Understanding Medicaid Home and Community Services: A Primer

U.S. Department of Health and Human Services
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Office of the Assistant Secretary for Planning and Evaluation

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Understanding Medicaid Home and Community Services: A Primer

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Dear Reader,

Medicaid is the major public payer of long-term services and supports for millions of low-income Americans. When Medicaid was first enacted, payment for long-term services was made solely to institutions such as nursing homes. In the following decades, people with disabilities of all ages and their advocates played a significant role in the evolution of the Medicaid program. They asked for the resources they needed to live independently and the government responded. Medicaid now pays for a comprehensive range of home and community services that provide alternatives to unnecessary institutional care.

Many states have led the way in using Medicaid to design innovative and fiscally responsible long-term service programs. These programs enable people with significant disabilities to live in their communities and offer consumers more control over the services they receive. The recent Supreme Court decision in *Olmstead v L.C.* gives legal weight to this policy direction. In her July 28, 1999, address to the National Conference of State Legislatures, Secretary Shalala stated clearly that "The Olmstead decision defines our mission: To build better systems of supports enabling people with disabilities to live life to the fullest."

Since then, the Department has received numerous requests from state officials, consumers, and other stakeholders for information on how to use the Medicaid program to increase the availability of home and community services. Medicaid is a flexible program but it is also a complex program. It is no surprise that there are a host of questions about what is allowable under Medicaid law and regulation. We are pleased to offer this Primer on Medicaid Home and Community Services to serve as a reference guide. Its purpose is twofold:

- To explain how the Medicaid program can be used to expand access to a broad range of home and community services and supports for people of all ages with disabilities, and to promote consumer satisfaction and control;
- To encourage a fundamental approach to the support of persons with disabilities that minimizes reliance on institutions and maximizes community integration in the most cost-effective manner.

I believe this Primer will be a useful tool for all those working to expand home and community services and supports to enable people with disabilities to live in the most integrated settings appropriate to their needs.

This Primer would not have been possible without the commitment and hard work of many people. However, I want to recognize a few individuals whose outstanding efforts and dedication made this Primer a reality:

Janet O'Keeffe, whose extensive knowledge of long-term service policy combined with her energy, her talent for organizing large quantities of complex information, and her ability to work with multiple constituencies, enabled us to complete this project;

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As the Medicaid program evolves to meet the needs of its beneficiaries, new policy and clarifications of existing policy will be made subsequent to the publication of this Primer. These will be disseminated through State Medicaid Directors' Letters and the State Medicaid Manual, both of which are available on the Health Care Financing Administration's website.

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Introduction

People of all ages with disabilities want the same opportunities every American wants: not just to survive, but to thrive. They want to live in their own homes and make decisions about daily activities, so they can go to school, work, church, recreation, and can participate fully in their communities. Historically, people with disabilities have not always been allowed this birthright. Society has often focused on a person's disabilities rather than his or her abilities. But changes in philosophy and law have led to a new approach. People with disabilities are now recognized as being able to live in their own homes and other community settings and to lead satisfying and productive lives when provided the range of services and supports they need to do so.

In the service system for elderly persons, these services and supports are referred to as long-term care. In the disability service system, the terms typically used are long-term services and supports or personal attendant services. All these terms are used interchangeably throughout this Primer.

Medicaid: An Evolving Program with Considerable State Flexibility

The major source of public funding for long-term services and supports provided in home and community settings is the Medicaid program. Medicaid was first enacted in 1965 as a companion program to Medicare.[1] It was designed as a joint Federal-state entitlement providing primarily medical care to low-income Americans.[2] When first enacted, Federal Medicaid funding for meeting the long-term service needs of people with disabilities and chronic conditions was available mainly when the person was placed in an institutional setting (e.g., a nursing home), with few avenues for securing Medicaid dollars to support individuals in their homes and communities. State dollars (and, in some cases, Federal dollars) funded "home care" programs, but only on a limited basis.

In the 35 years since its enactment, Medicaid's "institutional bias" has been progressively reduced through numerous amendments to Federal laws and policy. These amendments have offered new options for states to fund comprehensive home and community long-term services. Beginning in the early 1980s, there has been a steady increase in the options available to states to secure Federal Medicaid dollars to underwrite long-term services and supports in home and other community settings. As a result, states have considerably expanded availability of these services for persons of all ages with physical and mental disabilities. Many states are leading the way in designing innovative and fiscally responsible ways to enable more persons with disabilities to receive necessary services in their communities instead of in institutions.

At one time, only a small portion of Medicaid long-term care spending was directed to home and community services. Today, 28 percent of long-term care spending is for such services, and these outlays are one of the fastest growing components of total Medicaid spending.[3]

Some benefits may be offered through either the state's "regular" Medicaid program or through a home and community-based services (HCBS) waiver program. Moreover, a state may operate several HCBS waiver programs at once, each offering a distinct package of services and supports to a different group of individuals. These choices combine to give states considerable latitude in deciding which services and supports will be offered and in customizing benefit packages to meet the needs of particular groups.

Medicaid home and community services are available to beneficiaries of all ages with many different types of physical and mental disabilities and chronic illnesses. Because of the way Medicaid was originally designed and has been amended over time, distinct programs were developed to provide services to certain categorical populations, most notably women with dependent children. In the long-term care context, covered categories include the "aged, blind, and disabled." These three populations account for the majority of Medicaid long-term care spending on home and community services, primarily through the personal care option, the HCBS waiver program, and the home health benefit. The "aged and disabled" categories taken together include people of all ages who have physical or mental disabilities, including serious mental illness, mental retardation, and other developmental disabilities. The Primer discusses services for all these groups.

Regardless of an individual's age or condition, all persons with disabilities and their families share common goals—to choose how to live their lives and to have some control over their daily activities in the most integrated settings. The recent Supreme Court decision in *Olmstead v. L.C.* affirmed the right of persons with disabilities to do just this.[4] The Court stated that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Further, the Court noted that confinement in an institution severely diminishes the everyday life activities of individuals—including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.[5] The Court also noted, however, that nothing in the Americans with Disabilities Act (ADA) condones termination of institutional settings for persons unable to handle or benefit from community settings, and that a state's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

The Medicaid program can be an important resource to assist states in meeting the principles set out in the Olmstead decision. States may choose to utilize Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.[6]

As states work toward the goal of integrating persons with disabilities into the community, they may need to go through a process of fundamentally rethinking how programs serving people with disabilities should be structured and how long-term care resources should be allocated. The Medicaid program as currently structured provides many alternative ways to increase the availability of home and community services and still keep the costs of those services under control.

Subsequent chapters of this Primer stress that states need to consider their own unique needs, resources, and social/political/economic environment as they decide how best to use the Medicaid program to provide home and community services to persons with disabilities. An important context for this decision-making process is the set of demographic factors driving the need for publicly funded assistance by persons with disabilities.[7]

The first such factor is advances in medical technology, which have enabled increasing numbers of people with extensive congenital and acquired disabilities to both survive and live longer lives. The second is that the nation's population is aging and will continue to do so as the baby-boom cohort moves into its 60s and beyond. The population over age 85—numbering 4.0 million in

1998—is the group most likely to need assistance performing activities of daily living, and this is the group that is growing the fastest. By 2020, for example, an estimated 7 million people will be 85 and over.[8]

Finally, most of this assistance is provided by informal caregivers, typically the women in the family. However, high women's labor force participation rates, smaller families, and geographic mobility may make it very difficult for some families to provide such assistance for their members with disabilities.

Purpose, Audience, and Organization of This Primer

Medicaid now offers so many options for providing home and community services that they can be confusing for policymakers, state officials, advocates, and consumers alike. It does not help that the details of these expanded options tend to be buried in the minutiae of Medicaid legislative and regulatory provisions. To add to the confusion, the extensive flexibility states have to combine these options has resulted in 50 different state Medicaid programs. Even people who have spent years working in Medicaid do not always understand its many provisions.

This Primer is designed to encourage use of the Medicaid program in a manner that minimizes reliance on institutions and maximizes community integration in a cost-effective manner. Its intended audience is policymakers and others who wish to understand how Medicaid can be used—and is being used—to expand access to a broad range of home and community services and supports, and to promote consumer choice and control. In addition to comprehensive explanations of program features states can implement to achieve these goals, the Primer presents examples of state programs that have taken advantage of Medicaid's flexibility to expand home and community services for people of all ages with disabilities.

The service options reviewed in subsequent chapters span the full range of Medicaid choices. They address program modifications states can implement as a state plan option (without special waiver of Federal law), as well as those for which Federal waiver approval must be obtained. Options that do not require waivers offer especially important potential for expanding community services and supports.

The design of this Primer grew out of a series of discussions among Federal officials, state policymakers, service providers, and advocates regarding how to make the document as useful as possible. Each chapter provides an annotated bibliography, with full information on how to obtain each publication.

- *Chapter One* provides a brief overview of the legislative and regulatory history of Medicaid's coverage of home and community services and information on current home and community expenditures.

The next four chapters lay out and discuss the basic elements involved in Medicaid's financial and functional eligibility criteria and service coverage alternatives.

- *Chapter Two* provides an explanation of Medicaid's financial eligibility criteria, one of the most complicated areas of Medicaid law. It first discusses the general eligibility criteria all Medicaid beneficiaries must meet. It then focuses on the financial eligibility provisions most important for receiving services in home and community settings. It also discusses the options states can select to ensure that people with disabilities will be able to support themselves in home and community settings.

- *Chapter Three* focuses on Medicaid provisions related to health and functional criteria used to determine service eligibility for home health services, the personal care option, and the waiver program. It presents examples of states with service criteria that support a social model of long-term services and supports rather than a medical model. And it discusses ways in which states can design service criteria to ensure that they appropriately and adequately measure the need for services and supports among heterogeneous populations.

The Olmstead Decision[9]

The Olmstead case was brought by two Georgia women whose disabilities include mental retardation and mental illness. At the time the suit was filed, both plaintiffs lived in State-run institutions, despite the fact that their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the ADA to live in the most integrated setting appropriate.

The Supreme Court ruled that "Unjustified isolation . . . is properly regarded as discrimination based on disability."[10] It observed that (a) "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and (b) "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Under the Court's decision, States are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) the State's treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services. The Court cautioned however, that nothing in the ADA condones termination of institutional settings for persons unable to handle or benefit from community settings. Moreover, the State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

Under the ADA, States are obliged to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity." The Supreme Court indicated that the test as to whether a modification entails "fundamental alteration" of a program takes into account three factors: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the State; and how the provision of services affects the ability of the State to meet the needs of others with disabilities. (See Appendix II for the complete text of HCFA's guidance on the Olmstead decision.)

- *Chapter Four* presents the major service options states have to provide home and community services to people with disabilities and discusses the factors states need to consider when choosing among the various options.
- *Chapter Five* provides an in-depth discussion illustrating different coverage alternatives in the context of two specific services: case management and assisted living for elderly persons.

The last four chapters focus on key policy goals in the provision of home and community services and supports.

- *Chapter Six* discusses factors states need to consider when developing initiatives to *transition institutional residents back to home and community settings.* It also presents ways in which Medicaid can be used to facilitate this transition.
- *Chapter Seven* discusses options under Medicaid to *increase consumer choice and control* of home and community services.
- *Chapter Eight* discusses ways in which Medicaid can support *informal caregiving and family support* through various optional services.
- *Chapter Nine* addresses system design issues and discusses how Medicaid can be used to *create comprehensive, cost-effective long-term care systems.*

The Primer concludes with a series of Appendices that provide additional information about the Medicaid program.

This Primer has been prepared by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), with consultation from the Health Care Financing Administration (HCFA) in the United States Department of Health and Human Services (HHS). Designed to serve as a reference guide, it is written in easily understood language, but with sufficient annotation of source material to fulfill its technical support role. Some issues remain unresolved, because particular provisions of Medicaid regulations and state interpretations thereof are being challenged in the courts. Major unresolved issues are discussed where relevant.

* * *

This Primer describes the many options states have to use the Medicaid program to fund long-term care services and supports. It is up to state policymakers working with the disability and aging communities to identify the unique needs and goals of the state, and then use the information given in the following chapters (a) to choose the options best suited to a particular state and (b) to decide how the options chosen can be best used in that state.

Endnotes

1. P.L. 89-97, Title XIX of the Social Security Act.

2. The Federal government provides matching funds on an open-ended basis for every dollar a state chooses to spend on Medicaid services.

3. Burwell, B. (April, 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group.

4. *Olmstead v. L. C.*, 119 S.Ct. 2176 (1999).

5. Ibid.

6. Health Care Financing Administration. (February 1, 2000). Fact Sheet: Assuring access to community living for the disabled. (Available from www.hcfa.gov/facts.)

7. Because the focus of the Primer is on long-term care services and supports, the Primer uses the term persons with disabilities to refer primarily to that group of persons with disabilities who need long-term care services in general, and home and community services in particular.

8. U.S. Census Bureau (www.census.gov).

9. Information in this text box is available from the following website: www.hcfa.gov/medicaid/smd1140a.htm, which contains additional information regarding the Olmstead decision.

10. The Olmstead decision interpreted Title II of the ADA and its implementing regulations, which oblige states to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." (28 CFR 35.130(d)).

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CHAPTER 1

Medicaid Coverage of Home and Community Services: Overview[1]

Long-term care includes a broad range of health and health-related services, personal care, social and supportive services, and individual supports. This chapter recounts the legislative, regulatory, and policy history of Medicaid coverage of long-term care services. Both institutional and home and community long-term care services are covered, with the latter described in greater detail. (Medicaid's coverage of primary and acute care is not included in the discussion.)

Introduction

Medicaid is an entitlement program, which is designed to help states meet the costs of necessary health care for low-income and medically needy populations. States qualify to receive Federal matching funds to help finance these costs by filing a state Medicaid plan document with the Federal Health Care Financing Administration (HCFA).[2] States have substantial flexibility to design their programs within certain broad Federal requirements related to eligibility, services, program administration, and provider compensation.

Program Evolution and Current Spending Allocations

From its beginnings as a health care financing program primarily for welfare recipients, Medicaid has been amended and expanded in a patchwork fashion to cover a range of populations. Initially, Medicaid was the medical care extension of Federally funded programs providing cash assistance for the poor, with an emphasis on dependent children and their mothers, elderly persons, and persons with disabilities. Legislation in the 1980s extended Medicaid coverage to an expanded group of low-income pregnant women and poor children, and to some low-income Medicare beneficiaries who were not eligible for cash assistance.

When first enacted, Medicaid's main purpose was to cover primary and acute health care services, such as doctor visits and hospital stays. Mandatory coverage for long-term care was limited to skilled nursing facility (SNF) services for people age 21 and older. States were given the option to cover home health services and private duty nursing services. In response to the high costs of nursing facility care, combined with criticism of Medicaid's institutional bias, states and the Federal government began to

look for ways to provide long-term care services in less restrictive, more cost-effective ways. In 1970, home health services for those entitled to nursing home care became mandatory. Since 1970, Medicaid has evolved into a program that allows states considerable flexibility to cover virtually all long-term care services that people with disabilities need to live independently in home and community settings.

The Federal Medicaid statute requires states to specify the amount, duration, and scope of each service they provide, which must be sufficient to reasonably achieve its purposes. States may not place limits on services or arbitrarily deny or reduce coverage of required services solely because of diagnosis, type of illness, or condition. Generally, a state plan must be in effect throughout an entire state (i.e., amount, duration, and scope of coverage must be the same statewide). There are certain exceptions to these rules. Two major ones: (a) states operating home and community based services (HCBS) waivers need not offer all services covered under the waiver to all beneficiaries in the state; and (b) targeted case management services offered as an optional benefit under the state plan are not subject to the statewideness rule.[3]

In 1999, every state was providing home and community services under one or more of the available options, and Medicaid had become the nation's major public financing program for long-term care services for low-income persons of all ages with all types of physical and mental disabilities. Data since 1988 show how Medicaid long-term care service spending has been changing.

In 1988, Medicaid spending for all long-term services totaled $23 billion.[4] Nearly 90 percent of those dollars paid for institutional services in nursing facilities and intermediate care facilities for persons with mental retardation (ICFs/MR); only 10 percent went for home and community services. Over the next eleven years, Medicaid spending for all long-term care services grew by 9.8 percent per year, reaching $63.9 billion by 1999. Spending for institutional services increased more slowly (at 7.6 percent per year). Spending for home and community services grew at the rate of 20 percent per year. From a low level of expenditures, home and community spending reached $17.9 billion in 1999.[5]

HCBS waiver programs accounted for the majority of this growth. In 1999, HCB waiver services accounted for 16.6 percent of all Medicaid long-term care services, compared with 9.4 percent in 1994 and only 4.4 percent in 1990. In 1996, expenditures for HCB waiver services surpassed spending for services provided under the home health benefit and the personal care option combined for the first time. In the eleven years from 1988 to 1999, the proportion of total Medicaid spending that went to all home and community services (waiver, personal care, targeted case management, and home health combined) grew from 10 to 28 percent.[6] Following the Supreme Court's 1999 *Olmstead* decision, a state may decide to make increased use of the Medicaid program to increase both the amount and share of its resources going to home and community services.

Expansion of home and community services relative to institutional services has been particularly pronounced for individuals with mental retardation and other developmental disabilities. In 1990, 144,000 such individuals were served in ICFs/MR, compared with 45,000 receiving HCB waiver services. By 1999, the number served in ICFs/MR had dropped to 118,000 while the number participating in HCBS waiver programs had increased to almost 262,000.[7]

It should be noted, however, that the share of Medicaid long-term care spending going to home and community services in most states is much lower than the nationwide figure of 28 percent would lead one to expect. In 1997, for example, that share was less than 8 percent in half the states. In the same year, however, five states spent more than 20 percent of their Medicaid long-term care resources on home and community services, with Oregon and New York heading the list (at 40 to 50 percent). The median annual per capita Medicaid expenditure on home and community services has also increased (rising from $310 to $522 between 1992 and 1997).[8] This overall figure again masks considerable state variation—from $1180 per person age 65 or over in New York

down to $29 in Mississippi.[9]

Major Contours of the Medicaid Program's Home and Community Service Provisions

The remainder of this chapter presents a brief overview of the Medicaid law, regulations, and policy that give states the flexibility to create comprehensive home and community service systems for persons of all ages with all types of physical and mental disabilities. To provide context for the discussion, Table 1-1 lists the major relevant provisions of Medicaid law. This chronological summary illustrates the progressive expansion of Medicaid long-term care services away from a primary focus on institutional care. (Chapters 4 and 5 discuss service options and factors to consider when choosing among them.)

Home Health Services

There has been some misunderstanding about the coverage criterion for home health services because it is linked to the coverage criterion for nursing homes. States are mandated to cover nursing home care for categorically eligible persons age 21 and older. This mandate *entitles* persons age 21 and older to nursing facility care. States have the option to cover nursing home care for other Medicaid beneficiaries as well—e.g., persons under age 21 and the medically needy. In states choosing this option, the medically needy and persons under age 21 would also be *entitled* to nursing home care. However, being *entitled* to nursing home care does not mean that one is *eligible* for nursing home care. In order to receive Medicaid covered nursing home care, entitled persons must also meet nursing home *eligibility* criteria (called level-of-care criteria).

Since 1970, home health services have been mandatory for persons entitled to nursing facility care.[10] Confusion about eligibility for home health services has arisen because the term *entitled* to nursing facility care has sometimes been erroneously interpreted to mean that people must be *eligible* for nursing facility care—i.e., that they must meet a state's nursing facility level-of-care criteria—in order to receive home health benefits. This erroneous interpretation has persisted notwithstanding its conflict with home health regulations prohibiting a state from conditioning eligibility for home health services on the *need for* or discharge from institutional care.[11] The Medicaid Assistance Manual further clarifies that states may not limit home health services to individuals who require a skilled level of health care as defined by Medicare (i.e., needing skilled nursing or therapy services).[12] (See Chapter 3 for additional information on the home health benefit.)

Federal regulations require that home health services include nursing, home health aides, medical supplies, medical equipment, and appliances suitable for use in the home. States have the option of providing additional therapeutic services under home health—including physical therapy, occupational therapy, and speech pathology and audiology services.[13] States may establish reasonable standards for determining the extent of such coverage based on such criteria as medical necessity or utilization control.[14] In doing so, as noted, a state must ensure that the amount, duration, and scope of coverage are reasonably sufficient to achieve the purpose of the service.[15]

In 1998, following the ruling of the U.S. Court of Appeals for the Second Circuit in *DeSario v. Thomas*, HCFA sent a letter to state Medicaid Directors clarifying that states may develop a list of pre-approved items of medical equipment as an administrative convenience but must provide a reasonable and meaningful procedure for requesting items that do not appear on such a list.[16] (See Appendix II for the complete text of the HCFA letter.) All home health services must be medically necessary and authorized on a physician's orders as part of a written plan of care.

Home health services are defined in Federal regulation as services provided at an individual's place of residence. In 1997, however, the Federal Court of Appeals for the Second Circuit ruled that home health nursing services may be provided outside the home, as long as they do not exceed the hours of nursing care that would have been provided in the home.[17] The states covered

Table 1-1. Medicaid's Legislative Provisions Regarding Long-Term Care Services

1965	Establishment of Medicaid[18] — Mandatory coverage of SNFs — Optional coverage of home health services and rehabilitation services.
1967	Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate for children under 21.[19] States given the option to provide services under EPSDT that were not covered by their state plans.
1970	Mandatory coverage of home health services for those entitled to skilled nursing facility services.[20]
1971	Optional coverage of intermediate care facilities (ICFs) and ICFs/MR.[21]
1972	Optional coverage of children under 21 in psychiatric hospitals. (This institutional coverage provides the "institutional alternative" for HCBS waiver services for this group.)[22]
1973	Option to allow people receiving supplemental security income (SSI) to return to work and maintain their Medicaid benefits.[23]
1981	Establishment of home and community based services (HCBS) waiver authority.[24]
1982	Option to allow states to extend Medicaid coverage to certain children with disabilities who live at home but who, until this 1982 provision, were eligible for Medicaid only if they were in a hospital, nursing facility, or ICF/MR. Also known as the Katie Beckett or TEFRA Provision.[25]
1986	Option to cover targeted case management. States are allowed to cover such services without regard to the statewideness and comparability requirements.[26]
	Option to offer supported employment services through HCBS waiver programs to individuals who had been institutionalized some time prior to entering the HCBS waiver program.[27]
1988	Establishment of special financial eligibility rules for institutionalized persons whose spouse remains in the community, to prevent spousal impoverishment.[28]
1989	EPSDT mandate amended to require states to cover any service a child needs, even if it is not covered under the state plan.[29]
1993	Removal of requirements for physician authorization and nurse supervision for personal care service provided under the state plan. States were given explicit authorization to provide personal care service outside the individual's home.[30]
1997	Removal, under the Balanced Budget Act of 1997, of the "prior institutionalization" test as a requirement for receiving supported employment services through an HCBS waiver program. Addition of first opportunity for states to create a Medicaid "buy-in" for people with disabilities.
1999	Additional options under the Ticket to Work and Work Incentives Act for states to create a buy-in program for people with disabilities and to remove employment barriers.[31]

by this ruling are New York, Connecticut, and Vermont. (See Chapter 3 for additional information on this ruling.)

EPSDT

The Federally mandated EPSDT program for children from birth to 21 years entitles Medicaid eligible children to services found necessary to diagnose, treat, or ameliorate a defect, physical or mental illness, or a condition identified by an EPSDT screen. The original 1967 legislation gave states the option to cover treatment services not covered under the state's Medicaid plan. In 1989, Congress strengthened the mandate by requiring states to cover all treatment services, *regardless of whether or not those services are covered in the state's Medicaid plan.*[32]

As a result, the EPSDT component now covers the broadest possible array of Medicaid services, including personal care and other services provid-

ed in the home. For example, Wisconsin covers up to eight weeks of intensive in-home services for children with serious emotional disturbances, including parental skill training in behavior management techniques.

Optional Institutional Services

Options for covering institutional services assumed greater importance after 1981, when the waiver authority was created. This was because HCB waiver services can be provided only insofar as they provide an alternative to institutional care. *If a state is not covering a particular type of institutional service, it will not be able to offer that type of service in the community under an HCBS waiver program.*

The 1971 addition of services provided by ICFs and ICFs/MR as an optional benefit moved the Medicaid program into financing additional nursing home care. Adding optional institutional coverage of ICFs/MR made Federal matching funds available to help finance home and community services for persons with mental retardation (which had previously been supportable only with state funds), thus providing the institutional alternative for MR/DD waivers. Likewise, optional coverage of ICFs made Federal matching funds available for community coverage of a non-skilled level of care through aged/disabled waivers.[33]

Optional Home and Community Services

When Medicaid was enacted, states were given the option of covering a wide range of services, several of which can be used in home and community settings. They include rehabilitation services, private duty nursing, physical and occupational therapy, and transportation services. In 2000, every state provided at least one optional service.

The rehabilitation option, in particular, offers states the means to provide a range of supportive services to people in home and community settings. Medicaid defines rehabilitation services as any medical or remedial services recommended by a physician for maximum reduction of physical or mental disability and restoration of a recipient to his or her best possible functional level.[34] Rehabilitation services can be provided to people with either physical or mental disabilities.

The rehabilitation service option is a very flexible benefit, because services may be furnished either in the person's residence or elsewhere in the community. 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 for persons who have a mental illness. In 1996, 31 states used the rehabilitation option for both categorically needy and medically needy populations; 13 additional states used it just for the categorically needy; and 9 states had Medicaid demonstration programs for rehabilitation services.[35]

The rehabilitation option is not generally used to furnish long-term services and supports to individuals with disabilities other than mental illness. During the 1970s and 1980s, a few states secured HCFA approval to cover daytime services for persons with MR/DD under either the clinic or the rehabilitation option. However, HCFA ultimately ruled that the services being furnished were *habilitative* rather than rehabilitative and consequently could not be covered under either option.[36] (This issue is discussed in more detail in Chapter 4.)

The main basis for HCFA's ruling was that habilitative services could only be furnished to residents of ICFs/MR under the state Medicaid plan or through an HCBS waiver program for individuals otherwise eligible for ICF/MR services. A few states have maintained their state plan coverage of these services. Other states have terminated those coverages in favor of offering similar services through an HCBS waiver program.[37]

Personal Care Services

Since the mid-1970s, states have had the option to offer personal care services under the Medicaid state plan, making these services one of the longest standing Medicaid home and community benefits. This option was first established administratively under the Secretary's authority to add coverages over and above those spelled out in Section 1905 of the Social Security Act, if such

services would further the Act's purposes. In 1993, Congress took the formal step of adding personal care to the list of services spelled out in the Medicaid statute.[38]

When the option for states to offer personal care was created, it had a decidedly medical orientation. The services had to be prescribed by a physician, supervised by a registered nurse, and delivered in accordance with a care plan. Moreover, they could be provided only in the person's place of residence. Generally, the personal care services a state offered were tied mainly to assisting individuals in activities of daily living (ADLs)—bathing, dressing, eating, toileting, and transferring from a bed to a chair. Personal care workers could provide other forms of assistance (e.g., housekeeping and laundry) only on a limited basis and only if they were incidental to delivery of personal care services.

Starting in the late 1980s, some states sought to broaden the scope of personal care services and provide them outside the individual's home in order to enable beneficiaries to participate in community activities. In 1993, Congress not only formally incorporated personal care into Federal Medicaid law but also gave states explicit authorization to provide personal care outside the individual's home.[39] Congress went even a step further in 1994, allowing states to: (1) use means other than nurse supervision to oversee provision of personal care services, and (2) establish means other than physician prescription for authorizing such services. In November 1997, HCFA issued new regulations concerning optional Medicaid state plan personal care services to reflect these statutory changes.[40]

In 2000, 27 states covered personal care services under their Medicaid state plans.[41] However, Federal-state Medicaid outlays for these services, which totaled roughly $3.5 billion in FY1999, have grown at a relatively slow pace during the 1990s.[42] This slow pace is at least in part because some states are electing to cover personal care services through more flexible and easy to target HCBS waiver programs instead of adding the coverage to their state plan or expanding the state plan coverage they already have in place.

In January 1999, HCFA released a State Medicaid Manual Transmittal that thoroughly revised and updated the Agency's guidelines concerning coverage of personal care services. The new Manual materials made it clear that personal care services may span provision of assistance not only with ADLs but also with 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. HCFA also clarified that all relatives except "legally responsible relatives" (i.e., spouses and parents of minor children) could be paid for providing personal care services to beneficiaries.

The Manual further clarified that, for persons with cognitive impairments, personal care may include "cueing along with supervision to ensure the individual performs the task properly." And it explicitly recognized that provision of such services may be directed by the people receiving them. This consumer direction includes the individuals' supervision and training of their personal care attendants. [For the complete text see Appendix II.] Consumer direction of personal care services has been a feature of many personal assistance programs for many years (both under Medicaid and in programs funded only with state dollars). For example, consumer-direction was built into the Massachusetts Medicaid personal care program from its inception. The HCFA Manual clearly acknowledges and sanctions this model. (See Chapter 7 for in-depth discussion of consumer direction.)

But neither the statutory provisions nor the revised Federal regulations and HCFA State Medicaid Manual guidelines dictate that a state *must* change the scope of its pre-1993 personal care coverage. In order to take advantage of these changes, a state must file an amendment to its state plan. Taken together, therefore, these groundbreaking changes in Federal policy can help pave the way for a state to make its coverage of these services much broader than was the case in the past. But the states must act to bring about these changes in their own personal care programs.

Other State Plan and Optional Services

In addition to services listed under the "long-term services and supports" rubric, many other Medicaid benefits are relevant in meeting the needs of individuals with disabilities and chronic conditions. For example, states can provide powered wheelchairs and other mobility equipment through their coverage of medical equipment and supplies suitable for use in the home.[43] State plans also cover many therapeutic services (e.g., occupational and physical therapy) that enable people with disabilities to achieve and maintain optimal functioning. (See Chapter 4 for further discussion.)

Establishment of HCBS Waiver Authority

In 1981, Congress authorized the waiver of certain Federal requirements to enable a state to provide home and community services (other than room and board) to individuals who would otherwise require SNF, ICF, or ICF/MR services reimbursable by Medicaid. The waiver programs are called 1915(c) waivers, named after the section of the Social Security Act that authorized them.[44]

Under 1915(c) waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs include: case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, "such other services requested by the state as the Secretary may approve," and "day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness."

All but the last were included when the statute was first enacted in 1981. Services for individuals with a chronic mental illness were added in the late 1980s. Neither the statute itself nor HCFA regulations further specify or define the scope of the listed services. However, the law that created the waiver program expressly permits the Secretary to approve services beyond those specifically spelled out in the law, as long as they are necessary to avoid institutionalization and are cost-effective. In the 19 years of the program's existence, HCFA has approved a wide variety of additional services.

In the early 1990s, HCFA first issued a standard HCBS waiver application format for states to submit requests to operate an HCBS waiver program. The standard format includes definitions of services states commonly cover in their HCBS waiver programs. The services listed in the standard format appear there because they: (a) are included in the listing contained in the statute, or (b) are additional services frequently offered by states. The standard HCBS waiver application format now contains HCFA-suggested definitions of services states may cover under their HCBS waiver programs. HCFA revises this standard format periodically, occasionally adding new services. (A complete listing of HCFA's service definitions is in Appendix I.) The services a state may offer are by no means limited to those that appear in the standard format. (See Chapter 4 for a detailed discussion of HCB waiver service coverage possibilities.)

All states have HCBS waiver programs. In June 2000, there were 242 waiver programs approved by HCFA.[45] States typically operate three or four, but some states offer more. Colorado, for example, operates ten. Federal-state spending for HCB waiver services totaled $10.6 billion in 1999. Roughly two-thirds of this underwrote HCB waiver services for people with developmental disabilities; the remaining third paid for HCB waiver services for other population groups.[46]

Nationwide, the number of individuals participating in HCBS waiver programs increased from 240,000 in 1992 to an estimated 622,000 in 1998, reflecting an annual rate of increase of 17.2 percent. Individuals with developmental disabilities accounted for 39.7 percent of all waiver participants in 1998, about the same proportion as in 1992. Waiver programs for individuals with other disabilities (e.g., younger persons with non-developmental disabilities and/or persons over age 65 with disabilities) accounted for an estimated 57.1 percent of all participants in 1998. Highly targeted HCBS waiver programs (e.g., programs serving individuals with HIV/AIDS, persons with mental illness, persons who have had a brain injury or another brain disorder, and children with severe

medical disabilities) accounted for the remaining 3.2 percent of program participants.[47]

Average cost of HCB waiver services

In 1998, the cost of HCB waiver services was about $14,950 per participant. However, there were marked differences in costs among HCBS waiver target populations. The average cost of HCB waiver services for people with developmental disabilities was $29,353 per participant. In contrast, HCBS waiver programs that serve seniors and/or younger persons with non-developmental disabilities incurred an average cost per participant of $5,362.[48] The differences in HCBS waiver costs among target population groups stem from a wide variety of factors. Major factors that affect costs include: (a) differences in the intensity of the services particular target populations require; and (b) the extent to which other state plan services can meet the needs of the target population (and thereby reduce the costs of the additional services that are furnished through HCBS waiver programs). Historically, the costs of supporting individuals with developmental disabilities through HCBS waiver programs have been well above costs of supporting other target populations, because a relatively high percentage of waiver participants with developmental disabilities have been receiving residential rather than in-home services.

The Katie Beckett Provision

The Katie Beckett provision is a statute—the Tax Equity and Fiscal Responsibility Act (TEFRA) 134—added to Medicaid in 1982. Katie Beckett is the name of the child whose parents petitioned the Federal government for her to receive Medicaid services at home instead of in a hospital, and whose plight led the Reagan Administration to urge Congress to enact the provision. TEFRA 134 gives states the option to cover noninstitutionalized children with disabilities. Prior to enactment of this provision, if a child with disabilities lived at home, the parents' income and resources were automatically counted (deemed) as available for medical expenses. However, if the same child was institutionalized for 30 days or more, only the child's own income and resources were counted in the deeming calculation—substantially increasing the likelihood that a child could qualify for Medicaid. This sharp divergence in methods of counting income often forced families to institutionalize their children simply to get them medical care.

TEFRA 134 amended the Medicaid law to give states the option to waive the deeming of parental income and resources for children under 18 years old who were living at home but would otherwise be eligible for Medicaid-funded institutional care. Not counting parental income enables these children to receive Medicaid services at home or in other community settings. Many states use this option, which requires states to determine that (1) the child requires the level of care provided in an institution; (2) it is appropriate to provide care outside the facility; and (3) the cost of care at home is no more than the cost of institutional care. In states that use this option, parents may choose either institutional or community care for their Medicaid eligible children.

Targeted Case Management

Until 1986, the only practical avenue available for a state to secure Medicaid funding for freestanding case management services (i.e., case management services not delivered as part of some other service or conducted in conjunction with the state's operation of its Medicaid program) was through an HCBS waiver program. Coverage of case management services in HCBS waiver programs was nearly universal at that time.

In 1986, Congress created the option for states to cover what were termed "targeted case management" services under their Medicaid plan.[49] The expressed statutory purpose of targeted case management is to assist Medicaid recipients in "gaining access to needed medical, social, educational and other services." This option is unique among services afforded under the state plan, in that states are exempt from the comparability requirement to make such services available to all recipients. A state is permitted to amend its state plan to cover case management services for *specified groups of Medicaid recipients* (hence the term targeted). It may also offer these services on a less-than-statewide basis (again via state plan amendment

instead of securing a waiver).[50] (See Chapter 4 for further discussion.)

Given the expressed statutory purpose of the benefit—to assist individuals to obtain services from a wide variety of public and private programs—the scope of services a state may furnish through the targeted case management option is relatively broad. Covered activities include assistance in obtaining food stamps, energy assistance, emergency housing, or legal services. Covered activities also include service/support planning (including assessment) and monitoring delivery of the services and supports in order to ensure they are meeting a beneficiary's needs.

Financial Protections for Spouses Living in the Community

The Medicare Catastrophic Coverage Act of 1988 established special financial eligibility rules for institutionalized persons, to allow a spouse who remained in the community to retain more assets and income than had previously been allowed under Medicaid's financial eligibility rules. The figures for retainable resources are adjusted annually to reflect increases in the Consumer Price Index.[51] The purpose of these rules is to prevent impoverishment of the spouse who is not institutionalized. States have the option to extend these rules to the spouses of beneficiaries receiving home and community services and also to follow the minimum maintenance allowance rules mandated for spouses of nursing home residents. (See Chapter 2 for a detailed discussion of these and other financial eligibility provisions.)

Program of All-Inclusive Care for the Elderly (PACE)

The Balanced Budget Act of 1997 (BBA) established the Program of All-inclusive Care for the Elderly (PACE) model of care as a permanent provider entity within the Medicare/Medicaid programs.[52] This provision enables states to provide PACE services to Medicaid beneficiaries as a state option, rather than as a demonstration as was formerly the case. The number of new PACE sites that can be established nationwide is limited to 80. The typical PACE program serves fewer than 300 individuals. PACE programs are funded by both the Medicare and Medicaid programs, and participants are generally eligible for both. PACE programs provide and manage all health, medical, and social services, and arrange other services as needed to provide preventive, rehabilitative, curative, and supportive care.

The PACE approach provides an alternative to institutional care for persons age 55 and over who require a nursing facility level of care. Services are provided in adult day health centers, homes, hospitals, and nursing homes. PACE providers receive payment only through the PACE capitation rate and are responsible for provision of all items and services covered under both Medicare and Medicaid. The individuals enrolled in PACE receive benefits solely through the PACE program.

* * *

This brief overview of Medicaid's statutory, regulatory, and policy provisions related to home and community services for people with disabilities provides a context for more detailed discussions in the chapters to come. Some of the institutional bias that remains in the program can be changed only by congressional amendment of Medicaid law (e.g., the requirement that a person must meet an institutional level-of-care standard to receive HCBS waiver services). But numerous provisions give state policymakers considerable freedom in designing their home and community service system to fit their state's particular needs. They have the option, in particular, to eliminate use of more restrictive financial criteria for HCBS waiver services than for institutional care. They also have considerable flexibility to create consumer-responsive systems that facilitate home and community living. (See Chapter 7.)

In the next several decades, as already noted, the U.S. population will age dramatically. Between 1987 and 1996, for example, the proportion of nursing home residents who were 85 and over rose from 49 to 56 percent for women, and from 29 to 33 percent for men. The severity of disability among the nursing home population has also been increasing. Almost 83 percent of nursing home residents in 1996 needed help with three or

more ADLs, for example, compared with 72 percent of residents in 1987.[53] Even if disability rates among older persons decline, more people will need long-term care services than at any other time in our nation's history.

Institutional care is costly. Given the projected demand for long-term care services, it is advisable for states to start planning now to create comprehensive long-term care systems that will enable people with disabilities—whatever their age or condition—to live in the community rather than rely on institutional residence and services. The Medicaid program can be the centerpiece of such a system—allowing states numerous options to provide home and community services that keep costs under control at the same time as they enable people with disabilities to retain their independence and their dignity.

Endnotes

1. The primary contributors to this chapter are Gary Smith and Janet O'Keeffe. In addition to the sources noted in the citations, a major source of information for this chapter is the *Medicaid source book: Background data and analysis (1993)*. Washington, DC: U.S. Government Printing Office.

2. The Federal government's share of medical assistance expenditures under each state's Medicaid program, known as the Federal Medical Assistance Percentage (FMAP), is determined annually by a formula that compares the state's average per capita income level with the national average. States with higher per capita incomes are reimbursed smaller shares of their costs. By law, FMAP cannot be lower than 50 percent or higher than 83 percent. In 1997, the average FMAP was 57.0 percent. States are also reimbursed for 50 percent of administrative costs. Congressional Research Service. (1993). *Medicaid source book: Background data and analysis (a 1993 update)* (p.5). Washington, DC: U.S. Government Printing Office.

3. Congressional Research Service. (1993). *Medicaid source book: Background data and analysis (a 1993 update)* (p.267). Washington, DC: U.S. Government Printing Office.

4. Data on long term services are from Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group.

5. Ibid.

6. Ibid.

7. Prouty, R., and Lakin, K.C. (Eds.). (May 2000). *Residential services for persons with developmental disabilities: Status and trends through 1999*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. (Study underwritten by the Administration on Developmental Disabilities and the Health Care Financing Administration).

8. Data compiled by John Drabek, Office of the Assistant Secretary for Planning and Evaluation from data collected by HCFA's Office of Financial Management.

9. Kane, R.L., Kane, R., Ladd, R.C., and Nielsen Vealie, W. (1998). Variation in state spending for long-term care: Factors associated with more balanced systems. *Journal of Health Politics, Policy and Law* 23(2): 363–390.

10. Section 1902(a)(10)(d) of the Social Security Act. Because state plan coverage of nursing facility services is mandatory for categorically eligible persons age 21 and older, home health services are mandatory for this population. If a state chooses to cover nursing facility care for younger persons, or for the medically needy, home health services become mandatory for these groups as well.

11. 42CFR 441.15 (c).

12. Medicaid Assistance Manual. 5.50.1 1977.

13. 42 CFR 440.70 (b).

14. 42 CFR 440.230(d).

15. 42 CFR 440.230(b).

16. Health Care Financing Administration. (September 4, 1998). Letter to State Medicaid Directors. (Available at www.hcfa.gov/Medicaid.)

17. *Skubel v. Fuoroli*. (No. 96-6201). United States Court of Appeals, Second Circuit. Decided May 13, 1997.

18. Social Security Amendments of 1965 (P.L. 89-97).

19. Social Security Amendments of 1967 (P.L. 90-248).

20. P.L. 90-248 effective July, 1970.

21. Act of December 14, 1971 (P.L. 92-223).

22. Social Security Amendments of 1972 (P.L. 92-603).

23. Section 1619 P.L. 96-265 of the Social Security Act .

24. Omnibus Budget Reconciliation Act of 1981 (OBRA 81, P.L. 97-35).

25. P.L. 103-66. Section 13601 (a1/5)8. Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA) con-

tains the amendment.

26. Consolidated Omnibus Reconciliation Act of 1985. P.L. 99-272. The provision became effective April 1986.

27. Consolidated Omnibus Reconciliation Act of 1985. P.L. 99-272. The provision became effective April 1986.

28. Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360).

29. Omnibus Reconciliation Act of 1989.

30. Omnibus Reconciliation Act of 1993. Section 13601 (a1/5)8. P.L. 103-66. The changes took effect on October 1, 1994. In November 1997, HCFA issued new regulations (42 CFR 440.167) concerning optional Medicaid state plan personal care services to reflect these statutory changes.

31. P.L. 106-170.

32. Omnibus Reconciliation Act of 1989.

33. In 1987, Congress abolished the distinction between SNFs and ICFs. Nursing facilities were mandated to provide both a skilled and intermediate level of care.

34. Section 440.130(d). Other licensed practitioners of the healing arts, within the scope of their practice under state law, may also authorize services under the rehabilitation option. The statutory definition is qualified by other provisions in the law.

35. Chris Koyanagi, Policy Director, Bazelon Center for Mental Health Law. Personal communication, May 15, 2000.

36. In 1989, Congress acted to permit states that had secured HCFA approval of these coverages to continue their coverages but other states were effectively barred from adding the coverage. The Omnibus Budget Reconciliation Act of 1989 (P.L. 101-239) Section 6411(g) prohibited the Secretary of Health and Human Services from ". . . withholding, suspending, disallowing or denying federal financial participation . . . for day habilitation and related services under paragraph (9) [clinic services] or (13) [diagnostic, screening, preventive and rehabilitative services] of Section 1905(a) of the Social Security Act on behalf of persons with mental retardation and related conditions, pursuant to a provision of its state plan as approved on or before June 30, 1989."Section 6411(g) put a moratorium on HCFA's taking actions against a state that already offered day habilitation under its state plan on or before June 30, 1989. It provided that the moratorium would only be lifted once HCFA issued final regulations that clarified the elements of day habilitation that could be offered under the state Medicaid plan as either clinic or rehabilitative services. Since passage of OBRA-89, HCFA has not issued such regulations.

37. Smith, G., Director of Special Projects, National Association of State Directors of Developmental Disabilities Services. Personal communication, July 2000.

38. The Omnibus Budget Reconciliation Act of 1993 (Section 13601(a)(5)); Social Security Act (Section 1905 (a)(24)).

39. Individuals who reside in certain types of facilities—nursing facilities, ICFs/MR, hospitals, and institutions for mental disease (IMDs)—cannot receive personal care services through the personal care option.

40. 42 CFR 440.167.

41. Five additional states offer personal care services to children under the EPSDT mandate. LeBlanc, A.J., Tonner, M.C. and Harrington, C. (2000) *State Medicaid Programs Offering Personal Care Services.* San Francisco: University of California. The report lists 26 states with the Title XIX personal care services optional state plan benefit. Since 1998–1999, when the data were collected, New Mexico has started the benefit, bringing the state total to 27.

42. Total FY 1999 expenditures for personal care services equalled $3,526,775. Source: Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group.

43. Section 440.70(b)(3).

44. Federal regulations concerning the program are found at 42 CFR 441 Subpart G. These regulations were last modified in 1994. HCFA guidelines concerning the HCBS waiver program are contained in Sections 4440 *et seq.* of the State Medicaid Manual. These guidelines are updated periodically.

45. Data obtained from HCFA website: www.hcfa.gov/ medicaid.

46. Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group.

47. Figures are based on: Harrington, C., Carrillo, H., Wellin, V., and Norwood, F. (July 2000). *1915(c) Medicaid home and community-based waiver participants, services, and expenditures, 1992–1998.* Based on HCFA 372 Form Data. San Francisco CA: University of California San Francisco (UCSF). And Prouty, R. and Lakin, K.C. (eds.) (May 2000). *Residential services for persons with developmental disabilities: Status and trends through 1999.* Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute for Community Integration.

For both 1992 and 1998, University of Minnesota fig-

ures for individuals with developmental disabilities receiving HCBS services through the Arizona 1115 demonstration waiver were added to the UCSF figures. Where data were missing in the 1998 UCSF figures, 1997 data were used instead, except in the case of HCBS waiver programs for persons with developmental disabilities (for which University of Minnesota figures were used).

48. Average costs are calculated by dividing total expenditures by the total number of persons who participate during a year, regardless of the length of time they receive waiver services. (See endnote #47 for data source.)

49. Section 915(g) was added to the Social Security Act.

50. HCFA guidelines concerning targeted case management services are found in the State Medicaid Manual in Sections 4302 et seq.

51. P.L.100-360. (1993). *Medicaid source book: Background data and analysis (a 1993 update)* (p. 224). Washington, DC: U.S. Government Printing Office.

52. P.L. 105-33.

53. Rhoades, J.A., and Krauss, N.A. (1987, 1996). *Nursing home trends.* Rockville: Agency for Health Care Policy and Research; (1999). Medical Expenditure Panel Survey (MEPS) Chartbook No.3. AHCPR Pub. No. 99-0032.

Annotated Bibliography

Feder, J. (May/June 2000). Long-term care in the United States: An overview. *Health Affairs* 19 (3): 40–56. (16 pages)

This article describes how long-term care is financed in the United States. It emphasizes the current inadequacies of the Medicare and Medicaid programs and encourages changes that will provide affordable services to those in need. The article describes reasons for beneficiary dissatisfaction with the scope, mix, quality, and financing of long-term care, which varies among states. The article also includes an overview of the population that needs long-term care, mechanisms for financing, policy implications of various proposals to improve access to long-term care, and issues policymakers should consider when seeking to improve the system.

Harrington, C., LaPlante, M., Newcomer, R.J., Bedney, B., Shostak, S., Summers, P., Weinberg, J., and Basnett, I. (January 2000). *Review of federal statutes and regulations for personal care and home and community based services: A final report.* San Francisco: Department of Social and Behavioral Sciences, University of California. (169 pages)

The paper identifies provisions of law and regulation that contribute to institutional bias in the Medicaid program. It provides a comprehensive overview of Medicaid statutes and regulations related to the provision of long-term care services. The paper also makes policy recommendations to reduce institutional bias and thereby increase the availability of home and community-based services through the Medicaid program. *The document may be ordered for $15.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

Harrington, C., Carrillo, H., Wellin, V., Norwood, F., and Miller, N.A. (March 2000). *1915(c) Medicaid home and community based waiver participants, services, and expenditures, 1992–1997.* San Francisco: Department of Social and Behavioral Sciences, University of California. (26 pages)

This paper presents historical data on home and community based waiver participants, services, and expenditures. It describes the number and type of 1915(c) HCBS waiver programs that states operated between 1992 and 1997. It reports on trends in the number of participants and expenditures by target group and by service and discusses factors related to expenditure growth. *The document may be ordered for $5.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

Coleman, B., and Tucker, N. (1999). *Trends in Medicaid long-term care spending.* Washington, DC: AARP, Public Policy Institute. (6 pages)

This publication briefly discusses Medicaid expenditures for long-term care. It shows that there has been a steady increase in long-term care spending, particularly for home and community-based services (HCBS) waiver programs for people with mental retardation and other developmental disabilities. It compares allocation of Medicaid long-term care spending for HCBS waiver programs, personal care services, and home health services. A table of Medicaid home care expenditures for all states is included. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3860 or search their website at www.research.aarp.org. Publication ID: DD38 January 1999.*

The Kaiser Commission on the Future of Medicaid. (February 1996). *Medicaid and long-term care.* Washington, DC: Author. (8 pages)

This policy brief discusses Medicaid's provision of

long-term care services. It highlights Medicaid spending on long-term care, mandated services, and eligibility requirements. Particular attention is paid to nursing home care and the laws that seek to ensure quality of care. *It may be obtained free of charge from the Kaiser Family Foundation website at www.kff.org or ordered from their publications line at (800) 656-4533.*

Burwell, B., and Crown, W. (1994). *Public financing of long-term care: Federal and state roles.* Cambridge: The MEDSTAT Group. (40 pages)

This paper provides an overview of public financing of long-term care services for elderly persons through Medicare, Medicaid, and other public programs. It presents statistics, characteristics of publicly-financed programs, and the variation in financing across the 50 states. It discusses utilization trends and the allocation of federal and state monies to pay for services such as home health and personal care. Graphs and tables enhance the presentation. The paper also discusses cost containment methods employed by funding sources, quality assurance measures, and access to care issues. It emphasizes the states' primary role in shaping the publicly financed long-term care system and the policy implications of that role. The paper provides a thorough understanding of the history of public funding for long-term care, financing options that states have employed, and considerations that must be taken into account when providing long-term care. *The paper can be obtained free of charge by writing to Pauline Chouinard at The MEDSTAT Group, 125 Cambridge Park Drive, Cambridge, MA 02140.*

Websites

The following websites provide some information about Medicaid, long-term care, or home and community services. This list is not inclusive of all the resources available on the internet, but provides a good starting point for finding information.

Federal Government Websites

Administration on Aging: www.aoa.gov

Agency for Healthcare Research and Quality: www.ahrq.gov

Assistant Secretary for Planning & Evaluation (ASPE): aspe.hhs.gov

Health Care Financing Administration (HCFA): www.hcfa.gov

HCFA's Medicaid information: www.hcfa.gov/medicaid

Medicare/Medicaid (500 Sites): whatsonthe.net (click on *Medicare/Medicaid* under *Health*)

Murphy's Unofficial Medicaid Page: www.geocities.com/CapitolHill/5974

National Association of State Medicaid Directors: www.aphsa.org (click on *Links*)

State Government Websites

Intergovernmental Health Policy Project: www.ncsl.org

National Academy for State Health Policy (NASHP): www.nashp.org

National Association of State Mental Health Directors: www.nasmhpd.org

National Conference of State Legislatures: www.ncsl.org

State and Local Governments on the Web: www.piperinfo.com/state

Foundations

Kaiser Family Foundation: www.kff.org

The Robert Wood Johnson Foundation: www.rwjf.org

Commonwealth Fund: www.cmwf.org

Associations and Organizations

American Association of Homes & Services for the Aging: www.aahsa.org

American Association of Retired Persons (AARP): www.aarp.org

American Public Human Services Association: www.aphsa.org

Bazelon Center for Mental Health Law: www.bazelon.org

Consortium for Citizens with Disabilities: www.c-c-d. org

Independent Living Research Utilization (ILRU): www.ilru.org

Liberty Resources: www.libertyresources.org

National Senior Citizens Law Center: www.nsclc.org

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CHAPTER 2

Financial Eligibility Rules and Options[1]

Medicaid's flexibility has resulted in wide differences among states that offer them opportunities to learn from and build on one another's experiences. This chapter explains what Federal rules require, and allow, states to do that affects financial eligibility for Medicaid for persons who need assistance in paying for long-term care needs that can be met by home and community services.

