for individuals with developmental disabilities, those with unstable claims history, or if the care plan value was at least $50 per month more than claims history.
Final caseload (for evaluation)[a]	2,008 persons	1,762 persons	2,820 persons

a. University of Maryland, Center on Aging, Cash and Counseling At-a-Glance, at [http://www.hhp.umd.edu/AGING/CCDemo/ataglance.html].

b. B. Carlson, et al. *Effect of Consumer Direction on Personal Care and Well-Being in Arkansas, New Jersey and Florida*, Mathematica Policy Research, Inc. May 16, 2005 [http://www.mathematica-mpr.com/publications/pdfs/consumerdirection3states.pdf].

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Under the Cash and Counseling Demonstration, each state gave the consumer a monthly allotment to pay for personal care services according to a budget developed by the individual and approved by the state. The individual hired, supervised, and managed the services provided by the direct care worker(s). The individual was also permitted to save money from the allotment to purchase items that increased his or her independence (e.g., microwave, accessible ramp).

Mathematica Policy Research, Inc. (MPR) has released findings from its Cash and Counseling demonstration evaluation. MPR found that participants in the demonstration as compared to a control group (1) were generally more satisfied with the services they received; (2) reported a higher quality of life; (3) had fewer unmet needs for personal care, household activities, transportation, and assistance with routine health care; (4) received more paid care (especially adults under age 65); and (5) did not have more adverse events or health problems and, in some cases, had fewer health problems.[40]

MPR also released findings on the effect of Cash and Counseling on Medicaid and Medicare costs. MPR found that Medicare expenditures did not significantly change. For Medicaid, the evaluation looked at two years of expenditures following an individual's enrollment; the demonstration generally increased personal care expenditures and total Medicaid expenditures, as described in more detail below.

- **Effect on Medicaid personal care expenditures for Arkansas and New Jersey):** Medicaid personal care expenditures for individuals enrolled in the Cash and Counseling project were higher than those in the control group and they received more paid care. The study attributes this difference to the control group receiving fewer hours of personal care than expected due, in part, to labor shortages.

- **Effect on Medicaid Home and Community-Based Waiver Expenditures for Florida**: Medicaid home and community-based waiver expenditures were higher for program participants than for the control group. The study indicates that the higher costs may have resulted from individuals being assessed as needing more hours of care when the spending plan was initially developed.

- **Effect on Medicaid expenditures for other long-term care services:** The Cash and Counseling demonstration showed some savings to services such as nursing facility, home health services, waiver services, and transportation. However, savings were not consistent across both the years of the evaluation and for all of the demonstration states.

- **Effect on total Medicaid expenditures:** In the three demonstration states, total Medicaid expenditures for individuals enrolled in the

[40] B. Carlson et al., *Effect of Consumer Direction on Adults' Personal Care and Well-Being in Arkansas, New Jersey, and Florida,* Mathematica Policy Research, May 16, 2005, at [http://www.mathematica-mpr.com/publications/pdfs/consumerdirection3states.pdf].

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> Cash and Counseling Demonstration were higher in the first year than the control group. In the second year, for Arkansas, there was no significant difference between the two groups in total Medicaid expenditures. In New Jersey and Florida, the expenditure differences persisted — total Medicaid costs for demonstration participants were also higher in year two.[41]

The experience of the three states led the Robert Wood Johnson Foundation to award additional funding to the Boston College, Graduate School of Social Work in the fall of 2002 to assess if other states would be interested in replicating the demonstration. Based on this assessment, in January 2004, the Robert Wood Johnson Foundation announced a $7 million grant program for the replication and expansion of the Cash and Counseling demonstration. In October 2004, eleven new states received this three year grant including Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia.[42] ASPE and the HHS, Administration on Aging have also provided funding for the expansion of this initiative.