Introduction

Medicaid today is a far different program from Medicaid as enacted in 1965. As originally conceived, Medicaid was to have served primarily the very poor and near poor who qualified or were close to qualifying for cash welfare. It was to have functioned much like private health insurance, with service coverage focused on acute care needs. Over time, Federal and state actions have expanded Medicaid's authority, the scope of its coverage of long-term care services, and its eligibility options for beneficiaries who are not "poor" by the traditional welfare-based definition. By the end of its first decade, Medicaid had become a major source of public funding for institutional long-term care. By the end of its third decade, it had become the major public funder of home and community long-term care services as well.

Medicaid is likely to become an even more dominant payer for persons being served in community settings in the future, because of the unique interplay of two program features. First, funding is based on an individual entitlement concept and there are no fixed or predetermined caps on a state's spending. The amount spent is a function of Federal, state, and sometimes local decisions about who is eligible, what they are eligible for, and what rates Medicaid pays for covered services to eligible beneficiaries. Second, states have enormous flexibility under Medicaid to design and tailor their home and community service systems.

Medicaid's role in financing long-term care has developed in sporadic increments—often in reaction to problems occupying center stage at a particular time. As a result of incremental policymaking combined with vast variations in how states cover long-term care, the various facets of Medicaid's financial eligibility provisions may appear to be disjointed. In particular, there are many provisions with major eligibility discontinuities—wherein a slight change in individuals' personal circumstances can result in huge differences in the kinds (and levels) of benefits they are eligible for. The purpose of this chapter is to put the relevant information together in a way that is most useful to state policymakers and advocates.

What Services Medicaid-Eligible Persons Receive

The highlights of Medicaid service coverage alternatives listed here provide a general context for the financial eligibility discussion of this chapter. (For full detail, see Chapters 4 and 5.)

- Once determined eligible for Medicaid, beneficiaries are entitled to the full range of Medicaid services covered in their state, for both their acute and long-term care needs. When long-term care services are provided through HCBS waiver programs under Section 1915(c) of the Social Security Act, or as a state plan service through the personal care option, only people specifically determined eligible for those programs can receive the services.
- Medicaid acute care coverage (e.g., hospital, physician, or prescription drug services) can be extremely important to persons who need long-term care services, especially if they do not have Medicare or private health insurance to cover those expenses.
- Medicaid services for children can be more extensive than Medicaid services for adults or than services typically covered under private insurers' well-child programs.
- Medicare and Medicaid cover many of the same services (e.g., hospital, physician, and home health services). For persons eligible for both Medicare and Medicaid, Medicaid generally pays beneficiary cost-sharing for all services covered by Medicare. Medicare beneficiaries eligible under any of their state-defined Medicaid eligibility groups typically receive Medicaid coverage of Medicare cost-sharing requirements, including premiums, deductibles, and coinsurance. They also receive Medicaid services covered by Medicaid but not Medicare. The most notable examples are prescription drugs, more extensive coverage of mental health services and long-term care institutional services, and personal care services, as well as home health services with a less intense medical orientation than services covered under the Medicare home health benefit.[2]
- States provide some long-term care services under Federal mandate. They provide others at their option, which may be provided either to all eligibles under the state's Medicaid plan or to selected groups under an HCBS waiver. Under an HCBS waiver program, states can provide services not viewed as strictly medical (e.g., homemaker or chore services and respite care).

Overview of Medicaid Financial Eligibility

Medicaid financial eligibility is deeply rooted in two Federally financed programs of cash assistance to help support low-income individuals and families: the former Aid to Families with Dependent Children (AFDC) program, which provided income support for low-income families with children, and the Supplemental Security Income (SSI) program for elderly persons, blind persons, and persons with disabilities. (In 1996, welfare reform legislation replaced AFDC with a new program, Temporary Assistance for Needy Families [TANF].)

Like AFDC/TANF and SSI, Medicaid is a means-tested entitlement. That is, anyone qualifies for Medicaid if (a) their income and assets do not exceed the state thresholds specific to their eligibility group, and (b) they meet all other relevant eligibility criteria.

Medicaid eligibility rules fall into two basic sets: categorical and financial. The categorical set defines particular categories of persons for whom Federal law permits coverage. Persons needing long-term care services generally fall into one of three Medicaid categories: persons who are age 65 or older, persons who are blind, and persons with disabilities. Medicaid criteria for determining who is blind or has disabilities are generally the same as they are for SSI, as established by the Social Security Administration. To qualify in a disability category, a person must have a long-lasting, severe, medically determinable physical or mental impairment. The person must also be unable to work—defined in 2000 in part as earning less than $700 per month (net of income-related work expenses), a level of earning considered by regulation as evidence of one's ability to engage in substantial gainful activity (SGA).

Anyone not meeting these criteria cannot receive Medicaid in a disability category of eligibility,

even if they have extensive medical needs or high medical bills. (Special exceptions—which allow Medicaid eligibility for certain former child beneficiaries of SSI disability benefits as well as for persons who do not meet one or more of the usual SSI disability criteria because they earn more than $700 per month—are discussed later in the chapter.)

Medicaid's financial eligibility rules for persons who are elderly or have disabilities are built on a foundation of SSI rules. But many exceptions and variations have been enacted over the years to make them work better for low-income persons needing health care but not cash assistance.

Basic Medicaid Eligibility Rules

- Categorical criteria—Eligible persons must
  - be age 65 or older, or
  - be blind, or
  - have disabilities (using the same criteria as for disability in SSI).
- Income and resources—Eligible persons must have incomes that are low or severely reduced by medical expenses. In addition:
  - Thresholds vary by eligibility category and family size.
  - Some thresholds are established by Federal law, some by states within broad Federal guidelines.
  - Thresholds must apply statewide (except under special waiver financial rules, which apply only if (a) the waiver is not statewide, and (b) there is a waiver-specified threshold).
- Legal status, residence, and eligibility redetermination—Eligible persons must
  - be a citizen or in appropriate immigration status.
  - be a resident of the state or, if not, eligible under an interstate compact.
  - report changes in circumstances and have eligibility periodically redetermined by the state.

Medicaid for SSI Beneficiaries

SSI is the Federally administered program that ensures a nationally uniform income floor for persons who are elderly, who are blind, and who have disabilities. To be eligible, both income and assets must be low. Forty states provide Medicaid to all individuals in any month in which they receive an SSI payment. Of these, 33 do so automatically, based on a list of SSI beneficiaries compiled by the Federal Social Security Administration. The other 7 require SSI beneficiaries to file a separate application with the state for Medicaid benefits. The remaining 11 states follow what is known as the 209(b) exception option, described below, which allows them to provide Medicaid to SSI beneficiaries only if they meet the state's criteria, which may be more restrictive than those for SSI.

General Rule

The general income rule for SSI specifies the level of "countable income" at or below which a person is financially eligible for benefits. Countable income includes cash income plus certain in-kind goods or services a person receives in a given month, *minus* certain amounts that are exempt from the SSI benefit calculation (discussed more fully below). In the year 2000, the maximum monthly SSI benefit paid to persons with no other income is $512 for an individual and $774 for a couple. Persons with income from other sources (e.g., Social Security or a pension) receive a lesser amount—equal to the difference between the full SSI benefit rate and the amount of their countable income from other sources. For example, the SSI benefit for an individual with countable income of $500 would be only $12 per month.

The general rule defines countable resources as cash or other property, including real property, that (a) were acquired some time in the past, (b) the individual has the right to access, and (c) could be converted to cash and used to cover current basic living needs. Individuals with up to $2000 ($3000 for a couple) in countable resources can qualify for SSI. SSI resource limits are often used as the minimum base for resource eligibility for Medicaid.

Exceptions

There are two major exceptions to the general rule: the state 209(b) option and protection for cer-

tain former SSI beneficiaries. (Mandatory Medicaid protection for certain children with disabilities and certain working persons with disabilities is discussed later in this chapter.)

State 209(b) option

Medicaid for the "Aged, Blind, and Disabled" had historically always been linked to receipt of cash assistance benefits. When SSI replaced state-only programs of aid for elderly persons and persons with disabilities, it was expected to lead to large increases in the numbers of SSI beneficiaries. The 209(b) option was enacted along with SSI in 1972 to enable states to avoid experiencing similarly large increases in Medicaid enrollment and costs.

Many Medicaid eligibility rules in 209(b) follow SSI. But states may choose, instead, to use some or all of the more restrictive Medicaid rules in effect in their state on January 1, 1972, shortly before SSI was enacted. Typically these states have retained at least some of their pre-SSI rules on countable income or resources. Some use more stringent criteria for determining blindness or disability.

To counterbalance the potential negative effects of the 209(b) option on SSI beneficiaries, Federal rules require 209(b) states to allow any residents who are elderly, blind, or have disabilities—including those with too much income for SSI—to spend down to the state's Medicaid income standard if their expenses for medical and remedial services so erode their income that their "net" remaining income would be less than a standard set by the state. This requirement creates a medically needy-like program for this population, even in states that have not chosen specifically to cover the medically needy as an option, as in Indiana, Missouri, and Ohio. Spend-down rules for 209(b) are virtually identical to spend-down rules for the medically needy (discussed below).

Medicaid protection for certain former SSI beneficiaries

Federal law requires all states, including 209(b) states, to provide Medicaid to former SSI beneficiaries who would, but for increases in their Social Security benefits, continue to be eligible for SSI. Congress passed this provision to ensure that Social Security increases, intended to improve people's lives, did not harm this group instead by causing them to lose Medicaid as well as SSI. Most of the individuals affected have incomes just marginally above the income levels at which they might qualify for SSI/Medicaid combined benefits. In fact, many persons who could qualify for Medicaid under these provisions do not apply for the program, most likely because they are not aware of them. Improved understanding of these protections may help increase the Medicaid enrollment of this group.

Former SSI Beneficiary Groups with Medicaid Protection

- People who lost SSI when they received automatic cost-of-living adjustments (COLAs) in Social Security (sometimes nicknamed "Pickle people" after Congressman Pickle, one of the sponsors of the original COLA legislation)
- Adult children with disabilities who lose SSI because they become entitled to Social Security benefits based on a parent's Social Security entitlement
- Individuals ages 60–64 who lose SSI due to receipt of Social Security benefits for widows and widowers with disabilities

Countable Income or Resources

The concept of countable income and resources may seem arcane but is important. Neither SSI nor Medicaid determine eligibility by comparing a person's total income and resources to the dollar thresholds that apply in the person's eligibility category. Rather, they count only certain types and amounts. (This practice has a close counterpart in income tax rules, which exempt certain types or amounts of income from taxation and allow certain types or amounts to be deducted from otherwise taxable income.) For this reason, an individual can have total income or resources higher than the nominal eligibility limits (i.e., higher than $512 in total income or $2000 in total resources for SSI) and still qualify for benefits.

SSI Rules

SSI rules reduce a person's gross income to get countable income in three important ways. First, SSI disregards the first $20 of every applicant/recipient's income. Second—and of great significance to people with disabilities who work—SSI provides a disregard of earnings from work, amounting to the first $65 plus one-half of the remaining earnings amount. Third, spouses or children with disabilities in families with other members who are ineligible can qualify for SSI at higher gross amounts of family income, because SSI counts only the portion of the nondisabled spouse's or parent's income that is left *after* SSI subtracts amounts to cover the basic needs of nondisabled family members. (SSI may apply several other special-purpose reductions also.)

SSI rules reduce gross resources in determining whether resources are below the SSI $2000/$3000 thresholds, by exempting the home (regardless of value) and (within limits) such things as an auto, household goods, surrender value of life insurance, burial funds, and property essential to self-support.

Medicaid Exceptions

In general, states use SSI rules in determining what is countable income and resources for Medicaid eligibility.[3] But states have the option to liberalize their Medicaid rules of what is countable. Such disregards redefine how income or assets are countable in such a way that the eligibility limits specified in the law, while still theoretically applicable, can be greatly exceeded.

Examples of Provisions That Can Reduce Countable Income or Resources

- Allow more than the standard SSI income disregard of $20
- Disregard more earnings from work
- Disregard all or part of certain types of resources that are limited under SSI, for example, income-producing property essential to self-support, burial funds, cash value of life insurance

It is important to note that this state flexibility comes with certain restrictions. First, the different counting methods must not disadvantage anyone, even if relatively more people would benefit than would be disadvantaged. Second, although a state may restrict its more liberal counting method to eligibility groups it selects, the group(s) must be specifically defined in Medicaid law—for example, working persons with disabilities, the poverty-related groups, or the 300 percent of SSI groups (all of which are discussed more fully below). Thus, states are not permitted to carve out a subgroup of their own definition (e.g., one based on medical diagnosis or place of residence).

Third, flexibility in counting income is highly limited for medically needy eligibility groups (described below), because Federal law imposes a ceiling on medically needy income levels (133 1/3 percent of the highest amount paid to an AFDC family of the same size). States are not permitted to exceed this ceiling, which limits opportunities for states with medically needy income levels at or close to the ceiling.[4]

While Federal rules give states broad flexibility to expand eligibility, actual adoption of more generous alternative methods must, of course, conform to a state's budget considerations and political decisions.

Eligibility Expansion Options Including, but Not Specific to, Home and Community Services

Certain state Medicaid options for across-the-board eligibility expansions capture anyone who meets the criteria, including but not limited to persons needing long-term care services. Because these options cannot be targeted, they involve cost implications for states that make them unlikely candidates for a state looking for narrower home and community service expansions. States may be encouraged to adopt these wider options, however, for other excellent reasons. Persons eligible under any of these options receive the full range of acute and long-term care

services covered under the state plan, for example. In addition, if they meet the state's criteria for HCBS waiver participation (e.g., level of care, diagnosis, or place of residence) they can receive waiver services.

General Eligibility Expansion Options

- 100 percent of poverty option
  - Allows states to provide full Medicaid benefits to all elderly persons or persons with disabilities with countable income below poverty and low resources.
- Medically needy option
  - Allows eligibility for those who would qualify except for income.
  - Higher income persons must spend down. And states may not cover medically needy who are elderly or have disabilities without also covering medically needy pregnant women and children.

Two Hypothetical Spend-Down Situations

Assume the state's medically needy income level for an individual is $450 per month.

- For individuals with monthly countable income of $550, the spend-down liability is $550 minus $450 (= $100), a difficult but perhaps manageable amount for a person with very high recurring medical expenses.
- For individuals with monthly countable income of $950, spend-down liability is $950 minus $450 (= $500), a manageable amount only for those with time-limited medical needs or those in nursing homes who do not need income to maintain a home and other expenses of living in the community.

100 Percent of Poverty Option

States have the option to raise the income level at which any elderly person or person with disabilities in the state can qualify for Medicaid as high as 100 percent of the Federal poverty level ($8350 for one person in calendar year 2000, increasing incrementally for additional family members). The state's eligibility limits on countable resources must be at least as high as SSI levels ($2000 for one, $3000 for a couple).[5]

It bears repeating here that what is compared to these eligibility levels is countable (not total) income and assets. At the very least, states must disregard the same kinds and amounts of income and resources that SSI disregards.

Medically Needy Option

States can cover people with too much income to qualify in any other eligibility group under the medically needy option. There is no specified ceiling on how much income a person can have and still potentially qualify if their medical bills are high enough. However, a number of caveats limit the attractiveness of the medically needy option for higher income persons needing long-term care, especially home and community services, relative to the more narrowly targeted options discussed in the next section. Caveats include the following:

- Individuals must fit into one of the Medicaid-coverable categories—for example, be age 65 or older or meet the Social Security Act criteria for disability. If not, they cannot qualify as medically needy no matter how low their incomes or how extensive their medical need.
- At a minimum, states choosing this option must first cover medically needy pregnant women and children. Most states that cover the medically needy also extend it to elderly persons or persons with disabilities.
- States may not restrict eligibility based on medical condition, type of services needed, or place of residence.
- Eligibility limits on resources are typically the same as for SSI.[6]
- States must use a single eligibility level for income and resources for all medically needy groups they elect to cover. In the case of income levels, this single level may not exceed 133 1/3 percent of the state's pre-welfare reform AFDC payment levels. Where these are very low, the

medically needy income levels may be kept to a level that is less than the SSI level.

- Medically needy persons with incomes above the state's threshold must spend down before becoming eligible for Medicaid benefits.

This last, the spend-down requirement, can be a major pitfall for higher income people who wish to qualify for home and community services through the medically needy provision. The reason is that medically needy persons with incomes above the state's Medicaid income threshold must spend down to that threshold *on a periodic basis* in order to remain eligible for Medicaid funding of the services they need.[7] Until their spend-down limit is reached, they are responsible for their own medical expenses. There is no Federal or state requirement that individuals spending down actually pay their bills. But as a practical matter, providers are unlikely to continue serving them if they fail to pay. Alternatively, states can offer people the opportunity to meet their spend-down obligation by paying it directly to the state in exchange for immediate coverage of all their medical expenses. In either case, however, persons with incomes well above the state threshold may have a spend-down liability that leaves them insufficient income to cover all their expenses at their current living standards.

Because of these limitations, spend-down works best for people in three kinds of situations: (a) they have a one-time, short-term need for assistance; (b) they are permanently in an institution and no longer need income to maintain their former lifestyle; or (c) their income is low enough to result in a spend-down liability that is affordable to them. (This is discussed further in Chapter 5.)

Eligibility Expansion Options That Can Be Targeted to Persons Needing Home and Community Services

This section discusses options states can use to apply income standards that allow persons with higher incomes to qualify—and can be targeted more narrowly to persons needing long-term care services in a variety of home and community settings.

Targetable Eligibility Expansion Options

- Provide State Supplemental Payments for special needs.
- Apply 300 percent income rule, including:
  - Miller trusts
  - Post-eligibility share-of-cost obligation to eligible persons.
- Ignore income or resources of ineligible spouses or parents.
- Extend spousal impoverishment protections.

State Supplemental Payments (SSPs) for Special Needs

- States can supplement the basic SSI payment.
- States can pay across-the-board SSPs to all elderly persons or persons with disabilities in the state, or they can target them to persons in supported living settings.
- States can provide Medicaid to people receiving an SSP who are not eligible for SSI.

State Supplemental Payments

Many states supplement the basic SSI level and pair these supplementary payments with automatic Medicaid eligibility. This combination of benefits enables beneficiaries to get the services they need in a variety of community settings.

The maximum monthly Federal SSI benefit ($512 in 2000) is assumed to be minimally sufficient to enable recipients to pay for a basic level of ordinary living expenses (food, shelter, clothing). Many states have elected to spend state-only, unmatched money to supplement the basic SSI rate in circumstances where they have determined that rate to be insufficient to cover living expenses necessary for minimally adequate living standards. These state supplements are state-determined and vary widely by state.[8] Some individuals have too much income to qualify for SSI but may qualify for an SSP benefit only. States can elect to make such persons automatically eligible for Medicaid, just as they can for SSI beneficiaries.

How a State Supplemental Payment (SSP) Might Work

In the year 2000, the Federal SSI monthly benefit rate is $512 for an individual. Assume a state sets its supplemental benefit at $200 (making the SSP benefit rate $712). Then,

- A person receiving Federal SSI would receive an additional SSP amount of $200 per month.
- A person with countable income of $612—from, say, Social Security or pension—would have $80 [$100 minus $20 disregard] too much income to qualify for SSI, but would still qualify for a $100 SSP benefit.

Few states provide across-the-board state supplements to SSI. Most target them specifically to persons who are unable to live entirely independently—who do not need the high level of medically oriented care provided in a nursing home or ICF/MR, but who can live comfortably in settings that provide them with some combination of non-medical assistance and non-intensive medical or related services. The additional income they receive through the state supplement can be used to pay for that additional level of service. Automatic Medicaid eligibility for state supplement beneficiaries provides an additional measure of assistance in paying for needed medical services. States have broad flexibility with respect to not only the level of SSP support but also the kinds of settings to be supported, quality standards, and oversight. States can pay SSPs for as many different types of supported living settings as they wish.

For states that restrict SSPs to persons in supported living settings, the required services vary widely. They can consist of as little as housekeeping or general supervision, or they can extend to various levels of assistance with ADLs. They can include single-family homes, group homes, adult foster care, congregate or domiciliary care, and other settings defined by the state. (The opportunities and limitations of SSI state supplements for persons in assisted living settings are discussed in greater detail in Chapter 5.)

As with many other Medicaid options, the option states have to provide Medicaid to SSP beneficiaries not eligible for SSI is subject to certain conditions. The SSP must be based on need. And the state must pay the SSP on a regular basis to anyone in the supported living setting to which the SSP applies who, but for income, would qualify for SSI. There is no rule obligating the state to establish such settings throughout the state. If the particular type of living setting supported by a state's SSP happens to exist only in limited areas of a state, the state is permitted to pay SSPs just to persons in those settings.

300 Percent of SSI Income Rule

This option was originally created so that states not wishing to cover the entire category of medically needy could at least cover higher income persons residing in a medical institution. States electing this option may establish a special income threshold, applicable to a person's gross income (all income, not just countable income), as high as 300 percent of the maximum SSI benefit. Persons who qualify based on income must also have resources within Medicaid eligibility limits. States typically use the same asset limits as SSI, but they may use more liberal Medicaid exemption rules.[9]

When originally created, the 300 percent option was limited to persons in institutions, because home and community alternatives to nursing home services were extremely limited and not much in the public view. But when home and community waiver services were enacted into law in 1981, the law allowed states to make beneficiaries of these services eligible on the same basis as persons in institutions—thus extending the 300 percent option to the home and community context.

The goal was laudable: to enable states to neutralize incentives for a person to choose nursing home over community services simply because of Medicaid eligibility rules. But the effectiveness of the 300 percent option in increasing access to home and community services is limited by two important factors. First, it can only be applied to persons receiving home and community services under a waiver program. There is no authority allowing states to use the option to expand eligibility for persons receiving such services outside a waiver program, for example, personal care serv-

Overview of the 300 Percent Income Rule

- Allows eligibility for persons with gross incomes at or below 300 percent of current SSI—$1536 in 2000.
- Allows states to use the option for persons residing in a medical institution. If they do so, states can also extend the 300 percent of income level to eligibility for HCB waiver services.
- Allows states to provide HCB waiver services to children without regard to their parents' income or assets and to married individuals without regard to their spouse's income.
- Requires states to impose a post-eligibility cost-sharing burden (discussed further below).
- When the 300 percent rule is a state's only option for providing Medicaid to higher income persons in medical institutions (i.e., the state does not have a medically needy program), allows persons to achieve eligibility by diverting excess income into a Miller trust (discussed below).

ices provided under the state plan. Second, individuals eligible under this option, whether in an institutional setting or under an HCBS waiver program, are subject to a post-eligibility share-of-cost obligation (described below).

Miller trusts

In states where the long-term care eligibility of higher income persons is limited to those qualifying under the 300 percent eligibility option, individuals with too much income to qualify for Medicaid long-term care services even under the 300 percent rule may still qualify by diverting their income into what is known as a Miller trust. Miller trusts are not limited to persons needing Medicaid for nursing home care or HCB waiver services. State Medicaid agencies may choose, but are not required, to play a role in helping establish these trusts.

To qualify as a Miller trust, contributions must consist solely of the individual's funds (income such as monthly Social Security or pension benefits, but not resources) and must be used solely for the benefit of the individual. There are no limits on how much income can be placed in the trust. But if amounts paid out of the trust exceed the fair market value of goods and services on behalf of the individual, then the individual may be at risk of a penalty for an uncompensated asset transfer resulting in loss of Medicaid coverage for needed services. Additionally, amounts paid out of the trust count as income—whether paid directly to the beneficiary or paid to purchase something on their behalf (other than medical care). This "income" must be under the eligibility level in the state and is subject to post-eligibility share-of-cost rules. Finally, the trust must specify that the state will receive any amounts remaining after the person's death, up to the amount the state paid in Medicaid benefits for the Miller trust owner.

Protected amounts in calculating post-eligibility share-of-cost obligation (an obligation that applies only to certain beneficiary groups)

Persons who become eligible for Medicaid under the 300 percent option, whether in a nursing home or in a waiver setting, are typically expected to pay a share of their income toward the cost of their care, which they pay providers directly.[10] This post-eligibility share-of-cost obligation can be quite high, depending on the individual's circumstances and the options the state has chosen. However, unlike nursing home care, which requires beneficiaries to contribute all but their personal needs allowance and other amounts described below, state waiver programs have greater flexibility to determine how much income a person can retain. Some states require little or no cost sharing by waiver beneficiaries. As with the medically needy spend-down provision, Federal rules do not require the individual to actually pay the share-of-cost amount. But care providers can ensure payment through their usual bill collection activities.

The share-of-cost calculation is made by subtracting from total income certain amounts that are protected for the individual's personal use. The remaining income is the individual's share-of-cost obligation. The Medicaid program reduces the amount it pays for Medicaid services by the amount the individual is expected to pay. Protected amounts include:

- Amounts to cover basic needs.

States must allow persons in nursing facilities and ICFs/MR to keep a minimum of $30 per month to cover personal needs. States also have the option to establish a higher amount across the board, or to establish higher amounts for reasonable classifications, for example, for persons receiving income from sheltered workshops.

The small size of the personal needs allowance for individuals in an institutional setting is because the institution provides for most of the individual's basic living needs, and receives Medicaid payment for these services as part of the nursing home's per diem payment rate. States establish higher allowance amounts for persons eligible under the 300 percent rule in HCBS waiver programs, because waiver participants must cover their living expenses out of pocket. A state can set the allowances for this group equal to the income eligibility thresholds that apply to other Medicaid eligibility groups in the state (e.g., at the SSI or medically needy income levels). The most generous HCBS waiver programs allow eligible individuals to retain all their income for personal use, thereby effectively eliminating any beneficiary liability for a share of cost and making Medicaid pay the entire cost of covered services. State decisions depend in part on budget concerns, because the less beneficiaries spend as share-of-cost transfers, the more the state must contribute.

- Allowance for a spouse or other dependents.

  States must deduct income to provide for a spouse of an individual in a medical institution. The amounts protected for spouses of institutionalized persons are governed by the rules designed to protect against spousal impoverishment (discussed in the next section). States must also provide for the needs of spouses of persons eligible for HCB waiver services under the 300 percent eligibility option. At a minimum, Federal regulations require states to establish what they determine to be a reasonable amount. But Federal law gives states the option to be more generous to these waiver spouses by applying spousal impoverishment rules.

- Home maintenance allowance (at state option).

  Persons eligible under the 300 percent option can retain an additional amount for up to six months if needed for maintenance of a home. In the case of institutionalized persons, this allowance is limited to those who can reasonably be expected to return to their homes.

- Amounts to cover other medical expenses.

  States must allow nursing home, ICF/MR, and HCBS waiver beneficiaries to retain enough income to pay for additional medical costs they incur that are not paid for by Medicare, Medicaid, or any other payer.

To Deem or Not to Deem—Defining the Income and Resources of a Beneficiary's "Household"

Currently, states typically follow Federal SSI rules on whether or not to count (deem) income/resources of a spouse or parent in determining a person's financial eligibility. These rules impart a substantial institutional bias by ignoring the income/resources of spouses or parents when assessing eligibility if a person is living in an institution, but counting them when the person needing long-term care services lives at home.[11]

These different deeming rules make it much more likely that a person will meet Medicaid's financial eligibility test if they live in an institution than if they live at home. Thus, families considering how to get long-term care services for a spouse or child with disabilities may find that these deeming rules leave no realistic alternative to institutionalization.

States can overcome this institutional bias by choosing not to deem the income/resources of spouses or parents available to persons eligible under an HCBS waiver program. Doing so provides access to home and community services on the same financial basis as long-term care services provided in an institutional setting. *It is important to emphasize that the option not to deem does not extend to persons living and receiving long-term care services outside the waiver context*, except with

Examples of Spousal Income Protection

Assume the minimum protection allowance ($1406) applies.

Example 1:

Beneficiary's income	$2000
Spouse's income	None
Beneficiary income protected for spouse	$1406
Beneficiary income for share-of-cost calculation	$594 ($2000 – $1406)

Example 2:

Beneficiary's income	$2000
Spouse's income	$1000
Beneficiary income protected for spouse	$406 ($1406 – $1000)
Beneficiary income for share-of-cost calculation	$1594 ($2000 – $406)

Example 3:

Beneficiary's income	$2000
Spouse's income	$2000
Beneficiary income protected for spouse	None
Beneficiary income for share-of-cost calculation	$2000

respect to children in those states that have elected the Katie Beckett or TEFRA option.[12]

Spousal Impoverishment

In 1988, Congress mandated that states allow married couples separated by the institutionalization of one spouse to protect a certain amount of assets and income for the non-institutionalized spouse. This mandate applies regardless of how the institutionalized person establishes eligibility. Prior to this law, states protected no assets, and the amounts of income they protected for the support of the at-home spouse were at welfare-like levels—a devastating event for middle-class couples facing, perhaps for the first time in their lives, a need for public assistance because of the high cost of nursing home care.

Spousal impoverishment protection is available under two circumstances: (a) residence in a nursing facility or (b) residence in the community under an HCBS waiver program. The waiver option enables states to level the playing field by protecting spousal income/assets for waiver participants to the same extent as they do for spouses of Medicaid residents in institutions.

How spousal impoverishment protection works is described here for states that wish to use it for home and community service beneficiaries under an HCBS waiver program. There are two decisions states make within the Federal limits: (a) how much *income* to protect and (b) what amount of *assets* (resources) to protect.

Income protection

Income is protected for the spouse after the person needing long-term care has been determined eligible for Medicaid. The minimum monthly protected spousal income amount is $1406 in the year beginning July 2000. Additional amounts, up to a maximum of $2103, are protected if the spouse has unusually high housing costs or if the state has chosen to protect more than the minimum amount for all spouses. If income belonging to the spouse is less than the protected level, the Medicaid beneficiary can transfer his or her own income to the spouse to make up the shortfall. States count any remaining income of the Medicaid beneficiary, less the allowance for the spouse, in calculating the share of the Medicaid service costs the beneficiary is responsible for.

Resource protection

The resource amount protected for the spouse is

Examples of Spousal Resource Protection

- The non-Medicaid spouse in a couple with combined total assets of $16,824 or less is allowed to keep the entire amount and the institutional spouse meets the assets eligibility criterion without delay.
- In a state using the Federal minimum level, couples with total countable assets of $100,000 will have $50,000 protected for the at-home spouse. The remaining $50,000 is attributed to the institutionalized spouse, making that person ineligible for Medicaid until $48,000 is used up (assuming the applicable Medicaid resource eligibility level is the typical $2000).
- In a state electing a higher minimum protected amount of, say, $75,000, couples with combined countable assets of $100,000 will have $75,000 protected for the non-Medicaid spouse. The remaining $25,000 is attributed to the institutionalized spouse, making that person ineligible until $23,000 is used up (again assuming the typical $2000 as the applicable Medicaid resource eligibility level).
- In a state protecting the highest amount allowed ($84,120), a spouse in a couple with total assets of $84,000 would keep the entire amount.

determined as part of the process of determining the Medicaid eligibility of the person needing services. Countable resources belonging to either or both members of the couple are combined and divided in half. The amount actually protected for the spouse is either that half or the level the state has chosen to protect, whichever is higher, subject to a Federal minimum (at and below which the entire amount is protected) and maximum, $16,824 and $84,120, respectively, as of January 2000. States have the option of setting a higher minimum level but cannot exceed the Federal maximum.

Any resources not protected for the spouse are considered available to the person needing care, who is not eligible until such resources are within Medicaid eligibility limits.

Minimum and maximum amounts of both income and resources increase every year based on the cost-of-living increase as published by the Department of Health and Human Services. In addition, Federal law requires states to have administrative and judicial procedures in place that allow petitioners to seek higher protected amounts of the spouse's assets. For example, the spouse can petition for higher protected assets if the income those assets produce is needed for that person's reasonable living expenses.

Provisions Specific to Children with Disabilities

Two eligibility provisions—one mandatory, the other at states' option—were enacted specifically to serve children with disabilities. The mandatory provision relates to children—sometimes called Zebley kids—rendered no longer eligible by a 1996 change in the SSI definition of disability for children. The Zebley designation comes from a court case, upheld by the Supreme Court, contesting the 1996 change.[13] The optional provision—sometimes called the Katie Beckett or TEFRA option—allows for eligibility for a child with severe disabilities living at home, regardless of the financial circumstances of the child's parents.

Zebley Children

The welfare reform legislation of 1996 made it more difficult for children to qualify as disabled SSI beneficiaries by changing the definition of disability for children. The major impact of this change has been on children with mental disorders. In 1997, a new Federal requirement was enacted protecting Medicaid eligibility for former child beneficiaries of SSI who lost it due to this definitional change. This protection is retroactive to the original SSI change in 1996. It cannot produce actual eligibility changes, however, unless both state and family follow through and take all necessary administrative steps to get the child enrolled specifically in the state's Medicaid program. It is important to note that children who apply for SSI for the first time, and are found

ineligible for it might still qualify for Medicaid or for the Children's Health Insurance Program (CHIP) in their states, based on the family's income.

Katie Beckett Option

The Katie Beckett or TEFRA option, enacted permanently into law in 1982, enables states to provide Medicaid to certain children with disabilities living at home who need extensive care but who would, without the option, be unable to qualify because their parents' income or resource levels put them above the financial eligibility cutoff.

Before this option became available, children with disabilities were typically eligible for SSI and, thus, Medicaid only if they lived in institutional settings. This was because of deeming rules similar to those discussed above. Most state Medicaid programs followed SSI deeming rules on how income and resources are counted. Under these rules, institutionalized children were not considered part of their parents' households. Parental income and assets were therefore ignored, regardless of their magnitude. But children living with their parents *were* considered part of the parental household, making parental income and assets deemed available to the children, and substantially reducing the likelihood that children with disabilities would be eligible for Medicaid services, no matter how great the children's service needs might have been. This arrangement made it possible for children with disabilities in non-poor families to get Medicaid for institutional care but not for equivalent care provided at home.

The TEFRA option, which was enacted to create equity between the two settings in financial eligibility, is limited in the following ways. First, home care for the child must be appropriate. Second, the estimated cost of community services for the child may not exceed the cost of institutional care. Third, the child must require the level of care normally provided in an institution, making the TEFRA option unavailable for children whose disabilities do not require this level of care. In states that use the TEFRA option parents may choose either institutional or community care for their Medicaid-eligible children, subject to the above requirements.

States need to consider the following points when choosing between the TEFRA option and the HCBS waiver option for covering children with disabilities. First, states may not impose enrollment caps under the TEFRA option, as they can under the HCBS waiver option. If elected, the TEFRA option must be open to anyone who qualifies anywhere in the state. Second, states must provide to children eligible under both the TEFRA option and the HCBS waiver option the same EPSDT benefits provided to all other Medicaid children in the state. However, the HCBS option allows states to offer additional services of a nonmedical nature. Finally, states may impose a share-of-cost obligation on children in an HCBS waiver program but not on children eligible under the TEFRA option.

Reducing Financial Barriers to Employment for Persons with Disabilities

Any benefit program that uses an income cutoff to determine eligibility contains a powerful disincentive for beneficiaries to work, if the earnings from that work would put them above the financial eligibility level for benefits. To the extent that Medicaid coverage is needed in order to live, the problem becomes an absolute barrier to employment rather than simply a "disincentive."

In order to preserve the incentive for persons with disabilities to work to their maximum without fear that doing so will cause them to lose their medical coverage, Federal law mandates states to disregard certain earnings amounts in determining eligibility for Medicaid. States have additional options to protect the earnings of people with disabilities who have higher earning potential.

Federal Provisions[14]

Since 1982, SSI and Medicaid have been provided for certain SSI disability beneficiaries who succeed in work and earn more than what is termed the

Substantial Gainful Activity (SGA) amount of $700 per month.[15] Such an individual will continue to receive an SSI benefit and Medicaid the same as any other SSI recipient in their state, provided their countable income is within SSI qualifying limits.[16] Individuals with earnings up to about $1100 per month are typically able to qualify under this provision while still receiving SSI cash benefits.

Former SSI beneficiaries with even higher earnings may continue to qualify for Medicaid, although they earn too much for SSI, as long as their earnings are below a state-specific level that is roughly equivalent to the value of the total SSI and Medicaid benefits they would receive if they did not work.[17] The Medicaid component of this amount is the average amount spent by Medicaid for beneficiaries with disabilities in the relevant state. States must provide Medicaid to individuals with earnings above even this level, if they can show that their medical expenses are higher than the state average used for the cutoff calculation. SSA administers both provisions, not states.

Little use was made of these protections at first because they were not widely understood. Thus, the number of working persons with disabilities whose earnings were protected in this manner in 1982, the first full year of implementation, was just under 6000. By September 1999, however, the number had risen to nearly 100,000.[18]

State Options

Advocates for persons with disabilities argue that use of the work incentive provisions has not grown even more rapidly for several reasons. First, there is an absolute cap on income for eligibility for every case (although the cap amount varies from individual to individual). Thus, however high that limit may be, there is an absolute drop-off point at which increased additional earning will result in losing Medicaid eligibility. Second, low limits on resources or assets mean that working persons with disabilities are also unable to increase their savings without jeopardizing their Medicaid eligibility. Third, receipt of SSI benefits was the gateway to receipt of medical assistance, thus making work a less viable option than dependence on public programs.

Finally, eligibility under these provisions ends if the individuals' conditions improve and they no longer meet the SSI disability criteria, even though they may still need long-term services and supports to continue to work. Congress recently addressed some of these Medicaid access problems with laws enacted in 1997 and in 1999.[19]

The 1997 provision allows states the option of expanding eligibility for persons with disabilities who have countable income from all sources up to 250 percent of the Federal poverty level—$20,875 for an individual, $42,625 for a family of four in the year 2000. These individuals need not ever have received SSI but they must, except for the level of their earnings from work, qualify for SSI.

More generously, the 1999 provision gives states the option to cover individuals with disabilities who now work without regard to their earnings from work and to raise or even eliminate eligibility limits on income from other sources or limits on assets.

States that have elected this option can also elect to continue coverage for persons eligible under that option whose disability remains severe—but whose medical condition has improved to a point that they no longer meet the usual Medicaid eligibility criteria defining disability.

A state has the option to impose a monthly premium or other cost-sharing obligations for their Medicaid benefits on these higher income persons on a sliding scale based on income. However, states choosing the 1999 option are required to charge 100 percent of the premium for those with more than annual adjusted gross income (AGI as defined for Federal income tax purposes) of $75,000.[20] The premium payment features have given rise to the term "buy-in" to describe these options.

The state, not the Social Security Administration (SSA), makes the eligibility determination for these state work incentive options.[21]

Asset/Resource Transfers: Permissions and Penalties[22]

Federal law imposes a penalty on persons who give away savings or transfer ownership of their assets for less than fair market value (termed uncompensated transfers) and who, in so doing, make their assets appear low enough to meet Medicaid's eligibility limits. States must apply this penalty to persons seeking Medicaid coverage for nursing homes, other medical institutions, and HCB waiver services under institutional eligibility rules. States have the option of applying the penalty to all persons living in the community.

The purpose is the obvious one of denying benefits to persons who could, in fact, afford to pay for those benefits with their own assets. These Medicaid rules apply to all eligibility groups in all states.[23] But individuals seeking Medicaid for payment of long-term care services, and those who work to assist them, particularly need to be aware of these rules, because the structure of the penalty makes its effects fall most heavily on such beneficiaries and their spouses, children, or survivors.

Structure of the Penalty

Both SSI and Medicaid deny benefits for persons making uncompensated asset transfers. The nature and effective duration of the penalty, however, differ between the two programs.[24] The following discussion relates to the Medicaid provisions.[25]

The general Medicaid rule is that states must determine whether an applicant, beneficiary, or someone acting on their behalf transferred assets (including the home) at any time during the 36 months prior to applying for Medicaid.[26] If the person did not receive fair market compensation, then states presume the transfer was made for the purpose of meeting Medicaid resource eligibility thresholds and qualifying for benefits. States are required to have procedures in place that allow applicants to rebut that presumption.

Permissible Transfers

Certain transfers can be made without penalty:

- Transfers made to a spouse or a third party for the spouse's benefit.
- Transfers of a home to a minor child or child with disabilities, or siblings or adult children who have lived in the home *before* the beneficiary was admitted to an institution or the waiver program, and who meet certain other conditions.[27]
- Transfers by Medicaid applicants/recipients to their blind children or children with disabilities or to a trust for those children's benefit.
- Assets transferred into a trust solely for the benefit of a person under age 65 with a disability. Eligible trusts include:
  - *Special needs trusts* (unused portions must revert to the state on the death of the individual, up to the total Medicaid amount spent on the individual's behalf)
  - *Pooled trusts* established by a nonprofit association that manages multiple accounts (same rule on unused portions).

These trusts are not counted in Medicaid's resource eligibility determination.

When a state has determined that an impermissible transfer has taken place, it must deny coverage for long-term care services in an institution or HCB waiver services. Coverage may also be denied at state option for such non-institutional long-term care services as home health or personal care provided outside the waiver context. Note: *Such penalties do not affect the person's eligibility to receive any other services under the state's Medicaid plan.*

The duration of the penalty is calculated by dividing the uncompensated value of the transferred assets by the monthly cost of care in a private nursing facility. The same formula is used for persons applying for HCB waiver services. Several rules reduce the practical effects of the penalty:

- The penalty period begins the month the transfer occurred, even if the transfer was

Effect of Transfer on Benefit Loss: Example

- $20,000 is withdrawn from savings and received by an adult child.
- The transfer occurs in January.
- Monthly cost of nursing facility services is $4,000.
- This makes the penalty period five months ($20,000 divided by $4,000).
- The penalty period begins in January; it therefore ends in June.
- The penalty period is the same, whether or not the person uses services and whether the needs are institutional or less costly community services.
- On the assumption that all other Medicaid eligibility criteria are met, a person who applies in January is eligible for all services except for the long-term care services. A person who waits to apply in July can receive all Medicaid services immediately, because the penalty period has already expired.

made many months before the individual applies for Medicaid. Thus, a transfer will have no practical effect if it was modest and occurred relatively early in the look-back period before the individual applies for Medicaid.

- States calculate the duration of the penalty based on nursing facility rates—whether the person who has transferred assets is actually in a nursing home or seeking home and community care—even though the monthly cost of services in the community is likely to be substantially lower.

- The penalty calculation is the same regardless of (a) whether the person was living at home or in a facility at the time of transfer and (b) whether the person was actually using or paying for services.

- States must make exceptions in cases of undue hardship.

Estate Recoveries

Federal law requires all states to recover assets from the estates of two groups of Medicaid beneficiaries after their deaths: those who were age 55 or older when they received Medicaid benefits, and those who received Medicaid nursing facility or ICF/MR benefits regardless of age. At a minimum, states must use the same definition of estate that is used for probate law in that state. They are permitted to use a broader, state-established definition that captures additional assets. States are mandated to recover any amounts they have paid on the individual's behalf for long-term care services (whether facility care under the state plan or home and community care under waiver), as well as any hospital costs and prescription drug benefits related to the condition requiring long-term care services. They also have the option of recovering all amounts spent on Medicaid benefits. But state recovery actions must be delayed if there is a surviving spouse or, in certain cases, a child or sibling living in the home. And states have the option of not recovering at all in the case of very small estates, if the cost of doing so is likely to exceed the amount that can be recovered.

Endnotes

1. The sole author of this chapter is Letty Carpenter.

2. Additional information about the Medicare program can be obtained from the Medicare Handbook (available at www.hcfa.gov).

3. Section 1902(r)(2) of the Social Security Act.

4. This limitation applies only to income and only to certain optional eligibility groups. There are no such limits on using 1902(r)(2) to liberalize rules for *resources.*

5. As described above, under Section 1902(r)(2) of the Act, a state can elect to disregard more generous amounts.

6. States can use higher levels or additional disregards under the 1902(r)(2) exception described above.

7. Typically this is every month. In some states it is every six months. But in the latter case the person must be able to spend-down an amount that equals six times their monthly "excess" income before becoming eligible.

8. State-by-state information concerning supplements for SSI beneficiaries may be found in State Assistance Programs for SSI Recipients: January 1999. (July 1999) Social Security Administration, Office of Policy, Office of Research, Evaluation, and Statistics. Available at the

Colorado's Coverage Criteria for Home Health Benefits

Rather than instituting a blanket homebound requirement, Colorado's regulations state that home health services will be covered under the following specific circumstances: "When the only alternative to home health services is hospitalization or the emergency room; OR the client's medical records accurately justify a medical reason that the services should be provided in a client's home instead of a physician's office, clinic, or other outpatient setting, according to one or more of the following guidelines:

1. When the client's condition prevents him/her from going to another health care setting to obtain the service, such as a client with quadriplegia who needs aide services to get in and out of bed;
2. When going to an outpatient setting for the service would constitute a medical hardship due to the client's condition;
3. When going to an outpatient setting for the needed service is contraindicated by the client's documented medical condition, such as a client who must be protected from exposure to infections;
4. When the client's medical condition requires teaching that is most effectively accomplished in the client's home on a short-term basis;
5. When going to an outpatient setting for the service would interfere with the effectiveness of the service. Examples include: (1) when hours of travel would be required; (2) when services are needed at a frequency that makes travel extremely difficult, such as IV care three times a day; (3) when a client needs regular and unscheduled catheter changes, and having home health in place will prevent emergency room visits for unscheduled catheter changes due to blockage or dislodgment; (4) when there is a history of noncompliance with outpatient services that has led to adverse consequences, including emergency room use and hospital admissions.
6. When a client is unable to perform the health care task him/herself, and has no unpaid family/caregiver able and willing to perform it."

efit in 1993, Tennessee limited home health services to 60 visits per year and required beneficiaries to be "homebound." When HCFA granted an 1115 waiver creating TennCare, home health services were among the benefits covered by the capitation rate. One of HCFA's waiver conditions was removal of the homebound requirement and the limit on number of home health visits. The state agreed to these provisions and promulgated consistent regulations.

In 1997, however, the managed care organization providing Medicaid's home health services in the state sought to exclude all "custodial" services from their contract, and to require home health beneficiaries to meet the same definition of medical necessity that the organization uses for its commercial market enrollees. This definition requires home health users to be homebound and excludes coverage for beneficiaries who require care on a "custodial" basis or over a long period. Disabled beneficiaries not meeting the new definition are directed to nursing homes—at greater cost to the state but reduced cost to the plan. A lawsuit was subsequently brought to bar the state from continuing to deny medically necessary home health services to TennCare members and from requiring disabled TennCare beneficiaries to be placed in nursing homes in order to receive services.

The general issue for states is how to ensure that managed care contracting does not result in denial of necessary services to beneficiaries. Clearly, when home health benefits are included in a managed care contract, the contractor has an incentive to restrict provision of such benefits in order to contain costs. To guard against this potential, it is very important for states to specify in their managed care contracts *who* will determine eligibility for home health benefits and *what* service criteria will be used. Clear and precise terms are crucial. Eligibility criteria that are framed in very general terms—*medical necessity*, for example—can be

Unresolved Issue: Provision of Services Outside a Beneficiary's Home

A Connecticut lawsuit challenged HCFA's regulation requiring that Medicaid home health care services be provided exclusively in a beneficiary's place of residence.

The Court of Appeals ruled that the Medicaid statute is ambiguous with respect to whether home health care services must be provided exclusively at the recipient's residence.[9] Specifically, the court ruled that "the Medicaid statute neither allows nor prohibits reimbursement for home health services outside the recipient's residence. The statute merely provides that states may include 'home health care services' in their Medicaid programs. 42 U.S.C. Section 1396d(a)(7).[10] It does not define home health care services, and though the statute implies that the services will normally be rendered in the home, neither the context of the provision nor the structure of the statute indicates whether the home is the exclusive locus of the necessary services."

The court went on to hold that "the regulation as written is invalid," because the restriction of home health care services to a recipient's residence "ignores the consensus among health care professionals that community access is not only possible but desirable for disabled individuals." The court further stated that the assumptions behind the restriction of services to the recipient's residence were medically obsolete, and that "the technology and knowledge now exist to allow many people with disabilities, elderly or not, to venture into the community, where before they would have been considered permanently homebound."

To ensure that the ruling would not result in increased costs for the state, the court expressly limited recipients of Medicaid-covered home health nursing services to the number of hours of services to which they would be entitled if the services were provided exclusively at the recipient's place of residence.

The Second Circuit ruling affects only the three states in its jurisdiction: Connecticut, Vermont, and New York. HCFA is currently reviewing a request to change its regulation to be congruent with the Court's ruling. Such a regulatory change would generalize the substance of the Court's decision to apply to all states.

interpreted very differently in a managed health care plan that customarily provides acute care benefits than in a state plan designed to provide long-term care services.

The appropriate context for making decisions about limits on home health benefits, as noted, is the whole state system of home and community coverage. A state may opt to cover a very limited number of registered nurse and home health aide visits through the home health benefit, for example, but provide additional coverage for those with greater needs through its waiver program. (This leaves any additional service needs of individuals not eligible for waiver services unmet, of course. Chapters 4 and 5 discuss in detail the factors to consider when making such coverage decisions.)

Personal Care Option

Personal care services provided through the state plan are an optional benefit. When personal care services were first authorized, services had to be prescribed by a physician in accordance with a plan of treatment. In 1993, Congress removed the requirement for physician authorization and gave states the option to use other methods to authorize benefits in accordance with a service plan approved by the state. There are no other Federal statutory or regulatory requirements regarding coverage under the personal care option. Nor are there guidelines for minimum or appropriate service criteria. Within the broad parameters of the Federal definition of personal care services, states are free to determine criteria for service eligibility as well as the amount, scope, and duration of the benefit.

In the absence of prescriptive requirements for service criteria, the Federal definition of personal care services becomes the primary guide for establishing service criteria. The State Medicaid Manual defines the scope of personal care services as:

> "a range of human assistance provided to persons with disabilities and chronic conditions of all ages, which enables them to accomplish tasks they would normally do

for themselves if they did not have a disability. Assistance may be in the form of hands-on assistance (actually performing a personal care task for a person) or cueing so that the person performs the task by him/herself. Such assistance most often relates to performance of activities of daily living (ADLs) and instrumental activities of daily living (IADLs)."[11]

Persons with cognitive impairments can also be offered services through the personal care option. As the Medicaid Manual states:

> "An individual may be physically capable of performing ADLs and IADLs but may have limitations in performing these activities because of a cognitive impairment. Personal care services may be required because a cognitive impairment prevents an individual from knowing when or how to carry out the task. For example, an individual may no longer be able to dress without someone to cue him or her on how to do so. In such cases, personal assistance may include cueing along with supervision to ensure that the individual performs the task properly."[12]

Given the Federal Medicaid definition of personal assistance, it follows that appropriate service criteria should be based on a need for assistance with ADLs or with IADLs. There is a considerable body of research on ADLs and IADLs to guide states in designing their service criteria. Generally, ADLs are more frequently used than IADLs to determine service eligibility, because they are widely believed to measure a greater level of need. But a number of states use both ADLs and IADLs in their service criteria. This is consistent with research showing that dependencies in multiple IADLs also indicate a high level of need.[13] Limitations in performing some IADLs, such as meal preparation and medication management, may actually pose a greater health risk than an ADL limitation in bathing and dressing. Recent research has shown, for example, that inability to use the telephone actually indicates a very high level of impairment.[14]

An important consideration when selecting service criteria is that the level of impairment required for eligibility match the services covered. For example, if a state requires applicants to be severely impaired, the maximum number of service hours permitted should be sufficient to enable such people to remain in the community even if they have little informal care. Otherwise, requiring too high a level of impairment could prevent those without informal care from receiving necessary services.

It is also important to ensure that assessment and authorization methodologies do not inadvertently exclude certain categories of potential beneficiaries, such as persons with cognitive impairment. Failure to include criteria that measure the functional limitations relevant to these individuals—such as the need for cueing to perform ADLs—can lead to their exclusion. States may be inadvertently making such exclusions. Even though 26 states offered personal care services in their state plans, for example, a survey of state agencies serving persons with developmental disabilities found that services through the personal care option play little or no role in paying for long-term services for this group.[15]

Historically, Michigan used to be the most noteworthy example of a state that optimized the personal care benefit as a means of funding home and community services for people with developmental disabilities. Michigan built many of its community services on personal care as the baseline core benefit, for example, weaving it into foster home settings and other types of living arrangements. However, in the 1995 amendments to the state's HCBS waiver program for people with mental retardation and developmental disabilities, Michigan started moving to waiver funding of services for these groups.

In effect, states have a very high level of discretion to determine who will receive personal care services through the state plan. However, states may not violate Medicaid comparability requirements by restricting services to those with a particular diagnosis or condition (e.g., by making benefits available only to people with spinal cord injuries or people who use wheelchairs, or to people who are likely to require nursing facility services).

Illustrative Service Criteria for Personal Care Services: State Examples

Massachusetts

To be eligible for personal care services in Massachusetts, Medicaid beneficiaries must have a permanent, chronic disability. The service criteria are specified in terms of hours of assistance needed—rather than type, number, or level of ADL and IADL impairments. Individuals must need a minimum of 10 hours per week of assistance with ADLs, or 14 hours of assistance with a combination of ADLs and IADLs. The average hours for most consumers is 42 per week. The program serves both self- and non-self-directing consumers and allows surrogates to manage services for those who cannot do so themselves.

Massachusetts specifies as ADLs to be assessed all aspects of mobility (walking, transferring, using durable medical equipment); bathing, personal hygiene, and grooming; dressing and undressing; basic exercises such as range of motion; preparation and ingestion of meals and clean up; assistance with bowel and bladder needs; and assistance with medication administration. The IADLs the state assesses are housekeeping, laundry, shopping, ability to make visits to health care providers, and unique needs (e.g., care and maintenance of wheelchairs).

Arkansas

To be eligible for personal care service in Arkansas, a person must have physical dependency needs and require assistance to perform the following tasks and routines: eating, bathing, dressing, personal hygiene, bladder and bowel requirements, taking medications, laundry, incidental housekeeping, and shopping for personal maintenance items.

New York

To be eligible for personal care services in New York, individuals must need some or total assistance with a wide range of tasks connected with daily living, nutritional and environmental support functions, and health-related tasks. The services must be essential to maintain the individuals' health and safety in their own home. Tasks that are considered include bathing, dressing, feeding, grooming, toileting, walking in and outside the home, transferring, meal preparation in accordance with modified diets, medication administration, and skin care. Nutritional and environmental support functions include meal preparation, housekeeping, laundry and ironing, shopping, bill payment, and other essential errands.

Given that personal care services are subject to statewideness and comparability requirements, states understandably have cost concerns about increasing access to these services by using less stringent service criteria, even though they can control costs by limiting the amount, scope, and duration of services. As mentioned at the beginning of this chapter, there is no "correct" decision regarding service criteria. Whether or not particular service criteria are appropriate and make sense depends on the broader context of a state's policy goals for its entire long-term care system (i.e., whether the criteria fit logically into the overall plan for providing services to people with long-term care and support needs through multiple programs).

To ensure that their programs do make sense within their particular service systems, some states design "wraparound" state-funded programs to provide services to people who do not meet either Medicaid's financial criteria or the state's service criteria. The Connecticut Home Care Program for Elders has three levels of service, for example, with Level One and Level Two funded solely with state funds. Level One serves people who meet neither the Medicaid asset test nor the waiver service criteria. Level Two serves people who meet the waiver service criteria but not the asset test.[16] Level Three serves those who meet both financial and service criteria. In this framework, the stringency of the institutional service criteria is not a major issue, because there is an alternative source of services for those who do not meet them.

HCB Waiver Program Services

To be eligible for HCB waiver services, individu-

als must first meet a waiver's targeting criteria, such as age and diagnosis or condition. For example, a state may have a number of waivers targeting different groups: persons age 65 and older, persons ages 18 to 65 with physical disabilities, children who are technologically dependent, persons with mental retardation and other developmental disabilities, persons with AIDS, and persons with traumatic brain injury. (See Chapter 4 for a full discussion of waiver programs.)

Individuals who meet the targeting criteria must then meet service criteria, which for HCBS waiver programs are the level-of-care criteria used to determine eligibility for either a hospital, nursing facility, or ICF/MR. Level-of-care criteria explicitly describe the type and level (or severity) of functional limitations or needs an individual must have in order to be admitted to an institutional setting.

These criteria usually include measures of need for assistance with ADLs and for other services, including nursing and medically related services. A determination that a person meets the required level-of-care criteria is based on information gathered through a formal assessment process carried out when a person applies for services. In the case of ICF/MR services, the person must have mental retardation or a "related" condition and be found to need various supports necessary to improve or maintain functioning. In the case of nursing facility services, the need for skilled and unskilled nursing care is generally assessed, as is the need for assistance with ADLs and other aspects of functioning.

The requirement to use the same or equivalent service criteria for HCB waiver services as for institutional placement stems from the waiver program's primary purpose: to offer an alternative to institutionalization.[17] This is a statutory requirement added by Congress in part to address concern about the cost of expanding HCB services: States must demonstrate that they are providing waiver services only to people who are eligible for institutional placement. HHS cannot waive this requirement or lessen its impact by regulation. Thus, states would only be able to use substantively different service criteria for waiver than for institutional services (i.e., criteria not based on the need for institutional services) if Congress amended Medicaid law.

When the waiver authority was enacted in 1981, home and community services could be provided under a waiver program only to persons who met the level-of-care criteria for *either* an SNF, an ICF, or an ICF/MR. In 1987, the Omnibus Budget Reconciliation Act eliminated the distinction between SNFs and ICFs and mandated a new nursing facility benefit, which included ICF services, all of which were previously optional. The former ICF level of care is now the minimum institutional standard. The only Federal requirement for persons to receive an ICF level of care is that the individuals need either health-related care and services that are above the level of room and board or, due to their mental or physical condition, require supportive services that can be made available only through institutional facilities. Within this broad definition, states are free to set whatever service criteria they choose for nursing facility care, which (or their equivalent) are then used to determine eligibility for waiver services.

Misperceptions

A common criticism of nursing facility level-of-care criteria is that they are "medically biased," that is, (a) they do not adequately assess functional limitations and their impact on the need for long-term care, or (b) they give greater weight to nursing and medical needs than to functional needs. However, no Federal statute or regulation mandates that states adopt this medical approach when setting nursing facility service criteria.

Medicaid law does require that institutional services be medically necessary. But, as noted, there is no Federal definition of this term, and states are free to define it broadly (e.g., medically necessary services are those that promote optimal health and functioning). Thus, the requirement that services be medically necessary does not mean a state is required to use only medical—or even any medical—service criteria to determine eligibility for nursing facility services.[18] Nor must a state give greater weight to medical and nursing needs than to functional needs.

No clear line separates medical from functional

Illustrative Uses of Functional Measures to Determine Eligibility for Nursing Facility and Waiver Services: State Examples

Connecticut

To be eligible for nursing facility or HCBS waiver services in Connecticut, a person must need either hands-on assistance or supervision with three critical needs. The critical care needs that are assessed are eating/drinking, toileting, transferring, bathing, dressing, medication management, and meal preparation. Alternatively, a person must have cognitive impairment and behavioral problems. The determination of critical needs is the central factor in Connecticut's level-of-care determination, but other factors are also considered, including diagnosis, nursing needs, and informal supports.

Indiana

To be eligible for nursing facility or waiver services in Indiana, a person must have either nursing needs or 3 out of 14 functional needs. Functional needs include assistance with eating, mobility, transferring, turning/positioning, dressing, bathing, toileting/continence, daily supervision or assistance to ensure compliance with a prescribed medication regime, and supervision or assistance to maintain safety due to confusion and/or disorientation.

Kansas

Kansas uses a scored instrument to determine eligibility. The functional measures assessed are (a) ADLs: bathing, dressing, toileting, transferring, eating, mobility; and (b) IADLs: such as meal preparation, medical management, telephone use, laundry/housekeeping, shopping, and money management. A person must need assistance with both IADLs and ADLs. Several risk factors are also assessed: impaired cognition; incontinence; falls; lack of informal support; and abuse, neglect, and exploitation. Because the instrument is scored and the measures are weighted, several combinations of functional need and risk can equal the required score. For example, a person with memory problems and impaired decision making who needs supervision with two ADLs and assistance with three IADLs would be eligible.

needs. Health status and functioning are closely interrelated; immobility due to paralysis or even frailty can lead to serious medical problems in multiple body systems. Thus, failure to address functional limitations can result in serious medical problems that require not only nursing home care, but hospitalization as well. The primary reason people need long-term care services is because they have functional limitations. Even if people require specialized health care (e.g., for injections or catheterization), research has shown that people can meet these needs themselves if they are not physically or mentally impaired. Thus, the single most important measure of need is what functional limitations a person has.

For ICF/MR placement, all states use functional measures in their level-of-care criteria. Kansas determines eligibility for either ICF/MR or HCBS waiver services, for example, with an evaluation instrument called the Developmental Disabilities Profile (DDP). The DDP measures the extent to which a person is able to carry out certain life activities or might need services to address various needs (e.g., medical needs or behavioral issues). Other states use alternative instruments (e.g., the Inventory for Client and Agency Planning, ICAP), or specify other types of assessments that must be conducted to determine the need for assistance in various functional domains.

Another common misperception about Medicaid level-of-care criteria is that an institutional standard requires a severe level of medical need or functional limitation. There is no such Federal requirement. However, states are concerned that making their institutional level-of-care criteria less stringent will result in many more people being eligible for (and placed in) nursing facilities. But research shows that the overwhelming majority of persons with long-term care needs would rather be served in the community. And people who do not want to go to a nursing home are unlikely to change their minds just because the bar for nursing home eligibility has been lowered. The same is true for people with mental retardation or devel-

opmental disabilities.[19] Stringent criteria have unintended effects on HCBS waiver programs, such as limiting assistance states can provide to those who need only a small amount of help to remain in the community.

However states define their nursing home level-of-care criteria, many people who meet those criteria will remain in the community, even without formal services. A recent study in Connecticut, for example, found that many persons with severe functional limitations (three or more ADL impairments), who met the nursing facility level-of-care criteria, chose to go without nursing home or HCB waiver services rather than spend down to Medicaid eligibility or be subject to estate recovery provisions. (Most of the people interviewed in that study were able to remain in the community because they had extensive informal care supplemented by small amounts of privately paid care.)[20]

States' concerns about increasing the number of people admitted to nursing facilities are understandable. However, this effect can be minimized, if not avoided completely, if states initiate steps to screen persons *prior to nursing facility admission* to determine whether services could be provided in home and community settings. Oregon and Colorado are examples of states that have pursued this strategy successfully. Implementation of such programs (called nursing home diversion programs) to ensure that as many people as possible are served in home and community settings—whether through services in the state plan, the personal care option, or waiver—will help ensure that only those who truly cannot be served safely and cost-effectively in the community will be admitted to nursing facilities.[21]

Availability of HCB services can and does reduce the demand for institutional services. The best evidence of this phenomenon is found in the mental retardation/developmental disabilities sector, where, since the advent of HCBS waiver programs, (a) the number of individuals served in large public institutions has declined (from 128,000 in 1980 to under 50,000 in 1999), and (b) the total number of individuals served in large institutional ICFs/MR of all types (public and private) dropped by more than 40 percent between 1982 and 1998.[22] The most important likely result of broadening institutional eligibility criteria is that states are able to furnish important services and supports to individuals in the community, which will help them remain independent and enjoy a better quality of life.

With regard to states' concerns about induced demand (large numbers of persons who would never have gone to a nursing home applying for home and community services once they are available), caps on waiver enrollments enable states to control utilization and overall outlays. This explains in part why every state operates HCBS waiver programs but only about half cover personal care services through the state plan.

Major Considerations in Setting Service Criteria: A Recap

Federal policies with respect to service criteria establish a framework within which states have wide latitude to chart the course of action that best suits their unique long-term care service system.

Three considerations, in particular, should guide state choices in setting their service criteria:

- Service criteria should be developed with an eye toward the full constellation of services and supports a state offers, whether through the Medicaid program or via other state and local resources. In other words, criteria should not be crafted for specific programs without considering the criteria for other long-term care programs in the state. The criteria should fit together so that all individuals needing long-term care services in the state are able to obtain the particular services appropriate to their needs.

- It is important to recognize that there is a constant tug-and-pull among state policy aims. On the one hand, states desire to make services and supports broadly available. On the other hand, states must manage their budgets. Sometimes states impose service criteria for cost-containment reasons, whose stringency undermines the state's ability to promote appropriate access. Careful management of different com-

ponents of the benefit package and establishment of an efficient service delivery system can help a state to work its way between these potentially conflicting objectives.

- Concern that using less stringent criteria—especially with respect to the waiver/institutional eligibility connection—will result in higher demand for (and spending on) institutional services seems to be misplaced. Broader eligibility criteria have been shown to enable a state to obtain Federal financial participation to provide HCB waiver services to a greater number of individuals with substantial impairments, without experiencing an increase in requests for nursing facility and other institutional admissions. Experience confirms that most consumers want to remain in their homes and in the community. Their ability to do so is strengthened through the provision of HCB services.

Endnotes

1. The primary contributors to this chapter are Janet O'Keeffe and Gary Smith.

2. The ADL and IADL scales are based on a developmental model: children learn to eat, toilet, bathe, and dress themselves before they develop the mental ability to do more cognitively complex activities such as using the telephone and managing money. When cognitive abilities start to deteriorate (as in a person who develops dementia) the ability to perform activities that require more complex mental functioning (IADLs) is generally lost before the ability to perform ADLs. In fact, states are not bound by the definitions implied by this developmental model. States are free, for example, to define ADLs as whatever tasks/activities they consider important to define a need for long-term care.

3. Assistants who work with individuals who have cognitive impairments or behavior issues need specialized training.

4. States are permitted to make provision for "outliers"—those individuals whose condition responds less well than expected to the services for their condition, and who, as a consequence, may receive more services for a longer period.

5. The frequency of further physician review of a beneficiary's continuing need for medical equipment and supplies is determined on a case-by-case basis, based on the nature of the item prescribed.

6. Some states link their Medicaid home health benefit with the Medicare benefit through state statutes and/or regulations. A number of states also tie their Medicaid reimbursement methods directly to the Medicare home health reimbursement methods. Harrington, C., LaPlante, M., Newcomer, R.J., Bedney, B., Shostak, S., Summers, P., Weinberg, J., and Basnett, I. (January 2000). *Review of Federal statutes and regulations for personal care and home and community based services: A final report.* San Francisco: University of California, Department of Social and Behavioral Sciences.

7. 42 CFR 440.230(c) and 42 CFR 440.240.

8. 42 CFR 440.240.

9. *Skubel v. Fuoroli.* (No. 96-6201). United States Court of Appeals, Second Circuit. Decided May 13, 1997.

10. When Medicaid was first enacted in 1965, coverage of home health services was optional. In 1970, Congress made coverage of home health services mandatory for those entitled to skilled nursing facility services.

11. State Medicaid Manual, Part 4—Services, Section 4480.

12. State Medicaid Manual, Part 4—Services, Section 4480.

13. Kassner, E. and Jackson, B. (1998). *Determining comparable levels of functional disability.* Washington, DC: AARP Public Policy Institute.

14. Spector, W.D. and Fleishman, J.A. (1998). Combining activities of daily living with instrumental activities of daily living to measure functional disability. *Journal of Gerontology.* 53B: S46-S57.

15. Gary Smith, Director of Special Projects, National Association of State Directors of Developmental Disabilities Services. Personal communication, March 12, 2000.

16. Eligibility rules for Level One and Level Two of the Connecticut Home Care Program for Elders allow applicants to retain up to $16,392 in assets. Allowable income is the same for all three levels: $1500 per month. Cost sharing based on income is required.

17. States may use different evaluation instruments and processes for determining eligibility for HCBS waiver services than for institutional placement as long as they can explain in their waiver application how and why they differ and also provide assurances that the outcome of a different assessment instrument or process is

"valid, reliable, and fully comparable to the forms used for hospital, nursing facility or ICF/MR placement." See Section 4442.5(B)(5) of the State Medicaid Manual.

18. For reimbursement purposes, many states distinguish between those who need a skilled level of care and those who need lower levels of care; others use case mix reimbursement. The need for medical and skilled nursing services is always assessed when determining if a person needs a skilled or high level of care. It is when assessing applicants for ICF or minimal levels of care that states differ widely in the measures they use—some using functional measures only, some nursing measures only, and most a combination of both. O'Keeffe, J. (1996). *Determining the need for long-term care services: An analysis of health and functional eligibility criteria in Medicaid home and community based waiver programs.* Washington, DC: AARP Public Policy Institute.

19. Gary Smith, personal communication, May 11, 2000.

20. O'Keeffe, J., Long, S.K., Liu, K., and Kerr, M. *How do they manage? A case study of elderly persons functionally eligible for Medicaid waiver services but not receiving them.* (1999). Washington, DC: AARP Public Policy Institute.

21. In a study of 42 states' nursing facility level-of-care criteria, respondents in states that used less stringent criteria said that most beneficiaries with lower levels of need could be safely served in the community. O'Keeffe, J. (1996). *Determining the need for long-term care services: An analysis of health and functional eligibility criteria in Medicaid home and community based waiver programs.* Washington, DC: AARP Public Policy Institute.

22. Smith, G. *Medicaid long term services for people with developmental disabilities.* (2000). Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

Annotated Bibliography

Tonner, M.C., LeBlanc, A.J., and Harrington, C. (March 2000). *State long term care screening and assessment programs.* San Francisco: University of California. (36 pages)

This study of state screening and assessment programs reports data collected by a telephone survey of state officials in all 50 states and Washington, D.C. It examines several features of screening and assessment programs, including coordination across multiple long-term care programs, and the use of uniform need criteria, standard assessment tools, and automated databases. *The document may be ordered for $5.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

O'Keeffe, J. (March 1999). *Elderly persons with cognitive and other mental impairments: Can they meet Medicaid level-of-care criteria for nursing homes and for home and community based waiver programs?* Pub. #9704, Washington, DC: AARP, Public Policy Institute. (40 pages)

This study investigates whether persons ages 65 and older, with functional limitations caused by cognitive and other mental impairments, can meet states' Medicaid level-of-care (LOC) criteria for nursing home and home and community based services waiver programs. A review of 42 states' Medicaid LOC criteria found that persons with cognitive and other mental impairments may find it difficult to be eligible for long-term care services in many states. The report includes a state-by-state description of Medicaid LOC criteria relevant for persons with cognitive and other mental impairments. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3860 or search their website at www.research.aarp.org.*

O'Keeffe, J. (December 1996). *Determining the need for long-term care services: An analysis of health and functional eligibility criteria in Medicaid home and community based waiver programs.* Pub. #9617, Washington, DC: AARP, Public Policy Institute. (113 pages)

This report provides, through text and tables, an overview and comparison of the criteria that 42 states use to determine eligibility for nursing home and home and community based services waiver programs. *To obtain a free copy of this document, contact AARP's Public*

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CHAPTER 4

Options for Designing Service Coverage: General Considerations[1]

To remain in their homes and communities, many people with disabilities and chronic conditions need long-term services and supports that can range from personal assistance to more specialized services. Federal Medicaid law and policy give states great latitude to offer individuals a wide range of home and community services through the state's "regular" Medicaid program. States can offer an even more comprehensive service range by operating one or several home and community based services (HCBS) waiver programs. This chapter explores Medicaid coverage options, including important issues states need to consider in selecting the particular combination of home and community services and benefits that best suits their respective needs.

Introduction

Twenty-five years ago, the Medicaid program offered few avenues for securing Federal dollars to support people with chronic illnesses and disabilities in home and community settings. Except for limited home health services, Federal Medicaid funding for long-term care was available only when persons were placed in an institutional setting (e.g., a nursing facility, an ICF/MR, or a medical rehabilitation or mental health facility). Changes in Federal Medicaid policy over the years now make it feasible for states to provide home and community services to individuals who need long-term services. As a result, states have considerably expanded availability of home and community services. Indeed, the fact that Medicaid offers so many options for furnishing such services can be confusing for policymakers, state officials, advocates, and consumers alike.

The wide range of home and community service options available to states comes through one or both of two alternative Medicaid funding routes: (1) a state's "regular" Medicaid program and/or (2) one or several HCBS waiver programs, each offering a distinct package of services and supports to different groups of individuals. Combining these alternatives in creative ways gives states substantial latitude in designing their Medicaid home and community service coverages and customizing benefit packages to meet the needs of particular groups. Using waivers in this manner also gives states considerable flexibility to manage the cost of services and the rate of growth in the number of people served. Because of this flexibility, states vary considerably in the services and supports they offer.

This chapter begins with an overview of the broad types of Medicaid home and community services and supports a state may offer. It then describes major Federal and state considerations that influence decisions concerning whether to offer a service as a regular Medicaid program benefit or via an HCBS waiv-

er program. The chapter concludes with more detailed descriptions and illustrations of coverage options—focusing first on services that may be offered under the regular Medicaid state plan and then on services that may be offered under an HCBS waiver program.

Medicaid Home and Community Services: An Overview

Home and community services can be thought of as falling into five overarching categories. It is useful to consider these in generic terms before proceeding to a detailed discussion of how they are treated in Medicaid law and policy.

Personal Care and Assistance. Personal care and assistance involves helping individuals perform everyday activities when they have a physical or mental impairment that prevents them from carrying out those activities independently. These activities can include Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include eating, bathing, dressing, toileting, transferring from bed to chair, and maintaining continence. IADLs include activities such as light housework, laundry, transportation, and money management. (ADLs and IADLs are discussed in more detail in Chapter 3.)

Providing personal care and assistance can take the form of a paid worker (e.g., a personal care attendant or a home health aide) helping the individual each day in the home or elsewhere in the community. This assistance is also furnished to individuals in other community living arrangements, such as group homes and assisted living facilities.

Individuals with various types of disabilities often require this form of basic assistance throughout their lives. Hence, it is a major, if not the primary, reason many individuals seek Medicaid long-term care services. States use several different terms to describe assistance with ADLs and IADLs, which may be provided as part of the home health benefit, as a personal care option under the state Medicaid plan, or through a waiver program.

Health-Related Services. Long-term health and health-related services include a wide range of skilled and unskilled nursing services to address chronic conditions (e.g., tube feedings, catheterization, range of motion exercises).

These services are covered under Medicaid's home health benefit, but can also be covered under a waiver program. The major source of primary and acute health care benefits for persons with disabilities is the basic Medicaid state plan. States also have the option to offer additional health care services to supplement these benefits through an HCBS waiver program. These services may be provided under a state's personal care benefit through the state plan when they are delegated by a nurse and when the practice is recognized and permitted under state law. (Nurse delegation is discussed in detail in Chapter 7.)

Specialty Services. Specialty services encompass an enormous range of services related to the specific nature of an individual's impairment. By and large, these services share the common aim of assisting individuals to improve their functioning.

Psychiatric rehabilitation services address the needs of individuals who have a mental illness. Habilitation services enable persons with mental retardation to acquire or improve skills to help them become more independent. Assistive technology helps persons with many different types of disabilities become more self-sufficient. States may offer these services through various options, including an HCBS waiver program. Many types of assistive technology (e.g., motorized wheelchairs, communication devices) are forms of medical equipment and supplies covered under the mandatory home health benefit.

Adaptive Services. In order to remain in their own home or elsewhere in the community, many individuals with physical impairments benefit from home and vehicle modifications.

Home modifications include installing wheelchair ramps, widening doorways, and retrofitting bathrooms and kitchens so that individuals with physical impairments can get around their homes. Vehicle modifications include modifying a car or a van so that a person can get around the commu-

nity. These services can be covered under HCBS waiver programs.

Family and Caregiver Supports. These supports are designed to help the family and friends who provide such enormous support to individuals with disabilities. Various Medicaid options are available to maintain and strengthen these supports.

Respite services to provide relief to the individual's primary caregiver is one of these services. States may also offer training and education services to caregivers, to strengthen their ability to meet the needs of the person they are caring for. These services can be covered under waiver programs. Training and supports may also be offered as component parts of other benefits, such as home health. (Services to support caregivers are discussed in detail in Chapter 8.)

Social Supports. Social supports are intended to help individuals take an active part in both their family and community. Such supports help avoid social isolation.

Social supports such as companion services, for example, provide assistance so that individuals can participate in community activities (e.g., by providing a personal attendant to enable the individual to attend church). These services can be covered only under HCBS waiver programs.

Case/Care Management or Service/Care Coordination. Case management and care coordination services help individuals who need services and supports from several sources. Some of these may be available through a state's Medicaid plan. Some can be obtained through other public programs. Still other supports are available, though possibly harder to access, from private sources.

A common feature of home and community services is the provision of case managers, who may also be called care coordinators or service coordinators. They frequently prepare or facilitate preparation of an individual plan to map out how all the services and supports a person might need will be identified and delivered. Additionally, they play an active role in monitoring the quality and effectiveness of home and community services. Several Medicaid options are available for covering case management and care coordination services. (These options are discussed in detail in Chapter 5.)

As states consider which home and community benefits to offer, and how to offer them, it will help to keep in mind this golden rule: There is no bright line to distinguish "long-term services and supports" from other types of Medicaid benefits. Many benefits not mentioned in this overview are very much a part of the mix required to meet the needs of individuals with disabilities and chronic conditions. For example, individuals who need mobility aids (e.g., power wheelchairs) may find them through a state plan's coverage of medical equipment and supplies. A state plan may also cover many therapeutic services (e.g., occupational and physical therapy) that are also relevant to meeting the needs of many individuals. As a consequence, in crafting effective home and community service strategies, it is important to take stock of other services in the Medicaid state plan and to modify or possibly supplement them if needed. This is to ensure that the coverages chosen address key needs of the persons being served.

As states decide what home and community services and supports to offer, they need to consider certain Federal policy issues and state goals and objectives that constrain, or at least shape, the benefit choices a state can make. The next section addresses the Federal dimension. This is followed by a general discussion of state goals and objectives.

Federal Policy Considerations

As already emphasized, Federal Medicaid law and policy give states considerable latitude in deciding which Medicaid home and community services they will offer, and how. States do not have complete freedom, however. Certain important aspects of Federal policy need to be taken into account to ensure that a state's decisions about what coverages to offer are consistent with Federal requirements and limitations. Seven major Federal considerations merit discussion here. Although they affect state flexibility somewhat, they need not pose serious barriers to devel-

oping effective strategies to support individuals in their homes and communities.

State Plan Requirements. Whether mandatory or optional, services covered under a state's Medicaid plan are subject to two important statutory requirements. First, they must be available on a comparable basis to all Medicaid beneficiaries in an eligibility group in the state who require the service (i.e., the state plan may not offer a service only to persons who have a particular condition or offer it in different forms to different groups). This is called the "comparability" requirement. Second, services must be available statewide (i.e., the state cannot restrict availability of the service to particular geographic regions). This is called the "statewideness" requirement.[2] There are few exceptions to this statewideness requirement. Targeted case management is the major one.

When a state wishes to make home and community services available only to certain distinct groups of Medicaid beneficiaries (e.g., adults who have a physical disability), it must seek Federal approval of an HCBS waiver program. Under such a program both the comparability and statewideness requirements may be waived, to enable states to target services to distinct groups of Medicaid beneficiaries.[3]

Nonduplication. Federal policy provides that a state may not offer precisely the same service under an HCBS waiver program that it offers under its regular Medicaid program. The reason for this prohibition is simple. People who participate in an HCBS waiver program are already eligible, by definition, to receive the full range of services available under the state plan.

HCBS Waiver Coverage to Complement State Plan Coverage. An important exception to the nonduplication requirement for HCBS waiver programs is when the state offers a service under its Medicaid plan with restrictions but offers what are termed "extended" state plan services to provide more complete coverage through an HCBS waiver program.

Some states, for example, cover personal care services under their state plans to provide wide access to this basic assistance and then build on this coverage through waiver programs to provide additional services to specific target populations. States are permitted to use the extended state plan provision to cover the same service in the two programs but in greater amount, scope, and duration of coverage under the latter.[4]

Services That Cannot Be Offered under the State Plan. There are some services a state may not offer under its Medicaid state plan, because they either have not been specified in the authorizing legislation and implementing regulations (which list the services states must or may offer in their Medicaid programs) or may be provided only as a component of institutional services.

An example of the former is respite care (which explains why respite is one of the most common services offered under HCBS waiver programs). An example of the latter is habilitation. Under Federal law and policy, habilitation may be furnished as a state plan service only to residents of ICFs/MR or certain other very limited types of facilities (e.g., rehabilitation hospitals that serve individuals who have had a traumatic brain injury). A state can only offer habilitation services to non-institutionalized persons through an HCBS waiver program.

Service Objective. A state can only offer services that are materially related to the basic reasons a person needs long-term services and supports. This may seem obvious enough, but complicating issues sometimes arise. In the case of HCB waiver services, for example, a state may offer only services that either are necessary for persons to avoid institutionalization or would be available to beneficiaries if they were in a facility. This provision takes no account of other services and supports—such as guardianship services and leisure activities—that might be desirable but cannot be considered necessary given the aims expressed in Federal law. This does not imply that the state is prevented from providing such services and supports. It implies only that Medicaid dollars cannot be used to purchase them.

Room and Board Expenses. Federal Medicaid dollars are not available to pay for the "room and board" expenses (i.e., housing, food, and utilities) of non-institutionalized persons, except in limited

circumstances such as (a) out-of-home respite care, and (b) room and board of a live-in caregiver. Federal financial participation is available for room and board provided as part of respite care furnished in a facility that is approved by the state and not a private residence. Respite care is available as a service under HCBS waivers, but not as a distinct service under the state plan.[5]

The expectation is that individuals will use their own income and resources (e.g., Federal Supplemental Security Income [SSI] benefits and earnings from employment) to meet room and board expenses. This exclusion can complicate development of strategies to support individuals in the home and community. In contrast, room and board expenses are Medicaid-reimbursable in an institutional setting where individuals receive a significantly reduced SSI payment ($30/month) as a personal needs allowance.

Obligations of Other Public Programs. Medicaid is deemed a payer of last resort. This means that if another public program is obliged to provide a service to an individual, a state generally may not replace this funding with Medicaid dollars. For example, if two public programs such as Medicare and Medicaid cover the same service and an individual is eligible for the service in both programs, Medicare must pay first for the service. Medicaid can only pay once Medicare benefits are exhausted.

State Policy Goals and Objectives

Federal policies provide a framework within which states can weigh their options in deciding whether to offer a service under their Medicaid plan or through an HCBS waiver program. But a state makes its particular coverage choices in light of its own policy goals and objectives. Five major factors need highlighting in this connection.

State Budget Impact. States must balance their budgets on a regular basis—every year for most states. This can make a state wary of offering services under its statewide Medicaid plan, because Federal law prohibits rationing the amount of services furnished to individuals or limiting the number of persons who receive the service under that plan (as noted in the section on Federal policy considerations above).

Thus, states are understandably careful that the costs of offering a service under the state plan not significantly exceed available resources, because they are uncertain both about how many individuals might qualify and about how much it might cost to serve each person. One reason many states have turned to HCBS waiver programs to expand availability of non-institutional long-term care services is that the amount they will spend in the waiver context is predictable. This is because a state that offers services under an HCBS waiver program is obligated to serve no more than the number of beneficiaries the state itself establishes.

Inclusiveness. While state officials and policymakers must be concerned about expenditures, it is often equally important to them that services be available to all who require them. This is an argument against providing services through waivers and can lead states to cover a particular service under the state plan in order to ensure universal access. As discussed below, when deciding whether to cover a service under the state plan or a waiver program or both, states need to carefully consider how services provided in different programs can complement each other in providing people with disabilities the right service mix and amount.

Target Populations. Because services offered under a Medicaid state plan must be provided to all eligible individuals on a comparable basis, it can be difficult to vary services or service delivery approaches based on the needs of individuals who have particular impairments and specialized needs. In addition, it is sometimes easier for a state to craft a package of services and supports to meet the needs of specific groups than to seek a one-size-fits-all state plan coverage design.

These considerations frequently lead a state to select an HCBS waiver program as a vehicle for offering services to defined groups of individuals, because the service package can be fine-tuned to meet their distinct needs.

Maintaining a Unified Service Delivery System. While Medicaid is the major funding source for home and community services, it is frequently not

the only one. In many states, distinct state-funded service systems or networks have evolved for specific target populations—individuals who are elderly, who have a serious mental illness, or who have a developmental disability, for example. One group for which states have historically not developed specific programs or service systems is persons ages 18 to 64 who have physical disabilities—a group that is frequently underserved.

These state-funded service systems often play a crucial role in expanding home and community services for the groups they serve. But they vary considerably in the types and amounts of services they provide and the numbers of people they serve. It is important to maintain these service systems. But it is also important to ensure that they are integrated into a unified service delivery system for their particular target group. An effective way of achieving this integration for many states is the targeted approach permitted under a waiver program. This is a way of accessing Medicaid funding at the same time as ensuring consistency in financing and practice across an array of funding sources.

Eligibility. As discussed in Chapter 2, a state can qualify a wider range of individuals for Medicaid using an HCBS waiver program than it can under its state plan. Many individuals who might not qualify for Medicaid benefits through the state plan by virtue of their income, in particular, may be eligible for services under an HCBS waiver program.

* * *

The following two sections, respectively, provide detailed descriptions of the home and community services that can be provided (a) under the Medicaid state plan and/or (b) through HCBS waiver programs.

Home and Community Services under the Medicaid State Plan

Federal law distinguishes between services offered under a Medicaid state plan and services that may be offered when the Secretary of HHS—operating through HCFA—grants waivers for a state to operate an HCBS waiver program. The services that can be offered without a waiver are called Medicaid state plan services. Some of these (e.g., home health care) must be provided by every state that operates a Medicaid program. These are called mandatory services.[6] Others can be provided at state option. These are called optional services.

When a state covers a service under its Medicaid state plan, it may impose limits on exactly what will be provided and under what circumstances. Such limitations take three forms: (1) how often a person may receive a service (amount), (2) for how long (duration), and (3) the exact nature of what is provided (scope). But Federal law requires that such limitations not undermine a person's receipt of necessary assistance. Any limitations states establish generally must be based on clinical grounds. Limits must be sufficient to meet the needs of most people most of the time, but there is no requirement that states must meet all needs of all beneficiaries at all times.

A state's decision to offer an optional service under its Medicaid state plan amounts to a decision to make the service available to all individuals who require it, within whatever limitations on amount, scope, and duration the state may have established. This is why Medicaid beneficiaries are said to be "entitled" to state plan services.[7] A state has the option of covering under its state plan four main home and community services that are especially important for persons with disabilities: (1) personal care; (2) targeted case management; (3) clinic; and (4) rehabilitative services.

Personal Care/Personal Assistance

Prior to enactment of the Omnibus Reconciliation Act of 1993 (OBRA 93), personal care services offered through the state plan were limited in scope and had a medical orientation, due to the requirement that they be authorized by a physician and supervised by a nurse. OBRA 93—and implementing regulations effective in November 1997—gave states the option of substantially broadening the scope of personal care services, to furnish individuals a wide range of assistance in

everyday activities both in and outside the individual's home.[8]

In January 1999, HCFA released a State Medicaid Manual Transmittal that updated the Agency's guidelines concerning coverage of personal care services. In it, HCFA made clear (a) that personal care services include assistance with both ADLs and IADLs, and (b) that personal care for persons with cognitive impairments may include cueing along with supervision to ensure the individuals perform the task properly. Formerly such supervision generally was considered outside the scope of personal care. (See Appendix II for the complete text of HCFA's guidance on this issue.)

A state may now extend such services to include supervision and assistance to persons with cognitive impairments, which can include persons with mental illness or mental retardation as well as persons who have Alzheimer's disease and other forms of dementia. However, this supervision and assistance must be related directly to performance of ADLs and IADLs. Simple companionship or custodial observation of an individual, absent hands-on or cueing assistance that is necessary and directly related to ADLs or IADLs, is not a Medicaid personal care service. In particular, the Manual states:

> *Scope of services—Personal care services covered under a state's program may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages, which enables them to accomplish tasks they would normally do for themselves if they did not have a disability. Assistance may be in the form of hands-on assistance (actually performing a personal care task for a person) or cueing so that a person performs the tasks by him/herself. Such assistance most often relates to performance of ADLs and IADLs. . . . Personal care services can be provided on a continuing basis or on episodic occasions. Skilled services that may be performed only by a health professional are not considered personal care services.*

However, skilled services may be provided under a state's personal care benefit under the state plan when they are delegated by a nurse and when the practice is recognized and permitted under state law. (Nurse delegation is discussed in detail in Chapter 7.)

> *Cognitive impairments—An individual may be physically capable of performing ADLs and IADLs but may have limitations in performing these activities because [of] a cognitive impairment. . . . Personal care services may be required because a cognitive impairment prevents an individual from knowing when or how to carry out the task. For example, an individual may no longer be able to dress without someone to cue him or her on how to do so. In such cases, personal assistance may include cueing along with supervision to ensure that the individual performs the task properly.*

In October 1999, HCFA further revised the Manual to permit states to offer the option of consumer-directed personal care services. The Manual revisions explicitly recognized that provision of personal assistance services may be directed by the persons receiving such service, including those persons' own supervision and training of their personal care attendants. In particular, the Manual states:

> *Consumer-directed services—A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to their personal preferences, supervise and direct the provision of personal care services, and, if necessary, fire the provider. The State Medicaid Agency maintains responsibility for ensuring the provider meets State provider qualifications . . . and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the State may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving the services.*[9]

These manual materials describe a robust scope of personal care/personal assistance services a state may choose to cover under its Medicaid state plan—in keeping with contemporary views con-

shopping, and other routine household tasks—provided by a trained homemaker.

Homemaker services are a subset of personal assistance services, furnished when there is no other means of attending to general household activities. Generally homemakers do not provide assistance with ADLs. However, the same person may provide both personal assistance and homemaker tasks and many persons with disabilities prefer such an arrangement. Coverage of homemaker services is most common in HCBS waiver programs that serve elderly individuals, although it is sometimes included in programs serving other populations as well. Homemaker services may not be covered under a state's Medicaid plan on a stand-alone basis; they may be provided only as an adjunct to personal care services furnished under the Medicaid state plan.

Home health aide services: These are the same services provided under Medicaid's home health benefit, except that limitations on the amount, duration, and scope of such services imposed by the state's approved Medicaid plan are not applicable.

Home health aide services do not have to be provided by a home health agency. States are free to define home health aide services using different criteria (e.g., services provided by certified nurse assistants). Cost concerns lead many states to restrict the amount of home health aide services provided through Medicaid's mandatory home health benefit. For example, a state may impose a maximum number of hours a week for home health aide services. Under a waiver program, a state may permit a greater amount of such services, subject to the waiver cost cap. However, they must be in addition to services provided under the state plan.

Personal care services: Assistance with eating, bathing, dressing, personal hygiene, and other ADLs. May include assistance with meal preparation. May also include such housekeeping chores as laundry, bedmaking, dusting, and vacuuming, which are incidental to the assistance provided or essential to the health and welfare of the individual (rather than the individual's family).

This definition parallels the scope of personal care services that may be furnished under the Medicaid state plan. States frequently broaden the standard waiver definition to include assisting the individual with IADLs and with participation in activities outside the individual's home. A state may cover personal care services under both its state plan and an HCBS waiver program. But to do so it must demonstrate that the proposed HCBS waiver coverage is different from—or in addition to—services in the state plan (as discussed in the section on Federal policy considerations earlier in this chapter).

States may choose whether members of the person's family (excluding spouses and parents of minor children) may serve as providers of personal care. If a state chooses to allow family members to provide services, it may either require them to meet the same qualifications as other individuals providing such services or apply different stan-

A Frequent Problem in Designing Waiver Coverages: Tendency to Tie Them to Particular Service Settings

In designing HCBS waiver programs it is helpful to remember that services can be furnished in both the home and a wide range of community settings. Historically, in developmental disabilities services, for example, states have tended to identify "day habilitation" with particular sites. This has had the effect of preventing habilitation services from being furnished to individuals in everyday community settings where training could be used to assist the individual in mastering skills important in community life. Several states are now removing the ties of this service to specific sites.

Another example of problems that can be caused by tying a service to a particular setting can be found in the area of personal care/personal assistance. Personal care can be defined in a way that ties its delivery to a person's living arrangement. But it can also be defined more flexibly, to permit provision of personal assistance in both the home and other community settings (as in the case of Michigan's HCBS waiver program for people with developmental disabilities). Defined in this alternative fashion, personal assistance services can be furnished more flexibly and more in accordance with the individual's particular needs and preferences.

dards. HCFA policy guidelines generally discourage use of family members as providers of personal care services, except to the extent other providers are not available or special circumstances exist. States may also choose by whom and how frequently personal care services will be monitored. (See Chapter 8 for guidelines related to the payment of family members.)

Personal care services are found in nearly all HCBS waiver programs, irrespective of target population. They are the main vehicle states use to furnish services and supports to individuals living in their own homes who need either direct assistance in performing ADLs and IADLs or help in performing everyday household activities.

In some instances, these services are furnished to individuals who reside in living arrangements owned or managed by provider agencies—including foster living arrangements and group living arrangements. In these cases, Medicaid funding can be used along with other resources to meet the costs of supporting the individual in that living arrangement. In other words, the "personal care" component of the service is qualified for Medicaid funding under the HCBS waiver program. (See Chapter 5 for a detailed discussion.)

> *Chore services: Services needed to maintain the home in a clean, sanitary, and safe environment. This service includes heavy household chores such as washing floors, windows, and walls; tacking down loose rugs and tiles; and moving heavy items of furniture to provide safe access and egress.*

Chore services are distinguished from homemaker services by their sporadic nature and the fact that they generally require more effort or skill to perform. Coverage of chore services is typically found in HCBS waiver programs serving older persons and/or persons with physical disabilities. Chore services may be provided only as an adjunct to provision of personal care services under the state plan (not on a stand-alone basis under that plan).

> *Attendant care services: Hands-on care, of both a supportive and health-related nature, which substitutes for the absence, loss, diminution, or impairment of a physical or cognitive function. This service may include skilled nursing care to the extent permitted by state law. Housekeeping activities incidental to the performance of care may be furnished as part of this activity.*

Attendant care services are similar in scope to personal care services, although they may include greater emphasis on addressing the health care needs of beneficiaries. States may choose to have the attendant supervised by a nurse or by the beneficiary. Attendant care services are most commonly covered in HCBS waiver programs for people with physical disabilities, although they are covered in programs that target other groups as well. For example, Iowa's HCBS waiver program for persons with mental retardation includes coverage of "consumer-directed attendant care." Attendant care services may be furnished on a stand-alone basis under the Medicaid state plan when they are defined as personal care/personal assistance services.

Services usually furnished in settings other than a person's home

States employ HCBS waiver funding to underwrite a portion of the costs of supporting a person in living arrangements other than the person's home. Typically, HCBS waiver dollars underwrite the non-room and board component of these living arrangements, including personal care, training and supervision, as well as the provision of other services. Since HCFA's coverage definitions anticipate that individuals will receive various types of supports in such living arrangements, using these definitions avoids having to make separate payments for each distinct type of activity.

> *Residential habilitation: Assistance with acquisition, retention, or improvement in skills related to ADLs (which, as noted earlier, states can define as they choose), such as personal grooming and cleanliness, bed making and household chores, eating and preparation of food, and social and adaptive skills necessary to enable the individual to live in a non-institutional setting.*[25]

States have the option of covering habilitation services in two major ways: residential habilitation and day habilitation (described in the next major service category). Residential habilitation

combines habilitation, personal care, and supervision into a single service and is most commonly employed in HCBS waiver programs for persons with mental retardation and other developmental disabilities who are served in group homes or similar living arrangements. But residential habilitation services may also be furnished to individuals who have their own living arrangement. In covering residential habilitation services, a state may also include transportation services furnished on behalf of residents within the scope of the residential services (rather than covering such services separately). Room and board costs associated with furnishing residential habilitation services are not eligible for Medicaid funding.

Habilitation services (whether day or residential) may not be furnished under the Medicaid state plan except to individuals who are residents of ICFs/MR. Habilitation services outside an ICF/MR may only be furnished through an HCBS waiver program.

> *Adult foster care: Includes personal care and services, homemaker, chore, attendant care, companion services, and medication oversight (to the extent permitted under state law) provided in a licensed (where applicable) private home by a principal care provider who lives in the home.*

Adult foster care involves the provision of services and supports to individuals who live in the home of a non-relative caregiver responsible for meeting the individual's personal care and other needs.[26] Typically these living arrangements are made available to individuals with physical disabilities or who are elderly, although many states also use such living arrangements to support people with developmental disabilities in the community. Using this service definition enables states to pull all these services together into a single coverage (rather than covering each activity as a distinct service).

> *Assisted living: Personal care and services, homemaker, chore, attendant care, companion services, medication oversight (to the extent permitted under state law), and therapeutic social and recreational programming provided in a home-like environment in a licensed (where applicable) community care facility in conjunction with residence in the facility.*

States that cover assisted living in a waiver program can pull together under a single coverage a wide variety of services and supports (including health and therapeutic services) that are furnished to individuals who live in "assisted living" centers. (Coverage of assisted living is discussed in detail in Chapter 5.)

Specialized, disability-related services

Various specialized services may be furnished under an HCBS waiver program. These services, which can be provided to individuals with specific conditions and impairments, are usually furnished away from the individual's living arrangement. They include: (a) day habilitation and "extended habilitation" services; (b) adult day health services; and (c) mental health services.

> *Day habilitation: Assistance with acquisition, retention, or improvement in self-help, socialization, and adaptive skills to enable individuals to attain or maintain their maximum functional level.*

Day habilitation services are covered by nearly every state that operates an HCBS waiver program for people with mental retardation and other developmental disabilities. Generally, such services are furnished at a facility in the community. However, a growing number of states are encouraging provision of these services in other community locations, to promote community integration and improve the relevancy of skill training. Transportation services may be included in the scope of day habilitation services.

Although states have historically provided habilitation services under an HCBS waiver only to individuals with mental retardation or related conditions that occurred before age 22, neither Medicaid law nor implementing regulations restrict who may receive habilitation services in an HCBS waiver. Other individuals who do not have mental retardation or related conditions, such as persons with traumatic brain injury or other physical disabilities that occurred after age 22, may also benefit from habilitation services under the waiver. Accordingly, states may provide habilitation services—including the expanded habilitation services of educational, prevoca-

tional and supported employment services—under an HCBS waiver to people of all ages who qualify for the waiver. (See Appendix II for the complete text of HCFA's guidance on this issue.)

> *"Extended Habilitation Services."* Extended habilitation services include (a) prevocational services, (b) educational services, and (c) supported employment services.[27] In 1986, Congress amended the HCBS waiver statute to enable states to offer "extended" habilitation services. These services have traditionally been provided only to individuals with mental retardation and other developmental disabilities. However, recent HCFA guidance has clarified that they may also be offered to other groups who can benefit from them, such as persons who have had brain trauma or acquired brain disorder. (See Appendix II for the complete text of HCFA's guidance.)

Extended habilitation services can be combined with one another and with day habilitation to support individuals in a variety of ways (i.e., provision of one type of habilitation service does not exclude provision of others). But none of the extended habilitation services provided through HCBS waiver programs can be reimbursed if they are available through programs funded under either the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act (IDEA). States must document that these services are not available through those programs.[28]

(a) Prevocational services encompass assistance aimed at preparing an individual for paid or unpaid employment. The preparation is not job-task oriented. Rather, it includes teaching such concepts as compliance, attendance, task completion, problem solving, and safety. Prevocational services concentrate on skill training individuals might require to secure employment—including training directed to work goals such as improvements in attention span and motor skills (rather than explicit employment objectives). Medicaid law does not permit a state to offer what are termed "vocational services" (with the single exception of supported employment services, as discussed below)—making the definition of prevocational services decidedly habilitative.[29]

With respect to individuals with developmental disabilities, prevocational services cannot be provided under the Medicaid state plan except to residents of an ICF/MR. A state may include in the scope of these services costs of transportation to and from the site at which this training takes place. About three-quarters of the states operating HCBS waiver programs for people with developmental disabilities offer this service, generally at fixed sites in the community.[30]

(b) Educational services encompass special education and related services as defined in IDEA, to the extent they are not available under an IDEA-funded program. These services may be furnished as supplements to special education services provided to school-age individuals. But they may also be defined in an alternative way that can include education and training for adults no longer receiving special education services. Very few states offer educational services in their HCBS waiver programs.

(c) Supported employment services include those activities needed to sustain paid work by individuals receiving waiver services, including supervision and training. Supported employment services and supports may be offered to individuals when needed to obtain and maintain a job in the community regardless of the wage they earn. As with all waiver services, states may use their own definition of supported employment as long as the intent of the service is to assist individuals to obtain and maintain employment. In some states, provision of supported employment services is coordinated between the state vocational rehabilitation authority (which underwrites initial training costs) and the developmental disabilities program (which provides "follow-along" services through the HCBS waiver programs).

The services states offer under this coverage include "job coaching," which enables an individual to learn how to perform a job at a community employment site. Extended habilitation services may also include transportation costs associated with the person's getting to and from the job site, adaptive aids and equipment necessary for the person to secure a job, and other supports. Supported employment services may not be furnished under the Medicaid state plan except to

individuals who reside in ICFs/MR.

Adult day health: Health, therapy, and social services needed to ensure an individual's optimal functioning, furnished in an outpatient setting, four or more hours per day on a regularly scheduled basis, for one or more days per week.

These services are generally provided to older persons at senior centers or similar community facilities. Most states require that adult health programs have medical personnel available on site to address health care needs. Coverage of these services is nearly universal in HCBS waiver programs that serve seniors with severe impairments.

Supported Employment Services in Colorado's HCBS Waiver Program for People with Developmental Disabilities

The following are included in Colorado's supported employment services:

- Individualized assessment that may include community orientation and job exploration
- Individualized job development and placement services that produce an appropriate job match for the individual and his/her employer
- Ongoing support, training, and facilitation in job finding, job skill acquisition, job retention, career development, and work-related activities
- Intervention and training needed to benefit from supported employment services and other supports that would help remove or diminish common barriers to participation in employment and to the building of community relationships.

As a component of adult day health services, states have the option to cover transportation between the individual's place of residence and the adult day health center.

Services for individuals with serious persistent mental illness

A state may cover three specialized services for individuals who have serious persistent mental illness: (a) clinic services; (b) day treatment or other partial hospitalization services; and (c) psychiatric rehabilitation services. These services also may be offered in HCBS waiver programs serving other target populations that include individuals who have a "dual diagnosis" (e.g., mental retardation and a psychiatric condition). Clinic and day treatment services are primarily for diagnosis and treatment of mental illness. In contrast, psychiatric rehabilitation services are aimed primarily at achieving maximum reduction of physical or mental disability and restoration of maximum functioning.

The standard HCFA definitions of these services encompass a wide range of assistance to individuals who have a mental illness and are in keeping with contemporary views on mental health services. These views stress the need not only to treat the mental illness but also to assist individuals to function in their communities.

Clinic services: Outpatient mental health therapy and treatment.

States that select this option may offer mental health clinic services to HCBS waiver participants. The advantage of covering these services under an HCBS waiver program is that they may be furnished in locations other than clinic sites.[31]

Day treatment or other partial hospitalization services: Services necessary for diagnosis or treatment of an individual's mental illness. These services can include diagnostic services, psychotherapy, family counseling, occupational and activity therapy, medications, and training and education of the individual.

Day treatment services are akin to outpatient mental health services. Their purpose is to maintain the individual's condition and functional level and to prevent relapse or hospitalization. Partial hospitalization services are very similar to a hospital inpatient program, except the individual does not stay in the hospital 24 hours a day. With respect to adult services, day treatment is a term sometimes used interchangeably with partial hospitalization. But for children, it often means a facility-based day program that includes schooling, with supplemental mental health rehabilitation and/or counseling as well. The scope of services a state may furnish under an HCBS waiver

program is relatively broad. And unlike the Medicaid state plan clinic option, these services are not restricted to particular sites.

> *Psychiatric rehabilitation services: Medical or remedial services for maximum reduction of physical or mental disability and restoration of maximum functioning. Specific services include (a) restoration and maintenance of daily living skills (grooming, personal hygiene, cooking, nutrition, health and mental health education, medication management, money management, and maintenance of the living environment), (b) social skills training in appropriate use of community services, (c) development of appropriate personal support networks, (d) therapeutic recreational services (focused on therapeutic intervention rather than diversion[32]), and (e) telephone monitoring and counseling services.*

Psychiatric rehabilitation services integrate the provision of clinical mental health services with provision of other supports to address the full range of needs an individual with a mental illness might have. Day treatment services, in contrast, are confined largely to clinical services.

Health-related services

This category covers a variety of skilled services that persons with disabilities or chronic conditions may need but that either cannot be provided, or are provided on a more limited basis, under the state plan.

> *Skilled nursing: Services within the scope of a state's Nurse Practice Act that are provided by a registered professional nurse, or by a licensed practical or vocational nurse under the supervision of a registered nurse.*

This option enables a state to cover nursing services not available through the Medicaid state plan. Frequently, it is used in states where the Nurse Practice Act dictates that nurses perform various services on behalf of consumers (administer medications and injections, change feeding tubes, and so forth).

> *Private duty nursing: Individual and continuous care (in contrast to part-time or intermittent care) provided by licensed nurses within the scope of state law.*

Private duty nursing is similar to skilled nursing except that it is more intensive and can cover situations when a nurse must be with the person for extended periods throughout the day—including 24-hour-a-day coverage if needed to attend to the person's health care needs.