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Self-Determination Initiative

In 1997, the Robert Wood Johnson Foundation established the Self-Determination Program for Persons with Developmental Disabilities and awarded $5 million to 19 states to explore consumer-directed alternatives to providing long-term care services to individuals with a developmental disability.[43] The following 19 states received grant awards: Arizona, Connecticut, Florida, Hawaii, Iowa, Kansas, Maryland, Massachusetts, Michigan, New Hampshire, Minnesota, Ohio, Oregon, Pennsylvania, Texas, Utah, Vermont, Washington and Wisconsin.

The projects varied in their scope and activities from broad-based planning and system reform to small pilot projects. For example, Utah established a statewide foundation for self-determination which built on its preexisting efforts to change the role that consumers played in discussing the services they needed with professionals. Wisconsin, on the other hand, focused its initiative on three demonstration counties and developed an initiative to support approximately 300 individuals to direct their own services and supports through an individualized budget. The evaluator of the project, the Human Services Research Institute (HSRI) made general observations about the projects a few of which are described below:

- States that had already built flexibility into their service delivery system found it easier to develop, manage and finance consumer-direction;

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[41] S. Dale and R. Brown, *The Effect of Cash and Counseling on Medicaid and Medicare Costs: Findings for Adults in Three States*, Mathematica Policy Research, Inc., May 2005 at [http://www.mathematica-mpr.com/publications/pdfs/cashandcounseling3states.pdf].

[42] For additional information about state projects, see [http://www.cashandcounseling.org/about/map.html].

[43] Ten other states received small technical assistance grants.

- State contracting policies were, at times, barriers to purchasing services and supports that were responsive to an individual's needs because they were outside the pool of state-approved contractors;
- The self-determination projects became a vehicle for increased self-advocacy among individuals with developmental disabilities and their representatives; and
- HSRI indicated that "'self-determination' is a concept that is evolving across the states with resulting variance in definition and operations."[44]

Independent Choices

In 1997, the Robert Wood Johnson Foundation funded 13 projects to test a variety of strategies for increasing consumer-direction for a variety of different disability groups. The National Council on Aging (NCOA) received funding to coordinate the 13 projects. Of the projects funded, nine were demonstrations and four were research projects. For example, the demonstration project in Oakland, California developed an emergency hotline for individuals who were unable to receive personal care services because of a worker absence or cancellation. A research project at the Family Caregiver Alliance in San Francisco examined the extent to which individuals with mild and moderate cognitive disabilities could express their preferences. This project found that these individuals could consistently state their preferences and choices and could play a role in decisions about their care. This project also found that close family members often had inaccurate perceptions of the individual's preferences.[45]

In 2002, the Robert Wood Johnson Foundation awarded additional funding to the National Council on the Aging (NCOA) and the National Association of State Units on Aging (NASUA) to continue to work with states to develop, promote and facilitate consumer-direction including assisting states in assessing their long-term care systems, holding public forums, and developing a plan to address specific barriers to consumer choice and control in their programs. The focus of this initiative included both Medicaid and non-Medicaid programs (e.g., programs established under the authority of the Older Americans Act). In addition to the state-specific activities, NASUA and NCOA continue to develop resource materials to promote consumer-direction in aging services including surveys of program administrators, case studies of particular programs, and a guide for consumers to evaluate degree of consumer-direction in their state's programs.[46]

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[44] V. Bradley, et. al,. *The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report*, Human Services Research Institute, Nov. 2001.