> *Extended state plan services: States may provide the same health and other services as available through the state plan, without the limitations on amount, duration, and scope specified in the plan. These services will be provided under the state plan until the plan limitations have been reached. They can include physician services; home health nursing services; physical and occupational therapy services; speech, language, and hearing services; prescribed drugs; dental services; vision services; and other state plan services.*

A state might choose to include these services in its HCBS waiver program because its state plan limits either the amount or scope of the services. (A) A state might limit the number of times an individual can receive physical therapy services, for example. By covering physical therapy as an "extended state plan" service, a state could provide for additional visits. (B) Or a state may require that physical and occupational therapy be provided only on a restorative basis (e.g., to individuals who have lost function as the result of an illness or accident). These therapies can also be valuable for individuals with permanent disabilities, however, because they can prevent deterioration and improve functioning.[33] An HCBS waiver program can include such coverage.[34]

Assistive devices, adaptive aids, and equipment; home and vehicle modifications

> *Environmental accessibility adaptations: Those physical adaptations to the home that either (a) are necessary to ensure the health, welfare, and safety of individuals or (b) enable them to function more independently in the home and without which they would require institutionalization.*

Home adaptations can almost never be covered under the Medicaid state plan. But Medicaid permits a wide range of adaptations under an approved waiver program.

Home and Vehicle Adaptations Included in Pennsylvania's HCBS Waiver Program

HCFA recently approved Pennsylvania's waiver program for individuals with mental retardation and related conditions. It includes the following household adaptations:

- Ramps from street, sidewalk, or house, including portable vehicle ramps
- Handrails and grab bars in and around the house
- That part of a smoke/fire alarm or detection system adapted for individuals with sensory impairments
- Outside railing from street to home
- Widened doorways, landings, and hallways
- Kitchen counter, major appliance, sink, and cabinet modifications
- Bathroom modifications for bathing, showering, toileting, and personal care needs
- Bedroom modifications of bed, wardrobe, desks, shelving, and dressers
- Workroom modifications to desks and other working areas
- Stair glider and elevating systems.

The waiver program limits physical adaptations to household vehicles to the following:

- Vehicular lifts
- Interior alteration such as seats, head and leg rests, and belts
- Customized devices necessary for the individual to be transported safely in the community, including driver control devices.

The various adaptations covered in Pennsylvania's HCBS waiver program are relevant to meeting the needs of individuals who have physical impairments regardless of the cause of their disability. In one form or another, coverage of these adaptations is very common in HCBS waiver programs that serve individuals with physical impairments, regardless of their age or specific condition.

Specialized medical equipment and supplies: Devices, controls, or appliances that enable individuals to increase their abilities to perform ADLs, or to perceive, control, or communicate with the environment in which they live. This service also includes items necessary for life support, ancillary supplies, and equipment necessary to the proper functioning of such items, and durable and nondurable medical equipment not available under the Medicaid state plan.

This coverage can address a variety of needs and purposes. These include providing:

- Aids and devices to enable persons with memory impairments to adhere to a medication schedule (e.g., medication administration boxes with timed alarms)
- Communication aids and devices, including expressive and receptive communication augmentative devices (e.g., electronic communication devices)
- Skill acquisition supports that make learning more purposeful and useful, including computers, computer adaptations, software, or instructional aids
- "Assistive technology" services. These cover a full range of services and adaptations that enable individuals with severe disabilities to use technology to perform activities on their own.

An enormous variety of devices and supplies can be offered under this coverage. Again, it is more common than not for HCBS waiver programs that serve persons with physical impairments to cover these services. One of the main benefits of covering many of these services is that they can reduce the need to provide workers to perform tasks on behalf of individuals, enabling them to be more independent and self-sufficient.

In addition to equipment and devices, states may cover other types of services in order to provide assistance in a different form. California's developmental disabilities waiver program, for exam-

ple, covers "communication aides," which are "those human services necessary to facilitate and assist persons with a hearing, speech, or vision impairment to be able to effectively communicate with service providers, family, friends, co-workers, and the general public." Allowable communication aides include (a) facilitators; (b) interpreters and interpreter services; (c) translators and translator services; and (d) readers and reading services.

Personal emergency response systems or PERS: Electronic devices that enable certain individuals at high risk of institutionalization to secure help in an emergency. PERS services are limited to those individuals who live alone, who are alone for significant parts of the day, or who have no regular caregiver for extended periods of time, and would otherwise require extensive routine supervision.

These systems are covered in HCBS waiver programs that serve a variety of populations, particularly elderly persons. Equipping consumers with this capacity reduces the need for on-site oversight and makes it possible for individuals to live more independently and safely. Some states have defined PERS more broadly than the standard definition. California's HCBS waiver program for people with developmental disabilities, for example, covers the following items as PERS: (a) 24-hour answering/paging; (b) beepers; (c) MedicAlert bracelets; (d) intercoms; (e) life-lines; (f) fire/safety devices, such as fire extinguishers and rope ladders; (g) monitoring services; (h) light fixture adaptations (blinking lights, etc.); (i) telephone adaptive devices not available from the telephone company; and (j) other electronic devices/services designed for emergency assistance.

Transportation: Services that enable waiver participants to gain access to waiver and other community services, activities, and resources specified by the plan of care. This service must be a supplement to mandatory assurance of medical transportation,[35] and to other transportation services that may be provided under the state plan.[36]

Coverage of transportation services can be complicated because of the need for coordination with "medical transportation" as available under the state Medicaid plan. General "medical transportation" must be used when the person needs to obtain a health care service (e.g., go to the doctor). Transportation services under an HCBS waiver program, sometimes called "non-medical transportation," can be used to pay for transporting individuals either to sites where home and community services are provided (e.g., an adult day health program) or to reach other community services (which must be reflected in the person's plan of care).

HCBS waiver transportation services can take a variety of forms—including reimbursing mileage expenses of a family member or a friend, if necessary to provide the transportation.

Family training and respite care

These services are provided to help family members in, and relieve them of, their caregiving responsibilities.

Family training: Training and counseling services for the families of individuals served under an HCBS waiver. Includes instruction about treatment regimens and use of equipment specified in the plan of care.

Respite care: Services provided to individuals unable to care for themselves, furnished on a short-term basis because of the absence or need for relief of those persons normally providing the care.

These services are discussed in detail in Chapter 8.

Additional Waiver Services That Have Been Approved by HCFA

Even though HCFA has expanded the number of services contained in its standardized format since it was first issued, the current list by no means exhausts all coverage possibilities and variations thereof. For example, waiver programs for older persons can cover home-delivered meals and protective services. Waiver programs for persons with acquired brain disorders can include family counseling to deal with behavioral and other problems and substance abuse counseling/services. Colorado covers training in child and infant care for a parent with a disability.

Mobile Crisis Intervention: A Waiver Service in California

California's developmental disabilities waiver program covers a service called "mobile crisis intervention." This is defined as immediate, time-limited, therapeutic intervention on a 24-hour emergency basis to an individual exhibiting acute personal, social, and/or behavioral problems which, if not addressed, are likely to escalate into situations which would threaten the health and safety of the individual and result in the individual being removed from the current living arrangement.

The following is an illustrative list of services states have included in their waiver programs that serve individuals with developmental disabilities. Many of these services are applicable to other disability groups and can be modified to address the unique needs of each target population.

Crisis intervention services. These services usually entail providing additional, frequently specialized, services to HCBS waiver beneficiaries who are in crisis, usually due to a behavioral problem or episode. The services typically enable specialists to be dispatched to stabilize the persons in their current living arrangement. Without such services, persons with developmental disabilities may face transfer from their current living situation to institutional settings because they, their parents, or their service providers are unable to respond appropriately to transitory crisis situations. Professional intervention has been demonstrated to be effective in resolving such crises and precluding or reducing their recurrence—thus preventing reinstitutionalization—through training of the individual or relevant others in how to manage the behaviors that precipitate the crisis situations.

Behavioral services. More generally, states often cover behavioral services in HCBS waiver programs for people with developmental disabilities and persons with acquired brain injuries. Provision of such services provides a means to secure specialists to address behavioral problems or issues on a continuing basis.

Community participation supports. Some waiver programs have distinct coverages that assist individuals to participate in community activities away from formal program sites. The aim is to encourage greater community integration and reduce use of site-based programs. For example, Colorado includes in the scope of the personal assistance services offered through its HCBS waiver program "mentorship activities, such as assistance with his/her participation on private and public boards, advisory groups, and commissions."

Housing coordination. Housing coordination involves providing an individual with assistance in locating community housing, including helping the individual gain access to various types of housing assistance. A few states have added this coverage to their HCBS waiver programs.

Supported living. Supported living involves bringing needed services and supports to individuals in housing they own or lease. Many states have launched supported living programs for people with developmental disabilities. They have done so in order to foster independence and community integration, as well as reduce the extent to which individuals who do not live with their families must rely on provider agencies for housing. Including supported living in an HCBS waiver program enables a state to tie together several types of services and supports into a single coverage—in much the same fashion as the "residential habilitation" coverage does for provider-operated living arrangements.

Many states have linked their coverage of supported living to making non-Medicaid supplementary funding available to assist individuals in meeting the expenses associated with setting up their own living arrangement (e.g., making deposits and acquiring furniture), or with rent when their own income and resources are not sufficient due to particularly high housing costs. Connecticut has set aside funds expressly for these purposes. Florida has a similar program.

Consumer training and education. Recently, some states have added coverage of consumer education and training aimed explicitly at teaching individuals skills they need to manage their own supports and advocate on their own behalf.

California's Definition of Supported Living in Its HCBS Waiver Program for People with Developmental Disabilities

Supported living services in California include any individually designed service, or assessment of the need for service, which assists an individual consumer to live in a home that they own or lease, which is not licensed, and which is not the place of residence of a parent or conservator, with support available as often and for as long as it is needed.

The purposes of supported living services include assisting the consumer to make fundamental life decisions, while also supporting and facilitating the consumer in dealing with the consequences of those decisions; building critical and durable relationships with other individuals; choosing where and with whom to live; and controlling the character and appearance of the environment within their home. Supported living services are tailored to meet the individual's evolving needs and preferences for support without having to move from the home of their choice.

Examples of supported living services activities include assistance with common daily living activities; meal preparation, including planning, shopping, cooking, and storage activities; routine household activities aimed at maintaining a clean and safe home; locating and scheduling appropriate medical services; acquiring, using, and caring for canine and other animal companions specifically trained to provide assistance; selecting and moving into a home; locating and choosing suitable housemates; acquiring household furnishings; settling disputes with landlords; becoming aware of and effectively using the transportation, police, fire, and emergency help available in the community to the general public; managing personal financial affairs; recruiting, screening, hiring, training, supervising, and dismissing personal attendants; dealing with and responding appropriately to governmental agencies and personnel; asserting civil and statutory rights through self-advocacy; building and maintaining interpersonal relationships, including a "circle of support"; participating in community life; and accessing emergency assistance (including selection, installation, maintenance, repair, and training in the operation of devices to facilitate immediate assistance in the face of threats to health, safety, and well-being).

* * *

The foregoing makes it clear that no exact recipe exists for deciding which services and supports to include in a particular HCBS waiver program. As some wit has put it: "What HCBS waiver programs have most in common is that they are all different."

Why are they so different? After all, states typically have a great deal in common in the groups of individuals with disabilities or chronic conditions that they wish to serve. There are several reasons for the differences, of varying importance.

Some of the large differences among HCBS waiver programs that serve similar target populations are less significant than meet the eye. Some states, for example, elect to break down their services into many distinct coverages, whereas others pull together various closely related services into one coverage category. One of Colorado's HCBS waiver programs for people with developmental disabilities, for example, covers a service it has named "rehabilitation engineering." Under this coverage, it offers services other states choose to break down into home modifications, assistive technology, adaptive aids, and so forth. How exactly services and supports are packaged is less important than making sure they are covered in one fashion or another. Again, the best starting point for designing and selecting HCBS waiver coverages is assessing the needs of the service population and developing a state's own concrete ideas about how those needs can best be met.

A more substantive reason why state HCBS waiver services vary so widely is differences among states in the services already covered under the state Medicaid plan. In states that have broad, comprehensive state plan coverages, the services a state offers under its HCBS waiver program will consist mainly of those that cannot otherwise be covered under the state plan. This explains why,

for example, some states cover therapeutic services under their waiver programs and others do not. It also explains why HCBS waiver programs that principally serve children usually offer fewer services than programs that principally serve adults with disabilities. Since Federal law mandates that states provide the full array of state plan services to children, whether or not they are covered under a state's plan, HCBS waiver programs for children furnish a more limited array of additional services.

Differences among target populations are also important. As discussed earlier, several types of HCBS waiver services cut across disability lines (e.g., personal care/personal assistance, service coordination, and home modifications). These—and other services—are needed by people with different types of disabilities and are covered in nearly all HCBS waiver programs. However, there are also differences among individuals that are linked to their disabilities and how those disabilities need to be addressed. For example, habilitation training is particularly important for people with developmental disabilities, such as mental retardation and acquired brain injury, because of the nature of their disability.[37] (Indeed, provision of habilitation usually accounts for a significant share of the expenditures in HCBS waiver programs that serve people with developmental disabilities and is one reason why these waiver programs tend to be relatively costly to operate.) However, habilitation training is not relevant in meeting the needs of most elderly individuals. Thus, state coverage decisions are very much tied to the specific needs of individuals in the target population.

Yet another substantive reason why states differ in the services and supports they offer through their HCBS waiver programs is that home and community services and supports are still developing. Approaches that seemed appropriate in the past give way to new approaches. And states vary in how quickly they embrace these changes. One of the best features of the HCBS waiver alternative is that it is sufficiently flexible to change with the times. Waiver programs that have been in operation for a relatively long period, for example, usually have changed considerably since they were first approved.

A key point to keep in mind is that states have considerable latitude to modify and even change their HCBS waiver coverages. Each year, states submit a high volume of amendments to their HCBS waiver programs which add, delete, and modify the services and supports states offer. As a consequence, each HCBS waiver program typically is a "work in progress." Coverages can be fine-tuned based on feedback from people with disabilities and service providers concerning problems or gaps. In this context, hindsight can be a powerful strategic planning tool.

Endnotes

1. The primary contributors to this chapter are Gary Smith and Janet O'Keeffe.

2. Sections 1902(a)(10)(B) and 1902(a)(1) of the Social Security Act.

3. Section 1915(c) of the Social Security Act. The relevant Federal statute authorizes the Secretary of HHS to grant these waivers.

4. It is increasingly common, for example, for states to offer, under HCBS waiver programs for people with developmental disabilities, supplementary dental services over and above the dental benefits available under the state plan, which are typically very limited. This "extended" coverage option can be and is employed for other Medicaid state plan services as well (physician services, prescribed drugs, vision services).

5. Section 1915(c)(1) of the Social Security Act prohibits payment for room and board under Medicaid waivers.

6. These services are listed in Section 1905(a) of the Social Security Act.

7. Adding or changing coverage of home and community services that Federal law permits to be covered under the Medicaid state plan requires a state to take various formal steps. A state adds, deletes, or changes a service in its Medicaid state plan by filing a state plan amendment with HCFA, which reviews the coverage and approves it so long as it conforms to Federal law and Federal regulations.

8. The 1997 regulations can be found at 42 CFR 440.167.

9. In the developmental disabilities service field, when people with cognitive impairments and severe disabilities are not able to direct all aspects of their services, other consumer-directed approaches have been employed. For example, "circles of support" are com-

posed of individuals' family and friends, who work in concert to provide assistance to help them realize their goals.

10. U.S. General Accounting Office. (May 1999) *Adults with severe disabilities: Federal and state approaches for personal care and other services.* GAO Publication No. GAO/HEHS-99-101. Washington, DC: GAO.

11. Among the states that offered personal care services in 1998, annual per capita outlays for such services (i.e., total personal care expenditures divided by the state's total population) ranged from less than $0.10 to a high of $94.37. Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group. (A few of the states included in the MEDSTAT data analysis cover personal care services only for children covered by the EPSDT mandate, which likely accounts for the very low amount spent in some states.)

12. The limits each state imposes are listed in U.S. General Accounting Office. (May 1999) *Adults with severe disabilities: Federal and state approaches for personal care and other services.* GAO Publication No. GAO/HEHS-99-101. Washington, DC: GAO.

13. For three of these states (AR, OK, WA), limiting personal care services to the categorically needy is a departure from policies on other benefits in their Medicaid programs, which are offered to both categorically eligible and medically needy individuals. Ibid.

14. This state option was added in Section 1915(g) of the Social Security Act.

15. HCFA guidelines concerning targeted case management services are in Sections 4302 *et seq.* of the State Medicaid Manual.

16. Activities related to eligibility determinations and service authorization may be reimbursed as administrative expenses.

17. States are required to ensure that appropriate transportation is available. See the transportation provisions in 42 CFR 431.53. Transportation may also be provided as a service under the state plan.

18. Defined in 42 CFR 440.90 with additional HCFA guidelines in Section 4320 of the State Medicaid Manual.

19. Defined in 42 CFR 440.130(d).

20. Teaching parents to anticipate and deal with a child's rage is an example of an activity that directly supports the Medicaid beneficiary. Marriage counseling for the child's parents does not and is not covered.

21. Much of the information provided here on the rehabilitation service option is drawn from Koyanagi, C. and Brodie, J. (July 1994). *Making Medicaid work to fund intensive community services for children with serious emotional disturbances.* Washington, DC: Bazelon Center for Mental Health Law. This publication is no longer available because it has been updated and published in two new companion reports. See the annotated bibliography at the end of this chapter for a description of these excellent publications.

22. Statutory authority for HCBS waiver programs is contained in Section 1915(c) of the Social Security Act. Applicable Federal regulations are found at 42 CFR 441 Subpart G. These regulations were last modified in 1994. HCFA guidelines concerning HCBS waiver programs are contained in Sections 4440 *et seq.* of the State Medicaid Manual. These guidelines are updated periodically.

23. With respect to services a state proposes to cover that depart from those that appear in the standard application format, HCFA requires that "the definition of each service must be exhaustive (e.g., a detailed list of each item of medical equipment that may be provided) or closed-ended (e.g., "only those medical supplies needed for the respirator-related needs of a respirator-dependent patient"). The definition may not include such phrases as "including but not limited to . . .," "for example . . .," "including . . .," "etc." In other words, the service must be defined in a fashion that makes clear exactly what will be furnished to the beneficiary.

24. When case management services are furnished under an HCBS waiver program, individuals have the right to select their case managers from among all qualified providers of such services.

25. The term "habilitation" is defined in the standard application as "services designed to assist individuals in acquiring, retaining and improving functioning." It is distinguished from "rehabilitation," which involves the *restoration* of function. Habilitation services have generally been provided to individuals who have cognitive impairments, including those due to mental retardation, brain trauma, or acquired brain disorders. However, habilitation services can be provided to anyone who can benefit from them, regardless of age or diagnosis.

26. Adult foster care services are also provided under the rehabilitation option as therapeutic foster care.

27. Both the states and various Federal agencies have emphasized the need to assist people with developmental disabilities to obtain employment in regular jobs in the community. In 1986 Congress permitted states to offer extended habilitation services through HCBS waiver programs, but restricted those services to

individuals who had been institutionalized some time prior to entering the HCBS waiver program. In spite of this restriction, nearly all states that operate HCBS waiver programs for people with developmental disabilities have added some of these services—particularly supported employment—to their programs. However, only a small portion of HCBS waiver participants with developmental disabilities have been provided this service, due in large part to the prior institutionalization test.

Congress agreed to remove this test as a provision of the Balanced Budget Act of 1997. This step prompted some states that had not previously covered supported employment services to add them to their waiver programs. By early 1999, most states had changed their coverage of supported employment services to broaden their availability to all HCBS waiver participants. In a recent letter to State Medicaid Directors, HCFA clarified that these services can be offered to all waiver participants who can benefit from them, not just to persons with mental retardation or other developmental disabilities.

28. This prohibition on reimbursement is in line with the Federal requirement that Medicaid be the payer of last resort when other public programs cover the same service.

29. However, individuals who receive prevocational services can be compensated for their work. In keeping with Federal hourly wage statutes, persons who are compensated at levels above 50 percent of the minimum wage are generally regarded as receiving vocational rather than prevocational services.

30. A state may furnish these services only in instances when similar services are not available through the state's vocational rehabilitation program (or in the case of older youth, special education programs).

31. States have the flexibility to define waiver services and provider requirements as long as they adhere to state mandates regarding licensure and certification and other applicable requirements.

32. Diversion as used here is defined as leisure activities without a treatment objective.

33. Another example is in the arena of prescribed drugs. The state plan might restrict the types of drugs that may be purchased. Sometimes individuals can benefit from medications not on the approved list and these can be secured as an "extended state plan" service. A few states have gone a step farther to cover nonprescription medications. Michigan's HCBS waiver program for people with developmental disabilities includes coverage of "extended pharmacy services," for example, which includes various over-the-counter items that are physician ordered.

34. When a state does not cover a health-related service under its state plan but desires to do so under its HCBS waiver program, the service is not considered an "extended state plan" coverage but a coverage in its own right. Services falling into this category can include (depending on what a state's basic Medicaid program offers) dietary services, special meals, respiratory therapy, psychology services, recreation therapy, and so forth.

35. Required under 42 CFR 431.53.

36. Defined at 42 CFR 440.170(a).

37. Persons of all ages with many different types of disabilities can benefit from habilitation services. Coverage of habilitation has generally been provided only to people with developmental disabilities, which are defined as those occurring before age 22. However, a recent HCFA letter to State Medicaid Directors clarifies that neither Medicaid law nor implementing regulations restrict who may receive habilitation services in an HCBS waiver. Individuals who do not have mental retardation or other developmental disabilities, such as persons with traumatic brain injury or physical disabilities that occurred after age 22, may also receive habilitation services through a waiver program. (See Appendix II for the complete text of HCFA's guidance.)

Annotated Bibliography

LeBlanc, A.J., Tonner, M.C., and Harrington, C. (2000). *State Medicaid programs offering personal care services.* San Francisco: University of California. (40 pages)

This paper describes the two predominant means through which Americans with disabilities receive personal care services: the Medicaid personal care service optional state plan benefit and the Medicaid 1915(c) home and community based services waiver program. It presents state and national data on the number of Medicaid personal care participants and program expenditures. It also describes how the states vary in their implementation of the two programs. *The paper may be ordered for $5.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

LeBlanc, A.J., Tonner, M.C., and Harrington, C. (2000). *Medicaid 1915(c) home and community based services waivers across the states: Program structure and barriers to growth.* San Francisco: University of

California. (33 pages)

This paper describes the program structure, policies, and administration of Medicaid 1915(c) home and community based services waiver programs. The paper also describes how states incorporate the waiver programs into their larger long-term care administrative structure. The authors also identify structural barriers to waiver program growth, including dispersed administrative structures, limits on financial eligibility, cost caps, and formal limits on service use. *The document may be ordered for $5.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

Koyanagi, C. (September 1999). *Making sense of Medicaid for children with serious emotional disturbance. A review of how states provide access to the most effective community based services for children on Medicaid who need mental health care.* Washington, DC: Bazelon Center for Mental Health Law. (90 pages)

This publication surveys 68 state programs and summarizes innovative approaches in several states using Medicaid under managed care and fee-for-service to finance wraparound services. *This report (CM-1) may be ordered for $18.90 from the Bazelon Center for Mental Health at www.bazelon.org; or send e-mail to pubs@bazelon.org or call (202) 467-5730 extension 41, or write to Bazelon Center for Mental Health, 1101 15th Street, N.W., Suite 1212, Washington, DC 20005-5002, or fax request to (202) 223-0409.*

Koyanagi, C. (September 1999). *Where to turn: Confusion in Medicaid policies on screening children for mental health needs. A report on states' use of EPSDT to identify children who need mental health services.* Washington, DC: Bazelon Center for Mental Health Law. (18 pages)

This publication discusses how states are currently failing to use Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program (EPSDT) to identify children who need mental health services. It includes a state-by-state comparison chart of EPSDT screening requirements and recommendations for advocates, policymakers, and program administrators. *This report (CM-2) may be ordered for $12.90 from the Bazelon Center for Mental Health at www.bazelon.org; or send e-mail to pubs@bazelon.org or call (202) 467-5730 extension 41, or write to Bazelon Center for Mental Health, 1101 15th Street, N.W., Suite 1212, Washington, DC 20005-5002, or fax request to (202) 223-0409. Special price for both publications (CM-3): $27. See on-line bookstore or e-mail pubs@bazelon.org for bulk discounts.*

U.S. General Accounting Office (May 1999). *Adults with severe disabilities: Federal and state approaches for personal care and other services.* GAO Publication No. GAO/HEHS-99-101. Washington, DC: Author. (86 pages)

This report provides an overview of how adults with disabilities received home and community based services under Medicaid in 1994. Data are derived from the 1994–1995 National Health Interview Survey. It also includes interviews with disability-related advocacy and research groups, a list of state programs that meet the needs of adults with severe disabilities, and a profile of four innovative personal care programs in California, Kansas, Maine, and Oregon. *This document can be downloaded free of charge from the Internet at frwebgate.access.gpo.gov or by calling the GAO Document Distribution Facility at (202) 512-6000, or by writing to 441 G Street, N.W., Room 6252, Washington, DC 20548.*

U.S. General Accounting Office (April 1999). *Assisted living: Quality of care and consumer protection issues in four states.* GAO Publication No. GAO/HEHS-99-27. Washington, DC: Author. (55 pages)

Although most assisted living costs are paid for privately by individuals, several state Medicaid programs fund services for residents in assisted living facilities and many other states have expressed interest in doing so. This study explores quality of care and consumer protection issues surrounding assisted living programs in California, Florida, Ohio, and Oregon (states chosen for their experience with assisted living programs). *This document can be downloaded free of charge from the Internet at frwebgate.access.gpo.gov or by calling the GAO Document Distribution Facility at (202) 512-6000, or by writing to 441 G Street, N.W., Room 6252, Washington, DC 20548.*

Mollica, R.L. (June 1998). *State assisted living policy: 1998.* Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. (295 pages)

This study identifies trends in the demand for and supply of assisted living facilities; barriers to the development of assisted living; and supply/demand factors that contribute to those barriers. It evaluates the concept of "assisted living," and describes the key characteristics of the universe of assisted living facilities. The study reviews assisted living and board and care policies in the 50 states and describes the primary approaches that states are taking to license assisted liv-

SSI website (www.ssa.gov).

9. Under Section 1902(r)(2), described above.

10. Post-eligibility share-of-cost rules also apply to persons in ICFs/MR, long-term hospitals, and other medical institutions, regardless of eligibility category. Persons who become eligible by meeting a medically needy spend-down obligation also face an additional post-eligibility share-of-cost obligation based on their remaining income.

11. This differential treatment comes about because SSI treats persons living in an institution as a separate household and eligibility unit than their family members. The 209(b) states are exceptions in that they continue to deem, even for persons who live in institutions.

12. Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982.

13. The U.S. Supreme Court decision was Sullivan v. Zebley, 493 U.S. 521 (1990). The decision became moot in 1997, when Section 4913 of the Balanced Budget Act of 1996 (P.L. 105-33) restored Medicaid to the children who had lost out under SSI's earlier definitional change.

14. Sections 1619 and, equivalently, 1905(q) of the Social Security Act.

15. The Social Security Administration has published a proposed rule to adjust the SGA level automatically each year for individuals with impairments other than blindness. The adjustments would be based on any increase in the national average wage index. SSA hopes to publish the final rules in time for them to become effective in January 2001.

16. The provision, which originated as a demonstration in 1980, was fully implemented in 1982 but not made permanent until 1986 in Section 1619(a) of the Act.

17. Section 1619(b).

18. Numbers from "Quarterly Report on SSI Disabled Workers and Work Incentive Provisions," (September 1999) Social Security Administration, Office of Research, Evaluation, and Statistics.

19. The 1997 provision is in Section 4733 of the Balanced Budget Act of 1997 (P.L. 105-33). The 1999 provision is in Section 201 of the Ticket to Work and Work Incentives Improvement Act of 1999 (P.L. 106-170).

20. States are not permitted to use Section 1902(r)(2), described above, as a way to get to a higher effective income level at which full premiums are charged.

21. Additional information on the Medicaid Buy-Ins may be obtained from the HCFA website devoted to the Ticket to Work and Work Disincentive Act (TWWDA).

22. The terms "assets" and "resources" are used interchangeably here. Medicaid law on transfers refers to "assets" (which may include income), while "resources" is the more generally used eligibility term (which does not include income).

23. This includes 209(b) states.

24. If the Social Security Administration finds a person ineligible for SSI because of a transfer of resources, that person still has the right to apply for Medicaid through their state and, because of the differences in how the penalty period is calculated, is likely to qualify with a shorter penalty period.

25. The penalty for resource transfers in SSI, recently enacted in P.L. 106-169, is a loss of SSI benefits for a period of time. If the Social Security Administration finds that resources were transferred for less than fair market value in the 36 months prior to application, then a penalty period begins in the month the transfer occurred. The duration in months is calculated by dividing the amount transferred by the maximum monthly cash benefit otherwise payable.

26. The period is 60 months if assets were transferred into or out of certain trusts.

27. Social Security Act, Section 1917(c) (2) (iii) and (iv).

Annotated Bibliography

Kassner, E., and Shirey, L. (2000). ***Medicaid financial eligibility for older people: State variations in access to home and community-based waiver and nursing home services.*** **Pub. #2000-06, Washington, DC: AARP, Public Policy Institute.** (27 pages)

This report focuses on the impact that Medicaid financial eligibility rules have on access to home and community based services for older people with disabilities. While some states use the same financial criteria to determine nursing home and waiver eligibility, there are other states that use more restrictive criteria to determine waiver eligibility. The report analyzes states' treatment of income and asset rules for nursing home and waiver eligibility as well as states' treatment of the income and assets of Medicaid beneficiaries' spouses. It also discusses the maintenance needs allowances permitted by state Medicaid waiver programs serving older people and makes policy recommendations for changing eligibility rules to enable more Medicaid beneficiaries to receive home and com-

munity based services. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3860 or search their website www.research.aarp.org.*

Schneider, A., Fennel, K., and Keenan, P. (May 1999). *Medicaid eligibility for the elderly.* Washington, DC: The Kaiser Commission on Medicaid and the Uninsured. (25 pages)

This publication is designed for both consumers and program designers. It discusses characteristics of the elderly population and Medicaid and Medicare policy regarding long-term care. It also discusses the options available to states to design their Medicaid programs. Tables and graphs help in understanding the complex eligibility process. Particularly useful for consumers is the clarification of the Medicaid eligibility "pathways" for low-income, elderly individuals. The document describes various options and how states have expanded Medicaid coverage. The document contains only a brief discussion on the provision of home and community services. *This document may be obtained free of charge from the Kaiser Family Foundation website at www.kff.org or ordered from their publications line at (800) 656-4533.*

Schneider, A., Strohmeyer, V., and Ellberger, R. (July 1999). *Medicaid eligibility for individuals with disabilities.* Washington, DC: The Kaiser Commission on Medicaid and the Uninsured. (28 pages)

This document highlights the complexities in the Medicaid program that create barriers to coverage for the population with disabilities. It focuses on four groups of individuals with disabilities as it explains the "pathways" to Medicaid eligibility. The document explains both the importance of Medicaid to low-income people with disabilities and the ways in which federal policies structure states' Medicaid eligibility options. This document makes a very complex issue understandable for both consumers and policy makers. *This document may be obtained free of charge from the Kaiser Family Foundation website at www.kff.org or ordered from their publications line at (800) 656-4533.*

Schneider, A., Fennel, K., and Long, P. (September 1998). *Medicaid eligibility for families and children.* Washington, DC: The Kaiser Family Foundation. (25 pages)

This publication reviews Medicaid eligibility policy for low-income children and nondisabled adults. It focus-

es on the complexity of Medicaid eligibility policy as a possible barrier to fully covering all children or adults who qualify. The paper summarizes state and federal policy options that may increase the number of people eligible for Medicaid, as well as enroll more of those who are eligible. *This document may be obtained free of charge from the Kaiser Family Foundation website at www.kff.org or ordered from their publications line at (800) 656-4533.*

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CHAPTER 3

Health and Functional Criteria for Service Eligibility[1]

In addition to general coverage criteria required by Federal Medicaid law, states set health and functional criteria to determine who in the large group that is financially eligible will receive home and community services in specific programs. For every Medicaid service, states have to answer two basic questions: (a) how to define medical necessity and (b) how to manage overall utilization. This chapter discusses health and functional criteria for service eligibility with respect to three major Medicaid service categories: the mandatory home health benefit, the personal care option, and HCBS waiver programs.

Introduction

Federal law and regulation specify the general eligibility and coverage requirements for mandatory and optional Medicaid home and community services. States are permitted to use additional service criteria to specify who, within the general eligibility group, will receive services. States use a number of different terms to describe these criteria: health and functional criteria, level-of-care criteria, targeting criteria, and service criteria. These terms are basically interchangeable. This Primer uses the term *service criteria.* How free states are in setting these service eligibility criteria depends on whether the service is Federally mandated or a state option and, if optional, whether it is offered under the state Medicaid plan or through a waiver program.

Service criteria generally include measures of functioning, which are typically defined in terms of everyday activities an individual is unable to perform without assistance because of physical or mental impairment. Such activities can include what are termed Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include eating, bathing, dressing, toileting, transferring from bed to chair, and maintaining continence. IADLs are tasks that require higher cognitive functioning than ADLs, and include activities such as light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management.[2] While IADL performance requires higher cognitive functioning than does ADL performance, assistants who provide help with most IADLs (e.g., shopping, housekeeping) will generally need less training than assistants who provide help with ADLs. This is particularly true when assistance with an ADL requires activities covered by Nurse Practice Acts (e.g., catheterization).[3]

For Federally mandated services (e.g., home health), states may set only two types of service criteria. They may make service eligibility criteria based on medical necessity and they may impose controls on

Federal Coverage and Eligibility Requirements for Medicaid Home Health Services

Examples given by the Office of General Counsel of questions that could be relevant in determining medical necessity

"1. Relation to medical condition: is the service required to identify, diagnose, treat, correct, cure, ameliorate, palliate, or prevent a disease, illness, injury, disability, or other medical condition, including pregnancy, or is the service required to assist the recipient in activities of daily living?

2. Medical reason for treatment: is the service provided for medical reasons rather than primarily for the convenience of the recipient, caregiver, or provider?

3. Clinical appropriateness: is the service consistent (in terms of amount, scope, and duration) with generally accepted standards of good medical practice?

4. Medical need for choice among alternate settings: is the service affording treatment generally provided to similarly situated individuals in the setting, or is there an alternate available setting where, under generally accepted standards of good medical practice, the same service may be safely and effectively provided? In other words, is there a medical need for the service to be provided in a particular setting, such as the home, as opposed to another covered Medicaid service provided in another readily available setting?" Of course, these questions would not apply where the ADA or Medicaid require that the beneficiary have a choice among alternate settings.

utilization. Both these criteria in fact allow considerable leeway, because they are not defined further in Federal law or regulation. The medical necessity limitation is often interpreted as requiring preauthorization—namely, authorization by a medical professional before the service begins—but these services do not have to be *medical* services (see further below).

Controlling utilization is typically understood to mean placing limits on either the number of times a service may be provided, or the period over which it can be provided, for a given condition.[4]

Optional benefits provided under a state's Medicaid plan (e.g., personal care services) carry no Federal statutory or regulatory provisions regarding the type or level of impairment a person should have to receive benefits. The only Federal rule is that the state must make the service equally available to all recipients who satisfy the service criteria that have been set. Within the parameters of the Federal definition of personal care services, for example, states are permitted to choose the measures they use to assess need, and the particular level and/or combination of needs a person must have. For example, one state may require a person to have 2 out of 5 impairments in ADLs. Another might require a person to have 3 out of 12 impairments in ADLs and IADLs. This freedom has resulted in considerable variation in states' personal care service criteria.

Designing Medicaid service criteria can be a major challenge for states, because competing policy objectives are involved. On the one hand, states want to ensure that service criteria identify all individuals who have legitimate needs for assistance. On the other hand, states must operate their Medicaid programs within financial constraints set by their state budgets. Since the number of people served is a major determinant of total program costs (the other being cost of the service), setting service criteria is a fundamental component of state financial decision making.

The complications implied by the tradeoff between coverage and costs can arise through unintended effects on other parts of the long-term care system. Take, for example, the issue of setting service criteria for nursing home admission. Since long-term care services delivered in an institutional context are extremely expensive, a state may wish to require applicants to meet stringent criteria of medical need or have a severe level of functional limitation. Supporting home and community services through an HCBS waiver program can be considerably less expensive. But Federal law requires that the service criteria a state sets for HCBS waiver applicants be the same as those applied to nursing home applicants. Stringent institutional criteria can be an obstacle to serving people in HCBS waivers, because some people who meet the criteria may be too impaired to be cared for safely and cost-effectively in the community unless they have extensive informal help. Very stringent service criteria may also result in premature institutionalization, if informal care networks "burn out" because

Federal Coverage and Eligibility Requirements for Medicaid Home Health Services

The mandatory home health services are: (a) nursing services provided on a part-time or intermittent basis by a home health agency that meets requirements for participation in Medicare; (b) home health aide services provided by a home health agency that meets requirements for participation in Medicare; and (c) medical supplies, equipment, and appliances suitable for use in the home. The optional home health services are physical therapy, occupational therapy, and speech pathology and audiology services.

- All services offered under the home health benefit are mandatory for all Medicaid beneficiaries entitled to nursing facility services under a state plan. This includes (a) categorically eligible persons age 21 and over, (b) persons under age 21 if the state plan provides nursing facility services for them, and (c) medically needy persons if the state plan provides nursing facility services for them.
- Services must be ordered by a physician as part of a written plan of care that the physician reviews every 60 days.[5]
- Services must be provided at the recipient's place of residence, which does not include a hospital, nursing facility, or ICF/MR.
- Eligibility of beneficiaries to receive home health services does not depend on their need for, or discharge from, institutional care.
- States may place coverage limits on home health services if the limits are based on considerations related to medical necessity or utilization control.

paid assistance is not available until a person is severely impaired.

Alternatively, states may decide they would rather serve more people and control utilization (and therefore costs) by limiting the amount of services provided. The problem here is that the more restrictions the state imposes on the amount, scope, and duration of services, the more likely it is that people with significant needs will be inadequately served in the community and end up in an institution—with substantially increased costs to the state.

There is no "correct" decision regarding service criteria. An approach that is appropriate in one state may not work in another. Each approach has tradeoffs and, as with most Medicaid decisions, each state's tradeoffs will vary depending on its unique service system. This underscores the need to make decisions about service criteria within the broader context of a state's long-term care system—which includes both institutional and home and community services and, with respect to the latter, several alternative funding streams.

States use various approaches to ensure that the service criteria for each program within its long-term care system not only match the policy goals for that program but also fit into the larger system. Several states achieve the combination of goals by using an assessment process that starts with an eligibility determination for the highest level of need—nursing facility/waiver services. If applicants do not meet the nursing facility level-of-care criteria, they are then considered in succession for other long-term care programs that have progressively lower need requirements. The waiver program may require three ADL limitations, for example, but the state-funded personal care program may require only two.

The remainder of this chapter provides information about Federal provisions related to the selection of service criteria for three home and community benefits: home health services, personal care state plan services, and waiver services. These three benefits account for the vast majority of Medicaid spending on home and community services. While similar services may be covered by all three benefits (e.g., assistance with ADLs), the three benefits differ in major respects. First, and most importantly, home health services are mandatory; the other two are optional. Second, home health services require physician authorization; the other two do not. Third, waiver beneficiaries have to meet institutional level-of-care criteria; home health and personal care beneficiaries do not.

Home Health Services

Home health services are a mandatory benefit for all individuals entitled to nursing facility care under a state's plan.

To receive home health services, Federal regulations specify that the services must be ordered by a physician as part of a written plan of care. Beyond this authorization procedure and the general requirement that services be medically necessary, a person is required to meet no additional Federal requirements in order to receive home health services.

Misperceptions

Misperceptions are common, however, that additional Federal requirements do further restrict who may receive home health services. First, many assume that individuals must be *eligible* for nursing facility care in order to receive home health services (i.e., that they must meet a state's nursing facility level-of-care criteria). This misunderstanding has most likely arisen because people have misinterpreted the word *entitled* to nursing facility care to mean *eligible* for nursing facility care. The Federal requirement specifies only the minimum coverage group and does not require that the individual meet a nursing facility level of care (i.e., be eligible). Second, it is widely but incorrectly believed that states must use Federal eligibility requirements for the *Medicare* home health benefit to determine eligibility for Medicaid home health services.[6] In particular, many incorrectly believe that to be eligible for Medicaid home health services, a person must meet the *Medicare* requirements of being homebound and in need of skilled services.

In fact, states *may not limit* Medicaid home health services to individuals who require skilled services as defined by Medicare (i.e., skilled nursing and therapy services).[7]

Additionally, while Federal regulations state that home health services must be provided in the home, there is no requirement that the beneficiary be homebound. Indeed, as a recent letter from HCFA to State Medicaid Directors clarifies, a homebound requirement violates Medicaid comparability requirements.[8] (See Appendix II for the complete text of this letter.)

Medicaid home health services must be provided by Medicare-certified home health agencies. This requirement does not create a linkage between the two programs, however. Federal Medicaid policy permits states to provide home health services to persons with a wider range of needs than is possible through the Medicare program.

Ways to Address Cost Concerns

States can address cost concerns without using the impermissible homebound criterion. For example, instead of using a blanket homebound requirement, a state may set limitations based on medical necessity, which take account of beneficiaries' unique needs (consistent with the Office of General Counsel examples quoted earlier in this chapter). Colorado's home health regulations provide a good example of how the provision of home health services can be limited to appropriate situations without instituting a homebound requirement (see box).

States can also control costs for the home health benefit by limiting the amount, scope, and duration of home health benefits—as long as all services in the state plan category are sufficient to meet the needs of most persons who need the services. For example, some states limit the number of home health visits to no more than one visit per day, combined with exceptions based on preauthorization. Others require preauthorization for additional visits or for more than four hours of service per day. And some states have blanket preauthorization requirements to ensure appropriateness.

For states that have capitated Medicaid health care benefits, and have provided contracts to private managed care organizations to provide those benefits, the extent of the home health benefit needs to be specified with particular care. The situation in Tennessee, where recent reductions in capitated home health benefits have resulted in a lawsuit, provides a good example of the issues raised. Prior to capitation of the home health ben-

ing. Medicaid reimbursement policy for assisted living is also discussed. Summaries of each state's policy and regulations covering assisted living and board and care are presented. The study is an excellent resource/reference guide. *To obtain a free copy of this report, write to the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or e-mail DALTCP2@osaspe.dhhs.gov.*

Schore, J., Harrington, M., and Crystal, S. (March 1998). *The role of home and community based services in meeting the health care needs of people with AIDS.* Final report. Princeton, NJ: Mathematica Policy Research. (149 pages)

This report reviews the recent literature describing the delivery and financing of home and community based services for people with AIDS, case studies of service provision in New York City and Los Angeles, and an analysis of use and reimbursement patterns for New Jersey Medicaid beneficiaries with AIDS. The case studies describe current provider approaches to delivering home and community based services to the AIDS population. A synthesis of information (i.e., evolution of improvements in AIDS treatment, changes in the AIDS population, and pressures to control spending) and their implications are addressed. *The report may be ordered for $12.00, plus shipping and handling, from Jackie Allen, librarian, Mathematica Policy Research, Inc., PO Box 2393, Princeton, NJ 08543-2393, (609) 275-2350, or e-mail jallen@mathematica-mpr.com.*

Schore, J., Harrington, M., and Crystal, S. (1998). *Serving a changing population: Home and community based services for people with AIDS.* Pub. #PR98-15. Princeton, NJ: Mathematica Policy Research, Inc. (10 pages)

This study examines the availability of and funding for home and community based services for people with AIDS. It includes a literature review, case studies, and an analysis of use and reimbursement patterns for New Jersey Medicaid beneficiaries with AIDS. It compares home care use and costs for Medicaid beneficiaries with AIDS in New Jersey's AIDS waiver program with those not served by a waiver. The study analyzes the challenges facing providers, planners and policymakers with regard to information needs, an integrated approach under managed care, and the needs of people with chronic illness. *This report may be ordered free of charge from Jackie Allen, librarian, Mathematica Policy Research, Inc., PO Box 2393, Princeton, NJ 08543-2393, (609) 275-2350, or e-mail jallen@mathematica-mpr.com.*

Schoff, J., and Schore, J. (January 1997). *The role of home and community based services in meeting the health care needs of people with AIDS.* Literature review. Princeton, NJ: Mathematica Policy Research. (92 pages)

This report reviews the literature published between 1993 and 1998 on the delivery and financing of home and community based services for people with AIDS. It describes gaps in information, services that are available (including program descriptions), funding sources, and managed care. Detailed program descriptions provide models that can be used to design AIDS programs. *The report may be ordered for $12.00, plus shipping and handling, from Jackie Allen, librarian, Mathematica Policy Research, Inc., PO Box 2393, Princeton, NJ 08543-2393, (609) 275-2350, or e-mail jallen@mathematica-mpr.com.*

Kassner, E., and Williams, L. (September 1997). *Taking care of their own: State-funded home and community based care programs for older persons.* Washington, DC: AARP, Public Policy Institute. (56 pages)

This document provides a summary and brief analysis of state-funded multi-service programs that provide home and community based services to older persons. The data are based on a 1996 survey undertaken by AARP and include a general description of existing types of programs as well as a more specific and descriptive chart on the different services offered in 49 states and the District of Columbia (Montana did not respond to the survey). The report is useful in conjunction with other studies that provide data on federally funded programs. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3860 or search their website at http://www.research.aarp.org.*

Lewin-VHI, Inc. (1996) *National study of assisted living for the frail elderly: Literature review update.* Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. (87 pages)

This document reviews published and unpublished literature on assisted living for the frail elderly from 1992 through September 1995. It synthesizes information gathered from 175 articles. It discusses current trends in assisted living and compares state policies and practices. *To obtain a free copy of this report, write to the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue,*

S.W., Washington, DC 20201, fax (202) 401-7733, or e-mail DALTCP2@osaspe.dhhs.gov.

U.S. General Accounting Office (1994). *Medicaid long-term care: Successful state efforts to expand home services while limiting costs.* GAO Publication No. GAO/HEHS-94-167. Washington, DC: Author. (50 pages)

This document provides a review of three states' (Oregon, Washington, and Wisconsin) experience in expanding government-funded home and community based services. It focuses on these states' experience in shifting the provision of long-term care from institutional to home and community based settings. This document explains mechanisms states have used to control costs. It also demonstrates how the use of home and community based care has enabled states to provide services to a greater number of people. Detailed descriptions of each state and relevant data enhance understanding of how to design and manage a successful program. *This document can be downloaded free of charge from the Internet at frwebgate.access.gpo.gov or obtained by calling the GAO Document Distribution Facility at (202) 512-6000, or by writing to 441 G Street, N.W., Room 6252, Washington, DC 20548.*

Leonard, B., Brust, J., and Choi, T. (1989). Providing access to home care for disabled children: Minnesota's Medicaid waiver program. *Public Health Report* 104: 465–72. (7 pages)

This article explores the availability of funding for home care under the Minnesota Medicaid waiver program. It discusses gaps in funding for home care as well

as barriers to coverage (i.e., complex applications and poorly coordinated systems of care). It also provides a brief history of services for technology-dependent children and a history of Minnesota's program and eligibility criteria. The article reviews 96 records in the Minnesota home and community based model waiver program and follows their outcomes (e.g., approval/denial of application, coordination of care between state agencies). The article includes recommendations to help states remove the obstacles consumers face when seeking home and community based services.

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CHAPTER 5

Factors to Consider When Choosing Coverage Options: Two Illustrative Services[1]

As is clear from Chapter 4's discussion, Medicaid provides multiple coverage alternatives for some services. The advantages and disadvantages of each may not be apparent until the state works through their different implications in the context of its own unique long-term care service system. This chapter provides guidance to states as they weigh the tradeoffs among different coverage alternatives for a particular service. To provide enough specificity to be useful, the discussion covers two particular service options: (a) case management/service coordination and (b) services provided to elderly persons in assisted living settings.

Introduction

When a state is faced with several alternative ways of covering a particular home and community service, the tasks of (a) choosing among different coverage alternatives and (b) defining the precise service require detailed analysis of each alternative in the context of a state's home and community system's service needs. This chapter illustrates the types of issues to be considered with two specific services: case management and assisted living.

Case management is chosen as the first illustration because it is the backbone of the formal long-term care delivery system. Its overarching purpose is to facilitate Medicaid beneficiaries' access to the direct services they need. Every state offers case management in some form under its Medicaid program and every state has to decide how best to cover it.

Assisted living is chosen as the second specific service example, because it provides an excellent illustration of the complex issues involved in defining a service so as to ensure its maximum usefulness within a particular state system. The focus here is on assisted living services provided under Medicaid to persons age 65 and older. By early 2000, 35 states were serving Medicaid beneficiaries in assisted living settings. Residential care alternatives to institutions have been offered to persons with mental retardation and developmental disabilities for some time. Making them available to elderly persons is a more recent, and less well understood, initiative.[2]

Coverage of Case Management: Illustration #1

Medicaid gives states three ways to cover case management services: 1) targeted case management, (2) HCBS waiver programs, and (3) administrative claiming.[3] This section discusses the advantages and

disadvantages of each option in obtaining Federal financial participation (FFP).

Targeted Case Management Services

A state may claim FFP for case management services under its Medicaid plan by offering them to a defined group of recipients, or to multiple groups as long as different provisions apply to each. For example, a state may offer one form of targeted case management services to recipients who have a mental illness and another to persons who are elderly and have physical impairments. The scope of targeted case management services that may be claimed for FFP can include: (a) conducting assessments, (b) assisting individuals and families to identify needed services and supports (whether the direct services are funded through the Medicaid program or otherwise), and (c) helping them obtain such services. (The State Medicaid Manual contains a thorough discussion of these activities.)

Advantages to states of offering targeted case management services:

- The state is free to define the population that will be targeted.

- These services may be offered to Medicaid eligible persons regardless of whether the person participates in an HCBS waiver program. Consequently, they may be made available without regard to type or funding source to all Medicaid-eligible individuals (including HCBS waiver participants) who need home and community services. This makes targeted case management a potentially very useful coverage option in establishing a broad-based coordinated service system.

- A problem for case management covered under an HCBS waiver program is that FFP is only available once the person has entered the program. Thus, case management costs incurred in advance of enrollment are not eligible for FFP. (Some pre-waiver case management costs may be covered if they are begun before waiver participation but completed on the first day the person is enrolled in the waiver program. See Appendix II for a recent HCFA letter to State Medicaid Directors regarding the earliest date of service for which FFP can be claimed.) Targeted case management services may be furnished irrespective of whether the person is enrolled in an HCBS waiver program, however, enabling most pre-enrollment costs associated with service coordination to be recouped.

- Once states were severely limited in obtaining FFP for targeted case management services furnished to institutionalized persons. Until recently, FFP was available only for services furnished to individuals in the 30-day period immediately preceding the person's discharge from the facility. Now, FFP is available for targeted case management services to assist and arrange for an individual's community transition for up to 180 days preceding discharge. This recent policy clarification by HCFA enables a state to involve community service coordinators earlier in the community placement process. FFP for such targeted case management services is available regardless of whether the person is enrolled upon discharge in an HCBS waiver program, receives other Medicaid home and community services, or is supported through alternative funding sources. However, FFP is not available if the person's community placement does not take place.[4]

- The costs of targeted case management services may be claimed at the service rate, which in many states is significantly higher than the 50 percent rate that applies to administrative claiming (see below).[5]

- The targeted case management option is compatible with state strategies to delegate provision of service coordination through contracts or memoranda of agreement with public or non-public agencies (or multiple sources). This is beneficial where counties are responsible for the provision of case management services. Such strategies can be useful in promoting consumer choice in selecting support coordinators from a variety of sources.

- When the targeted groups are those with serious mental illness or mental retardation and

other developmental disabilities, targeted case management enables a state to limit service providers to the case management authorities already established in state law. This allows states to tie delivery of targeted case management services into their already established single point of entry systems. In contrast, when case management/service coordination is offered under an HCBS waiver program, Medicaid freedom of choice of provider rules apply and a state must enable HCBS waiver participants to obtain case management/service coordination from any qualified provider.

Drawbacks to states of offering targeted case management services:

- Obtaining FFP for targeted case management requires "service claiming" (i.e., claims for reimbursement for a specific service delivered to a specific Medicaid recipient). Service claiming can generate considerable paperwork. It can also pose logistical problems in developing a reimbursement mechanism that enables the relevant authority to maintain base operation levels when the amount of case management varies individual-to-individual, month-to-month. The varying workload problem also arises when service coordination is offered as a distinct service under an HCBS waiver program. There are solutions for this problem, but they can involve their own complications.

- The necessity for service claiming can also make it difficult to obtain reimbursement for activities conducted on behalf of all recipients rather than distinctly for the benefit of a specific individual (e.g., staff development activities for case managers). Again, there are ways to address this problem (mainly through cost-apportionment—see further below under Administrative Claiming).

- Service coordinators often help support individuals in ways that fall outside the scope of targeted case management activities for which FFP may be claimed. FFP for targeted case management services is not available for "direct services." Examples are a case manager's driving an individual to a doctor's appointment (transportation) or helping the person manage their finances. Federal policy dictates that such direct services be claimed via other categories (e.g., making a claim for Medicaid transportation services). Having to assign some of the activities case managers routinely conduct on behalf of individuals to other categories creates administrative and billing complexity.

- Except for targeted case management services furnished to assist or arrange an individual's return to the community (i.e., community transition planning), Federal policy does not permit FFP for targeted case management services furnished to institutionalized persons. This limitation arises from the concern that activities performed for institutionalized persons by case managers not on the facility staff would duplicate activities facilities are required to conduct on behalf of their residents.

- Where a state provides external case management services to institutionalized persons, the general prohibition against FFP for targeted case management services furnished to institutionalized persons can result in a state having to turn to administrative claiming in order to underwrite the costs of external case management activities for institutionalized individuals. The need to employ separate streams for case management services depending on whether or not a person is institutionalized can cause complications for states.

HCBS Waiver Coverage

FFP is available for the costs of case management/service coordination when a state covers such services under its HCBS waiver program. This option differs little from targeted case management with respect to types of activities for which FFP may be claimed. The general interchangeability of these options is illustrated by the fact that all states operate HCBS waiver programs for people with developmental disabilities, but states divide about equally between those that use targeted case management coverage and those that cover service coordination as an HCB waiver service.

However, two significant aspects differentiate case management/service coordination covered as an HCB waiver service from targeted case management coverage:

- Under a waiver, availability of the service is restricted to individuals who are waiver participants.
- Under a waiver, a state may not limit case management service providers to established case management authorities—as it can under the targeted case management option.

Advantages to states of covering case management/service coordination as an HCBS waiver service:

- Covering case management/service coordination as an HCB waiver service tightly links availability of such services to the target population served through the HCBS waiver program. Thus, the scope of such coverage may be tied directly to the specific needs of the waiver population.
- Covering case management as an HCB waiver service enables a state to provide for more intensive service coordination for HCBS waiver participants than it might (for financial reasons) be prepared to offer a wider range of individuals.

Drawbacks to states of offering case management/care coordination as an HCBS waiver coverage:

- The service is limited to individuals enrolled in the HCBS waiver program.
- Claims for FFP may only begin, as noted, once the person has been approved for admission to the waiver program. This prevents the state from being reimbursed for pre-enrollment case management expenses. However, some pre-waiver case management costs may be covered (a) if they are begun before waiver participation but completed on the first day the person enrolls in the waiver, or (b) if they occur in the 180 days preceding transition from an institution to the community.

Administrative Claiming

Administrative claiming takes advantage of a provision in Federal law permitting states to claim FFP for administrative expenses they incur in operating their Medicaid programs. Such expenses may include costs of intake, assessment, service planning, arranging Medicaid services for recipients, and overseeing service delivery—many of the activities typically performed by case managers.

Administrative claiming differs from the targeted case management and waiver alternatives in one important aspect: It may not be used in conjunction with assisting recipients to access non-Medicaid services—even though such services might benefit the recipient. Case managers may work to coordinate access to all services in a care plan. But administrative claiming can only be used for the administration of the Medicaid program, as established by a time study or other method to apportion Medicaid and non-Medicaid costs.

Advantages to states of using the administrative claiming option for case management activities:

- It is not necessary to bill for distinct activities on behalf of specific individuals, because administrative claiming is not service-based. Administrative claiming is usually accomplished by apportioning the costs an organization incurs between those attributable to Medicaid recipients and those attributable to non-recipients and/or other state or Federal non-Medicaid programs. While the cost apportionment process can be complicated, this does not always constitute an additional barrier, because some organizations must do cost-apportionment in any case whenever they receive Federal funds for administering non-Medicaid programs.
- Thus, administrative claiming can be especially advantageous for states that operate a single point of entry system through human service authorities that also administer the provision of non-Medicaid benefits. Minnesota, for example, uses administrative claiming with respect to its county human service agencies

for a range of case management functions that are not specifically covered under the case management service for waiver beneficiaries (e.g., eligibility determination; administrative functions involving case managers such as program planning, development and outreach; and certain licensing and contracting functions).

- When points of entry are organized along target population lines, administrative claiming may be used to avoid some of the problems associated with service-based claiming, especially when most of the individuals receiving services are Medicaid-eligible in any case.

- Administrative claiming is consistent with models where a state has established, by law or regulation, a distinct network of local point-of-entry/case management authorities.

- In addition to helping a state underwrite the costs of its point of entry/service coordination system, administrative claiming can play an important role in helping states operate their home and community service systems through activities that are not keyed to meeting the needs of specific consumers (such activities can be conducted directly by the Medicaid state agency or provided by a vendor). Such activities include:

  — Outreach to make individuals and families aware of the availability of home and community services.

  — Quality assurance/quality improvement activities associated with the delivery of Medicaid home and community services.

  — Automated data systems to compile a wide range of information concerning beneficiaries of home and community services, including data to support quality improvement activities or aid in strategic planning.

  — "Hot lines" and similar administrative activities to aid beneficiaries in locating services or registering complaints.

  — Various state-level administrative systems activities—including conducting state-level review and approval of HCBS waiver plans of care and other types of service plans, operating payment systems, determining provider rates, responding to consumer complaints, and conducting service quality reviews.

- The administrative claiming option for case management activities provides states with the capability of securing FFP for external case management services furnished to institutionalized persons that does not hinge on whether the person's discharge from the facility is imminent. Administrative claiming may be employed to provide external oversight of the well-being of institutionalized persons as well as support "in-reach" activities to provide information concerning the availability of home and community services.

  Administrative claiming may also span case management activities that are directly tied to arranging and assisting a person's return to the community without respect to length of time involved. However, such activities must be tied to arranging Medicaid home and community services. The state Medicaid agency may obtain case management services for institutionalized persons via contract with a state program office or through local human services agencies. Organizing case management for institutionalized persons under the administrative claiming option may simplify use of Medicaid dollars to underwrite such services in comparison to other available service options.

Drawbacks to states of using administrative claiming for case management services:

- Federal reimbursement of administrative expenses is generally limited to 50 percent of allowable costs. In states where the service rate is greater than 50 percent, administrative claiming will yield less FFP.

- Administrative claiming is limited to activities related solely to administration of the Medicaid plan. Thus, the costs of activities that

assist individuals to access other sources of assistance have to be met out of state/local dollars. Alternatively, states can use the targeted case management option to cover these activities.

- Individuals lose the protections contained in Medicaid law with respect to provider freedom of choice, since administrative claiming usually restricts service coordination activities to a single provider source.

States May Use One, Two, or All Three of the Case Management Alternatives

Federal policy leaves it up to states to select the options or combinations of options that will be most effective in meeting the needs of individuals and families with long-term care needs. Federal policy does prohibit states from claiming the costs of the same activity of service coordination for the same individual under more than one alternative at the same time. But as long as this prohibition is observed, a state can use the three options to serve recognizably different purposes. For example, a state may combine service coordination as a distinct service for participants under HCBS waivers with targeted case management services for Medicaid recipients not being served by the waiver program. This allows the state to offer case management services under its state plan that are more limited in scope than those offered under an HCBS waiver.

Wyoming takes advantage of this possibility by offering targeted case management to individuals wait-listed for HCBS waiver services, in order to assist them in connecting with other sources of direct service assistance while awaiting waiver coverage. Sometimes a state may want to add administrative claiming to the case management mix. Although administrative claiming may not be used to assist recipients in accessing non-Medicaid services, it has the advantage of allowing FFP claiming for certain services that are not claimable under targeted case management or an HCBS waiver—including outreach, quality assurance/quality improvement, operating automated data systems, and various state-level administrative activities.

Coverage of Assisted Living for Elderly Persons: Illustration #2

It has long been recognized that, in order to reduce institutionalization, it is necessary to develop a range of residential options that provide supportive services. Given a choice, most people with long-term care needs would prefer to receive services in their own homes. However, some people prefer to live in residential settings other than their homes for a variety of reasons—such as the desire to have someone available 24 hours a day to meet unscheduled or emergency needs because they feel safer in such a setting. This preference is reflected in the recent private-sector growth in various forms of supported housing arrangements (called assisted living or residential care) for persons age 65 and older.

Services covered by or in an assisted living facility are governed by state law and regulations. There are no applicable Federal statutes, other than the Keys Amendment to the Social Security Act, which is applicable to board and care facilities in which a "substantial number of SSI recipients" are likely to reside.[6] State rules vary widely, and many are currently being updated because assisted living is a relatively new concept, not envisioned by many state legislatures or rulemaking bodies in the past.

Using Medicaid to pay for services in assisted living settings for elderly persons is of increasing interest to states looking to offer a full array of home and community services and to reduce nursing home use. By 2000, 35 states were using Medicaid to reimburse services to support assisted living for people with long-term service and support needs.[7] Twenty-four states cover services in assisted living settings under 1915(c) waivers; six cover it in their state plans through the personal care option; three cover it in both the waiver and the personal care option; one covers it through an 1115 waiver; and one covers it under a 1915(a) waiver.[8]

Assisted living may refer to a generic concept that covers a wide array of settings and services, or to a very specific model—or both—depending on who is using the term.[9] Twenty-nine states have a licensing category called assisted living, each with

its own definition.[10] Assisted living is also often used as a marketing term for facilities that may be licensed under another category, such as residential care facilities and personal care homes. The term is even used by facilities that are not licensed to provide services but whose residents receive services provided by outside agencies. As discussed in Chapter 4, HCFA includes a definition of assisted living in the standard HCBS waiver application, but states have the option to use a different definition. (See Appendix I for the full text of HCFA's definition.)

Assisted living is used here to mean *care that combines housing and supportive services in a homelike environment and seeks to promote maximal functioning and autonomy.* Medicaid will pay for services provided in assisted living facilities as long as the "homelike environment" is preserved. Thus, Medicaid will not pay for assisted living services if the assisted living facility is located in the wing of a nursing home (or ICF/MR). Emergence of assisted living as a residential rather than an institutional model—combined with changes in state licensing regulations—has provided many people who need supportive and health services with an important alternative to the nursing home. This type of living arrangement is very popular among private-pay older persons and their families. Covering assisted living through Medicaid provides safety net funding for this group, many of whom may one day be unable to afford it out of their own resources.

The logistics of setting up an assisted living program can be quite complex. Most important is the recognition that assisted living is more than just a setting for potentially cost-effective service delivery. It represents a philosophical approach to residential services that supports independent living, autonomy, and consumer choice—a philosophy that should guide decisionmaking for regulations and payment policy. In making such decisions, states must address a number of key issues, each of which is discussed in turn.

Target Population

Determining what population will be served will depend in large part on the state's current long-term care system and its policy goals. Is assisted living intended to fill a gap in the current set of options? Will the target population be different from the population usually served in board and care facilities? Is assisted living intended to enable people who cannot be served in their homes to avoid institutionalization?

Once these questions are answered, the state must decide which age groups will be served, and whether services will be designed to address the specialized needs of specific populations (e.g., persons with dementia). It is also crucial to make certain that licensing and other facility regulations in a given state match the target population. For example, if the state wants to target nursing home-eligible beneficiaries, the assisted living facilities will need to be able to serve a population with a nursing home level of need.

Service Delivery Models

The definition of assisted living varies from state to state and sometimes from residence to residence. Some states have used regulations or licensing requirements to define assisted living services. States using Medicaid HCBS waivers define the service to suit the purpose of their particular program. A variety of service delivery models are possible. The assisted living residence may be the provider of services, for example, or the service provider may be a separate agency. Yet a third alternative is to consider the assisted living setting a person's *home*; this permits a state to provide home and community services to persons in assisted living through the existing delivery system.

Whatever the model chosen, it is important to note that assisted living in no way compromises a person's right to receive other Medicaid services. The overriding criterion for receipt of services under any model is medical necessity.

Personal Care Option or Waiver or Both?

States can cover assisted living services through either a waiver program or the personal care option under the state plan or both. The waiver approach is advantageous in that states can

Coverage of Assisted Living through the Waiver Program: Oregon[11]

Oregon's Division of Senior and Disabled Services/Department of Human Resources licenses, pays for, and places Medicaid beneficiaries in two settings: assisted living facilities (ALFs) and residential care facilities (RCFs). The state has two classes of RCFs: Class I facilities provide only ADL assistance. Class II RCFs offer a range of services and can serve people who need a nursing home level of care. The Medicaid waiver program covers services in Class II RCFs and ALFs.

RCFs and ALFs can serve the same population but they operate under different regulations. When Oregon decided to regulate assisted living, it chose not to replace existing RCF rules. Instead, it added a new licensing category for assisted living with requirements that differ somewhat from its RCF rules.

Target Population. The waiver program serves adults age 18 and older. Assisted living residents who become Medicaid-eligible and individuals at risk of nursing home placement are given priority for assisted living services. Rather than set specific medical or functional criteria governing when a resident is no longer appropriate for assisted living, Oregon's regulations permit discharge when the facility can no longer meet the resident's needs or there is a "documented established pattern" of noncompliance with the resident agreement.[12]

Setting. The primary difference between RCFs and ALFs is the physical setting. RCFs provide single or double rooms with shared baths; individual kitchens are not required. Assisted living is defined as a setting that promotes resident self-direction and decisions that emphasize choice, dignity, privacy, individuality, independence, and home-like surroundings. ALFs must offer individual apartments with lockable doors, kitchen facilities, and private baths.

Services. Each resident is assessed and receives services in accordance with an individual service plan. Assisted living regulations specify that an interdisciplinary team assess the resident's needs and develop a service plan to respond to those needs. The team includes the resident (or legal representative) and two or more of the following: program case manager, facility administrator or designee, and licensed nurse if the resident is or will be receiving nursing services.

Services provided by RCFs and ALFs include three meals a day, modified special diets, personal and other laundry, a program of social and recreational activities, assistance with ADLs, essential household services (cleaning, dusting, bed making), health care assessments, oversight and monitoring of health status, health care teaching and counseling, an emergency response system, and assistance with medications. Nursing tasks may be delegated.

Each facility must also be able to provide or arrange for medical and social transportation, ancillary services for medically related care, barber/beauty services, hospice, home health care, and maintenance of a personal financial account for residents.

Staffing. RCFs must meet a specific staff-to-resident ratio, which varies based upon the facility size. ALF regulations are more flexible, requiring an adequate number of qualified staff to meet the unique care, health, and safety needs of residents.

Payment. Oregon assesses ALF and RCF residents and assigns a payment level based upon the individual's need for assistance with ADLs. In 2000, ALF rates ranged from $628/month for the least impaired group (generally requiring assistance with two to three ADLs) to $1773/month for the most impaired group (generally dependent in three or more ADLs). Room and board payments of $433.70/month are the responsibility of the resident.

broaden eligibility by using the 300 percent of SSI rule to reach persons in the community who would not ordinarily meet the financial qualifications for Medicaid. (The 300 percent rule is explained briefly below and in detail in Chapter 2.) However, since waiver services are available only to beneficiaries who meet the state's nursing home level-of-care criteria, serving people through a waiver will target a more severely impaired population than is generally served through the personal care option. The waiver program also offers the advantage of predictable

Coverage of Assisted Living through the Personal Care Option: Arkansas[13]

Arkansas does not currently have a licensing category called "assisted living." The state licenses Residential Care Facilities (RCFs), a board and care setting available to both private-pay individuals and Medicaid beneficiaries. Since the mid-1980s, Arkansas has provided Medicaid personal care services to residents of RCFs.[14] The Arkansas Medicaid program uses personal care rather than waiver funding for assisted living coverage because the RCF licensing category does not permit a nursing home level of services. The state is currently developing a more comprehensive assisted living program that will serve a more disabled population and be funded through a Medicaid waiver program.

Target Population. Adults age 18 and over are served. Residents must be independently mobile (i.e., physically and mentally capable of vacating the facility within three minutes). Residents who can use canes, wheelchairs, or walkers are considered independently mobile if they do not need more than verbal or limited physical assistance to vacate. Residents must be able to self-administer medications. They may not need more than intermittent nursing, have feeding or intravenous tubes, or be totally incontinent. Residents also may not have mental incapacity (mental illness, dementia, substance abuse, etc.) that requires a higher level of treatment or care than the facility is capable of providing.[15]

Setting. RCFs provide single or double rooms without kitchen facilities. Resident access to a kitchen is not required because meals are provided. Bathrooms may be shared. There must be at least one lavatory for every 6 residents and one tub/shower for every 10 residents.

Services. RCFs provide personal care (assistance with bathing, grooming, and dressing), supportive services (guidance, direction, or monitoring), activities and socialization, meals, housekeeping, and laundry. Residents may choose the RCF or an outside agency to provide personal care services, thus ensuring the Medicaid beneficiary's right of provider choice. Home health agencies are used to provide nursing services.

Payment. Medicaid payment for personal care services is based on the number of service hours provided (fee-for-service). The state limits the number of hours per month to 64, but the limit can be overridden with prior approval. Room and board is paid with SSI benefits ($512 minus a personal needs allowance).

costs for states concerned about utilization of a new benefit. The combination of nursing facility level-of-care eligibility criteria, a set number of slots (as is permitted in a waiver program), and expenditure caps will limit the number of people potentially eligible.

The personal care option is advantageous in that it will broaden eligibility by allowing a less severely impaired population to be served. This is because states may impose reasonable medical necessity criteria but may not restrict the benefit to persons who require a nursing home level of care. One disadvantage of using the personal care option is that it lacks the higher income eligibility standard used for waiver programs. When deciding which approach to use—or whether to use both—states may want to estimate how many people would be served under the different options in order to judge both the reach of the potential service and its likely cost.

Type of Waiver

When using the waiver program approach, should states add assisted living as a new service to an existing waiver program or implement it under a separate waiver program? From one perspective, adding to an existing waiver program is simple and minimizes reporting and tracking requirements. However, advocates for home and community services may perceive the addition of assisted living to the list of waiver services already covered as increased competition for a limited number of slots available for home services more generally. Coverage under a separate waiver program may be a better approach, not only for this reason but also because it enables a state to test the demand for and cost-effectiveness of assisted living *per se*. Separate waiver programs designed by a state to expand the total number of people served under waiver programs may also make it easier to reassure facilities in that state that they will have access to a sufficient number of consumers. Since providers receive

Medicaid payments based on the number of beneficiaries they serve, facilities may be reluctant to participate in the Medicaid program at all if they are unsure they will have a reliable source of potential residents.

To the extent that these statistics suggest an orientation toward serving a population that is less impaired than Medicaid waiver clients, facilities may not be capable of or willing to serve residents with greater needs.

Level of Care and Licensing Rules

HCBS waiver regulations require that any facility in which waiver services are furnished must meet applicable state standards. When services are furnished by the assisted living facility, the facility must meet the standards for service provision that are set forth in the approved waiver documents. Thus, states planning to cover assisted living through a waiver program need to be sure that the admission/retention provisions of state licensing requirements permit assisted living facilities to serve individuals who meet Medicaid's nursing home level-of-care criteria. Licensing must also address a facility's qualifications to provide assisted living services. In a few states, the facilities do not themselves provide these services. Instead, outside agencies come into the facility to provide them. For example, Minnesota covers assisted living provided by outside agencies to residents of facilities that provide only room and board and limited supervision. In such cases, the facility may need to meet only minimal housing standards, while the outside agency may be held to state licensing and program standards for home care providers. Residents in such settings may be personally responsible for making arrangements with an outside agency for service delivery, or, more typically, the state may provide case management services to assist the resident in doing so.

States that use a waiver program to provide assisted living need to contract with facilities that are willing and able to provide the services needed by someone who meets the state's Medicaid nursing facility level-of-care criteria. The assisted living industry is perceived as generally serving people with lighter needs. For example, about one-quarter of assisted living residents need no assistance with ADLs, according to a recent study by the National Center for Assisted Living.[16] The same study found that 43 percent of residents who move out of assisted living enter nursing homes.

Licensing and Contracting Issues

State licensing rules set the minimum requirements for Medicaid providers. The Medicaid program may set more stringent standards if desired, however. For example, some states allow facilities to offer rooms shared by two, three, or more residents. But since one of the purposes of assisted living is to foster independence and autonomy, some state Medicaid programs will only contract with facilities that offer private occupancy unless the resident chooses to share a room/unit. Some states also require facilities contracting with Medicaid to offer apartment-style units rather than bedrooms. (These include Oregon, Washington, and North Dakota.) Further, if licensing rules do not include sufficient requirements for facilities serving people with Alzheimer's disease, the Medicaid contracting requirements may specify additional training or other requirements.

Enabling Beneficiaries to Pay for Room and Board

Payment for room and board is one of the critical issues for states seeking to expand assisted living for Medicaid beneficiaries. Surveys by national associations have found that care in assisted living facilities may be unaffordable for many low-income individuals. Monthly fees in market rate facilities range from $800 to over $3500—with the majority in the $800–$2000 range. These fees vary by facility design and size of units and encompass amenities in addition to room and board. But assisted living facilities are marketed as a total package and people who are eligible for Medicaid cannot afford these fees.

Medicaid can be used to pay for assisted living *services*, but cannot pay for room and board. Except in very limited circumstances (such as a weekend stay provided as respite care under an HCBS waiver), the Medicaid beneficiary is

responsible for room or board costs, whether paid through pensions, savings, Social Security, or SSI.

States can and do use a number of approaches to ensure that the room and board rate for assisted living does not exceed the income available to Medicaid beneficiaries. These approaches include the following:

- States can examine the facility's monthly room and board charges to identify any coverable services—such as laundry assistance, light housekeeping, or food preparation—that can be reimbursed by Medicaid for a beneficiary who requires assistance with these IADLs. Including all coverable services in the state's assisted living service payment reduces the beneficiary's monthly payment solely to room and board and any other charges that Medicaid does not cover.

- Some states set only the service rate, leaving determination of the room and board rate to the facility. Florida and Wisconsin are examples of state Medicaid programs that set only the service rate. Beneficiaries choose among the assisted living facilities they can afford.

- Other states limit the room and board amount that can be charged to Medicaid beneficiaries. One option is to limit these costs to the amount of the Federal SSI payment rate. In the year 2000, that amount is $512 a month, which may be too low to provide a sufficient incentive for assisted living facilities to serve Medicaid beneficiaries.

- If the state has a State Supplemental Payment (SSP) program to supplement SSI payments, the assisted living room and board rate can be set at the amount that represents the Federal payment plus state payment. A few states have developed a supplemental payment rate specifically for beneficiaries in assisted living facilities, to provide them with sufficient income to afford the room and board component. Massachusetts has done this, for example, setting a payment standard of $966. The state uses its own funds to raise the Federal SSI payment to an amount sufficient for assisted living residents. (SSPs are discussed in detail in Chapter 2.)

- States are also exploring ways to provide assisted living services to residents of subsidized housing. Because subsidized housing is developed with tax credits and other specialized financing mechanisms, the rent component may be much lower than market rate and the resident may receive rental assistance that covers room and board costs. However, housing subsidy programs and Medicaid operate under very different rules. Careful planning and close collaboration is necessary to enable the programs to work together.

Assisted living and the special income limit: Post-eligibility treatment of income

Some states cover persons in an HCBS waiver program using the so-called 300 percent of SSI eligibility option (a person's income must be at or below 300 percent of the maximum SSI benefit—roughly $1500 per month.) This option is attractive for waiver programs that include assisted living, because it expands the program to include beneficiaries who are better able to afford the room and board costs of assisted living. To make this option effective, however, states must allow eligible persons to retain enough of their income to pay the room and board charges of an assisted living facility.

Medicaid beneficiaries who qualify under the 300 percent option are required to contribute toward the cost of their services. To determine the beneficiary's share of cost, the state must follow Medicaid rules governing post-eligibility treatment of income. These rules require states to set aside (protect) certain amounts of income for personal use and to assume the remainder is contributed to the cost of services. The state has the option to specify the amount of income that needs to be protected, and can take the costs of assisted living room and board into account when doing so. (See Chapter 2 for a detailed discussion of financial issues connected with the 300 percent option.)

Protecting sufficient income for room and board in assisted living, of course, reduces the amount the beneficiary pays toward the costs of services, thus raising service costs to the Medicaid program. When states are considering how much to protect, they need to balance this source of increased costs against the consequence of not

protecting sufficient income to pay room and board. In such a case, the beneficiary will not be able to afford room and board and share of service cost, and may be forced to move into a nursing home (where the room and board costs *are* covered by Medicaid).

Some states may be concerned about the fiscal impact of an across-the-board increase in the maintenance allowance. *But states are not required to increase the amount of income protected for all waiver beneficiaries who pay a share of cost in order to address the needs of beneficiaries who reside in assisted living.* States have the option to vary the amount of income that is protected based on the circumstances of a particular class of beneficiaries. For example, a beneficiary living alone may need to retain more income than a beneficiary living with a family member. A person living in an assisted living facility may have higher or lower need than a person living alone in a single-family home, or vice versa. Colorado, for example, allows people living in their home or apartment to retain nearly all their income and those living in personal care homes to retain an amount equal to the SSI benefit standard, which is the amount for room and board.

The state can further refine its treatment of income to account for variations in the cost of assisted living. Some states contract with both private (market rate) and subsidized assisted living facilities; the beneficiary's need for income will depend on the type of assisted living facility chosen. The "rent" component of the monthly fee charged by facilities built with low-income housing tax credits, for example, will be lower than the rent charged by privately financed facilities. If the state protects income based on the area's average monthly charge for room and board in private assisted living, the beneficiary living in a subsidized unit may be allowed to keep income that could be applied to service costs. But if income is protected based on the rent in subsidized units, beneficiaries may be allowed too little income to afford private market facilities. Setting a separate maintenance allowance for each setting allows a state to improve access to both private and subsidized assisted living facilities.

Income supplementation by family members or trusts for payment of room and board

When the beneficiary is unable to pay all room and board costs, family members may be willing to help pay them and other expenses not covered by Medicaid. A trust's funds may also be used to help pay for a beneficiary's costs not covered by Medicaid. However, families and trustees need to be aware of how any funds they contribute may affect beneficiaries' eligibility for various benefits (and therefore their net living standard). Any amount paid can reduce the recipient's SSI benefit—and in the worst-case scenario cause the recipient to lose SSI altogether, and with it potentially Medicaid as well. This is because SSI rules consider such supplementation in determining the individual's financial eligibility.

If the contribution is paid directly to the SSI beneficiary, it is counted as unearned income—the same as unearned income from any other source—and will reduce the individual's SSI benefit dollar for dollar. However, if the money is paid instead to the assisted living facility on a beneficiary's behalf, it is treated differently. SSI counts payment to the facility as "in-kind" income to the beneficiary and reduces the monthly Federal SSI benefit by up to one-third. Even if the "in-kind" contribution exceeds one-third of the SSI payment, the payment is only reduced by one-third. (See box.)

Medicaid rules follow SSI rules when families give money directly to an individual.[17] That is, the money counts as income just like any other unearned income. Therefore, if the individual is in a Medicaid eligibility group expected to pay a share of the cost of medical services, all a family cash supplement accomplishes is to increase the individual's share and decrease Medicaid's share of that cost. In some cases, as noted, such supplements can result in the individual losing eligibility altogether.

Medicaid also follows SSI rules regarding payments made by the family directly to a facility for room and board. These payments are counted as "in-kind" income, the dollar value of which is determined under special SSI rules. Thus, like a family payment made directly to the individual, the family's payment to the facility can affect

Effect of Income Supplementation on SSI Benefit

Assume that:

- Room and board charge is $800
- Individual has no income from other sources
- Full SSI benefit is $512
- The first $20 of unearned income is disregarded.

The difference between the SSI benefit and the room and board charge is $288. If the family pays $288 directly to the individual, this amount (minus the $20 disregard) is subtracted from the individual's SSI benefit, leaving only $264. The individual will be even less able to pay room and board costs than without the family's payment.

If the family pays $288 to the facility, then the individual's SSI benefit is reduced by one-third to $341. The family would then have to pay the difference between $341 and $800 (the room and board cost), which is $459. The consequence of the one-third reduction, then, is that the family must increase its supplementation from $288 to $459.

Because the rule states that the SSI payment will be reduced by up to one third, there is no limit on the amount of money that can be paid to a facility on behalf of the SSI beneficiary. If a family chooses, they can subsidize services other than room and board, as well as pay for room and board costs in more expensive facilities, without jeopardizing an individual's eligibility for SSI.

Medicaid eligibility as well as increase the individual's share of cost.

If families want to provide support to their family member who can cover room and board expenses, they should directly purchase anything other than food, clothing, and shelter. In an assisted living setting, for example, families could pay for any service not included in the facility rate or covered by Medicaid, such as cable television or personal phone service. In no such case may the state require supplementation.

Assisted Living and the Medically Needy

Medically needy beneficiaries are persons who, except for income, would qualify in one of the other Medicaid eligibility categories (such as being over age 65 or meeting the SSI disability criteria). Medicaid payments can begin for this group once they have spent down—that is, incurred expenses for medical care in an amount at least equal to the amount by which their income exceeds the medically needy income levels. (See Chapter 2 for additional discussion of this group and of medically needy income eligibility levels.)

The medically needy eligibility option can allow people who have income greater than 300 percent of SSI to become eligible for Medicaid services. But Federal law imposes two significant constraints on the use of this option:

- The state must cover medically needy children and pregnant women before it can elect to cover any other medically needy group. Additionally, the state may not place limits on who is eligible for Medicaid by using such characteristics as diagnosis or place of residence. Thus, it cannot use medically needy policies to extend Medicaid services only to HCBS waiver or assisted living beneficiaries.

- The maximum income eligibility limit that a state medically needy program may use is based upon its welfare program for families—levels that are typically lower than SSI. The income level must be the same for all medically needy groups in the state (i.e., states are not permitted to establish higher income eligibility levels for selected subsets of the medically needy, such as beneficiaries in assisted living settings).

These rules have several implications that states need to consider when trying to make the medically needy eligibility option work for higher income individuals in assisted living. (1) These individuals may find it more difficult to incur sufficient medical expenses to meet the spend-down requirements while living in the community than they would in a nursing home. The higher their "excess" income, the higher the amount of their spend-down—with the implication that only those with extremely high medical expenses may qualify. (2) Community providers are less willing to deliver services during the spend-down period, since payment cannot be guaranteed and collec-

tion may be difficult. (3) Spend-down rules combined with low medically needy income-eligibility levels mean that individuals may not have enough total income to pay both the bills they incur under the spend-down provision and the room and board component of assisted living. This is ironic since they start off with more income relative to other eligibility groups. As of the publication date, HCFA is actively examining this issue to find possible solutions (watch the HCFA website for updates).

Service Payment Rates: Adequacy Concerns

Unless the monthly rate is considered reasonable by assisted living facilities, they will not be willing to contract with Medicaid. In some states, rates in the $1500–$2500 a month range may be needed to attract enough facilities to serve Medicaid beneficiaries. When considering what rate might be necessary and reasonable, states might sample the rates charged by facilities (excluding very high end facilities) to assess (a) how they compare with Medicaid nursing home rates and (b) how many facilities might potentially contract with Medicaid at rates the state might be willing to pay.

It is also important for the state to be sensitive to the potential need to set payment levels that vary based on the assisted living residents' current needs. Doing so will enable people whose condition deteriorates to stay in the assisted living facility rather than having to move to a nursing home. A number of states use such tiered rates (including Arizona, Delaware, Oregon, and Washington). Rates set by case mix (as used in Minnesota, Maine, Wisconsin, and New York) also create incentives to accept people with high needs and retain people whose needs increase. Flat rates, in contrast, tend to force facilities to discharge residents whose needs exceed what can be covered under the rate.

As a final point, instead of reimbursing facilities on the basis of specific services delivered, states are permitted to develop a bundled monthly rate. A bundled rate is easier to administer for the state under a waiver program, and for providers under any coverage option.

Endnotes

1. The primary contributors to this chapter are Gary Smith, Janet O'Keeffe, Letty Carpenter, Robert Mollica, and Loretta Williams.

2. Mollica, R.L. (June 1998). *State assisted living policy: 1998.* Prepared for The Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and LongTerm Care Policy. Washington, DC: Department of Health and Human Services.

3. Case management activities are also covered routinely as a component of another service. For example, home health agencies that provide home health services are required to perform certain case management activities.

4. HCFA also clarifies that states can recoup the costs of service coordination furnished to individuals returning to the community through the HCBS waiver program when the person is enrolled in the HCBS waiver after discharge. As with targeted case management services, FFP is available for service coordination furnished during the 180-day period preceding institutional discharge. These service coordination activities are considered completed when the person enrolls in the waiver program.

5. The cost of HCBS waiver case management services can also be claimed at the service rate.

6. Section 1616(e) of the Social Security Act.

7. Some of these "assisted living" facilities may be termed "board and care," depending on the state.

8. Mollica, R.L. (June 1998). *State assisted living policy: 1998.* Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. Also, personal communication, June 19, 2000.

9. Settings called Assisted Living Facilities (ALFs) differ widely; some provide a high degree of privacy and services consistent with the philosophy of assisted living; others provide very little privacy and few services. National Association of State Units on Aging. 1999. *Advocacy practices in assisted living. A manual for ombudsman programs.* Washington, DC: Author; Hawes, C., Rose, M., and Phillips, C.D. (1999). *A national study of assisted living for the frail elderly.* Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy.

10. Not all of these 29 states reimburse services for Medicaid beneficiaries. Some states reimburse for serv-

ices in facilities licensed as board-and-care facilities, and others have created assisted living as a Medicaid reimbursed service even though the state may not have an assisted living licensing category.

The comparability requirement does not permit states to deny personal care services to persons in board-and-care homes. However, states are not required to pay twice for the same service (i.e., if the board-and-care facility provides personal care services, the beneficiary would be unlikely to demonstrate a medical need for personal care services from another provider and therefore would not be eligible for services).

11. Loretta Williams, National Association of State Units on Aging, with data from Mollica, R.L. (June 1998). *State assisted living policy: 1998.* Prepared for The Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. Washington, DC: Department of Health and Human Services.

12. Residents may be asked to leave under the following conditions: (a) their needs exceed the level of ADL services provided by the facility; (b) the resident's behavior interferes with the rights and well-being of others; (c) the resident has severe cognitive decline and is not able to respond to instructions, recognize danger, or make basic care decisions; or (d) the resident has a medical condition that is complex, unstable, or unpredictable and appropriate treatment cannot be provided.

13. Loretta Williams, National Association of State Units on Aging, with data from Mollica, R.L. (June 1998). *State assisted living policy: 1998.* Prepared for The Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. Washington, DC: Department of Health and Human Services.

14. An RCF is both (a) a setting in which personal care is provided and (b) a provider of personal care services. Arkansas allows personal care services to be provided in a person's home or other setting, such as an RCF. The state also allows RCFs to enroll in Medicaid as providers of personal care services. About 1500 Medicaid beneficiaries live in Arkansas RCFs.

15. The flexible standard used in Arkansas allows a person with mental impairments to be served in an RCF if the facility is capable of providing the necessary care and the individual's physician agrees that the setting is appropriate.

16. National Center for Assisted Living (1998). *Facts and trends: The assisted living sourcebook.* Washington, DC: Author. Some information on this report is on the website: www.ncal.org.

17. This discussion focuses on payments by family members. However, payments may also be made by a special needs trust on behalf of its named beneficiary. Many families set up such trusts for adult children with disabilities to ensure that they will be adequately taken care of throughout their lives.

Annotated Bibliography

National Association of State Units on Aging (NASUA) (1999). *Advocacy practices in assisted living: A manual for ombudsman programs.* Washington, DC: Author. (122 pages)

Developed specifically to provide technical assistance to ombudsmen, this manual contains information that will be useful to policymakers who are developing assisted living regulations or publicly funded assisted living programs. Included in the manual are an overview of assisted living trends and regulatory developments, benchmarks and a self-assessment questionnaire, an inventory of good practices and advocacy initiatives, and a list of assisted living resources. *The publication is avail-*

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CHAPTER 6

Transitioning People from Institutions to the Community[1]

The realization that many people with long-term care and support needs can thrive in integrated community settings has led to an increased commitment to transition people from ICFs/MR, nursing homes, and other long-term care institutions to the community. Since such persons have widely varying needs, the transition process presupposes that a wide range of community services and supports are in place or under development. Approaches and methods for developing the infrastructure needed to support community living are discussed in other chapters of the Primer. This chapter begins with a brief overview of how states have used Medicaid HCBS waiver programs to transition persons from ICFs/MR to the community. It then discusses (a) important factors states need to consider when planning transition programs for persons in nursing homes and (b) options for using Medicaid dollars to help cover certain transitional costs.

Introduction

Many states have been active in creating alternatives to institutional care for persons with disabilities, in order to provide services and supports in the most integrated setting appropriate to an individual's needs. The recent Supreme Court decision (Olmstead v. L.C.) gives legal weight to this policy direction.[2] State efforts to move persons out of nursing homes and other long-term care institutions into community settings can be an important part of a state's "comprehensive effectively working plan" for providing services to qualified persons in the most integrated setting, as described in HCFA guidance sent to states in January 2000. (See Appendix II for the complete text of this guidance.)

Transitioning people with disabilities from institutions to the community began in a serious way with the recognition that many persons with mental retardation and other developmental disabilities were living in large public institutions for whom institutional placement was not, in fact, appropriate. This recognition, starting in the 1970s, led to successful efforts by many states to sharply reduce the number of people living in large institutions (16 or more beds) by transitioning residents to a range of smaller, community settings. This dramatic wave of deinstitutionalization set in motion the realignment of state developmental disabilities service systems from institutionally dominated to community-centered systems.

The first section of this chapter provides a brief overview of the transition experience from ICFs/MR, distilling the lessons learned from the experience that apply to transition programs more generally. The chapter then discusses major factors states need to consider when setting up transition programs, focusing primarily on the transition of nursing home residents.

Lessons from the Transitioning Experience with ICFs/MR[3]

Medicaid funding for home and community services for persons with mental retardation and other developmental disabilities, particularly through HCBS waiver programs, has played a pivotal role in enabling a substantial majority of states to reduce (or in some cases, end completely) long-term care service delivery in large state institutions. Between 1992 and 1999, states closed more than 80 large public institutions. Eight states and the District of Columbia no longer have any large state institutions in operation. The number of individuals served in non-state ICFs/MR in these and other states has also declined, as states have shifted to using HCBS waiver programs as a means to pay for home and community services for people with developmental disabilities.

When HCBS waiver programs became available, many states (e.g., Colorado, Oregon, Vermont, New Hampshire) ceased sponsoring additional ICF/MR development altogether. For example, while closing the Laconia state institution in 1984, New Hampshire switched entirely to providing HCB waiver services to both former residents and individuals with similar needs already in the community.

The decline in ICF/MR utilization began about the same time that the number of people with developmental disabilities participating in HCBS waiver programs began to grow very rapidly. Between 1990 and 1999, the number of individuals participating in HCBS waiver programs for people with developmental disabilities grew nearly sixfold.[4] A major reason for increased use of HCBS waivers is the flexibility they afford states to offer services and supports that can accommodate individuals with a wide range of different needs in a targeted fashion without resorting to institutionalization (discussed further below).

The successful transitioning of people with developmental disabilities from institutions to the community demonstrates that HCBS services can be cost-effective substitutes for institutional services. However, the mere exchange of one source of funding for another is not the whole story. States that have been especially successful in closing large public facilities and reducing reliance on institutional and ICF/MR services overall have taken many other important steps to ensure that the needs of individuals with developmental disabilities could be met in the home and community. Many of these steps are equally applicable to beneficiaries with other disabilities being transitioned from nursing homes, state mental hospitals, and other institutions (as discussed further in the next section).

- *Development of community-based crisis and quick-response capabilities.* Maine established crisis response teams, resource coordinators, and emergency placement beds in small settings in each of its three regions as part of the initiative to close its Pineland Center facility. Pineland Center had functioned as a "crisis-placement" facility. By providing resources in the community to respond to crises and working out permanent solutions for the individual, a prime rationale for operating Pineland was eliminated. Development of a similar capability was instrumental in Vermont's closing its Brandon facility in 1992 and in Oregon's closing its Fairview facility in February 2000.

- *Being prepared to meet, in the community, the needs of individuals with multiple disabilities who need particularly intensive services.* Individuals are often portrayed as "requiring" institutional services, when they can actually remain successfully in home and community settings as long as they have relatively intensive supports. The need for such intensive services may continue indefinitely for some of these individuals. For others, a decrease in service intensity over time has been noted. States have taken steps to provide the needed services in a community setting by permitting development of HCBS waiver plans of care that allow costs above the average for institutions in that state. This allows states to decide on the plausibility of transitioning for a particular individual, without forcing individuals *de facto* to seek institutional care simply because of a cost cap.

- *Provision of higher than average funding allocations for individuals transitioning to the community.* States have found that the costs of community services for people being transitioned from

institutional services can be higher than the costs of HCB waiver services furnished to persons who have not been institutionalized. This cost differential arises in part because many institutionalized persons have multiple functional limitations that require more intensive service provision to enable them to remain in the community. But the main reason for higher costs is that such individuals tend to require more paid services simply because they frequently lack adequate networks of informal and community supports (a lack that led to their institutionalization in the first place).

Although most states accommodate transitioning individuals from institutional settings through their existing HCBS waiver programs, a limited number operate distinct HCBS waiver programs for people transitioning from institutional settings. For example, Georgia created a special HCBS waiver program for individuals who transitioned to the community during the state's closure of its 320-bed, Atlanta-based Brook Run facility in 1997. Closure of this facility resulted in cost savings that enabled Georgia to provide HCB waiver services to 180 additional individuals over and above the persons placed from institutional settings.

- *Development of family support programs.* Family support services are crucial in avoiding unnecessary placements and are used by many states to reduce reliance on institutional services. For example, Michigan reduced the number of individuals it served in large public facilities from over 6000 in 1977 to fewer than 300 in 1998—in large part by launching and sustaining family support programs.

- *Development of strong, locally centered community service systems.* In developmental disabilities services, creating a strong infrastructure at the community level has proven important in avoiding institutionalization and promoting quality service. Development of New Hampshire's locality-based, non-profit Area Agency system played a major role in facilitating closure of its Laconia facility. An important step in Michigan's transition activities was the state's strengthening of its network of local governmental Community Mental Health Service Programs. As part of its overall plan to close its Brandon facility, Vermont placed major emphasis on upgrading the skills of its community workforce and maintains a strong program of training community workers. In Kansas, the state developmental disabilities authority and the state's University Affiliated Program forged a partnership to improve the training and skills of the community workforce—a step that was instrumental in enabling the state to transition many institutional residents to the community.

- *Making large-scale investments in quality assurance and quality improvement capabilities.* Wyoming used such an investment to successfully place more than two-thirds of all the residents of its State Home and Training School in the community during the 1990s. The Division of Developmental Disabilities outstationed a cadre of field staff—initiating a comprehensive program of top-to-bottom reviews of community programs (including highlighting best practices), among other steps to improve worker training.

General Factors to Consider

Although states have much less experience transitioning people out of nursing homes than out of ICFs/MR, the earlier experiences transitioning persons with mental retardation and other developmental disabilities to the community provide valuable lessons for transitioning residents of nursing homes; and the same principles apply. The ability to achieve successful transitions from institutional to community-based living depends fundamentally on the ability to match the needs of the persons who have been living in nursing homes or other institutional environments with the availability of home and community services to meet those needs.

Persons leaving ICFs/MR have varying types and levels of need. Residents of nursing homes or other types of institutions are an even more heterogeneous group. In the same nursing home, for example, the individuals to be transitioned may

Nursing Home Transition Grants Program

To assist states in providing transition options to Medicaid beneficiaries residing in nursing homes, HHS—through the combined efforts of HCFA and ASPE—has sponsored a grant program entitled the "Nursing Home Transition Program." Its purpose is to assist current nursing home residents who choose to do so to move to home and community settings, remain there safely, and maximize their participation in community life. In 1998, grants averaging $175,000 were made to four states: Colorado, Michigan, Rhode Island, and Texas. In 1999, grants averaging $500,000 were made to four additional states: New Jersey, New Hampshire, Vermont, and Wisconsin. Each of the grantee states has implemented transition programs unique to their long-term care systems. HHS plans to continue making grants under this program for one additional year and perhaps longer. The 1999 Supreme Court decision in the Olmstead case, which requires states to develop plans for serving persons with disabilities in the community, has increased state interest in the program.

include a 75-year-old with cognitive impairment and multiple medical problems, a 45-year-old with quadriplegia, and a 25-year-old with a traumatic brain injury. They will have some needs in common. But they will also require services and supports tailored to their specific situations.

Whether a person currently resides in a nursing facility or an institutional facility the state is downsizing or closing, the steps in planning or arranging for community services are the same. In either case solid transitional planning is essential. However, additional challenges are involved when downsizing or closing an institutional facility, including maintaining the quality of facility services and worker morale, assisting workers to find other employment, addressing the "dual funding" problem (i.e., meeting the costs of maintaining facility operations while underwriting the costs of community placement), and ensuring that any special services provided in the facility will be available to individuals after they have left the institution.

Because each person has unique needs, the complexity and cost of an individual's actual transition process will vary. For this reason, it is crucial that transition programs be designed to operate with maximum flexibility. However, seven overarching steps need to be taken in setting up all transition programs, irrespective of the particular needs being addressed:

- Identifying and addressing administrative and legal barriers
- Identifying and educating residents with the desire and the potential for transition
- Involving and collaborating with key players in the disability arena
- Developing and implementing care management systems that support transition
- Identifying and addressing housing needs and payment sources
- Providing innovative and flexible funding mechanisms
- Establishing a quality assurance system that effectively balances risk and autonomy.

The remainder of this chapter discusses these activities as they relate to the transition of nursing home residents to the community. It is important to note that, although Medicaid can be used to help support many of these activities, states that have undertaken transition programs or facility closures emphasize that many costs associated with them are not covered by Medicaid. Such costs can include temporary rental assistance, furniture and clothing, and direct cash payments to individuals and families for one-time costs associated with the move.

Identifying and Addressing Administrative and Legal Barriers

The first step a state must take when considering whether to start a transition program is to analyze state Medicaid regulations and administrative policies. This is to identify any institutional bias that might make it difficult or impossible for some people living in nursing homes to be served in the community. If a state does not use the 300 percent special income rule for its HCBS waiver program, for example, some nursing home residents will

not meet the financial eligibility criteria for waiver services, even though they can be appropriately served in the community. Similarly, if Medicaid's maintenance needs allowance is too low to permit the person to cover realistic room and board costs in the community, persons living in nursing homes may be unable, simply for financial reasons, to transition to certain residential care facilities. (See Chapter 2 and Chapter 5 for in-depth discussions of such barriers.)

Identifying and Educating Residents with Desire and Potential for Transition

Medicaid flexibility gives states the means to develop home and community programs able to serve individuals with widely varying needs. States, however, face a number of challenges when developing a successful nursing home transition program. They must first establish who the target population will be: Individuals under age 60? Those with a lower level of need (versus those needing a skilled level of care)? Those who have been in a nursing home for less than a year?

Once the target population has been selected, states must then develop referral, screening, and assessment procedures to identify individuals residing in nursing homes (or other institutions) who have the desire and the potential to be transitioned successfully to the community. Some states have used the nursing home minimum data set (MDS)[5] or other screening and assessment tools as a baseline to identify potential candidates. The MDS is a core set of screening and assessment elements that forms the foundation of the comprehensive assessment for residents of long-term care facilities. By looking at factors captured in these data sets—such as medical needs, functional status, and lengths of stay—transition programs can screen for potential candidates, who can then be further assessed for transition. The MDS data also include limited information on consumer preferences, which states might find useful to review in their initial screen as well.

Using MDS data in this manner, while a useful step, is by no means sufficient. Many individuals who are good candidates for a transition program may not show up in the initial screening. Therefore, programs should not rely solely on screening tools but should work with persons and groups who know the nursing home residents, as well as the services and supports that may be available to them. Such knowledge can make them invaluable sources of information to identify appropriate candidates for the program. Nursing home ombudsmen, independent living centers, protection and advocacy organizations, and other local groups and programs can also serve as important partners in the identification process itself. A number of states use centers for independent living to assist in the identification of

Examples of State Transitioning Programs

Maine

The Alpha One Center for Independent Living in Maine instituted a state demonstration program in 1997 to move 40 adults under age 60 out of nursing homes. An independent evaluator is currently using the MDS database to profile and track individuals who leave the nursing home* and compare their characteristics with those of a similar population that remains in the nursing home.

The demonstration will track and compare functional status and quality of life changes. The results will yield a profile of required supports for successful community living. Another component of the evaluation will determine policy problems in the state that create barriers to community living.

Vermont

As part of its "One to One" transition program, Vermont has developed an assessment instrument, using a formula derived from the MDS to profile those individuals with a high potential for success in the community. Individuals are targeted for transition based on this assessment, their resource utilization groups (RUGs) classification, and other factors, including preference for community placement.

*For the individuals who leave the nursing home a modified MDS must be used, because the MDS itself is used only in an institutional context.

individuals and with the transition process. The expertise and capabilities of such community organizations should be tapped early on to assure effective collaboration. Finally, individuals for whom a successful transition plan could not be arranged during the initial attempt should be recontacted on a regular basis to discuss new options for achieving the transition goal.

Involving and Collaborating with Key Players

To develop processes and procedures that will result in the successful relocation of nursing home residents who are appropriate for home and community settings, states need to take account of the interests of multiple constituents. Nursing facilities have business interests to protect; legislators have budgets and constituents to consider; communities and community providers have capacity constraints; families and other potential caregivers may have multiple competing responsibilities.

A good way of taking these interests into account, and thus increasing a nursing home transition program's chance of success, is to develop partnerships with these key constituents. Partnerships can be with the consumer, the consumer's family and significant others, advocacy groups, Centers for Independent Living, housing authorities, other state agencies, the state legislature, and the nursing homes themselves. Some of these entities can also assist the state Medicaid program to identify the home and community service infrastructure necessary for a successful transition and help design service and support systems. It is important that the key constituent list include individuals or groups that are experienced in moving people out of nursing facilities and that they be involved at the earliest feasible point in the process.

Advocacy groups and consumers can be used to educate case managers about the consumer's needs and preferences. Nursing homes can be another valuable resource, and many welcome assistance with discharge planning. Nursing home social workers, for example, can work with residents and family members to identify necessary medical and other supports (therapists, physicians, mental health centers) and provide charts, MDS assessments, and plans of care. Nursing home staff can also help to identify candidates for transition.

Developing and Implementing Care Management Systems That Support Transition

Care management—also called case management and service coordination—is the process of using information from an assessment to develop a service plan. It involves working with a client (and family when appropriate) to identify the client's goals, preferences, and priorities, and to draw up a plan to provide the services necessary to support the client in the community. Care management also includes arranging for services, following up to ensure that services are in place, developing networks of individuals and organizations that can provide ongoing support, monitoring the client's situation on an ongoing basis, and adjusting the service package as needed.

Strong and flexible care management is central to the success of a transition program. Intensive care management systems can successfully relocate individuals into the community, often with long-term cost-savings. Medicaid allows states to pay for care management services related to transitioning an individual from an institution, as long as they do not duplicate regular discharge planning services paid for through another source. Medicaid-reimbursable care management services that help to ensure a successful transition include:

- Discussing options with the resident
- Arranging visits to potential settings
- Providing consumer education and training prior to discharge
- Arranging transportation on moving day
- Making sure the new location is appropriately furnished
- Implementing a plan of care so that services are available immediately when the beneficiary moves.

Colorado's Deinstitutionalization Pilot Project

A single entry point (SEP) program integrates multiple providers in a system that delivers long-term care services to persons with a wide range of conditions and service needs in a way that appears seamless to the clients. Colorado has expanded the role of its SEP program to provide case management services to residents in nursing facilities who can and choose to be supported in community settings. The SEP program was established in 1993 to provide integrated referral and assessment of potential clients for the state's HCBS waiver and state-only community care programs. Under the pilot program, the Colorado Department of Health Care Policy and Financing and the SEP program worked closely with nursing homes to identify potential clients. The state evaluated the transition program's cost and processes and measured client pre- and post-transition satisfaction.

The evaluation found that nursing home staff were the most frequent source of referrals and a critical resource for identifying candidates for successful transition. Factors associated with successful transitions included the availability of family support and the use of case management services. Age and functional limitations did not appear to be significant determinants of a successful transition. Most successful transitions occurred for those individuals residing in the nursing facility for less than one year. (See Chapter 9 for an in-depth discussion of SEP systems.)[6]

Three options are available for obtaining Medicaid reimbursement for care management services: case management as a waiver service, the targeted case management option, and administrative claiming.[7] (Chapter 5 describes in detail the advantages and drawbacks of each of these payment methods.)