[45] A. E. Benjamin and R. Snyder, "Consumer Choice in Long-term Care, To Improve Health and Health Care V," *The Robert Wood Johnson Anthology*, 2003, Chapter 5. For additional information, see [http://www.rwjf.org/publications/publicationsPdfs/ anthology2002/ chapter_05.html]. P. Nadash, "Independent Choices," *American Rehabilitation*, vol. 24, no. 3, summer/autumn 1998, at [http://www.independentliving.org/docs4/ar3983.html]

[46] This assessment tool was also developed in collaboration with the Home and Community-Based Resource Network, an organization working with states and the aging and disability

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Systems Change Grants to States

In fiscal years 2001 through 2005, Congress appropriated $287 million in grants to states to increase opportunities for community living for individuals of any age with a disability or long-term illness as part of CMS's discretionary research appropriation. Each fiscal year, Systems Change grant funds were separated into several grant categories. Some categories targeted certain activities (such as nursing facility transition or a mental health systems transformation). Other categories were defined broadly so that states could target the funds to issues identified in that state to improve the home and community-based long-term care system. Over the past five years, several specific grant categories have been specifically focused on developing consumer-directed long-term care programs. This was also a common activity identified by states in grant categories that allowed a broader set of activities. Grants have been awarded to 50 states, two territories, and the District of Columbia.[47]

Considerations in Implementing Consumer-Directed Services

As described earlier, the traditional Medicaid provider model for most beneficiaries receiving home and community-based services is through an agency. The provider must meet certain qualifications and have an agreement with the state Medicaid agency. The direct care worker is an employee of the provider agency, and the consumer has varying degrees of discretion over how services are provided. Although there is wide variation in consumer-directed long-term care programs, most states implementing these programs must shift the focus or redesign some of their administrative structures or program policies if the state wants to move their agency provided service model to a consumer-directed one. This section outlines some of the administrative and policy considerations for state Medicaid agencies in developing consumer-directed programs.

Eligibility

To participate in consumer-directed Medicaid long-term care programs, the individual must be Medicaid eligible and demonstrate need for that type of service (e.g., personal care). This means meeting financial standards and having a given level of impairment/disability. In some programs, a state may also require that the individual pass a cognitive or competency test to determine whether or not he or she is capable of directing the service and managing the cash allotment. Many programs allow a family member or legal guardian to direct the services on behalf of a child or an individual who is unable to express his or her preferences.

[46] (...continued)
communities to improve long-term care services. [http://www.consumerdirection.org].

[47] For a complete description of Systems Change grant activities, see [http://www.cms.hhs.gov/RealChoice/downloads/compendium.pdf].

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Fiscal Intermediary

In a traditional agency-based system, the provider agency bills the state for the Medicaid services it provides according to an established rate. In a consumer-directed model, the state or its contracted agency may take on other functions including tracking an individual's budget, paying different rates for different workers (if allowed by the program), and additional reporting requirements.

Several states implementing consumer-directed models have contracted with an organization usually referred to as a "fiscal intermediary" to assist in the administration of the cash benefit or individualized budget .[48] The fiscal intermediary assists the consumer with a variety of tasks depending on the program's design and policies including collecting the direct care workers' time sheets, issuing the checks to the direct care workers, or tracking the consumer's expenditures. Other responsibilities for the fiscal intermediary may include conducting criminal background checks of the direct care workers, filing tax reports, or making sure that amounts are withheld from the workers' earnings for Social Security and Medicare, unemployment insurance, and worker's compensation and other tax-related contributions.[49] Generally, the states pay fiscal intermediaries through Medicaid administration funding (50% state funding, 50% federal Medicaid funding), as an expense in each person's cash allotment (e.g., $10 per month, 5% of the cash allotment), or as a separate service under the home and community-based waiver program.

Service Consultant/Support Broker/Counselor

Most consumer-directed programs have an individual available to provide consultation and support to the consumer. The activities of the service consultant may include assisting the individual in developing his or her service plan or consulting with the consumer on any employer-employee issues (e.g., recruiting, firing). The role of this individual differs from the more traditional role of "case manager" in which the case manager is responsible for assessing the individual's needs, and coordinating and overseeing all of the services the consumer receives by provider agencies.

Consumer Education and Training

Under a consumer-directed program, consumers take on new roles and responsibilities including directing and managing workers, working with a fiscal intermediary to submit time sheets, and developing an individualized budget. States have offered various methods of training and ongoing support for these consumers. Some of these methods include conducting a formal training session, providing individual discussions with an individual's service consultant, matching consumers

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[48] The term "intermediary service organization" is also used.

[49] For a typology of fiscal intermediaries, see S. Flanagan and P. Green, *Consumer-Directed Personal Assistance Services: Key Operational Issues Using Intermediary Service Organizations*, The MEDSTAT Group, Oct. 24, 1997.

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with other individuals with a disability who are also participating in consumer-directed programs, and developing written training materials. For example, a consumer-directed program in New Jersey has developed a consumer guide for individuals not using a fiscal intermediary; the guide contains information on filing for tax status as an employer, workers' compensation, and paying wages and overtime.[50]

Determining a Consumer's Cash Allotment

Under the current Medicaid system, individuals are generally assessed to see how many hours of a particular service are required to meet their needs. The consumer is then eligible to receive that number of hours of service unless the number of hours exceeds the state's limits on the amount of services that can be provided and/or if the cost of those services exceeds amount permitted under a Section 1915(c) home and community-based waiver.

Under a consumer-directed approach, the state establishes a *total dollar value* to cover the participants' service(s). The formula to calculate the amount of this allotment can be based on a variety of factors including:

- The number of hours that would have been provided to the individual (based on an assessment of need) for receiving services through an agency-based model multiplied by the state's rate for personal care services;
- Historical expenditures of a particular individual or group (e.g., the average amount over the last three years);
- A decrease in the amount to reflect the average number of service hours actually used versus the number of planned hours (e.g., due to unplanned worker absences); and/or
- A periodic opportunity to reassess the allotment if the consumer's needs change.

Who Is the Employer?

A key consideration in implementing a consumer-directed Medicaid long-term care program is who will be the legal employer of the individual(s) providing the service (e.g., the direct care worker). The options for who serves as the employer include the following:

- the consumer;
- an organization that provides services to an individual;
- a fiscal intermediary;
- a provider agency that is participating in a consumer-directed model;
- the state Medicaid agency; or
- a self-employed direct care worker who is an "independent Medicaid provider."

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[50] [http://www.hhp.umd.edu/AGING/CCDemo/ccbook/].

These options show the great variation that can exist in a consumer-directed model.

The employer assumes certain fiscal and legal responsibilities based on federal and state laws. For consumers who have not previously been an employer, sorting out the federal requirements, the state laws, and the associated responsibilities can be confusing and administratively burdensome. These requirements can include employer contributions to Social Security and Medicare, federal and/or state unemployment taxes and workers' compensation.[51] Not surprisingly, in cases when consumers have been the employers, most states have contracted with a fiscal intermediary to assist consumers with these obligations.[52] Most consumers found this assistance to be very helpful.[53]

Service Providers

There are four primary issues for states to address in determining who can provide services under a consumer-directed long-term care program:

Provider Qualifications. Medicaid law requires states to have standards for determining which providers may participate in the Medicaid program. Federal law provides explicit standards and certification processes for some providers, such as home health agencies and nursing homes. For other providers, standards and procedures are generally governed by state laws, regulations, and licensure requirements. For example, the state may require that direct care workers complete a criminal background check. In general, independent Medicaid providers, as discussed earlier, must meet the same requirements for training and certification as direct care workers who are employed by an agency. For other types of consumer-directed programs, the state has flexibility in establishing the standards and requirements for who is allowed to provide personal care services.

Provider Rates. Under Medicaid, states have considerable latitude in determining how much providers will be paid for a particular service; however, the rates must be approved by CMS. Generally, states establish a single rate for a particular category of provider. Under a consumer-directed model, some states have permitted consumers to establish the rate that would paid to their particular direct care worker(s) so long as it fits within the individual's budgeted amount or allotment.