The targeted case management option is likely to offer the most flexibility, because it can be targeted specifically to persons who are being transitioned to home and community settings. The Federal statute defines targeted case management as "services which assist an individual eligible under the plan in gaining access to needed medical, social, educational, and other services." This definition enables states to coordinate a broad range of activities and services outside the Medicaid program that are necessary for the optimal functioning of a Medicaid beneficiary. States desiring to provide these case management services under the targeted case management option may do so by amending their state plans accordingly. If a state does not plan to offer the service to all Medicaid recipients, the amendment must specify precisely the group or groups to be served.

HCFA recently enacted a policy change making it possible to obtain Medicaid funding for case management services provided during the last 180 consecutive days of a Medicaid-eligible person's institutional stay, if provided for the purpose of community transition. When the case management services are provided under the targeted case management option, states may specify a shorter time period or other conditions under which targeted case management may be provided.[8]

Case management furnished as a service under an HCBS waiver may also be provided to institutionalized persons during the last 180 consecutive days prior to discharge. However, FFP is available only on the date the person leaves the institution and is enrolled in the waiver. In these cases, the cumulative total amount paid is claimed as a special single unit of transitional case management. See Appendix II for the complete text of the recent case management policy changes.

Identifying and Addressing Housing Needs and Payment Sources

Lack of accessible, appropriate, affordable, and safe housing can be a major barrier for transition programs. Waiting lists for support services often run up against even longer waiting lists for housing. In some cases, individuals may remain in nursing homes solely because there are no other housing alternatives. In such cases nursing homes could essentially become shelters for homeless people.

Housing needs differ, depending on individual needs. States have been working with their regional and local housing authorities with varying degrees of success to come up with creative solutions to housing problems. Stronger partnerships between

health and housing authorities at both the state and Federal levels are often cited as the most important need in the search for comprehensive approaches to maintaining people in the community.

Many states have chosen to offer assisted living, generally to persons age 65 and older. This term refers to a combination of housing and services in a residential environment that serves to maximize the autonomy and functioning of residents, many of whom require assistance to pursue their day-to-day activities. States do this by combining housing dollars from various sources (e.g., state, Federal, and private funds) with service dollars from Medicaid's HCBS waiver program or, to a lesser extent, through the Medicaid state plan personal care option.

In FY 2000, the U.S. Department of Housing and Urban Development (HUD) was authorized to offer funding to develop and/or convert Section 202 housing stock to assisted living facilities. HUD will provide subsidies to providers based on an approved state or local plan to furnish appropriate supportive services. Some analysts believe that conversion of Section 202 housing to assisted living has the potential to support a consumer-focused model, by organizing services around the resident rather than a facility. Others argue the reverse—that these opportunities can limit individual autonomy by tying housing to services. These observers would rather see housing and service dollars following people to their settings of choice. In any case, pairing HUD and Medicaid dollars to provide assisted living does provide certain low-income persons—particularly frail elderly persons—with an affordable alternative to nursing homes. (See Chapter 5 for a detailed discussion of factors to consider when using Medicaid to cover assisted living for older persons.)

Assessments for accessibility

Environmental modifications are often crucial to a state's ability to serve an individual in the community. FFP may be available for the costs of assessing accessibility and the need for modifications in a person's home or vehicle in three ways.

First, FFP may be claimed at the administrative rate for assessments to determine whether the person's home or vehicle requires modifications to ensure the health and welfare of an HCBS waiver participant. (Assessment costs incurred to determine whether an individual's needs can be met under an HCBS waiver may qualify for FFP regardless of whether or not the person is eventually served under the waiver.)

Second, the cost of environmental assessment may be included in the cost of environmental modifications under an HCBS waiver. Third, the assessment may be performed by another service provider, such as a home health agency or an occupational therapist. FFP is available at the service match rate when these providers perform assessment in addition to their other duties. (See Appendix II for the complete text of HCFA's guidance on FFP for assessing accessibility.)

Providing Innovative and Flexible Funding Mechanisms

One potential barrier to a successful transition program is inflexible funding streams. Even when home and community services are less expensive than nursing home care, it is often difficult for an individual to choose these services due to either one-time costs associated with transitioning or lack of coordinated funding. Typical one-time costs associated with moving into a community home include: first and last month's rent, security deposit, telephone deposit and installation fees, bed, linens and towels, and cooking utensils. Such costs will vary due to geographic differences in rents. One estimate puts them in the range of $1800.[9]

Transition programs need flexible funding arrangements that permit funding to shift from institutional care to home and community services by following individuals to the service setting of their choice. Oregon's regulations, for example, use state-only dollars to provide a special needs allowance for beneficiaries who are being diverted from entering or relocated from a nursing facility. Under this provision, payment for one-time needs can be authorized for household equipment and furniture, minor home repairs, rent or utility deposits, moving costs, property taxes, and transportation costs. Such special needs payments can be authorized only after all other sources of sup-

port (e.g., family, neighbors, friends, United Way, Salvation Army) have been utilized.

Establishing a Quality Assurance System That Effectively Balances Risk and Autonomy

Community living presents a different set of risks from those associated with living in an institution. Transition programs need to have a quality assurance (QA) system that monitors and helps ensure service quality and client safety, particularly for the first few months in the community setting. At the same time, however, such a QA system must respect individuals' autonomy by acknowledging their choice to assume risk. The balance is delicate and can be hard to achieve. Programs that use a consumer-directed model allow individuals to assume more individual responsibility and accountability in a residential care setting than does an agency-directed model (see Chapter 7 for a full discussion).

The assurances HCFA requires from states for approval of HCB waiver services include "necessary safeguards" to protect the "health and welfare" of persons receiving services in the community. Since HCBS waiver programs serve a diverse array of target populations, no one-size-fits-all application of these QA requirements can be prescribed. (Further discussion of quality assurance and improvement is outside the scope of this Primer.)

Obstacles to Look For

Although transitioning people out of institutions can save money over the long term, the process can incur major up-front costs that are not reimbursable by Medicaid. Given this, states may want to consider strategies that will divert people from entering institutions, particularly nursing homes, in the first place and ensure a quick return to the community if placement is unavoidable.

The ICFs/MR experience illustrates that the best transition program is one that makes sure that very few people will need to be transitioned. In the mental retardation and developmental disabilities field, this is known as the front door/back door connection. Little progress with transitioning can be made so long as the front door to the institution remains open; intervention before inappropriate placement (i.e., diversion) is easier than intervention after placement.

Hawaii's System for Transitioning People with Serious Mental Illness to the Community

In response to a Federal court consent decree, the Hawaii Department of Health, Adult Mental Health Division developed a program to identify persons residing in Hawaii State Hospitals who could more appropriately be served in the community. Each patient was assessed by clinical staff at the hospital and a discharge plan was developed for those so identified. These discharge plans were also used to develop a community service plan, which includes a variety of clinical, residential, and support services. State funds were used to develop new services, including case management, assertive community treatment, and housing. Medicaid funding pays for many of the services, but not for housing. As a result of this program, between 1997 and 1999 the state experienced an approximately 34 percent increase in discharges from the State Hospital.

Many persons who can be served successfully in the community are admitted to nursing homes from hospitals. In some cases, this may be because hospital social work staff, under pressure to discharge people quickly, may not be aware of or have the time to explore community options. As part of their approaches to expanding community placement strategies, Colorado and Texas have developed procedures specifically to divert appropriate individuals from nursing home placement after a hospital stay.[10]

Colorado's program serves as an example. Colorado developed its diversion program to address state-specific barriers to community placement. These included: (a) long delays in processing Medicaid eligibility prior to discharge from hospitals; (b) lack of general awareness of community options on the part of discharge planners and consumers; and (c) inadequate personal resources to stay in the community.

To respond to the first of these obstacles, Colorado instituted a hospital-based care management program that dispatches a special case manager to a pilot site hospital (both inpatient and outpatient settings) solely for the purpose of ensuring an expedited Medicaid eligibility determination process. The program is now in the process of developing a screening instrument to identify persons at risk of nursing facility placement, for use by hospital discharge planners and case managers. (Chapter 9 discusses ways to expedite eligibility determinations.)

Endnotes

1. The primary contributors to this chapter are Gavin Kennedy, Gary Smith, and Janet O'Keeffe.

2. The Court affirmed the rights of qualified individuals with disabilities to receive services in the most integrated settings appropriate to their needs. Under the Court's decision, states are required in specific circumstances to provide community services for persons with disabilities who would otherwise be entitled to institutional services. See Introduction for more information on the Olmstead decision.

3. The information in this section is drawn from the following sources: Prouty, R., and Lakin, K.C. (2000). *Residential services for persons with developmental disabilities: Status and trends through 1999.* Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living. Smith, G. (2000). *Medicaid long term services for people with developmental disabilities.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

4. Smith, G. (2000). *Medicaid long term services for people with developmental disabilities.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

5. Federal law mandates use of the MDS for all residents of facilities that are certified to participate in Medicare or Medicaid SNFs and hospital-based skilled nursing units. These facilities are required to conduct comprehensive, accurate, standardized, and reproducible assessments of each resident's functional capacity using a Resident Assessment Instrument (RAI). The RAI consists of the MDS, Resident Assessment Protocols (RAPs), and Triggers.

6. Bell, J. (1998). *The deinstitutionalization pilot project: Evaluation and status report.* Denver: Colorado Department of Health Care Policy and Financing.

7. Case management can also be provided as an integral and inseparable part of another covered service.

8. Medicaid funding is not available for targeted case management services provided to persons who are receiving services in an institution for mental disease (IMD), except for services provided to elderly individuals and children under the age of 21 who are receiving inpatient services.

9. Mike Oxford, Executive Director, Topeka Independent Living Resource Center, Topeka, Kansas. Personal communication. May 23, 2000.

10. The states funded these programs in part from a grant through the Nursing Home Transition Program highlighted earlier in the chapter.

Annotated Bibliography

O'Day, B. (1999). *Independence and transition to community living: The role of the independent living center.* Houston, TX: Independent Living Research Utilization (ILRU) Research and Training Center on Independent Living at The Institute of Rehabilitation and Research (TIRR). (101 pages)

This report discusses the need for community-based and transitional services. It discusses barriers to independent living, highlights centers with innovative programs, and offers policy recommendations. It also provides a brief overview of court cases and legislation affecting people with disabilities (including the Omnibus Budget Reconciliation Act of 1987, and the Americans with Disabilities Act). There is a discussion of ILRU's project to examine "state of the art" transitional services to support community entry for people with disabilities. The project offers information and technical assistance for providing transitional services effectively. Contact information for consultants is also provided. *This article may be obtained free of charge on-line at http://www.ilru.org/NewsStand/oday, or contact: ILRU Program, 2323 South Shepherd, Suite 1000, Houston, TX 77019, phone: (713) 520-0232 [voice], (713) 520-5136 [TDD], (713)-520-5785 [fax].*

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CHAPTER 7

Consumer-Directed Home and Community Services[1]

Individuals with disabilities want and expect to control their own lives. This includes having a direct say about the home and community services and supports they receive through the Medicaid program. Increasingly, states are implementing consumer-directed models of home and community service delivery that provide options for individuals and their families to direct and manage their own services and supports. Consumer-directed services are an alternative to traditional agency-based service delivery models and can be offered alongside traditional models. This chapter describes the main features of consumer-directed home and community services, and the interplay between consumer-directed options and Medicaid policy. It focuses on services furnished through the Medicaid personal care services state plan benefit and the 1915(c) HCBS waiver authority. The chapter includes examples of several states' consumer-directed models.

Introduction

Home and community service programs are frequently criticized for operating under a so-called *medical* or *professionally managed model*, under which professionals decide what services will be provided and how, when, and by whom. Many individuals feel these models do not meet their needs. Consumer-directed (CD) services first emerged in personal assistance services as an alternative to the individual's being limited to obtaining attendant services only from employees of professional agencies or from specific agencies licensed, certified, or otherwise authorized under a public program. A CD service model: (a) gives beneficiaries (and/or their families) the authority to develop service and support plans that reflect their wishes and preferences, and (b) gives them the choice of hiring/firing, scheduling, training, supervising, and purchasing services and, within the boundaries established by law, directing the payment of personal assistance workers and other service and support providers.[2]

Since its inception, the Medicaid program has been premised on the statutory principle that each beneficiary of service has the right to choose his or her own health care provider.[3] Over the past few years, as Medicaid's role in furnishing home and community long-term services has expanded, consumer direction and self-management of services have emerged as critical elements in enabling people with all types of disabilities to direct and manage their own services and supports. CD models are being increasingly used in the provision of Medicaid home and community long-term services. And state-initiated approaches, aimed at increasing the individual's choice and control with respect to Medicaid services and supports, continue to generate much interest throughout the country. These approaches include the Self-Determination for People with Developmental Disabilities, Cash and Counseling, and Independent Choices initiatives.

Personal Assistance Service Delivery Models: Two Ends of a Continuum

Two examples of state personal assistance service delivery models illustrate the ends of a continuum, with many different models falling between them.

Consumer-Directed Personal Assistance Service Delivery Models

Consumer-directed (CD) models enable individuals to hire and fire, schedule, train, and supervise their own personal assistance providers (usually termed aides, attendants, or workers), with few restrictions on who can be hired. A CD model typically puts all responsibility for recruiting and selecting an aide on the individual (or family) and usually assigns the individual responsibility for ensuring that the aide(s) know how to do the work and for training the worker(s) if necessary. Public programs occasionally assist in identifying potential candidates, by providing a worker registry or helping the consumer perform a criminal background check. A CD model may also make publicly funded consumer and worker training available. Although the number of hours of personal assistance authorized for the individual in any particular month might be limited, individuals have the authority to schedule when the assistance will be provided, and both consumer and worker are free to negotiate schedule changes. A full-fledged CD model also involves individuals in the process of paying their workers (e.g., by signing timesheets), even though the actual wages are paid from public funds.

Professionally Managed Service Delivery Models

Professionally managed models require that aides be employees of authorized home health or home care agencies. Agencies hire workers according to agency criteria and assign employees to serve particular consumers. Choice among agencies is limited by the number of authorized providers in the area where the consumer lives. Frequently, there is only one such agency. Consumer choice of agency aides is generally restricted to "veto" power—although dissatisfied consumers may ask to have a worker replaced, and the agency will generally honor such a request as long as another worker is available. Agencies may shift employees from one individual to another—although they typically try to honor individuals' requests to have the same workers on a regular basis. Agencies also schedule the aides' work hours and may determine whether or to what extent they will accommodate consumer scheduling preferences. Agencies also conduct aide training and supervision. Some public programs mandate minimum training and supervision requirements. Others leave it up to the agencies or state licensing laws to set such requirements. Since training, certification, and professional supervision requirements can affect service costs, the added value of such requirements needs to be carefully assessed.

This evolving concept, referred to alternatively as self-determination, consumer-directed services, and participant-driven supports, is having a significant impact on the development and implementation of home and community services and supports for people with developmental disabilities, physical disabilities, and serious mental illness, as well as elderly individuals who have all types of disabilities. Regardless of the nomenclature used, implementing the concepts of consumer direction or self determination enables states to offer individuals the opportunity, support, and authority to direct the services they receive.

The principles of consumer direction encompass the goal of affording consumers the authority and tools to craft their own services plans, with the freedom to use both traditional and nontraditional providers and to direct and manage their services and supports. In the CD model, the Medicaid beneficiary is his or her own "care/service manager" (with the assistance, at the discretion of the individual, of friends and family members). Individuals still have access to advice and professional expertise. However, this assistance takes the form of educating and supporting consumers to do their own care planning and service coordination, rather than doing such tasks for them.[4]

Assistance for individuals in managing and directing their home and community services and supports can be provided by paid professionals who are variously termed *service coordinators, support brokers, personal agents, counselors,* or *consultants.* This new terminology underscores the philosophical differences between professional case/

care management as typically practiced and supporting individuals in directing and managing their own services.[5]

The principles of CD services are also reshaping the provision of home and community services for individuals with cognitive disabilities. For example, *self-determination* for people with developmental disabilities embraces the principle that individuals should have the authority to select, direct, and manage their services. In self-determination, individuals may enlist and invite friends and family members (in the form of a "circle of support") to assist them in directing and managing services. The person's legal representative or a surrogate decision maker may also assist and advise the individual and perform some service management tasks.

Until recently, CD models have been seen as appropriate mainly for younger adults with physical disabilities, because these models originated in the independent living movement initiated by this group. However, research suggests that consumers of all ages and their families would like to be more actively involved in planning and directing the services they receive.[6] Not surprisingly, state policymakers, program administrators, and consumer constituency groups are increasingly recognizing CD principles as having broad applicability across the full spectrum of individuals who need home and community services, including elderly persons and persons with cognitive disabilities (e.g., persons who have a severe mental illness, a developmental disability, or dementia). CD service models are seen as an important means to improve consumer satisfaction with services, involve individuals and families in improving the quality of services, and promote cost-effective service delivery.

Limits on the permissible scope of consumer direction are necessary, of course, when services are financed with public funds. In many CD service models, limitations on consumer choice and control are delineated—with a clear distinction between the gate-keeping and monitoring functions necessary to maintain fiscal control and public accountability, on the one hand, and the CD features of the model, on the other.

It is also important to note that CD models can (and usually do) operate side by side with professionally managed service delivery models. Individuals and families differ in the extent to which they wish to take on full management of their services. Some people want to exercise a high level of control, while others prefer to have services and supports managed by a provider agency—so long as the agency is responsive to their needs and preferences. Consequently, neither individuals nor states face an *either/or* proposition. What is important is that home and community services afford a full range of options for consumer direction.

There is little doubt that CD service principles will fundamentally reshape the future provision of home and community services for people with all types of disabilities.

Consumer Direction and Medicaid

As the role of the Medicaid program in underwriting home and community services has expanded, questions have arisen concerning the compatibility of CD models and principles with Medicaid requirements. Part of the mythology that surrounds the Medicaid program is that Federal rules dictate the use of a medical or professionally directed model and that, therefore, the program cannot accommodate or might actually be hostile to CD models in the home and community services arena. This is not the case.

For example, Medicaid can cover long-term services provided by in-home aides or attendants in three ways—under the mandatory home health state plan benefit, the personal care services optional state plan benefit, and 1915(c) home and community-based services waiver programs. Of these, only coverage under the mandatory home health benefit limits the provision of services to Medicare/Medicaid certified home health agencies that meet Federal "conditions of participation"—conditions that limit the extent to which individuals can direct their own services. Only a few states (e.g., Colorado, Delaware) finance even a small amount of long-term home attendant care under the home health benefit. In no state, however, is the home health benefit the only or even

the primary mechanism for financing personal assistance services. Most states offer Medicaid personal assistance services either through the personal care services optional state plan benefit and/or under one or more 1915(c) waivers. Neither of these financing mechanisms requires states to adopt a medical or professional model of service delivery.

CD models for personal assistance services first took hold in various state non-Medicaid personal assistance programs, most notably the California In-Home Supportive Services (IHSS) program. These programs grew out of the independent living movement for people with disabilities during the 1960s and 1970s. Since then, and at a quickening pace in recent years, the essential features of CD services have been incorporated in many Medicaid home and community service programs:

- Although many states require that personal care services be provided by state licensed home care agencies (though not necessarily by Medicare/Medicaid certified home health agencies), other states allow CD organizations, such as independent living centers, to be personal care services providers. Many states also make it possible for beneficiaries to hire "individual providers" of attendant services, either directly or through CD provider organizations.

- Several states (most notably Oklahoma and Michigan) have covered Medicaid services provided by consumer-hired attendants under the personal care services optional state plan benefit for more than 20 years.

- New York's personal care attendant program, which began in the mid-1970s, relied exclusively on consumer-hired attendants for the first several years. It then shifted to a model in which the great majority of personal care services were provided by licensed home care agencies. Since 1995, however, New York state law has required that all local Social Services Districts (which serve as the local administrators for the Medicaid personal care attendant program) provide a CD service option to any Medicaid consumer of attendant care who wishes to self-direct.

- Medicaid-funded CD personal attendant services are available on a very large scale in California, where the IHSS program serves close to 200,000 consumers annually, including 135,000 Medicaid-eligible consumers whose services are funded via the Medicaid personal care services optional state plan benefit. Over 90 percent of IHSS consumers receive attendant care from aides whom they hire directly. Use of Medicaid funding to cover personal attendant services provided to Medicaid-eligible IHSS consumers began in 1994.[7]

- In providing services for people with developmental disabilities, several states (e.g., Minnesota, New Hampshire, New York, Utah, and Wisconsin among others) have successfully modified their HCBS waiver programs to add CD service options as part of broader initiatives to promote self-determination.

A recent study found that half of the personal care optional state plan benefit programs in 26 states and 60 percent of the HCBS waiver programs in 45 states provided for CD personal care attendants.[8] In several states, one of the conditions imposed on people receiving Medicaid personal care services is that the individual (or a family member/surrogate) be capable of directing and supervising his or her support workers.

The fact that CD principles have already been embraced by many states in provision of Medicaid home and community services furnishes the most direct evidence that Federal policy does not dictate the exclusive use of professionally directed service delivery models.

In May 1996, HHS Secretary Donna Shalala reaffirmed the department's support for home and community services and the principle of "offering consumers the maximum amount of choice, control, and flexibility in how those services are organized and delivered."[9] The Secretary listed a number of specific principles HHS supported, including several focusing on consumer direction:

- Promoting greater control for consumers to select, manage, and direct their own personal attendant services

CD Services for People with Developmental Disabilities

Self-determination is the ability of individuals to make the choices that allow them to exercise control over their own lives, to achieve the goals to which they aspire and to acquire the skills and resources necessary to participate fully and meaningfully in society (Oregon Institute on Disability and Development).

CD services for people with developmental disabilities are taking hold as an outgrowth of the self-determination movement.[10] Self-determination features the use of person-centered planning and individual budgets as tools that enable individuals to identify and direct their own services. Self-determination has also adopted some of the mechanisms (e.g., use of intermediaries) that were pioneered in CD personal assistance programs.

Individuals with developmental disabilities who participate in HCBS waiver programs frequently receive additional discrete services and supports (e.g., employment supports and habilitation) as well as personal assistance. Thus, CD models for people with developmental disabilities (in contrast to CD personal assistance models) often span multiple services.

Beginning almost two decades ago, many states clearly established that they would use person-centered planning methods in identifying which supports would be offered to meet the needs of waiver program participants. Wisconsin's HCBS waiver program for people with developmental disabilities has used person-centered planning to develop waiver plans of care since the program began in 1984.

In contrast to more traditional approaches, person-centered planning emphasizes individuals' expression of their life goals and the crafting of strategies to achieve these goals with a combination of paid and unpaid supports. In person-centered planning, the individual (along with other persons the individual chooses to invite to assist in developing the plan) is in charge of the support planning process. Several states (e.g., Michigan, Hawaii, and California) have changed their laws and policies to embrace person-centered planning as their principal tool in developing support strategies for people with developmental disabilities.

- Experimenting with alternative ways to pay for services (e.g., vouchers and direct cash payments) in addition to the traditional methods
- Encouraging use of alternative providers, including informal providers such as friends and relatives
- Developing new ways to help consumers train and manage their attendants.

In 1999, HCFA revised its guidelines concerning provision of personal care services under the Medicaid state plan, to clearly establish that states may employ CD models to provide these services. Section 4480 of the State Medicaid Manual states:

> "A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to personal preferences, supervise and direct the provision of personal care services and, if necessary, fire the provider. The state Medicaid Agency maintains responsibility for ensuring the provider meets state provider qualifications...and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the state may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving services." (See Appendix II for the complete text of this guidance.)

While these guidelines are specific to personal care/personal assistance services furnished as a Medicaid state plan benefit, they apply equally to similar services and supports that states furnish through HCBS waiver programs (under which states in any case have the latitude to offer services on a less restrictive basis than under their state

plans). The importance of these HCFA guidelines is that they clearly sanction the CD philosophy that has been in operation at the state level for many years—arrangements that also enable family members and other individuals to direct services (when the individual might not be able to do so by virtue of cognitive impairment, illness, or another reason).

While HCFA sanctions and supports CD models, Medicaid policy is still evolving to accommodate the principles (and some of the operating features) of CD service models. CD models depart from traditional Medicaid service delivery practices, featuring use of alternative administrative mechanisms and altering program/provider/beneficiary relationships. The basic framework of existing Medicaid policy is the product of a much earlier era. As such, it did not anticipate service models in which the consumer exercises considerable control. HCFA is taking several steps to clarify and update its program guidelines to accommodate CD service models, and has been working with states interested in offering CD services. Federal Medicaid policy poses certain issues with respect to the feasibility of operating some types of CD models (e.g., models based on "cashing out" Medicaid benefits). But it does not stand in opposition to CD models.

Several topics related to the interplay between Medicaid policy and CD services merit extended discussion, because they are often a source of uncertainty concerning the feasibility of furnishing Medicaid home and community services in a fashion consistent and compatible with CD principles. These topics include (a) service planning and authorization; (b) furnishing assistance to individuals in directing and managing their supports; (c) consumer choice and provider qualifications; and (d) performance of skilled nursing tasks. Each is discussed in turn.

Service Planning and Authorization

CD service models depart from professionally directed service models by affirming that the individual plays a very active and decisive role in service planning. Planning goals are identified in collaboration with the individual and specify in detail the services the person will receive. While person-centered planning methods have been associated mainly with services for persons with developmental disabilities, they are employed in home and community services for individuals with other disabilities as well.

With the exception of home health services, Medicaid policy does not dictate that home and community service plans must be prepared by medical, clinical, or case management professionals. Whether for HCB waiver services authorized in a plan of care or personal care/personal assistance services under the optional state plan benefit, states have considerable latitude with regard to empowering the individual to manage and direct authorized services. In personal assistance services, for example, many states already provide that individuals may directly schedule when authorized hours of services are to be furnished and alter the schedule to meet their needs. In an HCBS waiver program, states also may permit the individual to manage the schedule of service provision or alter the mix of authorized services to meet their changing needs without having to develop an entirely new plan of care. However, the statutory requirement that "services be provided pursuant to a written plan of care" must continue to be met. Specific provisions include the following:

> ***HCBS waiver program.*** Federal law requires that the services individuals receive through an HCBS waiver program be provided pursuant to a plan of care.[11] Neither Federal law nor regulations specify the process by which this plan of care is developed. The plan of care must meet the requirements spelled out in the State Medicaid Manual[12] and any other requirements included in the state's approved HCBS waiver request. The plan of care must also be consistent with the requirement that the state assure the health and welfare of the individual.[13] Person-centered or other alternative planning processes that yield a plan of care that meets these fundamental requirements are entirely acceptable with respect to the provision of HCB waiver services.

Personal care/personal assistance services. At one time, Federal regulations dictated that optional state plan benefit personal care/personal assistance services be authorized by a physician and supervised by nursing personnel. In the Omnibus Reconciliation Act of 1993, states were specifically authorized to use alternative service authorization methods, including those that do not require the involvement of medical personnel.[14] This change enables states to adopt alternative approaches to service planning for this benefit.

Furnishing Assistance to Individuals in Managing and Directing Services

Although CD service models are based on the individual's playing a direct role in identifying, arranging, managing, and directing his or her services and supports, a state may provide assistance to individuals in carrying out that role. Such assistance may include: (a) providing individuals with assistance, training, and education in supervising workers; (b) making the services of intermediary service organizations available (as described below); and (c) furnishing more intensive assistance in the form of "support brokers" or "personal agents."

With respect to intermediary services, a number of management activities may be considered necessary and reimbursable. These include assisting individuals with disabilities to manage workers who furnish services to them. Such activities are all part of a self-directed service delivery approach. Medicaid payment can be made for activities, furnished by an intermediary organization, that are set forth in an approved waiver, when they meet applicable Federal criteria.

HCFA is in the process of working with the states and other stakeholders to clarify the various payment options available to states to ensure fiscal accountability and the presence of an audit trail, and to ensure that these activities are supported and reimbursed in an appropriate manner. In CD personal assistance services and self-determination, consumer-selected intermediaries have emerged that provide a valuable service by assisting the beneficiary with, or relieving him or her entirely of, some of the burdens that arise when the consumer performs employment-related tasks. The establishment and use of consumer-selected intermediary organizations support the direction and management of services by beneficiaries and also facilitate Medicaid program administration. States have the flexibility to structure provider agreements, and can define provider qualifications for self-directed services broadly, to support individual choice and direction.

With respect to the use of support brokers or personal agents, questions often arise concerning the interplay between this type of assistance and case management services, since Medicaid policy prohibits the provision of duplicate services to an individual. In particular, does furnishing one type of service preclude provision of the other service concurrently? So long as the assistance furnished to an individual to help manage his or her services is distinct from the activities a case manager performs on the individual's behalf, both types of services may be furnished to an individual. For example, in the Pennsylvania Person/Family-Directed Supports HCBS waiver program for persons with mental retardation, HCFA approved the state's offering "personal support" services (which include support broker/personal agent-like activities) based on the state's demonstration that such services were different from, and did not duplicate, the case management services also furnished to waiver participants.

Consumer Choice and Provider Qualifications

The Medicaid "freedom of choice" principle establishes that individuals can select the provider(s) of the services for which they are eligible.[15] This principle applies to all Medicaid-funded services, including services furnished through HCBS waiver programs. The Social Security Act allows the Secretary to grant states a waiver of freedom of choice only in certain circumstances, and then only when other safeguards are in effect that preserve consumer choice.

Free choice of provider is absolutely necessary for individuals to be in the position of directing their

own supports. The Medicaid freedom of choice principle extends only to "qualified" providers, however. And therein lies the source of limitations and/or complications when seeking to implement CD service programs. Federal Medicaid policy (whether under the Medicaid state plan or through an HCBS waiver program) requires that a state spell out the qualifications required of providers and agree to contract only with providers who meet such qualifications.[16]

These qualifications must be reasonable (i.e., must relate to provision of the service), and they also must comport with state law. Within these stipulations, states have considerable latitude in establishing the qualifications required of providers of home and community services. The broader these requirements, the more people will qualify to provide services. Some states, however, limit provision of personal care services to entities that are licensed as "home care" or "home health agencies" or have been licensed to furnish community developmental disability services. This means, in turn, that individuals who provide home and community services and supports must be employees of such provider organizations. When provider qualifications are expressed in this fashion, they can pose barriers to promoting CD services. Some of these barriers arise from provisions of state Nurse Practice Acts, which frequently dictate that even non-health care related personal assistance be provided under the supervision of a nurse (and, not atypically, a nurse who him- or herself must be an employee of a licensed home care or home health agency).[17] (This topic is addressed in more detail below.)

Thus, a central task for states interested in promoting CD services is a thorough assessment of their provider qualifications to determine whether they need to broaden the types of organizations and individuals who may qualify as providers. It is not necessary to limit providers to traditional service agencies. Provider qualifications may be expressed solely with respect to the competencies and skills individual workers must possess. Many types of Medicaid HCB services may be furnished by friends, neighbors, and family members (other than spouses and parents of minor children). In various states (e.g., Kansas), families are encouraged to seek out individuals in their communities who can provide some types of HCB services for people with developmental disabilities.

Consumer-directed models are choice-based models. The problem often is that the choices are too few (there may be only one or two "qualified agencies" that serve the area where the individual lives). Revamping provider qualifications can be vital not only in promoting CD services but also in expanding the potential sources of home and community services for people with disabilities more generally.

Performance of Skilled Nursing Tasks

Although CD service models reject the medical model, avoiding it can be complicated by state laws and regulations concerning the performance of "skilled nursing tasks." Federal Medicaid policy does not dictate who must perform skilled nursing tasks, merely that such tasks be performed in compliance with applicable state laws. But state laws and regulations often dictate that such tasks be performed by or closely supervised by a licensed nurse—thereby creating obstacles to CD service models with a seeming bias in favor of agency provision of services. Liability concerns sometimes also stand in the way of promoting CD service models.

To avoid duplicating home health benefits already available through Medicare or under the Medicaid state plan, many HCBS waiver programs do not offer skilled nursing or rehabilitative therapies. However, "skilled" paraprofessional services still may be provided by personal care attendants under HCBS waivers or under the personal care services optional state plan benefit—as long as the services are provided in conformity with the state's Nurse Practice Act. A 1999 HCFA State Medicaid Manual transmittal specifically states:

> "Services such as those delegated by nurses or physicians to personal care attendants may be provided so long as the delegation is in keeping with state law or regulation and the services fit within the personal care services benefit covered under a state's plan. Services such as assistance

with medications would be allowed if they are permissible in states' Nurse Practice Acts, although states need to ensure that the personal care assistant is properly trained to provide medication administration and/or management.[18]

This policy and its applicability to optional state plan personal care services and HCBS waiver programs were reaffirmed in a July 2000 letter from HCFA to state Medicaid directors.[19]

Most states restrict performance of medical or "paramedical" tasks to licensed medical professionals, although most physician and nurse licensing laws do permit individuals to be trained to perform skilled services for themselves or for close family members. Federal Medicaid law references state licensing laws by requiring that state Medicaid plans comply with all "applicable" state and local statutes. Under the Nurse Practice Acts in most states, tasks such as catheterization, injections, and administering medications are considered invasive procedures, which may be performed only by paid personnel who are registered nurses or persons supervised by registered nurses.

Issues related to the performance of skilled nursing tasks stem from concerns about quality assurance and liability. Quality assurance is an important component of Medicaid home and community services but is beyond the scope of this Primer. The rest of this discussion focuses on liability issues.

In October 1997, the National Institute on Consumer-Directed Long-Term Care Services held a national conference to explore the pros and cons of various modifications to Nurse Practice Act statutes that relaxed restrictions on the performance of paraprofessional tasks by nonlicensed personnel.[20] One motivation for the conference was to find ways to reduce the very high costs of RN visits to the home—in some cases several times a day—without compromising the need for accountability. The conference focused on alternative approaches that had been implemented in several states. Two contrasting models emerged: *delegation* and *exemption*.

Delegation. Registered nurses (RNs) may delegate tasks considered within the scope of the nursing profession to individuals they train and supervise. Accountability for delegated tasks remains with the RN. Some Nurse Practice Acts hold nurse delegators strictly accountable for any negative outcomes of tasks performed by their delegates. Tort law refers to this kind of liability as *vicarious liability*, derived primarily from the legal doctrine of *respondeat superior*, literally meaning "let the master answer." Under this doctrine, the nurse is held liable for any injury caused by the negligence or wrongdoing of his or her delegates. Other Nurse Practice Acts only hold the RN *directly liable* in a legal sense for the delegation process. Thus, if the worker to whom a task was delegated negligently harms the consumer, the RN would be liable only if it were established that his or her assessment, training, supervision, or other aspect of the *delegating process* were performed negligently.

Obviously, whether a state's Nurse Practice Act appears to hold a nurse delegator vicariously liable for negligence by the individual to whom tasks were delegated or only directly liable for the delegating process has major implications for whether or not nurses, as a practical matter, will be willing to delegate. (Most Nurse Practice Acts do not differentiate between delegation in an inpatient setting, such as a hospital or nursing home, as contrasted with nurse delegation in the home care setting.)

Exemption. The exemption alternative provides a way to deal with liability concerns. The primary difference between specific delegation and exemption is in where the authority and responsibility associated with each lie. In an exemption approach, it is the implicit right of the person needing a service to manage provision of a service, as he or she prefers, as long as the provider of service falls within the exempt category. Nurses are not held responsible for provision of the service. But they may continue to play an important role in educating the provider and the consumer of the service—as well as, in some instances, monitoring the service over time.

Several states have dealt with the delegation issue by providing specific "exemptions" in their Nurse Practice Acts for consumer-hired personal attendants in Medicaid-funded programs. (Most if not all states exempt family members.) This approach

not only protects nurses, who may assist in training consumer-hired aides without assuming liability for the aides' subsequent actions. It also has the advantage of clearly protecting the state against liability for any harm that might be caused by consumer-directed aides. The exemption provision in New York's Nurse Practice Act for consumer-hired attendants, for example, contains language specifically stating that the exemption applies to the Medicaid-funded CD personal care attendant program. Kansas also exempts its Medicaid HCBS waiver program, which serves self-directed persons with disabilities, from the provisions of its Nurse Practice Act. California users of personal assistance services are allowed to take responsibility for such tasks as long as a physician authorizes them to do so.

As Medicaid home and community services expand, states increasingly will need to grapple with the interplay between their Nurse Practice Acts and affording individuals opportunities to select community workers to perform some nursing tasks, particularly when such tasks need to be performed on a daily or more frequent basis. At the same time, states will also have to grapple with striking the right balance between safety and autonomy for clients in CD programs.

Endnotes

1. The primary contributors to this chapter are Gary Smith, Pamela Doty, and Janet O'Keeffe.

2. For a more detailed description of CD service models, see Doty, P., Benjamin, A.E., Matthias, R.E., and Franke, T. (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery—Non-technical summary report.* Washington, DC: Department of Health and Human Services.

3. Section 1902(a)(23) of the Social Security Act

4. In Kansas, peers (persons with disabilities) are the professional counselors for the beneficiaries served by the physical disability waiver program for persons under age 65.

5. Case management is not a preferred term in CD service models, although it is still used. See, for example, Cooper, R. (2000). From management to support: No more "business as usual." *Impact, Vol.12*(4). University of Minnesota: Institute on Community Integration, Research and Training Center on Community Living.

6. See, for example: Simon-Rusinowitz, L., Mahoney, K.J., Desmond, S.M., Shoop, D.M., Squillace, M.R., and Fay, R.A. (1997). Determining consumers' preference for a cash option: Arkansas telephone survey results. *Health Care Financing Review, Vol.19*(2), 73–96. Mahoney, K.J., Simon-Rusinowitz, L., Desmond, S.M., Shoop, D.M., Squillace, M.R., and Fay, R.A. (Winter 1998). Determining consumers' preferences for a cash option: New York telephone survey findings. *American Rehabilitation, Vol.24*(4), 24–36. Eustis, N.N., and Fischer, L.R. (1992). Common needs, different solutions? Younger and older home care clients. *Generations, Vol.16*, 17-23. Doty, P., Kasper, J., and Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. *Milbank Quarterly, Vol.74*(3), 377–409. Doty, P., Benjamin, A.E., Matthias, R.E., and Franke, T. (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery—non-technical summary report.* Washington, DC: Department of Health and Human Services.

7. For nearly two decades, IHSS was funded almost entirely with state dollars (with some Federal funding via the Social Services Block Grant). This was largely because of concerns that accessing Medicaid funds would impose a "medical model" on service delivery—in view of the Federal requirements that Medicaid-funded personal care services had to be "prescribed by a physician" and "supervised by a registered nurse." Congress eliminated these requirements effective October 1, 1994, although states may continue to apply them at their discretion. The Federal statute now specifies that personal care services may be authorized for an individual by either a physician in a plan of treatment, or in accordance with a service plan approved by the state.

8. LeBlanc, A., Tonner, C.M., and Harrington, C. (2000). *State Medicaid programs offering personal care services.* San Francisco: University of California.

9. The Secretary's statement also expressed the Department's commitment to researching innovations to promote greater consumer choice and control in home and community services, including research and demonstration projects "to find imaginative, new ways to maximize consumer choice and self-determination. Many of the elements of this research agenda will have the immediate result of helping many people receive the supports they need. We will, for example, look at new ways to help consumers hire, train and manage their attendants, at alternative providers and experiment with offering consumers cash instead of services."

Several of the research projects have since been completed and information on them may be obtained by visiting http://aspe.hhs.gov/daltcp/home.htm. Others (e.g., the Cash and Counseling Demonstration/Evaluation in Arkansas, New Jersey, and Florida that HHS is co-sponsoring with the Robert Wood Johnson Foundation) are ongoing. In addition, several new projects have been launched, most notably the HCBS Resource Network, which is jointly sponsored by ASPE, HCFA, and AAA (all in HHS). Although the overall goal of the network is to promote development and improvement of state home and community service systems, the network has a special emphasis on assisting states in designing CD approaches to financing and service delivery.

10. In many states, the shift to CD home and community services for people with developmental disabilities is being supported by grants and other technical assistance from the Robert Wood Johnson Foundation.

11. Section 1915 (c)(1) of the Social Security Act

12. 42 CFR 441.301(b)(1)(i), Section 4442.6

13. Section 1915(c)(2)(A) of the Social Security Act

14. Section 1905(a)(24) of the Social Security Act

15. Section 1902(a)(23) of the Social Security Act.

16. Section 1902(a)(23) of the Social Security Act.

17. This topic is addressed in Flanagan, S. A., and Green, P. (1997). *Consumer-directed personal assistance services: Key operational issues for state CD-PAS programs using intermediary service organizations.* Cambridge, MA: The MEDSTAT Group. The authors include an especially clear discussion of the steps that may be taken to address some of the problems and issues while still ensuring that the health care needs of individuals are properly addressed.

18. HCFA Medicaid Manual Transmittal Part 4, No. 73, September 17,1999.

19. Olmstead Update Number 3. July 25, 2000. See Appendix II for the complete text of the letter.

20. The conference was a cooperative activity of the National Council on Aging and the World Institute on Disability, which was cosponsored by the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation, U.S. DHHS.

Annotated Bibliography

National Association of State Units on Aging (NASUA) (Draft, 1999). ***Consumer direction in home and community based services (HCBS): An assessment guide for states.*** **Washington, DC: Author.** (85 pages)

This guide was developed to help policymakers, consumer advocates, and consumers look broadly at the array of HCBS available in their states and identify ways to make services more responsive to consumers' needs and preferences. Included are a discussion of consumer direction principles and practices; benchmarks; a self-assessment instrument; factsheets on key issues (e.g., Medicaid, nurse practice acts, fiscal intermediaries); and a list of resources for more detailed information. *A free copy of the draft guide—or just the set of factsheets—is available from NASUA, 1225 Eye Street, N.W., Suite 725, Washington, DC 20005, (202) 898-2578. The final guide, which will also include states' experience in assessing their programs, will be available from NASUA for a nominal charge early in 2001.*

Flanagan, S., and Green, P. (October 1997). ***Consumer-directed personal assistance services: Key operational issues for state CD-PAS programs using intermediary service organizations.*** **Prepared for the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE), Division of Aging and Long-Term Care Policy (DALTCP). Cambridge, MA: The MEDSTAT Group.** (69 pages)

This policy study identifies practices for intermediary service organizations to use when implementing consumer-directed personal assistance programs. The report is basically an "advice manual" intended for state program administrators. *This report, minus appendices, can be found on the Internet at aspe. hhs.gov/daltcp/reports/cdpas.pdf. The full report and appendices may be ordered from the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or via e-mail at DALTCP2@osaspe.dhhs.gov.*

Doty, P., Kasper, J., and Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. ***The Milbank Quarterly*** **74 (3): 377-409.** (32 pages)

This article compares various uses of the Medicaid personal care services (PCS) option for providing attendant services to people with disabilities who need assistance with daily living tasks. It uses descriptive data from a 1984 and 1985 World Institute on Disability survey, and subsequent in-depth case studies of six diverse state Medicaid PCS programs.

Flanagan, S. (April 1994). *Consumer-directed attendant services: How states address tax, legal and quality assurance issues.* Prepared for the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE), Division of Aging and Long-Term Care Policy (DALTCP). Cambridge, MA: The MEDSTAT Group. (71 pages)

This study reviews 10 federal and state-funded consumer-directed attendant in-home care programs. Payment, employment-related taxes, quality assurance, and legal liability of CD programs are discussed. The authors suggest a model of consumer-directed care that incorporates the strongest features of the programs examined. *Order the full report from National Technical Information Service (NTIS), Department of Commerce, 5285 Port Royal Road, Springfield, VA 22161, or from the NTIS website, www.ntis.gov.*

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CHAPTER 8

Supporting Informal Caregiving[1]

Informal care is given without monetary compensation to persons who are ill or have disabilities, by families, friends, and neighbors. Informal caregivers provide enormous support to people of all ages and are the backbone of the nation's long-term care system. Active support of informal caregiving aids in keeping families together and avoids the high costs that are inevitable when individuals must rely solely on paid caregiving. Consequently, it is crucial for states to formulate policies that support and sustain informal caregiving. The Medicaid program gives states options that can strengthen and support informal caregiving. This chapter explains what options states have under current Medicaid law to do so.

Introduction

One in three Americans can expect to spend some time over the course of a year caring for family, friends, and neighbors without payment. This adds up to 52 million caregivers a year, helping 37 million family members and 15 million friends. These informal supports are referred to as informal caregiving in the service system for elderly persons and as family supports or natural supports in the disability community.[2]

Caregiving responsibilities are assumed by adults of all ages. But most informal caregivers are in middle age and almost three-quarters of primary informal caregivers are women. Up to age 70, women are more likely to be caregivers and to care for more than one person. They also provide more hours of care on average and more care over longer periods. The gender gap narrows at older ages, however, as the share of informal care provided by men increases.

The most frequent recipient of long-term care provided by an informal caregiver is an older person (age 65 or older). According to the 1994 National Long-Term Care Survey, over seven million Americans provide 120 million hours of informal care to about 4.2 million elderly persons with functional limitations each week. The estimated economic value of these hours of informal care ranges from $45–$96 billion a year.

About one in five elderly persons with functional limitations who receive informal care in the community (780,000) are SSI/Medicaid eligible. They receive on average 34 hours of unpaid help a week from an estimated 1.9 million informal caregivers. Nearly half (380,000) are as severely disabled as most nursing home residents—requiring assistance with three or more personal care tasks or having severe cognitive impairment. These "nursing home eligible" elderly persons on Medicaid receive an average of 52 hours of informal assistance a week.[3]

Roughly 4 million Americans of all ages who have mental retardation or another developmental disability also live in the community. Half a million of these live with parents over age 60, and this number will grow as the population ages. Only 10 percent of these noninstitutionalized individuals currently receive specialized residential services.[4] Nearly all the rest live with their families or in other living arrangements where families and friends provide continuing informal support.

Access to informal care clearly helps individuals remain in their homes and communities. There are 1.5 million elderly residing in nursing homes compared with 1.6 million elderly who have similar personal assistance needs but live in their own homes or in the homes of their adult children or other family caregivers. Two-thirds of all elderly persons with disabilities living in the community receive only informal care. An even higher proportion of adults under age 65 with disabilities (86 percent) depend entirely on unpaid assistance.[5]

At a fundamental level, informal caregiving is irreplaceable. The pool of community long-term care workers is inadequate and the public resources that would be needed to replace informal care with paid workers would be exorbitant. Yet, we cannot take for granted that current patterns of informal caregiving can be sustained. Of a number of factors that will make it difficult to sustain the same level of informal caregiving, the primary ones are: (a) continuing high numbers of women employed full time; (b) continued growth in the number of people requiring long-term care, mainly as a result of population aging; and (c) an increase in the proportion of persons age 85 and older, the group most likely to need long-term care. As the population ages, primary caregivers (whether spouses or adult children) will be much older themselves on average, making them less able to provide the level of informal care they might have given when younger.

For all these reasons, access to paid help needs to be expanded to more adequately complement the always essential efforts of family and friends. Strategies are needed to help keep informal caregivers from being overwhelmed by the stress of having to bear the whole care responsibility themselves. Paid help is also needed when informal caregivers face competing pressures from other family roles and/or paid employment, become ill, or need a break to pursue their own interests. The appropriate combination of informal and paid services can enable a family to continue caregiving over extended periods. Too often, however, paid supports become available only when a breakdown in informal care has precipitated a crisis.

Many policymakers and program administrators worry that expanding access to publicly funded services will result in the substitution of formal for informal care—with government paying for an ever greater share of the assistance that has traditionally been provided by families "for free." It is often impossible to determine, in particular cases, whether publicly funded services are, in fact, substituting for informal care that would otherwise have been available, or whether publicly funded services are necessary to compensate for an unavoidable lack of family caregivers. Controlled experimental design studies such as the National Channeling Demonstration have consistently found, however, that family members who have previously been providing services do not significantly decrease their efforts when publicly funded services become available. According to this and other caregiving research, when formal care is increased the care provided by families also increases. In other words, as care needs expand formal and informal care increase together.

Medicaid-funded home care programs serve both individuals who receive substantial amounts of informal care from family members and individuals who are almost entirely dependent on formal services. Most of the latter group simply have no immediate family or none nearby. They may have no spouse caregivers because they are widowed, divorced, separated, or never-married. They may have no adult children to provide informal care because they never had children at all, or because their adult children live too far away to provide day-to-day assistance. Or they may be in the period of young adulthood, when it is important developmentally for them to live independently from their family, particularly if the family has been providing care for many years.

Federal Medicaid Policy and Informal Caregiving

Federal policies present no substantial barriers to states in using Medicaid dollars to support people with substantial functional limitations who live with their families (and thus, by definition, have access to informal care). There are no Federal restrictions on the provision of HCB waiver services based on living arrangement, for example, other than that the person cannot reside in an institutional setting. The same is true with respect to personal assistance and other services furnished under the state Medicaid plan. Thus, home and community services can be furnished to individuals who live with their families or in their own home just as readily as to individuals who are served in formal living arrangements such as group homes or assisted living.

Whether provided under an HCBS waiver program or under the state plan, however, to be Medicaid-reimbursable the services must address the beneficiary's needs. This means that services cannot be furnished if they principally benefit the "family unit." States can (and most do) offer respite services under Medicaid HCBS waivers. And state programs do provide relief to caregivers from the challenges of continuous caregiving. This is appropriate. While these services clearly benefit the family caregivers, they are provided directly to the beneficiary, and there is no question that they are of principal benefit to the beneficiary.

States have enormous latitude in configuring their eligibility policies to expand access to home and community services for persons who live with their families (parents, spouses, or adult children). Federal Medicaid policy provides particularly important options to states for making such services available to *children* with severe disabilities who live in the family home. Certain features of Medicaid eligibility policies for services under the state plan can pose service barriers for such children unless they live in very low-income households. However, under an HCBS waiver program, a state may expand the financial eligibility of these children for Medicaid services by deciding not to include the income of their parents in the financial eligibility calculation. States may also extend Medicaid eligibility to children with severe disabilities, irrespective of whether the child will be served through an HCBS waiver program or the state plan, under the Katie Beckett option. (See Chapter 2 for a detailed discussion of financial eligibility options for home and community services.)

Two questions often arise concerning provision of Medicaid home and community services to individuals who have informal caregiving arrangements in place. One is the extent to which informal care is taken into account in conjunction with authorizing the provision of paid services. The other concerns making payments to family members to furnish services.

Availability of Informal Care

There is no Federal requirement that family members provide some minimum amount of care as a condition of service eligibility. Nor is there any stipulation that services may not be furnished if an informal caregiver is present. However, states can and do take into account the *amount* of informal care available to an individual. If a person needs 40 hours of support per week and informal caregivers are available, able, and willing to provide 20 hours, for example, then only 20 hours of paid supports will be authorized.

In practical terms, assessment of the need for paid supports may focus on specific tasks that an informal caregiver who lives with and is regularly available to assist the beneficiary is unable to perform. For example, an elderly spouse may be too frail to assist his wife with transferring into and out of bed, getting into and out of a wheelchair, or giving other forms of assistance that involve lifting and physical support.

Consideration may also be given to the kinds of household tasks family members typically expect to share or to do for one another when they live in the same household—as opposed to intimate personal care tasks that individuals normally do for themselves. Thus, many state programs expect that spouses, parents, or other adults who do not have disabilities and who live with the Medicaid service beneficiary will take responsibility for general household maintenance tasks. If she lives

in her daughter's home, for example, an elderly mother who requires assistance with bathing, dressing, and toileting and who is also unable to perform housekeeping tasks would, in many states, be eligible only for assistance with personal care tasks and not for homemaker/chore assistance. If the mother lived alone in her own home, in contrast, she would be eligible to receive homemaker/chore services in addition to assistance with personal care.

Adult children caring for parents may have conflicting responsibilities—such as employment and child care. In such cases, support planning may focus on those times of day and week when adult children are unable to provide informal care (e.g., while they are at work). Similarly, a child with severe disabilities might need after-school care until a parent comes home from work. Formal services provided in tandem with informal care may be viewed as supplemental, as supportive, or as regular respite care, if a beneficiary is receiving extensive informal care. (Formal respite care is provided in addition to the regular services furnished.)

Federal policy allows and encourages the "best practice" of matching home and community services to the unique needs of individuals and the circumstances of their informal caregivers. Thus, states can assess availability of informal caregiving and need for paid care by examining each situation on a person-by-person, household-by-household basis. And when authorizing home and community services, states may take into account the preferences as well as the needs of the beneficiary and the family. For example, when a young adult male beneficiary with a disability lives with his sister and her family, everyone may prefer, for reasons of privacy, to have a paid personal care attendant assist with bathing, whereas in the case of an elderly woman living with her daughter, both may feel that privacy concerns are better served by having the informal caregiver assist with bathing.