Hiring Friends and Family Members. Many individuals in consumer-directed programs are interested in hiring friends and family members to provide their services. Personal care services are quite intimate (e.g., bathing, dressing), and

[51] For additional information, see M. Kapp, "Consumer-Direction in Long-Term Care: A Taxonomy of Legal Issues," *Generations*, fall 2000 and S. Flanagan and P. Green, *Consumer-directed Personal Assistance Services: Key Operational Issues Using Intermediary Service Organizations*, The MEDSTAT Group, Oct. 24, 1997.

[52] Federal law allows a third party to act on behalf of consumers and their workers without being considered the employer.

[53] S. Flanagan and P.S. Green, "Fiscal Intermediaries: Reducing the Burden of Consumer-Directed Support," *Generations*, fall 2000, pp. 94-97.

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individuals may be more comfortable having someone they know provide this type of care. In addition, with direct care worker shortages in many states, individuals may have an easier time finding someone they know to provide care. In many cases, hiring friends and non-legally responsible family members is permitted under Medicaid. The friend or family member can either become an employee of a Medicaid provider agency or, if permitted by the state, be self-employed as an independent provider (which is described in the Medicaid State Plan section). If the state wants to pay *legally* responsible relatives as a direct care worker, this is permitted under one of three authorities: 1) under a Section 1915(c) home and community-based waiver, these individuals can be paid for providing "extraordinary" care; 2) under Section 1115 waiver authority, legally responsible relatives can be paid for providing services; and 3) starting in January 2007, states using the self-directed personal assistance option under Section 1915(j) can pay legally responsible relatives.[54]

Paying legally responsible relatives to provide care has caused some debate about an individual's responsibilities to provide care to a family member. Opponents say that legally responsible relatives have an obligation to provide care for a family member and that we are using public funds to pay for care that would otherwise by provided for free (informally). Proponents note that the care required can be intensive and can affect a parent's or spouse's ability to hold other employment and that paying family members can help ease the shortage of direct care workers which many states are experiencing.

Effect on Current Service Providers. Finally, some states implementing consumer-directed programs have encountered significant opposition from traditional agency-based providers who believe that consumer-directed options will negatively affect their businesses by drawing away consumers. The state may have to work with the provider community to overcome opposition to consumer-directed programs, particularly those types of programs that provide cash directly to the consumer to select his or her direct care worker.

Compliance with State Nurse Practice Act

Most states have laws and/or regulations that govern the practice of nursing broadly referred to as the "Nurse Practice Act." These laws and regulations generally prohibit certain types of services from being conducted by anyone other than a *licensed* nurse. The types of services most relevant for this discussion tend to be routine, daily needs for some individuals with a disability such as medication administration (both oral and injectable), urinary catheterization, gastrostomy tube feedings, and suctioning for individuals with a tracheostomy.[55] In developing a

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[54] States may pay legally responsible relatives outside of these three authorities, but pay for the services with 100% state funding.

[55] Gastrostomy tube feedings occur when an individual has a condition in which he or she has difficulty or is unable to take in food through the mouth and has a tube surgically inserted through the skin into the stomach to receive nutrients. Feeding the individual is generally required at least daily and often several times per day. A tracheostomy is a

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consumer-directed program, the state will need to review its laws and regulations to ensure that the consumer-directed program complies with the Nurse Practice Act.

There is significant variation in (1) the extent to which states' Nurse Practice Acts permit consumer-directed services and (2) the clarity with which the issue is addressed. Two specific vehicles used by states which are relevant for consumer-direction include *exemption* and *delegation*. An *exemption* provision describes in law or regulation who is not governed by the Nurse Practice Act. Some Nurse Practice Acts provide a general exemption for individuals who are providing personal care assistance to a family member. Under *delegation*, a nurse can delegate certain activities to another individual, but the nurse has oversight responsibility for those services.[56] If the state allows for delegation, the consumer-directed program will need to have processes in place for a nurse to delegate and oversee specific activities.

Fraud and Abuse

A commonly raised concern by policymakers in consumer-directed programs is the potential for fraud and abuse either by consumers who are given a cash allotment to purchase their services or by others who may exploit the consumer. According to Kevin Mahoney, the national program director for the *Cash and Counseling* demonstration (described later), after three and a half years the demonstration has found "no major instances of fraud and abuse."[57] Many consumer-directed programs include policies and procedures to minimize fraud and abuse and maintain accountability for public funds such as approving the consumer's plan for using the funding, tracking utilization of services and collecting receipts.

Quality

A final consideration for states in implementing consumer-directed programs is how to assure the quality of services provided to a consumer. Medicaid law and regulations prescribe quality of care standards in nursing homes that participate in Medicaid, and federal and state governments have a substantial role in surveying and certifying nursing homes.

Most community-based long-term care services do not have a similar level of federal requirements and oversight. Under the Medicaid state plan, states must set provider standards but otherwise have significant flexibility in how they monitor and implement community-based long-term care services. In the HCBS waivers, states

[55] (...continued)
surgically implanted opening directly into the trachea, which is used when there are difficulties with the individual's airway; the tracheostomy allows the individual to breathe. Suctioning periodically (e.g., every few hours) may be required to remove secretions.

[56] S. Reinhard, "Consumer Directed Care and Nurse Practice Acts," *Rutgers' Center for State Health Policy*, June 2001, at [http://www.aspe.hhs.gov/daltcp/reports/nursprac.htm].

[57] Testimony of National Program Director Kevin Mahoney, Boston College, in U.S. Congress, House Committee on Energy and Commerce, hearings, June 5, 2003 at [http://energycommerce.house.gov/108/Hearings/06052003hearing949/ Mahoney1513.htm].

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are required to provide assurances to CMS that the health and welfare of the HCBS waiver participant is protected and, in some cases must provide annual documentation to support these assurances.[58,59] CMS has been somewhat more proactive in recent action that required additional documentation from states for approval of Independence Plus waivers.

In most existing consumer-directed programs, consumers take on the primary responsibility of quality assurance. "Governmental quality assurance activities in consumer-directed programs are fairly minimal, consisting mostly of responding to complaints, periodic home visits and telephone contact with beneficiaries."[60] Although governmental activities have been limited, existing research has found that consumers have generally reported comparable or higher levels of satisfaction with the quality of their care and their own quality of life in consumer-directed models compared to agency-based models.[61]

Considerations for Future Policy Development

Over the last several years, Congress has enacted legislation expanding opportunities for consumer-directed services. In 2003, Congress enacted a demonstration project for consumer-directed chronic outpatient services as part of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Section 648, P.L. 108-173). The provision requires the Secretary of HHS to establish a budget-neutral demonstration within the Medicare program that permits beneficiaries with chronic conditions to direct their own personal care services within two years of enactment. More recently, as described earlier, Congress added a section to Medicaid law that allows states to operate self-directed personal assistance programs (Section 1915(j) of the Social Security Act).

There has been some interest by policymakers in exploring whether consumer-direction would be appropriate for services other than personal care and home and community-based waivers. A few federal grant programs sponsored by HHS have provided an allotment for individuals to purchase other health care services including mammogram screening for women in rural areas,[62] and primary care visits for

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[58] Section 1915(c)(2)(A) and 1915(c)(2)(E) of the Social Security Act, and 42 CFR 441.302.

[59] CMS has taken some steps to improve the quality of HCBS services by establishing guidelines for a quality assurance and improvement system which are needed for approval of Independence Plus waivers, by developing a protocol for CMS regional offices in reviewing HCBS waivers and by providing technical assistance to states.

[60] J. Tilly and J. Wiener, *Consumer-Directed Home and Community Services: Policy Issues*, Urban Institute, Occasional Paper Number 44.

[61] Ibid.