Payment of Family Caregivers

Federal Medicaid law permits family members to become paid caregivers unless those family members are legally responsible for the care of an individual (i.e., spouses and parents/guardians of minor children). The philosophy underlying this policy is that Medicaid should not pay a spouse or parent for services that most spouses or parents would normally be required to provide without charge. However, states have the option to pay even these family members under certain exceptional circumstances. For example, they may be paid for providing skilled nursing services (for which there is no presumption that the service would "normally" be provided free).

Personal care services

Other than spouses and parents of minor children, states may pay any family members to provide personal care services, including adult children of a parent, parents of adult children, siblings, and grandparents. Friends and neighbors may also be compensated for providing services that would otherwise need to be purchased on behalf of the beneficiary. In California's In-Home Supportive Services (IHSS) Program, for example, about 40 percent of consumer-hired personal attendants are related to the Medicaid beneficiary and an additional 30 percent are friends, neighbors, or other individuals the beneficiary already knows.[6]

In the standard application that states complete to secure Federal approval to operate an HCBS waiver, HCFA has provided explicitly that states may choose whether or not to pay for personal care (or closely related services) furnished by family members who are not spouses of beneficiaries or parents of beneficiaries who are minors. Thus, it is up to each state to decide whether it will make payments to a beneficiary's relatives to furnish personal care/personal assistance, including the circumstances under which such payments will be made.

If they choose to make such payments, states are permitted to establish provider qualifications for family members that differ from the qualifications for agencies or individual contractors who furnish such services. States that require criminal background checks for personal care attendants, for example, may exempt family members. In HCBS waiver programs for people with developmental disabilities, the most recent information

indicates that roughly half the states have elected to make payments to family members who provide personal care services.[7]

There are pros and cons to paying family members to provide services. The most powerful arguments in support of this practice are: (a) it addresses the problem nearly all states are encountering with respect to availability of workers to provide personal care/personal assistance and (b) relatives generally know and care about the person and are familiar to and trusted by the person. When people forgo or give up paid employment to provide care, common sense says they should be compensated.

In addition, on at least some quality measures, according to research findings, consumers who hire family members as their personal care attendants receive better care on average than those whose attendants are unrelated individuals, whether employed directly or through home care agencies.[8] Iowa's Elderly Waiver Program (enacted in 1989) is an example of a longstanding program that recently (1997) added a consumer-directed option under which beneficiaries may hire family members as personal care attendants.

Frequently expressed concerns about this practice are that (a) payments will be made for care that would be provided for "free" in any case and (b) conflicts and problems might arise if the family caregiver is not performing well. In response to these concerns, many states that pay family members allow such arrangements only when other sources of services are not available and the beneficiary will clearly benefit from the arrangement. In programs that enable consumers to direct their own services (e.g., California's In-Home Supportive Services Program, Michigan's Home Help Program), the freedom to hire a family member, friend, or neighbor is considered an important aspect of consumer choice and control. Again, "best practice" is to work out such arrangements on a person-by-person basis, including identifying any special safeguards that might be appropriate or necessary.

Non-personal care services

HCFA has affirmed at various times that there are circumstances where the most practical way to obtain a variety of services might include making payments to family members, especially when services are difficult to obtain from other sources. The rules that pertain to paying relatives to provide non-personal care services are not substantially different from the rules for obtaining such services from other sources. The relative must meet whatever provider qualifications the state may have established and charge no more than any other provider. Here again, HCFA expects that a state will limit payments to certain types of relatives or require a demonstration that the service is not otherwise available, that it may not be obtained as economically, and/or that there is clear benefit to the individual from the relative's providing the service. In the case of individuals who need transportation to attend an adult day health program but live in areas not served by transit systems, for example, a relative may be paid to transport the person to and from the program.

Within the broad parameters of Federal policy, it is up to states to define the particular circumstances under which family members will be paid to furnish services in the home and community. States can take various factors into account, including availability of other sources of the same services, costs of family member services versus costs of purchasing such services from conventional sources, and specific circumstances with

Oregon's Use of the Foster Care Concept

In its HCBS waiver program for elderly persons and younger adults with physical disabilities, Oregon enables certain family caregivers who bring HCBS waiver beneficiaries into their homes to qualify as providers of "relative foster care." Oregon has also encouraged the growth of small group adult foster care homes (each with up to five residents) that offer a surrogate family environment. These facilities cater primarily to elderly persons who have cognitive impairment but little need for hands-on assistance with personal care tasks. Many such persons are at high risk of placement in larger, more impersonal, board and care settings or nursing homes, because they do not have family caregivers with whom they can live and they are unable to live alone. Interestingly, only about half the elderly residents of Oregon's adult foster care homes are eligible for Medicaid HCB waiver services; the rest pay privately.

Examples of States' Family Payment Policies

Kansas. Kansas's policy on family reimbursement states that "unless one of the four criteria noted below are met, a spouse or parent of a minor child may not be reimbursed for providing personal care services.

1. Consumer's residence is documented in writing by three waiver provider agencies to be so remote or rural that waiver services would be otherwise unavailable.
2. Consumer's health, safety, or social welfare would be jeopardized and is so documented in writing by two health care professionals, including the attending physician.
3. Due to advancement of chronic disease, consumer's primary means of communication can only be understood by the spouse and is so documented in writing by the attending physician.
4. Written documentation from three waiver providers that delivery of waiver services to the consumer poses serious health or safety risks for the providers, thereby rendering waiver services otherwise unavailable."

Minnesota. Minnesota's regulation states that:

1. "Federal financial participation is not available for personal care or any waiver service when provided to beneficiaries by legally responsible relatives, i.e., spouses or parents of minor children, when the services are those that the persons are already legally obligated to provide.
2. Services provided by relatives or friends may be covered only if the relatives or friends meet the qualifications for providers of care, there are strict controls to assure that payment is made to the relative or friend as providers only in return for specific services rendered, and there is adequate justification as to why the relative or friend is the provider of care, e.g., lack of qualified provider in remote areas. Medicaid payment may be made to qualified parents of minor children or to spouses for extraordinary services requiring specialized skills (e.g., skilled nursing, physical therapy) which such people are not already legally obligated to provide."

respect to individuals and consumers. If states do choose to pay family members, they need to check other state regulations that may inadvertently create barriers to their use. Such regulations may include requirements for attendant training or certification, or for employment by licensed or certified home health agencies.

Services and Supports That Strengthen Informal Caregiving

Since the exact situation of each individual and his or her informal caregivers is unique, the specific services and supports needed to complement and strengthen informal caregiving will differ from household to household. For example, caregivers may be able to provide personal assistance needs in the early morning and evening but need other providers of assistance for most of the day. In this case, the services provided might include adult day health care or a similar program, plus occasional respite on weekends.

In other cases, more extensive supports might be needed, due to either the nature and extent of the person's condition or the extent to which informal caregivers themselves are unavailable or unable to support the person. Whether the person lives alone or with informal caregivers is frequently an important consideration. Given comparable levels of need, people who live alone usually require more paid help to complement the support they receive from their informal caregivers.[9]

Home and community services states may or do offer that are especially important in strengthening informal caregiving include:

- **Personal Care/Personal Assistance.** Most persons with severe functional limitations need help with personal care. States may offer these services to individuals who live with their family or spouse, especially in situations where the person's primary caregiver is unavailable to provide this support (e.g., if she or he works). Availability of personal care is especially important when the beneficiary

lives alone. Informal caregivers may be available to individuals only at certain periods of the day or certain days during the week and paid help can fill in when they are not available. Providing personal assistance enables individuals to continue to have a home of their own or, in the case of younger individuals with disabilities, enables them to set up their own living arrangement as part of their transition to adulthood. For states, supporting individuals in their own homes can be vastly more economical than the alternative of moving to a group home or an assisted living facility, simply because it will keep in place the informal caregiving currently available.[10]

- **Respite.** The aim of respite care is to provide informal caregivers (usually relatives) a break from their day-in day-out care responsibilities. At a practical level, respite services differ from personal care services only in that respite is usually furnished on an intermittent basis and explicitly to provide relief to the primary caregiver(s). Respite care, for example, can be provided in order to give parents a night or weekend off periodically from the intense caregiving associated with supporting children with especially severe cognitive and/or physical disabilities or medical needs. It is particularly needed if caregivers themselves become ill.

  Respite is also important for spouses or adult caregivers of older beneficiaries, including those with Alzheimer's disease and other dementias. Respite care benefits the individual directly by providing services usually furnished by the caregiver, and indirectly by helping avoid the "burnout" of their primary caregivers. Under HCBS waiver programs, respite can be provided in the family home by bringing a worker into the home while the caregivers are away for a few hours or overnight.

  Some states also allow respite care to be furnished at sites other than the family home, including especially designated respite care facilities. This out-of-home respite is used most often when the primary caregiver(s) will be away overnight or for extended periods, or even to enable the primary caregiver(s) to be at home alone during the respite period.

  States may establish whatever limits they elect with respect to the amount of respite that will be available to primary caregivers. Iowa's Elderly Waiver program, for example, specifies that paid family caregivers are not eligible for respite benefits. And it is not uncommon for states to cap the amount of respite at 30 days during a calendar year. Many states do not impose such caps in their HCBS waiver programs, however, leaving the amount of respite that will be authorized to be worked out during the individual planning process, based on the needs and circumstances of the particular informal caregivers.[11] Most states permit caregivers to "bank" respite benefits and to use the authorized amount whenever it is most needed. This practice recognizes that since respite is intended to renew the energies of the caregiver (for the direct longer term benefit of the beneficiary), its use should be determined mainly by caregivers. States have the option to permit "banked respite" to be carried over from one year to the next.

- **Home/Vehicle Modifications and Other Assistive Devices.** States have the option via their HCBS waiver programs to offer home and vehicle modification services that are necessary to secure beneficiaries in their present living arrangement. Such modifications may include constructing wheelchair access ramps to the home (regardless of whether the home is the caregiver's or the beneficiary's), modifying bathrooms and other parts of the house to make them accessible, and retrofitting vehicles (e.g., installing a wheelchair lift in a van). In addition, states may authorize the purchase of lifts and other devices that ease the burden of physically assisting an individual to transfer or go up and down stairs.

  These types of devices, and other accommodations that benefit the individual, strengthen informal caregiving by making it less taxing for caregivers to assist the individual. There is an enormous variety of devices and equipment that may be purchased through HCBS waiver programs or acquired as regular bene-

Modifications and Assistive Devices Covered in Utah's HCBS Waiver Program

Utah's HCBS waiver program for people with developmental disabilities provides a sense of the wide range of accommodations and devices states may offer through HCBS waiver programs.

Ramps

Lifts/elevators
- porch or stair lifts
- hydraulic, manual, electronic lifts

Modifications/additions to bathroom facilities
- roll-in showers
- toilet modifications/grab bars
- sink modifications
- water faucet controls
- bathtub modifcations/grab bars
- turnaround space adaptations
- floor urinal and bidet adaptations and plumbing modifications

Widening of doorways/hallways

Specialized accessibility/safety adaptations/additions
- door-widening
- grab bars and handles
- electrical wiring
- fire safety adaptions
- grab bars and handrails
- automatic door openers/doorbell
- medically necessary air filtering devices
- medically necessary heating/cooling adaptations
- voice-activated, light-activated, motion-activated, and electronic devices

Vehicle adaptations
- lifts
- seating modifications
- door modifications
- safety/security modifications
- steering/braking/accelerating/shifting modifications

Trained and certified canine assistance
- purchase of trained canine
- training for beneficiary and canine
- animal upkeep (dog food, license, tax, supplies)
- emergency and preventative veterinarian services

fits in a state's Medicaid plan. HCBS waiver dollars may be employed not only to make modifications and purchase and install equipment but also to provide for its upkeep and maintenance.

These accommodations are needed whether a beneficiary lives alone or with a spouse or other family member. For example, many states offer "personal emergency response system" (PERS) services. Equipping a person with PERS is an especially economical way to promote continued community presence and avoid institutionalization due to concerns about the person's safety during periods when neither paid nor informal caregivers are present. There are many types of such services, but all enable the beneficiary to summon help quickly in an emergency. When the informal caregiver is at work or when the beneficiary lives alone, PERS can provide peace of mind to informal caregivers that help can be summoned quickly in urgent or emergency situations.

- **Caregiver Training and Education.** Making caregiver training and education available to informal caregivers strengthens informal caregiving and has the added benefit of helping reduce reliance on costly paid help. Family members often find themselves thrust with little or no preparation into new caregiving roles. Informal caregivers want and would often prefer to support family members without relying on any paid assistance. But to do so, they require help in acquiring the necessary skills.

  For this purpose, a state may offer "caregiver training and education" as a distinct service

under an HCBS waiver program. This service may include: (a) underwriting the costs of trainers coming into the home to teach skills and techniques for addressing the beneficiary's needs, so that training can be customized to the individual and the caregivers; (b) underwriting the registration and materials costs for caregivers to attend special training and education classes; and (c) paying the expenses associated with caregivers attending workshops and conferences where they can obtain information that will better enable them to meet the needs of the beneficiary. (These expenses might include conference fees, arranging substitute care while caregivers are away, or paying for personal assistance at the training conference itself if the beneficiary accompanies the caregivers.)

Caregiver training may also be provided under the rehabilitation option. Rehabilitation services in Kentucky, for example, include home visits to: (a) assist family members and seriously mentally ill beneficiaries to practice effective communication techniques to defuse stressful situations that occur in home settings; and (b) coach family members trying to manage a severely acting-out child and to improve their behavior management skills.

- **Day Care.** To accommodate caregivers' work schedules, states may purchase day care services. These may include before- and after-school day care or day camp when school is out. The service can include sending a paid worker to pick up the beneficiary from school and to provide care until the parent(s) arrive home from work. In its HCBS waiver program for people with developmental disabilities, for example, Utah provides "latch key supports" specifically for this purpose. Like any other Medicaid service, such services may be authorized only to the extent that they cannot be obtained from alternative funding sources.

  Adult day care services are also beneficial to families providing informal care to older persons with Alzheimer's disease or other dementias, and to any informal caregivers who have an outside job and who are concerned about the safety of a person left alone at home.

- **Family-Directed Services.** Many families prefer to directly manage the services and supports the beneficiary will receive. They want to make decisions concerning the workers who will come to the family or the beneficiary's home to provide assistance. They also want control over the "care schedule." In the case of children with disabilities, the family—not the child—is the decision maker concerning services and supports. In the case of adults, families also may direct services and supports, especially when the individual is unable to do so. In this vein, states may elect to provide families additional assistance in directing services and supports, either through their service coordination systems or by authorizing families to secure the services of "support brokers" or "personal agents" to assist them in managing supports in full or in part. Pennsylvania's Person/Family-Directed Supports HCBS waiver program for people with mental retardation specifically makes this type of support available to families.

Supporting Families of People with Developmental Disabilities

In the area of long-term care services and supports for people with developmental disabilities, there is a long, robust history of state-operated "family support" programs. The aim of these programs is to provide supports that benefit *both* the individual and the family and, thereby, contribute to maintaining and sustaining the family unit. In many states, these programs have been in operation for nearly three decades. Many of the principles, values, and practices that have been incorporated into HCBS waiver programs for people with developmental disabilities are equally relevant in furnishing HCB services to individuals who have other types of physical and mental disabilities and are served in other types of waiver programs. And many states have similar programs targeted to family members providing eldercare, especially to persons with Alzheimer's disease or other forms of dementia. These programs are financed either entirely with state funds or through a combination of funding streams that may include some Medicaid funding.[12]

In addition, many states have taken important steps to support adults with developmental disabilities who want to have a home of their own rather than be served in a provider-operated group living arrangement. These "supported living" arrangements seek to combine paid and informal supports to enable individuals to live as independently as possible in their communities. Until recently, however, many states tended to confine provision of HCB waiver services to persons served in group homes or similar specialized, provider-operated living arrangements.[13]

Two major factors help explain why some states have not employed HCBS waiver financing for family support services. First, until states were given the go-ahead to expand their HCBS waiver programs to whatever level they desired, some states targeted HCB waiver services mainly to persons in the most costly settings. Second, stakeholders in many states have been leery of "Medicaiding" family support services, for fear that the result would undermine a very strong tradition of family control and direction of such services. In some states, for example, developmental disabilities family support programs operate by giving the family a monthly cash stipend. This gives the family complete control with respect to the goods and services they will purchase to meet the individual's and/or the family's needs. Since Federal Medicaid policy does not enable cash payments to be made to or on behalf of beneficiaries, such cash stipend programs have been "off-limits" for Medicaid financing.

But times have changed. States are now being confronted with extremely high demand for home and community services for people with developmental disabilities. Many different factors account for this high demand. One factor is the increasing longevity of people with developmental disabilities, many of whom now live with parents who themselves are elderly and less able to meet the needs of their adult children.[14] Another is that, unlike in the past, it is increasingly common for people with developmental disabilities to outlive their parents. Many states, even those that have substantially expanded the availability of home and community services over the past decade, have very long waiting lists for services.[15]

As a consequence, many states are rethinking the role that Medicaid HCBS waiver services might play in meeting the needs of people with developmental disabilities—particularly with respect to broadening availability of such services to individuals who live with their families or where other informal caregivers are providing support. While requests for services and supports often take the form of families seeking a group home placement, frequently (although not universally) in-home and family support services can meet the needs of the person without the person's having to leave the family home. States that make services and supports more readily available to people with developmental disabilities who live with their families in fact experience lower demand for group home and similar services.[16]

This rethinking is taking various forms. Some states have launched distinct HCBS waiver programs intended mainly to underwrite services and supports for these individuals. These programs do not offer group home and other standard residential services. Instead, they have been crafted principally to meet the needs of individuals who live with their families or on their own with informal caregiving available to them. These programs usually operate under stricter cost caps than the state's parallel HCBS waiver program, under which traditional out-of-the-family-home residential services are furnished. These stricter caps recognize that individuals have informal caregiving available. They also permit the state to give individuals and families considerable flexibility in selecting the mixture of services and supports that best meets their needs. It is important to reemphasize here that family support must be directed toward serving the beneficiary. Services that are primarily for the benefit of the family are not coverable under a Medicaid HCBS waiver.

Use of such caps helps the state avoid imposing service-by-service restrictions on utilization in order to maintain program cost-effectiveness. The flexibility afforded individuals and families also permits states to reflect many of the principles and values under which developmental disabilities individual and family support programs have operated for many years: namely, that the individual or the family be in a position to make sure that the services and supports they receive have

Examples of Waiver Programs to Support Persons with Developmental Disabilities

Oklahoma. In 1999, Oklahoma launched two HCBS waiver programs for persons with developmental disabilities: one for children who live with their families and another for adults who live with their families. Oklahoma launched these programs specifically to address the needs of individuals who had been wait-listed for services. In launching these programs, state officials also took steps to embody the principles of individual/family self-direction of services. In combination, these programs are expected to make HCB waiver services available to an additional 1500 individuals. The program for children operates under a cost ceiling of $10,000; the program for adults has a ceiling of $15,000. The difference in the ceilings recognizes that children will be in school, whereas adults may require day support services.

The program for adults offers the following services:

- homemaker
- respite
- family training
- residential habilitation
- prevocational services
- nutritional services
- supported environment
- psychological services
- environmental accessibility adaptations
- audiology, physical, occupational, and speech therapy services
- extended state plan services (adaptive equipment, specialized medical supplies, dental services, and transportation).

The services offered in the program for children are more limited—especially with respect to clinic services—because they are generally available for children as Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefits through the state's regular Medicaid program.

Pennsylvania. Pennsylvania's Person/Family-Directed Supports waiver program operates under a $20,000 per year cost cap. In combination with expansion of the state's long-standing Consolidated Waiver program (under which most individuals receive specialized community residential services), this Pennsylvania program is an integral element of the governor's recently announced multi-year plan to substantially reduce the waiting list for community mental retardation services.

Colorado. Since 1995, Colorado has operated Supported Living Services, a waiver program geared to serving adults with developmental disabilities who live with their families or on their own in the community. Under this program, individuals and families have considerable flexibility in selecting and managing their own supports. In some cases, "microboards" have been formed that enable families and friends (the person's "circle of support") to directly manage services and supports on behalf of the individual.

Other states have submitted or are considering submitting applications to operate similar programs.

been tailored to their needs and preferences. Availability of Medicaid funding allows states to offer more robust services and supports to families than has typically been the case with respect to state-funded family support programs, many of which allot only $3000 to $4000 to a family each year.[17]

Operating distinct waiver programs that target mainly individuals who live with their families has both pros and cons. One of the main advantages is that state officials and other stakeholders are often willing to entertain new approaches to furnishing home and community services when they are creating a program as opposed to modifying one that already exists. Supports and services can be selected that are especially relevant to meeting the needs of people who live with their families, paying particular attention to strengthening informal caregiving. The main disadvantage appears to be the administrative complications associated with operating multiple HCBS waiver programs for the same general target population.

Some of the same purposes can be achieved by including distinct, specially targeted benefits within a single HCBS waiver program. Examples of this approach include:

- **Utah.** In its single HCBS waiver program for

people with developmental disabilities, Utah offers assistance and support services intended to enable family members with a disability, who so desire, to remain and be supported in their family homes. The intent is to prevent or delay unwanted out-of-home placement. Services and supports can be provided either in or out of the home and may include provisions to assist the individual with a disability to obtain community supports. They may also include instructions, supervision, and training to the family/caregiver/individual in all areas of daily living. The supports may also include other activities identified in the individual's support plan as necessary for continued skill development, including:

— behavior supports

— special summer programs

— social skills development

— appropriate leisure time activities

— developing interventions to cope with problems or unique situations

— instruction and consultation for the beneficiary and other family members.

Services can be obtained through providers who have contracts with the state to provide family support services. Alternatively, families may choose the "family choice model," in which the family hires and trains the individuals to provide the supports. In this model, the family may use individuals age 16 and older as direct providers of support.

- **Illinois.**[18] The Illinois HCBS waiver program for people with developmental disabilities includes a supported living option intended for persons who live with their family or on their own. Service plans under this option are subject to a total cost cap of $18,000 per year. Within that cap, individuals and families may select from: (a) distinct services available only to individuals who select the supported living option (intensive case management, personal care, skilled nursing, respite, and transportation) and (b) certain services available to other program participants as well (day habilitation, behavioral services, and therapy services). Individuals and families may select the services they want as long as the total cost of the services does not exceed the maximum allowed. The supported living option is a distinct benefit nested in the state's HCBS waiver program. This enables states to define distinct benefits especially geared to individuals who live with their families.

Whatever approach a state takes, it can strengthen informal caregiving by ensuring that all its HCBS waiver programs—regardless of target population—contain a wide, diverse menu of services and supports that are important for individuals who live with their families as well as those who live on their own.

Endnotes

1. The primary contributors to this chapter are Gary Smith, Pamela Doty, and Janet O'Keeffe.

2. Unless otherwise noted, data on caregiving are drawn from the following publication: Office of the Assistant Secretary for Planning and Evaluation and Administration on Aging (1998). *Informal caregiving: Compassion in action.* Washington, DC: Department of Health and Human Services. Statistics on informal caregiving may vary according to the source because researchers use different definitions of caregiving and include different populations in their sample. For example, if one study examines informal care provided to people age 50 and older and another study looks only at care provided to people age 65 and older, there will be differences in the number of caregivers and the estimated economic value of their caregiving.

3. Numbers are based on data from the 1994 National Long-Term Care Survey. Data analyses were carried out by Pamela Doty of the Office of the Assistant Secretary for Planning and Evaluation, U.S. DHHS, and Mary Elizabeth Jackson of the MEDSTAT Group, Cambridge, MA.

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8. Doty, P., Benjamin, A.E., Matthias, R.E., and Franke, T.M. (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery. Non-technical summary report.* Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy.

9. According to the 1994 National Long-Term Care Survey, 86 percent of elderly persons living in the community who are as severely disabled as most nursing home residents (three or more ADL limitations and/or severe cognitive impairment) live with family caregivers and, on average, receive 60 hours of informal care per week supplemented by a little over 14 hours of paid assistance. In contrast, the minority (14 percent) of equally severely disabled elders who live alone receive, on average, 29 hours of informal help per week supplemented by 56 hours of paid assistance.

10. In developmental disabilities services, supporting individuals to live in a home of their own is usually called "supported living." Several states offer supported living services in their HCBS waiver programs for people with developmental disabilities, in order to encourage independence and integrated "everyday" living in the community rather than limiting "out-of-the-family-home" services to group living situations. Developmental disabilities supported living "models" include working out strategies to blend "natural supports" (i.e., informal caregiving) together with paid help to enable the individual to live in a home of her or his own. See: Smith, G. (1991). *Supported living: New directions in services to people with developmental disabilities.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

11. In 1990, Congress amended Section 1915(c) of the Social Security Act to specifically prohibit HCFA from imposing any limits on the amount of institutional respite services states might elect to provide in their HCBS waiver programs.

12. Feinberg, L.F., and Pillisuk, T. (1999). *Survey of fifteen states' caregiver support programs. Final report.* San Francisco, CA: Family Caregiver Alliance.

13. The vast majority of people with developmental disabilities of all ages live with their families. Yet as recently as 1998 only about one-third of all HCBS waiver participants with developmental disabilities lived with their families and an even smaller proportion (about 15 percent) lived in a home of their own. Within this overall average, however, there are large differences among states. In Arizona, for example, fully two-thirds of all beneficiaries with developmental disabilities who receive home and community services via the Arizona Long Term Care System live with their families.

14. Among individuals with developmental disabilities who live with their families, about 25 percent live with parents who themselves are older than 60.

15. Smith, G. (1999). *Closing the gap: Addressing the needs of people with developmental disabilities waiting for supports.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

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17. This type of HCBS waiver program is sometimes dubbed a middle-range program, because it fills the gap between limited state-funded family support programs and HCBS waiver programs intended mainly to buy specialized group-home and similar residential services.

18. HCFA was closely involved in reviewing the Illinois waiver program, since it replaced the program HCFA had cited in 1998–99 as being out of compliance.

Annotated Bibliography

Office of the Assistant Secretary for Planning and Evaluation and Administration on Aging (1998). *Informal caregiving: Compassion in action.* Washington, DC: Department of Health and Human Services. (31 pages)

A basic statistical chartbook with information and statistics on informal caregiving in the United States. *To obtain a free copy of this report, write to the Office of*

Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or via e-mail at DALTCP2@osaspe.dhhs.gov.

Arnos, P.S., Levine, C., and Memmott, M.M. (March/April 1999). The economic value of informal caregiving. *Health Affairs* 18 (2): 182-8. (7 pages)

Using large national data sets, this study explores the current market value of the care provided by unpaid family members and friends to adults with disabilities and chronic illnesses. Specific estimates for five states are also presented.

The National Alliance for Caregiving (NAC) and The American Association of Retired Persons (AARP) (1997). *Family caregiving in the U.S.: Findings from a national survey.* Washington, DC: Authors. (40 pages)

This report describes the various impacts of family caregiving in today's society, documenting the experiences and attitudes of persons who provide care to older Americans. The study is the first of its kind to address these issues systematically, using survey methodology, across four racial/ethnic groups within the United States: whites, blacks, Hispanics, and Asians. *To obtain a free copy of this document, write to AARP Fulfillment, 601 E Street, N.W., Washington, DC 20049. Be sure to include the stock number (D16474) and the title of the publication. Allow six to eight weeks for delivery.*

LifePlans, Inc. (1999). *A descriptive analysis of patterns of informal and formal caregiving among privately insured and non-privately insured disabled elders living in the community.* Washington, DC: Department of Health and Human Services.

This report is based on a study of how long-term care insurance benefits are used, whether claimants feel they are getting good value for the premiums they pay, and whether patterns of formal (paid) and informal (unpaid) service use differ for long-term care insurance claimants compared to similarly disabled persons without long-term care policies. The report provides basic socio-demographic and service utilization profiles for both groups and discusses the implications of the study's findings for the service delivery system and for the design of private and public long-term care programs and policies. *To obtain a free copy of this report, write to the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or via e-mail at DALTCP2@osaspe.dhhs.gov.*

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CHAPTER 9

Creating Comprehensive Cost-Effective Systems: System Design Issues[1]

Making home and community services readily available to and accessible by individuals with long-term care needs requires that states design comprehensive, cost-effective delivery systems. Design dimensions that need to be addressed include establishing meaningful access to home and community services, managing dollars, and making sure that Medicaid home and community service delivery is coordinated with other community service programs. Federal Medicaid law and policy give states considerable latitude in designing and implementing such systems.

Introduction

Too often, persons in need of home and community services lack them, not because services are literally unavailable, but because the service system makes the process of gaining access to them cumbersome, confusing, and even unfriendly to consumers. Indeed, individuals and their families can find the process so difficult or upsetting that they simply give up and go on struggling without the services they need.

States can largely eliminate these difficulties if they design home and community services systems that have five major components:

- An outreach, application, and enrollment process that is truly accessible to people with disabilities (and their families)
- A structure that connects individuals with the services they need
- Effective management of dollars in ways that promote economical delivery of home and community services, thereby making such services available to the maximum number of people
- Payment and contracting mechanisms that encourage provider participation
- Coordination among and across programs, so that duplication is avoided at the same time that individuals with disabilities are ensured access to vital supports that address home and community service needs—outside as well as within the scope of the Medicaid program.

Each is discussed in the sections that follow. The whole system design task needs to be approached in the context of state laws and policy goals, historical factors, and the unique needs of a variety of target populations. Federal Medicaid law and regulations must also be taken into account. But as the follow-

ing discussion makes clear, these allow states considerable latitude in working out a system design that best fits their circumstances and program management objectives.

Outreach, Application, and Enrollment

The outreach, application, and enrollment process is the component of the home and community service system that is charged with (a) making all potentially eligible individuals aware of the availability of services, and (b) ensuring that those who are eligible for services are enrolled in the Medicaid program. All these steps must be completed as rapidly as possible, since a consumer's need for services may be critical.

The next three subsections describe a variety of actions states may take in implementing effective outreach, application, and enrollment system components. Some of the activities described may be paid as Medicaid administrative expenses. To qualify under this cost category, activities must be determined necessary for the proper and efficient administration of the state's Medicaid program.[2] It is important to note that Medicaid reimbursement is not limited to activities conducted by Medicaid agency staff. Reimbursable activities may also be conducted by other agencies, organizations, and individuals through contractual or cooperative agreements with the Medicaid agency.

Outreach

Outreach covers the set of activities the state undertakes to identify and inform potential applicants about the availability of home and community services and to provide information about how and where consumers can get them. There are many different ways to disseminate information concerning home and community services. Effective outreach programs incorporate several strategies to reach consumers on their own terms.

Activities can include collaborating in outreach with the "generic" human services networks individuals are likely to access or contact when they seek services (e.g., Area Agencies on Aging, seniors programs, Independent Living Centers, community developmental disabilities agencies, mental health centers, public health agencies that provide Maternal and Child Health Services, and homeless shelters). For example, a state may provide periodic, repeat orientation training for a network's intake staff to make sure they are well acquainted with what home and community services are available. In addition, states can reach out to other community networks (e.g., faith-based organizations) to which individuals might turn for assistance and guidance. These activities may be reimbursable under Medicaid when all Federal requirements are met.

State personnel might also attend conferences and meetings of consumer organizations, to make presentations concerning available services and to field questions from individuals interested in knowing more details about them. In addition, state personnel can work with such organizations to prepare newsletter articles concerning home and community services. Yet another potentially useful tool is preparing and distributing videos. The important point about these activities is, not only to provide basic information about available home and community services, but also to put a more human face on the information by including stories of and by persons who have benefited from them.

Addressing cultural diversity is particularly important. States may do this by making information available in relevant languages and/or contracting with individuals and community organizations to conduct outreach activities in a culturally appropriate and sensitive fashion. Similarly, states need to ensure that individuals with communication, cognitive, or sensory impairments can have access to such information.

The advent of the Internet provides exciting new opportunities to make information concerning home and community services more accessible to individuals and families. However, these opportunities may not be realized unless state agency and Medicaid program websites are designed with the information needs of consumers seeking services in mind. Additionally, they need to be accessible and usable by individuals with a wide range of physical, sensory, and cognitive disabili-

ties. States can become familiar with Federal guidelines for website access by going to www.access-board.gov. When designing or redesigning their sites to address such needs, states may want to consider teaming up with consumer organizations to launch sites that are distinctly consumer-oriented and consumer-friendly.

Application

Application is the next step in the process of gaining access to home and community services. The crucial point here is to ensure that the application process is, in fact, accessible to persons with severe physical and/or cognitive limitations.

Some consumers may be reluctant to apply for Medicaid for a number of reasons. A "welfare stigma" still attaches to the Medicaid program and some people may be anxious about the application process because it represents a "failure"—the inability to provide for themselves or their children. Others may be concerned about revealing personal financial information to "strangers." Still others may find the paperwork requirements to prove financial eligibility difficult to meet.

Overcoming these problems can be done in several ways. States should (a) encourage potential applicants to enlist trusted allies (e.g., family members and friends) to assist them in the application process, and (b) have sufficient staff so that the necessary time can be spent with applicants to ensure the process is understood and satisfactorily completed. In addition, the application forms themselves, along with associated materials, must be clear and easy to understand. To this end, such materials should be pretested and revised until they are readily understood by consumers. Another potentially useful strategy is employing people with disabilities (e.g., self advocates) to provide assistance and information to help applicants through the process.

States may also provide special training in disability issues and concerns to intake workers. In addition to being knowledgeable about home and community services generally, intake workers must be well-versed in any special provisions or rules that affect eligibility for people with disabilities. The importance of such training is highlighted by the fact that in some states which have adopted particular eligibility options (e.g., the TEFRA 134 option for children with severe disabilities), staff at intake/eligibility levels have not been made aware that the options are available.

States also might consider conducting customer satisfaction/feedback surveys. This is a good way to obtain first-hand information about how consumers feel about the Medicaid application process. Alternatively, individuals who have been through the process recently might be convened in focus groups, to discuss their experiences and provide ideas for making the process more consumer-sensitive and -friendly.

Yet another step is using outstationed or mobile workers to take applications and answer questions at locations around the community (including the consumer's own home), where individuals might be more comfortable than in an agency office. Advances in computing make it possible for workers to take applications almost anywhere. Using mobile workers can be especially important in rural areas and for reaching people who do not have transportation. To facilitate the application process, outstationed workers may be located at hospitals, nursing homes, or rehabilitation facilities to link with discharge planning teams. States may also contract with other human service networks to perform initial intake activities for the consumers they serve (e.g., Independent Living Centers or Area Agencies on Aging), so long as decisions concerning enrollment are made by the entity designated by the state to make the final eligibility determination. Additionally, states may find it useful to identify the points in the application process at which the current system facilitates institutional placement or establishes the institutional option as the norm, and to target educational efforts about home and community services at those points.

Finally, states can take steps to improve access to home and community services by individuals with disabilities who have limited English proficiency. Federal policy (Title VI of the Civil Rights Act of 1964) prohibits discrimination based on national origin. Entities that receive Federal Medicaid funds (including public agencies and

service providers) must take affirmative steps to accommodate the needs of individuals with limited English proficiency, whether in accessing Medicaid services or during provision of such services. FFP is available for state expenditures related to the provision of oral and written translation administrative activities and services provided for CHIP or Medicaid beneficiaries. It is also available for such activities or services, whether provided by staff interpreters, contract interpreters, or through a telephone service.[3] Similarly, FFP is available for providing interpreter services as an accommodation for hearing-impaired individuals as required by the ADA, to the extent that they are not otherwise available without charge.

Enrollment

After individuals apply for home and community services, they can only start receiving such services after the state determines they meet financial eligibility criteria (if they are not already eligible for Medicaid services) along with a state's health/functional criteria (consistent with Federal guidelines), and after a service plan has been drawn up and approved. In order to begin services as quickly as possible and thereby avoid hardship for the beneficiary, it is important that these activities be completed as expeditiously as possible. Some of the steps that states take to expedite the process include preparing service plans at the same time that level of care determinations are being made, or preparing provisional service plans to start some services immediately until a full service plan can be worked up. In other cases, states have eliminated requirements they deem unnecessary (e.g., dropping a requirement that the physician approve the service plan).

In sum, creating an effective home and community services program requires a commitment to changing the environment for delivery of long-term services—including conducting outreach and other education activities that inform individuals and service providers about the types of services available and making all parties aware of the full range of opportunities available to them. It is important that outreach, application, and enrollment processes be geared to making information about these opportunities widely available wherever and whenever decisions are being made about long-term services (e.g., as a part of discharge planning from institutional settings or when individuals first seek long-term services).

Connecting Individuals with the Services They Need

Designated case managers or service coordinators are responsible for conducting or coordinating the activities involved in connecting individuals with disabilities to home and community services. Under regular state Medicaid plan benefits (e.g., the personal care state option), there is no Federal requirement that service beneficiaries have a designated case manager, but many states provide one nonetheless.

This section discusses the program design options available to states for providing case management services to persons eligible to receive home and community services. The design of case management systems varies dramatically from state to state and program to program. Case managers or service coordinators may be public employees, work for private organizations, or be independent contractors. In some systems, case managers are responsible for all elements of service planning/authorization. Elsewhere, service coordinators prepare service plans that must be approved by the administering public agency. Typically case managers have additional responsibilities as well, including monitoring service provision, providing ongoing assistance to the individual in addressing problems in community living, and addressing emergency/crisis situations. (See Chapter 5 for a detailed discussion of case management financing alternatives for states.)

States follow one of two principal organizational models in addressing this aspect of system operation: (a) organizing around specific target population groups, or (b) using a single structure to encompass all target groups.

Organizing around Target Population Groups

Organizing home and community service delivery systems around specific target population groups

Organizing around Target Populations: Two State Examples

Aging Services in Indiana

Indiana organizes delivery of home and community services around the network of Area Agencies on Aging (AAAs). The AAAs administer programs funded under the Federal Older Americans Act (OAA). With the launch of Indiana's CHOICES HCBS waiver program, the AAAs were also designated to perform preadmission screening for Medicaid long-term care services, so that delivery of these services could be integrated with OAA and other locally available services for seniors.

Developmental Disabilities Services in Kansas

In Kansas, services for people with developmental disabilities are organized around 28 local, nonprofit Community Developmental Disabilities Organizations (CDDOs). Kansas law specifies that these organizations are the single point of entry for developmental disabilities services. The CDDO provides or arranges for service coordination for people who have a developmental disability, develops local strategic plans to improve service delivery and availability in the region served by the CDDO, manages local provider networks, and integrates local and state funding of developmental disabilities services. By law, the majority of the governing board of each CDDO must be individuals with developmental disabilities or members of families that include someone with a developmental disability. The CDDO also serves as the local point of entry for Kansas's HCBS waiver program for people with developmental disabilities.

(e.g., people with mental illness, elderly persons, people with mental retardation and other developmental disabilities, and so forth) is the more typical state pattern. Many states, for example, have state laws that establish organizational structures for the delivery of services to specific target populations. These state "governing laws" are especially common with respect to services for people with developmental disabilities and people with mental illness. In such cases, states usually seek to integrate delivery of Medicaid home and community services into these more established structures. This enables states to use preexisting, established points of entry, and facilitates development of a "seamless" service delivery structure.

When services are organized along target population lines, a state administering agency is typically charged with overseeing delivery of services to the specific target population, including operation of the point of entry system. In some cases, the state administering agency operates the points of entry system directly through regional offices, as permitted by Federal policy. With respect to HCBS waiver programs, for example, there is provision for state Medicaid agencies to enter into administrative agreements with other state agencies to conduct and manage various aspects of the operation of these programs. Such agreements help avoid the emergence of bifurcated administrative structures and permit the state Medicaid agency to take advantage of the expertise of other state administering agencies.

Using a Single Structure to Encompass All Target Groups

In this model, a local entity serves as the single point of entry for individuals with disabilities of all types. Sometimes called the one-stop shopping model, this organizational structure establishes one place to go for individuals and families wishing to gain access to long-term care services of many types, including home and community services. These single point of entry systems themselves may have specialty branches or linkages to specialty provider networks. This type of model is less common for home and community services than the model organized along target population lines.

Pros and Cons of the Two Models

Pros and cons are associated with each model and there are exemplary systems organized along both lines. Advantages cited in support of organizing

Minnesota's Single Point of Entry System

The state of Minnesota provides several home and community benefits (e.g., personal assistance) that cut across target population lines, along with specialized services keyed to the needs of particular target populations. In Minnesota, delivery of human services is organized around county human service agencies. These agencies are designated the single point of entry to all types of services—including public assistance, social services, health, and long-term services. Thus, anyone in Minnesota who needs publicly funded services can gain access to them through the county human service agency. This structure enables the individual (or family) to access the full range of services and supports Minnesota makes available, including home and community services. With respect to long-term services, counties manage intake, assessment, preadmission screening, and service authorization.

Minnesota's system is especially well positioned to tie together state and local programs. In its larger counties, specialty branches are also commonly found within the human services agency to meet the needs of specific target populations (e.g., people with developmental disabilities). One reason why Minnesota is organized in this fashion is that counties themselves are required to provide a portion of the funding for various services. In addition, many Minnesota counties provide a significant amount of local tax dollars, over and above required state matching requirements, to underwrite human services.

service systems along target population lines include: (a) it ensures that the specific needs of each target group are addressed in an expert, focused, and unified fashion; (b) it provides for the coordination of multiple Federal, state, local, private, and third-party funding streams that are especially relevant to meeting the needs of the target population; (c) it facilitates optimal use of the service delivery systems associated with different target populations, some of which are very large and complex in their own right and, thus, require dedicated management and oversight; and (d) it fits well with long-standing service systems. Disadvantages often cited with respect to organizing systems along target population lines include: (a) duplication of administrative structures; (b) overspecialization of services; (c) difficulties in coordinating the delivery of specialized services with services and benefits applicable to a wide range of target populations; and (d) difficulties in having their specific needs met for populations that do not have a designated service delivery agency in their state.

Advantages cited in support of the single structure model include: (a) it avoids individuals and families having to figure out which of many systems might best meet their needs; (b) individuals with disabilities have many needs that cross disability category lines and can be best addressed through a unified service system; (c) individuals and families can be afforded better access to a wider range of services than are available within more narrowly defined specialized systems organized around particular target populations; and (d) integrated systems are more economical to operate from an administrative cost standpoint, because they avoid duplicative organizational structures. Frequently cited disadvantages of such systems include: (a) they can be especially complex to administer; and (b) the specialized needs of specific target populations may be neglected.

Federal policy leaves it to each state to determine how best to organize its home and community service delivery system(s), as evidenced by the disparate organizational structures presently in place. The main Federal policy requirements in this arena are two: a state must administer its program uniformly across the state (unless a waiver of statewideness has been approved); and Medicaid services must fall under the authority of a single state agency that is responsible for ensuring the Medicaid state plan is being followed.

Federal policy does dictate that HCBS waiver programs be structured along target population lines. However, this policy does not dictate that a state establish a distinct, separate point of entry service delivery system for each HCBS waiver program. Nor does it prevent a state from designing HCBS waiver programs that define and offer benefits

Waiver Program Structures: Two State Examples

New Hampshire

New Hampshire has two distinct HCBS waiver programs: one for people with developmental disabilities and one for individuals with acquired brain injuries. Both of these programs are operated through the state's developmental services systems, using the state's long-standing network of developmental services area agencies as points of entry. While there are some differences in the needs of each target population, tying the HCBS waiver program for people with acquired brain disorder into the developmental services system enables individuals to gain access to an established provider network and avoids the expense associated with having to establish new points of entry for a relatively small HCBS waiver program.

Utah

Utah operates three HCBS waiver programs serving, respectively, (a) people with developmental disabilities; (b) individuals who have a physical disability but who are not developmentally disabled; and (c) individuals who have had a traumatic brain injury. All three are operated through the Division of Services for People with Disabilities (DSPD) service delivery system, and all employ the same point of entry—DSPD's regional offices.

that cut across a variety of target populations.

Whichever organizational model a state chooses, the following common system design considerations need to be taken into account, to ensure access by and responsiveness to individuals with long-term service needs and their families:

- *Local entry offices must be available in all parts of a state*, including rural areas. This may entail the use of multiple entry mechanisms. For example, in Montana (a very large and very rural state), case management services for home and community services for people with developmental disabilities are furnished by a combination of state regional office personnel and private contractors. The private contractors furnish service coordination in areas of the state that are too far away from the regional offices or too sparsely populated to justify the expense of setting up a state regional office.

- *There must be adequate resources to underwrite case management/service coordination activities.* Delivery of home and community services very often involves coordination across multiple public and private programs, as well as with informal caregiving networks, and intensive collaboration with individuals and families. Without adequate resources for service coordination, bottlenecks inevitably slow the provision of services and supports as well as undermine ongoing monitoring of service delivery.

  The amount of service coordination resources needed to ensure that service delivery systems are responsive to individuals and families depends on several factors—including family involvement, the degree to which the individuals desire and are able to serve as their own case managers, and the extent to which the individuals' disabilities may place them at risk. In developmental disabilities services, for example, many states seek to maintain case manager to consumer ratios between 1:30 and 1:45 in the case of adults; but higher workload ratios are common in the case of children with involved families.

- *Case management/service coordination must be conflict free.* This will help ensure that individuals and families are made aware of all service options, that they can exercise free choice of provider(s), and that there is a third party to whom consumers can turn if service problems are encountered. There should also be safeguards to ensure that service coordination is operating in the best interests of consumers. For this purpose, several state HCBS waiver programs are structured so that certain key aspects of service coordination may not be provided by any agencies or individuals also paid to furnish direct services to the individual.

- *System activities should be conducted in a culturally and disability-competent fashion.* This includes translating materials into different languages/media and providing interpreters (linguistic or sign-language services, for example) as necessary to accommodate the needs of the individual or the family.

As this discussion implies, operating an accessible and responsive point of entry network can be costly. Federal law and policy provide various options to secure FFP in these expenses, with respect to both operation of the point of entry system and various other administrative expenses.

States may obtain FFP for this purpose in three major ways: through the targeted case management optional state plan service, through an HCBS waiver program, or through administrative claiming. (Chapter 5 provides a detailed discussion of the pros and cons of each of these approaches.)[4] For a structure organized around target groups, there may not be much difference between the three alternatives. For a single point of entry system, however, the targeted case management option is particularly advantageous for two reasons. First, targeted case management may be made available to all Medicaid-eligible individuals (including HCBS waiver participants) who need home and community services without regard to type of funding source. This coverage option can be very useful in establishing a broad-based service coordination/point of entry system. Second, in the case of individuals with a developmental disability or a mental illness, a state may limit the providers of targeted case management services to the case management authorities already established in state law. This enables states to tie delivery of targeted case management services for these populations into point of entry systems that are already established.

Managing Dollars: General Considerations

At both Federal and state levels, it is enormously important that services and supports underwritten with taxpayer dollars be delivered in a cost-effective and efficient manner. States have limited dollars. If services are extremely costly, policymakers may feel they have no choice but to restrict access to home and community services or not offer them at all.

Maximum cost-effectiveness is particularly crucial given the expected increase over time in the number of individuals seeking HCB waiver services. This anticipated steady increase stems principally from demographic factors, such as the aging of the nation's population. As a result of people with developmental disabilities enjoying increased longevity, the demand for developmental disabilities services is increasing at a rate higher than population growth alone. There are large numbers of such individuals who now live with aging family caregivers. As these caregivers become less and less able to support the family member with a developmental disability, there has been a marked increase in the demand for residential services, including services offered through HCBS waiver programs.[5]

In designing an HCBS waiver program, a state should take into account future demand for services. Some of this demand may be absorbed by turnover among individuals served in the program (due to loss of Medicaid eligibility, voluntary termination, an individual no longer requiring services, or death). Such turnover is often insufficient, however, to enable a state to serve all individuals who seek and are eligible for HCB waiver services. If future demand is not accounted for, a waiting list can result or individuals might have to seek more costly institutional services instead.

Spending for home and community services is affected by two factors: the number of individuals who receive such services, and the per capita costs associated with furnishing services to such individuals.[6] In this context, managing dollars often boils down to developing strategies that address the demand for home and community services while, at the same time, taking steps to ensure that per capita costs are no greater than strictly necessary to acquire the services and supports individuals need.

As home and community services have unfolded over the years, managing dollars has come to

revolve around two tests: budget neutrality and cost-effectiveness:

- The **budget neutrality test** involves comparing total spending for long-term care services with and without offering home and community services. In other words, it asks the question: If home and community services are offered, will there be an offsetting decline in spending for institutional services or will overall spending increase?

- The **cost-effectiveness test** involves comparing per recipient spending on furnishing institutional services to per recipient spending on furnishing home and community services to the same group of individuals. A home and community service program is said to be cost-effective if its per recipient expenditures are no greater than the per recipient expenditures in institutional settings.

Budget neutrality is complex to assess, because it depends on determining how people who need and would benefit from long-term care services and supports will react when home and community services become available. Most individuals strongly prefer to remain in their homes and communities, even though many have functional limitations just as severe as those of individuals who receive institutional services. Thus, when institutional services are the only long-term services offered, many individuals will not seek formal long-term services and supports at all unless they are impossible to avoid (e.g., when a person's condition deteriorates to the point where constant care is required or overwhelms the informal caregiving the person has available).

For this reason, the number of individuals who meet institutional admission criteria is far greater than the number who actually seek institutional services. When home and community services are offered, however, people who would not accept institutional services will come forward to obtain home and community services, because such services match up better with their desires. That is, the overall expressed demand for long-term services and supports is greater when home and community services are offered in addition to institutional services than when they are not.

The budgetary impact of this increase in expressed demand depends on whether offering home and community services will lead to a sufficient reduction in demand for institutional services (typically much more expensive to provide) that is large enough to underwrite the costs of making home and community services available. Only when one completely offsets the other is budget neutrality achieved. For more than two decades, researchers have been analyzing the effect of newly offered home and community services on demand. Not surprisingly, this research affirms that more people will seek services when states make available services and supports in the home and community. Further, this research seems to show that achieving budget neutrality hinges on employing one of two strategies.

The first is to impose very stringent eligibility tests for receipt of home and community services. These tests do narrow the demand for home and community services. But they also make ineligible many individuals with severe disabilities who could benefit from home and community services. The second strategy is to provide residential alternatives (e.g., assisted living) that divert demand away from institutional services. In home and community services programs for people with developmental disabilities, for example, most states offer a variety of residential alternatives. This reduces demand for ICF/MR (institutional) services, which are very costly (approximately $78,000 per individual for a full year's services in 1998). Due at least in part to the rapid expansion of HCBS waiver programs for people with developmental disabilities, overall utilization of ICF/MR services has been declining steadily since 1993.

It is, in fact, extremely difficult to achieve budget neutrality when offering or expanding home and community services as an alternative to institutional services. A state's ability to achieve budget neutrality is tied in large part to its historical willingness to tolerate numbers of people with unmet needs. As unmet need is reduced, the pressure on states to increase the total number of persons served (in all long-term service settings, both institutional and HCBS) is correspondingly lessened.[7] However, budget neutrality is but one of many policy objectives states pursue with respect to long-term services and supports. Other objec-

Demand for ICFs/MR in Kansas

In 1993, about 2800 individuals with developmental disabilities in Kansas were receiving either ICF/MR or HCBS waiver services. About 1800 were served in ICFs/MR (including 900 individuals in large state-operated facilities). By January 2000, about 6000 individuals were receiving either ICF/MR or HCBS waiver services. The number served in ICFs/MR had dropped to fewer than 850 (with 380 of those in large state-operated facilities). During this period, the state closed one of its large public facilities and considerably reduced the number of persons served in the remaining two. Some privately operated state facilities also closed down because of high vacancy rates.

tives include ensuring that individuals with disabilities have a good quality of life, are able to remain in their homes and contribute to their communities, and remain as independent as possible. The narrowness of the budget neutrality test obviously does not take into account these other important policy objectives and considerations.

In recognition of these other objectives, Federal policy does not dictate that states manage Medicaid long-term services (institutional and/or home and community services) in a way that achieves budget neutrality, except in very special circumstances (associated with the use of some special waiver authorities). When cost tests are employed (as in HCBS waiver programs), they are cost-effectiveness rather than budget neutrality tests. As a consequence, states are free to expand home and community services to whatever extent they desire in pursuit of their policy aims. In developmental disabilities services, for example, many states (e.g., New York, Maryland, Montana, Pennsylvania) have launched multi-year initiatives to reduce the number of individuals who have been wait-listed for home and community services. These states expect to finance the cost of these substantial expansions through their HCBS waiver programs for people with developmental disabilities.

State strategies to expand availability of home and community services include leveraging current state and local funds as matching dollars to secure additional Federal Medicaid dollars. It is not unusual, for example, for a state to combine existing and newly appropriated state dollars to underwrite the costs of home and community services expansion. This type of leveraging is permissible.