[62] T.J. Stoner, et al., "Do Vouchers Improve Breast Cancer Screening Rates? Results from a Randomized Trial," *Health Services Research*, Apr. 1998, pp. 11-28.

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migrant workers.[63] The purposes of these allotments were to increase access to a particular service and to encourage utilization of primary care using a capped funding source. Under these initiatives, the allotment required relatively minimal effort by consumers in both the time and level of responsibility required. In contrast, most of the consumer-directed long-term care programs described in this report required ongoing participation and responsibility by consumers and a higher level of state infrastructure to implement and oversee the projects.

The potential for future activities in consumer-directed care, including program growth and policy implications, has not yet been fully explored. However, initial findings from research and demonstration activities have shown increased consumer satisfaction, reduced unmet service needs, and an overall increase in Medicaid expenditures without consistent offsetting decreases in other services. As Congress looks at policy questions related to consumer-directed programs and evaluates the experience of existing federal and state programs, it may want to consider the following policy questions:

- **Should participation in consumer-directed programs be voluntary or mandatory?** Most existing consumer-directed programs are voluntary. Depending upon the program and type of service, there may be tasks that are time-consuming or challenging, such as managing the cash allotment, finding and making informed decisions about qualified providers, or supervising workers. Some consumers using long-term care services or other health care services may be unable or unwilling to assume these tasks or may be satisfied with the services they receive from a traditional provider.

- **What types of services are most compatible with a consumer-directed model?** Existing consumer-direction programs have generally included services that are ongoing and predictable such as personal care. Other services that follow this pattern may be appropriate for consumer-direction (e.g., home health services, physical therapy, and adult day care). However, current models of consumer-direction may be less viable for services that are less predictable (e.g., inpatient hospital visit) or for conditions that are subject to acute flare-ups.

- **How much financial risk should the consumer have? For example, should standards be established for determining an individual's cash allotment?** The existing consumer-directed models have minimal financial risk for the consumer. The programs are voluntary, the cash allotment is based on an assessment of needs, the service utilization pattern is generally ongoing and predictable, and the individual's functional limitations are periodically reassessed.

[63] D.P. Slesinger and C. Ofstead, "Using a Voucher System to Extend Health Services to Migrant Farmworkers," *Public Health Reports*, v. 111, Jan./Feb. 1996, pp. 57-62.

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- **To what extent does the consumer have access to and information about potential service providers?** Many individuals who volunteered for the existing consumer-directed programs had a pool of individuals willing to provide direct care services. In addition, the work required minimal skills, and the consumer generally knew the qualifications of the individual providing the services. Three considerations in consumer-direction for other services are (1) the potential pool of qualified providers, (2) consumer's access to those providers, and (3) the availability of information to distinguish between the qualifications and services of different providers.

- **Is the administrative infrastructure available to support a consumer-directed model?** Fiscal intermediaries have played a significant role in implementing existing consumer-directed services. However, these types of organizations have generally maintained a fairly specialized role in the marketplace. If consumer-direction were expanded, the number of fiscal intermediaries available may need to expand and their activities may need to change depending on the type of service.

- **What role, if any, should the federal government have in assuring the quality of consumer-directed services?** Designing a system of quality in community-based long-term care services that balances the consumer's preferences, the individual's safety, and accountability to the public is an ongoing challenge for both state and federal policymakers. Some policymakers believe that the current monitoring and regulatory approach applied to institutions to assure quality is not appropriate for community-based services and see an expanded role for consumer-directed approaches in improving quality. They suggest that opportunities for consumers to direct and manage their services will increase quality because the consumers can define "quality" based on what is important to them, choose providers who can meet those preferences, and oversee the delivery of those services. On the other hand, others counter that consumers may be less likely to report or fire a friend or family member who is not providing quality services. It appears likely that if consumer-directed services were expanded more broadly, policymakers may need to develop more specific quality assurance mechanisms that would insure that consumers get the services they need.

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