The main practical questions that arise when a state desires to expand availability of home and community services concern whether to use Medicaid state plan coverages or provide such services through an HCBS waiver program. Either option allows a state to impose various limitations in order to keep per recipient costs to pre-established targets. The main difference between the two is that an HCBS waiver program provides states with authority to limit the number of people who may receive benefits, whereas state plan services must be available to all individuals who meet whatever service eligibility criteria a state may have established—making utilization of a new state plan benefit (and its associated costs) hazardous to predict, and potentially costly to implement.

One reason states are employing HCBS waiver programs so extensively as a means to underwrite the expansion of home and community services is that the authority states have to limit the number of beneficiaries permits them to better predict spending and keep it within available state dollars. With respect to some policy objectives, especially in terms of making benefits broadly available, state plan coverage of home and community services is the best choice.

As has been said, the HCBS waiver program contains an explicit cost-effectiveness test. It must be emphasized, however, that concerns about both budget neutrality and cost-effectiveness permeate all state strategic planning with respect to long-term services and supports (whether in an institutional or a home and community context).

Managing Dollars: HCBS Waiver Programs

Federal law requires a state to ensure that its HCBS waiver program is cost effective.[8] Cost-effectiveness in this context is defined by compar-

ing the overall per capita costs to the Medicaid program of furnishing services to individuals in home and community settings with the overall per capita costs of serving individuals in an institutional setting. This test is spelled out in Medicaid regulations by the formula:

$$D + D' < G + G'$$

where:

D is the average per capita cost of HCB waiver services

D' is the average per capita cost of other Medicaid services furnished to HCBS waiver beneficiaries

G is the average per capita cost of furnishing institutional services

G' is the average per capita cost of other Medicaid services furnished to institutionalized persons.[9]

Institutional costs are defined as those incurred in the type of institutional setting to which the HCBS waiver program in question serves as an alternative. In an HCBS waiver program for people with developmental disabilities, for example, waiver costs would be compared to the costs of services furnished in an ICF/MR. In the case of an HCBS waiver program for medically fragile children, inpatient hospital costs might serve as the point of comparison.

The formula takes only Medicaid expenditures into account. It does not include public outlays on any non-Medicaid benefits that might be available to individuals in the community but not to institutionalized persons (e.g., public assistance, housing assistance, food stamps, and similar benefits).

The formula does include the costs of *other Medicaid services*, both for people who participate in an HCBS waiver program and for people served in institutional settings. The main reason why these other costs are included is to make sure that like is being compared with like. Usually, institutional reimbursements include health care services. When individuals are not institutionalized, the same services are obtained through the state's regular Medicaid program. Including other Medicaid costs also recognizes differences among states in the benefits available through the state Medicaid plan for people in the community. If a state provides extensive personal assistance services under its state plan, for example, not including the costs of such services would result in a distorted comparison between the costs of supporting a person in the home and community versus the costs of serving that individual in an institutional setting.

The present formula took effect in 1994. It replaced a much more complicated formula requiring that a state demonstrate not only that its HCBS waiver program would be cost effective but also that it would be budget neutral, upon implementation, with respect to the projected costs of furnishing only institutional services to the target population.[10]

The cost-effectiveness formula has no caseload factor. A state may limit the number of individuals who may receive benefits through an HCBS waiver program, however, by specifying a maximum number of beneficiaries for each year the program will be in operation. A state may change this maximum number at any time by notifying HCFA of the change.

HCFA evaluates HCBS waiver cost estimates in terms of unduplicated beneficiary counts.[11] Once the specified maximum is reached, a state is permitted to deny enrollment to individuals and place them on a waiting list until "slots" open up under the enrollment cap (due, as already noted, to ineligibility of current beneficiaries, beneficiaries moving to another state, institutionalization, people voluntarily leaving the program, or death). Furthermore, a state may tie its enrollment limit directly to appropriations made by the state legislature for HCB waiver services.

The HCFA standard HCBS waiver application format has an entire section, Appendix G, for state documentation of its estimates of the formula values. The values for institutional costs are already known or readily obtained. Factor D is estimated by projecting the extent to which individuals are expected to use the various services the program

will offer and how much the state expects to pay for such services. Often these estimates are based on the state's experience in operating home and community services with state or local funds. Factor D' is estimated in various ways, including looking at the costs of services for Medicaid beneficiaries in the same eligibility categories, or costs in HCBS waiver programs that serve similar populations. Splicing together the figures needed to complete Appendix G can be complicated in the case of a brand new program. Once a program is in operation, however, preparing the figures in conjunction with a renewal request is less complicated because there is cost experience on which to base estimates.

Always keep in mind that the estimates a state makes in submitting an application (or a renewal) are just that: estimates. Once a program goes into operation, use of particular types of services may be different than expected and it may be necessary to pay different rates than originally expected. In addition, each request (whether to start a brand new waiver program or renew an existing one) covers a multi-year period. The longer the period covered by the request, the more likely it is that estimates will be off the mark one way or another.

The state incurs no penalty if, upon actual implementation, the figures for the various factors in the formula turn out to be different than the estimates, *provided that the program is cost-effective according to the statutory test.* If a state estimates that the average cost of furnishing HCB waiver services will be $15,000 per individual, for example, but the cost turns out to be $16,000, the state will not be penalized so long as that test is met. Similarly, if a state estimates that 45 percent of all individuals will use personal assistance services but 53 percent actually do, Federal payments will not be reduced provided that the program still meets the overall cost-effectiveness test. In other words, the figures a state uses to come up with its estimate of Factor D in the formula are not considered "line item" budgets.[12]

Federal policy gives states various options with respect to managing per recipient costs. In particular, a state may impose a "hard" or absolute limit on the maximum dollar value of HCB waiver services that will be authorized for any beneficiary, or it may decide not to impose such a limit but, instead, to manage its program to meet a target average cost per beneficiary (sometimes called an aggregate cost limit). States may also take other measures designed to keep HCBS waiver outlays at targeted per recipient levels.

Hard cost limits

A hard limit sets a maximum dollar ceiling on the benefits an individual may receive. A state may set this limit equal to the costs of institutional services, but it may also set it higher or lower.[13] The main advantage to a state of a hard dollar limit in operating an HCBS waiver program is that the state can be more confident that it will achieve its targeted per recipient spending level, since there is a ceiling on maximum expenditures. The main problem in operating a program with a hard dollar limit is that individuals who need services and supports that require outlays in excess of the limit (even by a little) will be denied admission to the program and, hence, be able only to receive institutional services to meet their needs. This poses problems because it is often these individuals who are most at risk of institutionalization in the first place. Hard limits set well below the costs of institutional services lead to heightened demand for institutional services. Hard caps set nearer to institutional per recipient costs enable the needs of more individuals to be met in the home and community.

A state may soften the impact of a hard dollar cap by providing for approval of plans of care that exceed the dollar cap in specific situations (e.g., when an individual's condition requires provision of services in excess of normal levels). A state may also exempt certain services from being counted against the dollar cap. For example, the costs of furnishing home modifications may push an individual over the limit. But since home modifications are usually a one-time expenditure, a state may decide not to count these costs and instead look solely at the costs of services provided on a continuing basis.

More than one dollar cap is permitted when a state designs a waiver with multiple service options. A state may also place reasonable limits on the amount, scope, and duration of particular waiver services. A state may even operate multiple HCBS waiver programs for the same target

population—with different cost limitations for each program based on beneficiary characteristics, living situation, or other factors.

Managing to a targeted average

Managing its program to stay within a targeted per recipient cost average allows a state to approve service plans above institutional cost levels, or the targeted average, in the expectation that other plans of care will come in well below those levels—thus balancing the costs of the high service plans. HCBS waiver programs that operate in this fashion are usually able to accommodate a wider range of consumer needs than programs that operate under fixed cost caps.

Many HCBS waiver programs use the targeted average approach. Its main disadvantage is that costs are less predictable, especially for a new program, because they depend on whether enrollment patterns match the assumptions made. Costs are more predictable in longstanding programs, because information is available on actual utilization patterns among program participants.

One way states can achieve some predictability concerning HCBS waiver per recipient costs, while avoiding the disadvantages associated with the use of hard caps, is to impose special controls over use of services that might be particularly vulnerable to over-utilization. A state may impose unit limitations on services and/or require that use of certain services beyond established threshold levels be subject to additional professional or clinical review, for example. A particular advantage of this approach is that it enables the state to better ensure that the health and welfare needs of consumers are identified and met. The disadvantage of such controls is that, although costs are more predictable, the controls can cause problems in their own right, especially with respect to accommodating the needs of particular individuals and families. A variation on this approach is found in the Illinois supported living option benefit described in Chapter 8. This establishes an overall dollar limit that governs a service group but affords flexibility to the individual (or family) in deciding the exact mixture of services that will be used.

Correcting common misperceptions

There is no Federal requirement that dictates that the costs of supporting a particular individual via an HCBS waiver program may not exceed institutional costs. States may extend HCB waiver services to individuals who require extraordinary levels of support. Many states accommodate individuals who require costly supports in the community by virtue of their disability, while continuing to operate HCBS waiver programs that meet Federal cost-effectiveness tests. A state may find it necessary to impose hard cost caps for budgetary or other reasons, but the use of such caps is not dictated by Federal policy.

The HCBS waiver cost-effectiveness test does not discriminate against individuals who have complex conditions. Since HCBS waiver cost-effectiveness is measured against the cost of institutional services, a state may find it difficult to accommodate certain individuals, because the costs of serving them may be many times the institutional average and a state might not be able to accommodate such individuals even using aggregate cost caps. However, Federal law gives a state the latitude, when requesting a waiver, to compare the costs of serving individuals *with these intensive needs* in an institutional setting (rather than the average costs for all people receiving institutional services).[14] The average annual cost of nursing facility care in a state might be $36,000, for example. If the cost of serving a person who has had a brain injury in such a facility is $50,000, that higher figure may be used as the point of comparison.

There is no requirement that HCBS waiver programs be budget neutral with respect to Federal financial participation. Thus, Federal policy places no restrictions on the number of individuals a state may serve in its HCBS waiver program(s). Each state may establish whatever limit it chooses and may change its limits whenever it wishes.

Payment and Contracting Policies

An important aspect of system design for ensuring access to home and community services while promoting cost-effectiveness involves two intertwined topics: payment and contracting for serv-

ices. Payment policies should encourage the economical and efficient delivery of services, while also enabling a sufficient number of service providers to participate to ensure that the needs of clients are met. Further, contracting policies should foster efficient service delivery and may aid in expanding services availability.

Payments

It is frequently, but mistakenly, believed that Federal policy prescribes precise methods states must follow in purchasing Medicaid services. In fact, Federal policy requirements with respect to Medicaid payments are quite basic:

- States may generally not pay a provider any more than the provider charges other third parties for the same service.
- Except in certain circumstances (discussed below), a state's payment must be tied to actual delivery of a covered service to a particular beneficiary.
- State payment levels must be high enough to attract sufficient providers to meet the needs of beneficiaries.
- States are expected to be "prudent buyers," seeking out providers who will furnish services most economically while avoiding providers that have excessive costs.

Within these broad parameters, Federal policy gives states considerable latitude in the methods they use to make payments for home and community services. Thus, states may (and do) use any of a wide range of methods to determine the amount they will pay for home and community services. States may also use different methods for different services. Methods in current use include:[15]

- **Fee-for-Service Price Schedules.** The state establishes a uniform payment rate that applies to all providers of a service (e.g., compensating nursing services at the rate of $35 an hour regardless of the organization furnishing the services). Personal assistance attendant services are frequently reimbursed on this basis.
- **Cost-Based Payments.** The state bases payment rates on the allowable costs incurred by the specific provider, usually accompanied by upper limits on costs to encourage cost-effective service provision.
- **Negotiated Rates.** The state bases payment rates on the specific provider's actual or expected service costs.
- **Difficulty-of-Care Payments/Rates.** The state pays providers amounts that vary based on expected differences in the intensity of services and supports specific individuals require. Such methods seek to improve access to services for individuals with particularly complex needs and conditions.
- **Market-Based Payments.** The state purchases goods and services from generic sources (as in the case of engaging a contractor to install a wheelchair ramp or to connect an individual to an emergency response system offered by the local telephone company).

Medicaid payments for services are unit-, encounter-, or item-based. Units are usually expressed in terms of time (e.g., hours, days, months). Encounters may include contacts—an intervention (e.g., a mental health counseling session) that may differ in duration depending on the needs of the consumer, or various other means of establishing a documentable tie between the payment and an activity on behalf of the individual. Payment rates are tied directly to the billing unit or encounter established by the state. Medicaid accountability requirements mandate that claims for service payment be based on defined activities performed on behalf of eligible beneficiaries. Item-based payments are employed to secure home and vehicle modifications (e.g., installing a van-lift) as well as equipment and supplies (e.g., communication devices). Item-based payments are used for one-time purchases or buying supplies from approved sources. (For managed care purchasing alternatives see discussion later in this chapter.)

State payment methods for home and community services are not usually reviewed in depth by

HCFA during its review of state Medicaid plan amendments or an HCBS waiver application renewal. Such methods may be reviewed in the course of other Agency activities to ensure they comply with basic Federal requirements.

Correcting common misperceptions

There is no Federal requirement that payment may only be made for services furnished "face to face." It is not true that providers may only be paid for the time during which they are providing direct, "hands on" services in the presence of an individual. It can obviously take time for a worker to travel to the individual's home. In the case of certain services, advance preparation may be required. And case managers frequently conduct activities on behalf of individuals (e.g., arranging for an assessment or locating home and community services) that do not require the consumer to be present. When payment policies fail to take such additional time and effort required into account, providers understandably can be reluctant to offer services.

Medicaid payments may be made for all these types of activities, since they are recognized as integral to delivering the home and community service. States may compensate providers for the time they spend in addition to the face-to-face part of the activity in either of two ways: (a) directly, as long as the activity falls within the scope of the service itself (as defined by the state in its Medicaid State Plan or waiver program), and benefits a specific individual, or (b) indirectly, by adjusting reimbursement rates to take into account the additional activities necessary to furnish the service.

There is no Federal rule against making "wraparound" payments. A wraparound payment is a single payment to a provider for provision of multiple services to a particular individual (in lieu of making a distinct payment for each specific service). For example, a worker who comes to an individual's home may, during the course of the visit, provide personal care, perform homemaker services, help balance the person's checkbook, and provide skill training. In an instance like this, the worker should not have to submit four distinct claims for payment, or keep track of the exact amount of time spent on each activity (which is likely to vary from visit to visit). To avoid unnecessary paperwork and potential billing complications, a state may define an HCB waiver service that includes or "wraps around" the full range of activities that might be performed routinely on behalf of an individual. When states offer "residential services" (e.g., assisted living or group home services), for example, the associated service definitions encompass a wide range of activities on behalf of residents. A similar approach may be used with respect to services furnished to individuals in their own or the family home.

Apart from their value in avoiding unnecessary complications in billing and services reimbursement, wraparound payments can also help prevent over-utilization of services, promote more efficient service delivery, and improve flexibility. When a variety of services is wrapped into a single definition and paid on a single-fee basis, service providers have greater latitude to deploy resources when and as needed among the individuals they serve, taking into account changes in consumer needs or special situations that arise from day to day. Service-by-service payment arrangements, in contrast, frequently encourage providers to furnish excessive services in order to capture revenue.

Just how far states may go in collapsing the services they offer through an HCBS waiver program into single "wraparound" services has increasingly become an issue over the years. On occasion, HCFA has required states to break into separate categories services they were trying to wrap up in a consolidated service definition (sometimes called bundling). HCFA's concerns about bundling revolve mainly around whether an individual's choice of provider may be constricted if a single provider is receiving payment for several services.[16] Such concerns arise generally when a state is proposing to bundle an especially wide range of services, which might prevent some providers from participating because they are not able to furnish the full range. It should be emphasized that HCFA has no hard-and-fast rule against bundling or wraparound service definitions. When concerns do arise, they are worked out between HCFA and the state on a case-by-case basis.

There is no Federal rule that all services must be paid based on hourly rates. States establish hourly pay-

North Dakota's Per Diem Rates for Supported Living Services

North Dakota establishes individual per diem rates for people with developmental disabilities who receive supported living services through the state's HCBS waiver program. These rates are based on the hours of staff services and supports specific individuals are expected to require as spelled out in their service plans. North Dakota prices out the costs of these services for a month and converts the overall cost to a per diem rate. Because actual services furnished to any particular consumer may vary from the hours upon which the service plan was based for various reasons, North Dakota requires that providers reconcile the total amount of supports furnished to supported living participants against total payments for such services. If spending for direct supports is significantly less than payments for such supports, North Dakota recovers the difference. This guards against the potential that providers might profit by withholding services. It also enables provider agencies to shift direct staff resources among individuals as needed.

ment rates for many types of services. However, other billing/payment units may also be used. Residential services are typically reimbursed using daily or per diem payments, for example, because such services do not vary substantially from day to day. Some states make payments for adult day health and developmental disabilities day habilitation services on a daily basis. And in some cases, states make monthly payments for services (e.g., for residential services and case management services). With respect to respite care services, states often use a variety of payment units (e.g., hourly payments for short-term respite but daily payments for extended respite). The use of per diem or monthly payments can simplify provider billings and payments, as well as make it easier for provider agencies to predict their revenue.

Contracting

In order to promote access to home and community services, as well as to give individuals as many choices as possible among providers, it is important that states (a) design their service delivery systems to encourage as many providers as possible to participate and (b) seek to simplify their contracting mechanisms.

Federal Medicaid law and policy requires that states enter into provider agreements with agencies and individuals qualified to furnish Medicaid services; Medicaid payments may not be made without such provider agreements. Further, Medicaid law generally requires that payments be made directly to the service provider rather than to an intermediary organization.

These requirements have posed practical problems for states in implementing home and community service programs—some of which stem from state-specific factors, especially when state law directs that a local service authority (e.g., a designated regional or local mental health/developmental disabilities authority) manage the purchase of services on behalf of individuals who live in a particular service region or catchment area. These policies also can cause headaches in purchasing services from individual contractors (e.g., personal care attendants) with respect to both executing agreements and making timely payments.

In addition, states themselves have laws and regulatory requirements that can lead to additional complications in service contracting. State procurement rules might dictate, for example, that contracts be based on the results of a Request for Proposals (RFP) process. These and similar rules may make it especially difficult for a state to rapidly acquire needed goods and services on behalf of individuals.

Various avenues are available to states, consistent with the requirements of Federal Medicaid law and policy, that facilitate contracting for home and community services and expansion of the available provider pool.

The Organized Health Care Delivery Systems (OHCDS) alternative

An OHCDS is an organization that furnishes one or more Medicaid services itself and has agreements with other organizations or individuals that furnish additional services. Federal rules permit a state to contract with an OHCDS to purchase services on behalf of beneficiaries. These rules mandate that the affiliation of other organizations

OHCDS Arrangements: State Examples

Massachusetts. The state's Department of Mental Retardation (DMR) has been deemed an OHCDS for the state's HCBS waiver program for people with mental retardation. DMR furnishes case management services to program participants through its regional and area offices. Use of the OHCDS arrangement in Massachusetts has enabled DMR to follow congruent contracting policies for both Medicaid and non-Medicaid services. Providers bill and are paid by DMR, which in turn recoups Federal Medicaid payments.

Missouri. In its HCBS waiver program for people with mental retardation and other developmental disabilities, the state has designated its regional mental retardation and developmental disabilities offices as OHCDSs. These regional offices furnish service coordination to HCBS waiver participants as well as other individuals. Missouri selected the OHCDS mechanism in order to encourage and make it easier for individuals and families to secure services from "non-traditional" providers (e.g., neighbors, friends). The regional office takes care of ensuring that the selected individuals meet requirements and enters into agreements with them. These providers submit bills to and are paid by the regional offices.

with an OHCDS must be voluntary. They also prohibit a state from dictating that individuals must obtain services exclusively from an OHCDS. When a state purchases services from an OHCDS, the OHCDS itself enters into agreements with affiliate providers, including negotiating a reimbursement rate with the affiliate. These agreements must meet basic Medicaid requirements. Affiliate providers are paid by the OHCDS according to the provisions of their contracts. The OHCDS, acting as a Medicaid provider, submits these claims to and is paid by the state.

OHCDS arrangements are used in many states to simplify contracting and payments and are recognized in the Federal HCBS waiver guidelines contained in the State Medicaid Manual. New York, in particular, has used this type of arrangement for several years in purchasing state Medicaid plan personal care/personal assistance services. OHCDS contracting has several advantages:

- It can match up well with typical home and community service structures, which often feature contracting with "master providers" that seek out and contract with other agencies and individuals to furnish services to individuals.
- It helps avoid some of the problems and complications independent contractors face when they must seek payment through a state's Medicaid claims processing system. For example, if a family wishes to hire a neighbor to provide respite, standard Medicaid contracting and claims submission procedures might discourage such an arrangement. The OHCDS mechanism can enable agreements to be entered into more quickly, with the OHCDS addressing the complications of Medicaid claiming.
- The OHCDS mechanism can be particularly apt in aligning contracting and payment practices when a state or local program authority is involved in the purchase of services. It enables the state to use common contracting and payment processes for both Medicaid and non-Medicaid services, thereby avoiding duplication.
- A provider is not restricted to furnishing services through an OHCDS. The provider may elect to bill the Medicaid agency directly, and be paid directly as well.

Other ways to improve service availability

Other alternatives are available to states as well. For example, Medicaid law and regulation permit providers to assign Medicaid payments to governmental entities (again on a voluntary basis).[17] This provision enables voluntary (re)assignment of Medicaid payments by a provider to a governmental entity (e.g., a county human services authority or a state program agency). Instead of the Medicaid payment being made directly to the provider, it is made to the governmental entity. This arrangement enables the governmental entity to make payments for services directly to providers, and to recoup Medicaid funds once the

service billing has been processed through a state's claims payment system. This arrangement may be used, for example, to enable a county human services agency to pay a personal assistant the consumer has selected, prepare and submit the claim for services provided, and receive the Medicaid payment to recoup the payment to the personal assistant. This permits more timely payments to be made to the personal assistant. In some states and localities, such an arrangement has greatly facilitated consumer-direction and self-determination in the provision of services, both through HCBS waiver programs and under the Medicaid state plan.

Medicaid law also provides for the assignment of claims to billing agents who, in turn, take care of the paperwork in obtaining Medicaid reimbursement. This alternative facilitates the use of financial intermediaries in consumer-directed models.

A key objective for states is to offer individuals and families a wide range of choices in the providers (agency or independent contractor) from which they obtain the home and community services they are authorized to receive. The alternative contracting mechanisms just described can aid in achieving this objective. A state may take other steps as well, including:

- Making sure the provider qualifications required of home and community services do not unnecessarily exclude potential suppliers—including independent contractors or other nontraditional sources of goods and services. For example, private housecleaning services can be an appropriate source of homemaker or chore services, rather than requiring such services to be furnished by human service agencies.

- Avoiding Request for Proposals (RFP) processes that have the effect of narrowing the number of agencies from which services can be purchased. Winner-take-all processes, for example, can discourage entry of new providers into a state's program and may violate Medicaid freedom of choice requirements. Request for Qualifications (RFQ) processes can frequently serve as appropriate substitutes. They enable a state to qualify multiple agencies to furnish services while also satisfying legitimate concerns about organizational capabilities and qualifications. The RFQ process was used successfully by Georgia, in identifying several qualified provider organizations to furnish services to individuals through a targeted HCBS waiver program. This program was implemented to facilitate community placement of individuals with mental retardation out of various state facilities.

- Cross-certification of providers among home and community services. Rather than having distinct provider requirements for each program serving a particular target population (except as necessary and appropriate), states can adopt common standards for similar services, and accept the certification of a provider for one HCBS waiver program as demonstrating that the provider meets the qualifications of other programs where similar services are furnished.

Innovative Mechanisms for Organizing Home and Community Services under Medicaid

As in the general health arena, there is interest in new mechanisms for organizing home and community services. These mechanisms generally build upon managed care arrangements to organize home and community service systems in ways that are potentially beneficial to both purchasers and consumers. It is important to note that, while application of managed care arrangements in the market for acute care services has become widely accepted, implementation of such arrangements in the long-term services market is still in its experimental stages and, as a consequence, is uncommon. The market for long-term services is very different from the market for acute care services, and the outcomes achieved through managed care technologies in acute care delivery may not be replicable in the long-term services field. Recently, however, some states have started implementing such arrangements (e.g., Minnesota, Texas, Florida.) They are doing so in pursuit of several goals:

- To tie payments for services to people rather than to specific services (i.e., through capitation)
- To purchase bundled services rather than individually distinct services
- To give providers and consumers of services flexibility to allocate resources in response to individualized needs
- To give providers and consumers flexibility to use Medicaid resources for new types of supportive services that might not otherwise be covered under the state Medicaid plan
- To promote more cost-efficient use of resources by placing providers/health plans at risk for the cost of services provided to consumers
- To reward with increased market share those providers/health plans that provide higher quality services
- To help promote quality by allowing consumers to choose among multiple providers/health plans that are competing with one another for market share.

Many of these objectives can also be achieved through a fee-for-service system. But proponents argue that managed care mechanisms make attainment of them easier. The next section discusses some of the specific managed care vehicles potentially available to states for organizing home and community services under Medicaid.

Prepaid Health Plans

Medicaid statute and regulation, as recently revised under the Balanced Budget Act (BBA) of 1997, recognizes two broad types of managed care entities with which states can enter into risk contracts. The first consists of comprehensive risk plans, or Managed Care Organizations (MCOs). These are entities that accept risk for a comprehensive package of Medicaid benefits (although one or more services covered under the regular state plan may be "carved out" of the comprehensive risk contract).[18] The other type of entity is a Prepaid Health Plan (PHP), which, by default, accepts risk for a less comprehensive package of Medicaid benefits. A managed care entity that accepts risk only for a benefit package that includes all services provided under an HCBS waiver program, for example, would be considered a PHP.

The differences between an MCO and a PHP are fairly technical and will not be discussed in detail here.[19] Both MCOs and PHPs often enact a utilization or care management function, whereby a primary care provider or managing entity authorizes medically necessary services before care is delivered and has a panel of providers to whom beneficiaries go to for care.

A small number of states have used the PHP authority as a purchasing strategy for home and community services. Florida has contracted with United Health Care under the PHP authority since the mid-1980s, for example, to manage its entire Medicaid home and community service population in three counties: Dade, Broward, and Palm Beach.

Wisconsin uses the PHP authority for purchasing services under its Partnership Program. Wisconsin's PHP contracts bundle payments, not only for services covered under the state's HCBS waiver program but also other selected Medicaid health and long-term services benefits (e.g., personal care services). The PHP contracting mechanism gives the managing organization considerable flexibility to organize, provide, or obtain services on behalf of enrollees. This mechanism also enables the PHP to apply any savings it might achieve in providing existing services to providing enrollees with additional benefits and/or enhancing service delivery. Consumer choice is maintained, because individuals may opt to enroll with the PHP or continue to receive services through the state's fee-for-service long-term services system.

1915(b) Waivers

The Balanced Budget Act (BBA) of 1997 allows states the option to submit a State Plan Amendment to mandate enrollment of certain groups of Medicaid eligibles into MCOs or PHPs.[20] Prior to the BBA, states had to obtain authority under a 1915(b) waiver or a Section 1115 demonstration to mandate enrollment of any group in managed

care organizations.[21]

Among the groups exempted from this option, however, are those individuals who are eligible for both Medicare and Medicaid ("dual eligibles") or other persons receiving long-term care services. Thus, some states have used 1915(b) freedom of choice waivers to implement managed care purchasing strategies for their Medicaid long-term care populations. Section 1902(a)(23) of the Social Security Act specifies that Medicaid beneficiaries be allowed to gain access to care from any Medicaid participating provider. However, since PHP and MCO networks consist of a finite group of providers, and often the beneficiary must obtain authorization for care, 1915(b) authority can be used to waive Section 1902(a)(23).

1915(b) waivers allow states to waive Medicaid's freedom of choice provisions to require particular groups of beneficiaries to receive their Medicaid-covered benefits through a managed care plan.[22] Many states use 1915(b) waivers to provide mental health and substance abuse services to their general welfare-related Medicaid beneficiaries.[23] Under these managed care models, such Medicaid beneficiaries may receive their physical health services through either the fee-for-service system or a managed care entity. But they must obtain their acute mental health and/or substance abuse services through a separate managed entity specializing in the delivery and management of these services.[24]

A smaller number of states have used 1915(b) waivers to provide long-term mental health services to persons with severe and persistent mental illness. These programs may be either part of a broader managed care initiative or an initiative targeted specifically to the needs of persons with severe and persistent mental illness. As part of a relatively broad mental health/substance abuse managed care program, for example, Colorado contracts with a variety of managed care entities (but primarily Community Mental Health Centers operating as PHPs) to provide a broad range of inpatient and outpatient services, including 24-hour residential care, to Medicaid beneficiaries with long-term mental health needs. By purchasing services for Medicaid beneficiaries with severe and persistent mental illness through such managed care models, Colorado is creating incentives for providers to meet the needs of the population more cost-effectively, while adhering to state and Federal quality standards. These models also allow mental health providers some flexibility in providing services that are not covered under the regular state plan.

1915(b) waivers cannot be used alone as a vehicle for providing home and community services to elderly and nonelderly Medicaid beneficiaries through managed care models. However, as discussed further below, a few states are now using what are called combination 1915(b)(c) waivers to finance and deliver such services through managed care strategies.

Combination 1915(b)(c) Waivers

A combined 1915(b)(c) waiver program is a relatively new vehicle for organizing the financing and delivery of home and community services under managed care models. The 1915(c) waiver authority allows a state to cover home and community services that are not eligible for Federal matching funds under the regular state plan. The 1915(b) waiver authority allows a state to deliver these services to persons in need of long-term care services through a managed care contracting approach.

The 1915(b)(c) waiver combination is somewhat cumbersome because, even though the waivers are intended to work in combination with one another, each waiver program must be submitted and evaluated separately under existing regulatory requirements. For example, each waiver must meet its own cost neutrality or cost-effectiveness test independently, without taking into account the cost impacts of the other. Also, each waiver has its own duration and its own reporting requirements, which states must comply with. Nonetheless, 1915(b)(c) waiver combinations are often perceived as preferable to Section 1115 waivers as vehicles for implementing innovative HCBS financing and delivery programs. This preference is likely because the 1915(b)(c) review process is quicker and more circumscribed. Section 1115 demonstration negotiations between states and HCFA are not as definitive and some-

Texas's Use of Combined 1915(b)(c) Waiver Authority

The Texas STAR+PLUS program operates under a combined 1915(b)(c) waiver. STAR+PLUS is a pilot program using a managed care delivery system to integrate acute health services with long-term care services for individuals with disabilities (including seniors). By integrating care in this manner, the state aims to: (a) provide the appropriate amount and types of services to help people stay as independent as possible; (b) serve people in the least constrained setting consistent with their safety; (c) improve care access, quality, and outcomes; (d) increase accountability for care; and (e) control costs. The project is expected to serve approximately 60,000 SSI and SSI-related Medicaid beneficiaries who are elderly or have disabilities.[25] Participants must choose from one of three health maintenance organizations (HMOs), two of which also offer Medicare managed care.

STAR+PLUS will benefit Medicaid beneficiaries by providing a continuum of care with a wider range of options than were formerly available and increased flexibility to meet individual needs. The program is expected to increase the number and types of providers available to Medicaid clients and move individuals into the health care mainstream. HMOs are required to assess all STAR+PLUS enrollees to determine needs and to develop appropriate care plans. By placing HMOs at full risk for nursing facility and expanded home and community services, STAR+PLUS presents HMOs with an incentive to provide innovative, cost-effective care from the outset, in order to prevent or delay the need for more costly institutionalization.

Long-term services and supports provided by the HMOs include day activity and health services, personal assistance, and nursing facility care. Additional services provided to HCBS waiver participants are adaptive aids, adult foster home services, assisted living, emergency response services, medical supplies, minor home modifications, nursing services, respite care, and therapies (occupational, physical, and speech/language). HMOs may also provide additional "value-added" services to clients, such as home and community services to those living in the community who are not currently enrolled in an HCBS waiver program.

Care coordination is an integral STAR+PLUS service. All HMOs must assign clients a care coordinator, who plays a central role in integrating care. This person is responsible for coordinating the client's acute and long-term care services, even for dual-eligible clients who receive Medicare from a provider who is not affiliated with the STAR+PLUS HMO's Medicare plan.

times have more specified terms and conditions of approval that require more intense reporting.

In 1998, Michigan implemented a Section 1915(b)(c) waiver program for people with developmental disabilities. Through this program, Michigan has been able to establish a uniform package of benefits for people with developmental disabilities. Previously, Medicaid state plan long-term services (including most ICF/MR, personal care, and clinical services) did not align with the benefits available through the state's HCBS waiver program for people with developmental disabilities. The Section 1915(b)(c) program permitted the state to align both state plan and HCBS waiver benefits to make a single package available to eligible persons with developmental disabilities and, thereby, remove artificial distinctions between state plan and waiver benefits.

Michigan decided to use the PHP contracting mechanism to contract for services with its existing network of county-based Community Mental Health Service Programs (CMHSPs). Instead of making service-by-service, consumer-by-consumer payments for long-term developmental disability services, the CMHSPs are now receiving capitated payments in advance and must manage the dollars they receive (within a "risk corridor") to meet the needs of individuals within their catchment areas. Contracting for and paying service providers is the responsibility of the CMHSP.

As in the case of Wisconsin's PHP system, the PHP contracting mechanism enables Michigan's CMHSPs, when they realize cost savings, to either purchase alternative services on behalf of enrollees or provide additional services beyond those mandated in their contract. Michigan's PHP contracts place affirmative requirements on PHPs to ensure that individuals are able to choose among service providers. In addition, state law requires that consumer service plans be developed using person-centered planning principles.

Section 1115 Waivers

Section 1115 demonstrations are the broadest Medicaid waiver authority available to states that wish to test innovative approaches to financing and delivering medical and supportive services to Medicaid beneficiaries. The general purpose of the Section 1115 demonstration authority is to allow states to experiment under the Medicaid program with new policies that could potentially further the overall objectives of the Medicaid program. Any policy experiment proposed under a Section 1115 demonstration must be a program model that has not been tested previously. It must also be an experiment that cannot potentially be conducted within the boundaries of more limited waiver authorities such as 1915(b) or 1915(c) waivers. And it must be amenable to rigorous evaluation, so that the results of the policy experiment can be used for further Medicaid policy development.

Fewer Section 1115 demonstration programs are currently being tested than in the recent past, particularly in the long-term care arena, for two reasons. First, both HCFA and states are electing to use more circumscribed waiver authorities whenever the program models to be tested fit within the boundaries of these more limited waivers. Second, since Section 1115 demonstrations are not subject to prescribed processing times, negotiations between states and HCFA, particularly on issues related to the requirement for rigorous evaluation methodologies, can take years to complete. States are increasingly reluctant to undergo such a long negotiating period in order to conduct a policy experiment.

In the area of home and community service development, the Section 1115 waiver program of greatest importance is the Arizona Long Term Care System (ALTCS). Originally implemented in 1989, ALTCS is a statewide managed care program for all Medicaid beneficiaries in need of long-term care services. All elderly and nonelderly persons with disabilities who qualify for Medicaid-covered long-term care benefits—whether nursing home care or home and community services—receive all their Medicaid-covered benefits, including acute care services, from a managed care plan (called a program contractor in ALTCS).

There is one program contractor per county. Thus, Medicaid beneficiaries do not have a choice of multiple plans, although ALTCS is now moving to a program model in which multiple program contractors will compete for business in Arizona's largest county—Maricopa (which includes Phoenix). ALTCS program contractors receive a monthly capitation payment for each long-term care beneficiary enrolled in their plan, and operate under financial incentives to meet the long-term care needs of their enrollees through the most cost-effective care plan. Under the ALTCS program model, Arizona has significantly expanded its use of home and community alternatives to nursing home services for its Medicaid clients. Independent evaluations of the program have generally concluded that the ALTCS program model is more efficient than Medicaid long-term care systems that rely on fee-for-service models.[26]

Program of All-Inclusive Care for the Elderly (PACE)

Since the early 1980s, states have been operating PACE demonstration sites as Section 1115 demonstrations. As of June 2000, PACE sites had been approved in 12 states. The PACE demonstration programs are modeled after the integrated system of acute and long-term care services developed by On Lok Senior Health Services in San Francisco, California. The Balanced Budget Act of 1997 (BBA) established the PACE model of care as a permanent provider entity within the Medicare/Medicaid program and enables states to provide PACE services to Medicaid beneficiaries as a state option rather than a demonstration.

PACE is a capitated benefit that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. Participants in PACE must be at least 55 years old, live in the PACE service area, and be certified by the appropriate state agency as eligible for a nursing home level of care. The PACE program becomes the sole source of services for its Medicare and Medicaid enrollees. The program is voluntary; beneficiaries may disenroll at any time.

An interdisciplinary team of professional and paraprofessional staff assesses participants' needs, develops care plans, and delivers all services (including acute care services and, when necessary, nursing facility services), in an integrated manner. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant's needs. The PACE service package must include all Medicare- and Medicaid-covered services and any other services determined necessary by the multidisciplinary team for the care of the PACE participant.

PACE providers receive monthly Medicare and Medicaid capitation payments for each eligible enrollee. Medicare-eligible participants not eligible for Medicaid pay monthly premiums equal to the Medicaid capitation amount. But no deductibles, coinsurance, or other type of Medicare or Medicaid cost-sharing applies. PACE providers assume full financial risk for participants' care without limits on amount, duration, or scope of services.

Endnotes

1. The primary contributors to this chapter are Gary Smith and Janet O'Keeffe.

2. States establish and administer their Medicaid programs in accordance with Federal statutory and regulatory provisions and submit their administrative expenditures to HCFA for approval.

3. HCFA letter to state Medicaid directors, August 31, 2000. Available at the following website: www.hcfa.gov/medicaid/smd83100.htm.

4. HCFA's policies with respect to the use of these alternatives are contained mainly in Section 4302 of the State Medicaid Manual. See also: Cooper, R.E., and Smith, G. (1998). *Medicaid and case management for people with developmental disabilities: Options, practice and issues.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

5. Smith, G. (1999). *Closing the gap: Addressing the needs of people with developmental disabilities waiting for supports.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.; Smith, G. (1999). *A supplement to Closing the gap: Addressing the needs of people with developmental disabilities waiting for supports.* Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.

6. Per capita costs, in turn, are affected by the extent to which individuals use the particular home and community services a state offers and the price paid for the services. Issues with respect to pricing are addressed separately in a later section of this chapter.

7. It is also difficult to achieve budget neutrality due to political pressures and practical concerns at the state level. For example, it would be difficult to close down a nursing home even if 90 percent of the residents were moved into HCBS waiver programs.

8. Section 1915(c)(2)(D) of the Social Security Act.

9. 42 CFR 441.303(f)(1).

10. Sometimes called the cold bed rule.

11. 42 CFR 441.303(f).

12. At the conclusion of each year, the state is required to prepare and submit to HCFA a special report (Form HCFA 372) that provides data concerning the actual cost-effectiveness of the state's program. When these data suggest that the state's estimates do not correspond to actual program experience, the state may be encouraged to amend its waiver to ensure that estimates are reasonable, as required by law.

13. The HCBS waiver application form provides directly for a state establishing a "hard cap" on the costs of institutional services. A state may select or reject this limit as it pleases. However, if rejected, a state must specify substitute limits of its choosing for the options contained in the application.

14. Section 1915(c)(7)(A) of the Social Security Act.

15. A discussion of the technical pros and cons associated with each of these methods is beyond the scope of this Primer.

16. HCFA is concerned that institutional models of care not be replicated in the community. In an institution, the facility assumes responsibility for identifying and meeting a resident's needs. In HCBS models, this responsibility is separate from the community-based milieu in which the individual lives. This separation is fundamental to the concept of community integration and the provision of services in the most integrated setting appropriate to a person's needs.

HCBS waiver programs are not intended to foster the re-creation of multiple (presumably smaller) "institutions" dispersed throughout the community. Rather, the program supports freedom of choice of providers for service and support needs. This purpose underlies

HCFA's expressed concern that "bundled" services may infringe on a beneficiary's freedom of choice by (a) limiting providers to those who can furnish the full range of bundled services, and (b) removing individuals' ability to participate fully in community life by eliminating their choice of service modality and provider.

17. Section 1902(a)(32)(B) of the Social Security Act and regulation 42 CFR 447.10(c).

18. Carving out a particular service means that it will not be included in the capitation rate but furnished by another provider.

19. For a more detailed discussion see Hamilton, T. (1995). *Using pre-paid health plan authority to provide integrated acute and long term care services under Medicaid.* Wisconsin Department of Health and Social Services.

20. Even after the State Plan Amendment became an option under the BBA, there are still certain groups that states cannot mandate enrollment for (e.g., children with disabilities).

21. Both 1915(b) and 1115(a) contain the authority to waive Section 1902(a)(23), the right of Medicaid beneficiaries to have freedom of provider choice.

22. Freedom of choice here means that under Medicaid's traditional fee-for-service system, Medicaid beneficiaries are free to receive Medicaid-covered services from any Medicaid-certified provider of their choosing. Under a 1915(b) managed care waiver, Medicaid beneficiaries must receive their Medicaid-covered services (i.e., those services covered under the managed care contract) from those providers included in their managed care plan's network.

23. These are recipients of benefits under Temporary Assistance for Needy Families (TANF), the successor of Aid to Families with Dependent Children (AFDC).

24. For a description of state Medicaid managed care programs for mental health and substance abuse services, see *State profiles, 1999, on public sector managed-behavioral health care* (May 2000). Washington, DC: Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

25. SSI-related beneficiaries are those who meet the SSI disability criteria but are not receiving SSI benefits because they have too much income or for other reasons.

26. McCall, N., Wrightson, C., Korb J., Crane, M., Weissert, W., and Wilkin, J. (1996). *Evaluation of Arizona's health care cost containment system demonstration.* Prepared for the Health Care Financing Administration by Laguna Research Associates.

Annotated Bibliography

Coleman, B. (October 1998). *New directions for state long-term care systems [2nd Edition].* Pub. #9809, Washington, DC: AARP, Public Policy Institute. (30 pages)

This issue paper describes the strategies used by states to increase and improve the organization, financing, and delivery of publicly funded long-term care services, particularly home and community based care services. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3860 or search their website at www.research.aarp.org. Publication ID: 9809.*

Wiener, J., and Stevenson, D. (August 1998). *Long-term care for the elderly: Profiles of thirteen states.* Washington, DC: The Urban Institute. (61 pages)

Part of the Urban Institute's "Assessing the New Federalism" project, this paper analyzes long-term care services for older adults in thirteen states (AL, CA, CO, FL, MA, MI, MN, MS, NJ, NY, TX, WA, and WI). It summarizes initiatives by these states to control the rate of increase in Medicaid long-term care expenditures for the elderly. *This article may be obtained free of charge from the Urban Institute website at www.urban.org/authors/wiener or by contacting the Urban Institute at (202) 833-7200.*

Weiner, J., and Stevenson, D. (May/June 1998). *State policy on long-term care for the elderly: States approach their long-term care policies differently, but all agree that curbing spending is top priority. Health Affairs* 17 (3): 81-100. (20 pages)

This article discusses state initiatives to provide long-term care. It looks at state objectives, difficulties in cutting costs, and Medicare maximization policies. The

Acronyms

AAA	Area Agencies on Aging
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
AFDC	Aid to Families with Dependent Children
AGI	Adjusted Gross Income
ALF	Assisted Living Facility
ASPE	Assistant Secretary for Planning and Evaluation
BBA	Balanced Budget Act
CD	Consumer Directed
CDDO	Community Developmental Disabilities Organization
CD-PAS	Consumer Directed Personal Assistance Services
CMHSP	Community Mental Health Service Program
COLA	Cost of Living Adjustment
DDP	Developmental Disabilities Profile
DMR	Department of Mental Retardation
DSPD	Division of Services for People with Disabilities
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
FFP	Federal Financial Participation
FMAP	Federal Medical Assistance Percentage
HCBS	Home and Community Based Services
HCFA	Health Care Financing Administration
HHA	Home Health Agency
HMO	Health Maintenance Organization
HUD	Housing and Urban Development
IADL	Instrumental Activities of Daily Living
ICAP	Inventory for Client and Agency Planning
ICF	Intermediate Care Facility
ICFs/MR	Intermediate Care Facilities for persons with Mental Retardation
IDEA	Individuals with Disabilities Education Act
IHSS	In-Home Supportive Services

IMD	Institution for Mental Disease
ISO	Intermediary Service Organization
LOC	Level of Care
MCO	Managed Care Organization
MDS	Minimum Data Set
MR/DD	Mental Retardation and other Developmental Disabilities
OAA	Older American Act
OBRA	Omnibus Budget Reconciliation Act
OHCDS	Organized Health Care Delivery Systems
PACE	Program of All-inclusive Care for the Elderly
PERS	Personal Emergency Response System
PHP	Prepaid Health Plan
RAI	Resident Assessment Instrument
RAP	Resident Assessment Protocol
RCF	Residential Care Facility
RN	Registered Nurse
RUG	Resource Utilization Group
SEP	Service Entry Point
SGA	Substantial Gainful Activity
SNF	Skilled Nursing Facility
SSA	Social Security Administration
SSI	Supplemental Security Income
SSP	State Supplemental Payment
TANF	Temporary Assistance for Needy Families
TCM	Targeted Case Management
TEFRA	Tax Equity and Fiscal Responsibility Act

Appendix I

Section 1915(c) Waiver Format Appendix B—Services and Standards

Appendix B-1: Definition of Services

The State requests that the following home and community-based services, as described and defined herein, be included under this waiver. Provider qualifications/standards for each service are set forth in Appendix B-2.

a) _____ Case Management

__ Services which will assist individuals who receive waiver services in gaining access to needed waiver and other State plan services, as well as needed medical, social, educational and other services, regardless of the funding source for the services to which access is gained.

__ Case managers shall be responsible for ongoing monitoring of the provision of services included in the individual's plan of care.

1.__Yes 2.__No

Case managers shall initiate and oversee the process of assessment and reassessment of the individual's level of care and the review of plans of care at such intervals as are specified in Appendices C & D of this request.

1.__Yes 2.__No

__ Other Service Definition (Specify):

_____

_____

_____

b) _____ Homemaker:

__ Services consisting of general activities (meal preparation and routine household care) provided by a trained homemaker, when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him or herself or others in the home. Homemakers shall meet such standards of education and training as are established by the State for the provision of these activities.

Note: The format of this form has been changed to conserve space.

__ Other Service Definition (Specify):

_____

_____

_____

c) _____ Home Health Aide services:

__ Services defined in 42 CFR 440.70, with the exception that limitations on the amount, duration and scope of such services imposed by the State's approved Medicaid plan shall not be applicable. The amount, duration and scope of these services shall instead be in accordance with the estimates given in Appendix G of this waiver request. Services provided under the waiver shall be in addition to any available under the approved State plan.

__ Other Service Definition (Specify):

_____

_____

_____

d) _____ Personal care services:

__ Assistance with eating, bathing, dressing, personal hygiene, activities of daily living. This services may include assistance with preparation of meals, but does not include the cost of the meals themselves When specified in the plan of care, this service may also include such housekeeping chores as bedmaking, dusting and vacuuming, which are incidental to the care furnished, or which are essential to the health and welfare of the individual, rather than the individual's family. Personal care providers must meet State standards for this service.

1. Services provided by family members (Check one):

__ Payment will not be made for personal care services furnished by a member of the individual's family.

__ Personal care providers may be members of the individual's family. Payment will not be made for services furnished to a minor by the child's parent (or stepparent), or to an individual by that person's spouse.

Justification attached. (Check one):

__ Family members who provide personal care services must meet the same standards as providers who are unrelated to the individual.

__ Standards for family members providing personal care services differ from those for other providers of this service. The different standards are indicated in Appendix B-2.

2. Supervision of personal care providers will be furnished by (Check all that apply):

__ A registered nurse, licensed to practice nursing in the State.

__ A licensed practical or vocational nurse, under the supervision of a registered nurse, as provided under State law.

__ Case managers

__ Other (Specify):

_____

_____

3. Frequency or intensity of supervision (Check one):

__ As indicated in the plan of care

__ Other (Specify):

_____

_____

4. Relationship to State plan services (Check one):

__ Personal care services are not provided under the approved State plan.

__ Personal care services are included in the State plan, but with limitations. The waivered service will serve as an extension of the State plan service, in accordance with documentation provided in Appendix G of this waiver request.

__ Personal care services under the State plan differ in service definition or provider type from the services to be offered under the waiver.

__ Other (Specify):

_____

_____

e) _____ Respite care:

__ Services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence or need for relief of those persons normally providing the care.

__ Other (Specify):

_____

_____

FFP will not be claimed for the cost of room and board except when provided as part of respite care furnished in a facility approved by the State that is not a private residence.

Respite care will be provided in the following location(s) (Check all that apply):

__ Individual's home or place of residence

__ Foster home

__ Medicaid certified Hospital

__ Medicaid certified NF

__ Medicaid certified ICF/MR

__ Group home

__ Licensed respite care facility

__ Other community care residential facility approved by the State that its not a private residence (Specify type):

_____

_____

__ Other service definition (Specify):

_____

_____

f) _____ Adult day health:

__ Services furnished 4 or more hours per day on a regularly scheduled basis, for one or more days per week, in an outpatient setting, encompassing both health and social services needed to ensure the optimal functioning of the individual. Meals provided as part of these services shall not constitute a "full nutritional regimen" (3 meals per day). Physical, occupational and speech therapies indicated in the individual's plan of care will be furnished as component parts of this service.

Transportation between the individual's place of residence and the adult day health center will be provided as a component part of adult day health services. The cost of this transportation is included in the rate paid to providers of adult day health services. (Check one):

1.___Yes 2.___No

__ Other service definition (Specify):

_____

_____

Qualifications of the providers of adult day health services are contained in Appendix B-2.

g) _____ Habilitation:

__ 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. This service includes:

__ Residential habilitation: assistance with acquisition, retention, or improvement in skills related to activities of daily living, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. Payments for residential habilitation are not made for room and board, the cost of facility maintenance, upkeep and improvement, other than such costs for modifications or adaptations to a facility required to assure the health and safety of residents, or to meet the requirements of the applicable life safety code. Payment for residential habilitation does not include payments made, directly or indirectly, to members of the individual's immediate family. Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid. Documentation which shows that Medicaid payment does not cover these components is attached to Appendix G.

__ Day habilitation: assistance with acquisition, retention, or improvement in self-

help, socialization and adaptive skills which takes place in a non-residential setting, separate from the home or facility in which the individual resides. Services shall normally be furnished 4 or more hours per day on a regularly scheduled basis, for 1 or more days per week unless provided as an adjunct to other day activities included in an individual's plan of care.

Day habilitation services shall focus on enabling the individual to attain or maintain his or her maximum functional level and shall be coordinated with any physical, occupational, or speech therapies listed in the plan of care. In addition, day habilitation services may serve to reinforce skills or lessons taught in school, therapy, or other settings.

__ Prevocational services not available under a program funded under section 110 of the Rehabilitation Act of 1973 or section 602(16) and (17) of the Individuals with Disabilities Education Act (20 U.S.C. 1401(16 and 17)). Services are aimed at preparing an individual for paid or unpaid employment, but are not job-task oriented. Services include teaching such concepts as compliance, attendance, task completion, problem solving and safety. Prevocational services are provided to persons not expected to be able to join the general work force or participate in a transitional sheltered workshop within one year (excluding supported employment programs).

Check one:

__ Individuals will not be compensated for prevocational services.

__ When compensated, individuals are paid at less than 50 percent of the minimum wage.

Activities included in this service are not primarily directed at teaching specific job skills, but at underlying habilitative goals, such as attention span and motor skills. All prevocational services will be reflected in the individual's plan of care as directed to habilitative, rather than explicit employment objectives.

Documentation will be maintained in the file of each individual receiving this service that:

1. The service is not otherwise available under a program funded under the Rehabilitation Act of 1973, or P.L. 94-142; and

__ Educational services, which consist of special education and related services as defined in sections (15) and (17) of the Individuals with Disabilities Education Act, to the extent to which they are not available under a program funded by IDEA. Documentation will be maintained in the file of each individual receiving this service that:

1. The service is not otherwise available under a program funded under the Rehabilitation Act of 1973, or P.L. 94-142; and

__ Supported employment services, which consist of paid employment for persons for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting. Supported employment is conducted in a variety of settings, particularly work sites in which persons without disabilities are employed.

Supported employment includes activities needed to sustain paid work by individuals receiving waiver services, including supervision and training. When supported employment services are provided at a work site in which persons without disabilities are employed, payment will be made only for the adaptations, supervision and training required by individuals receiving waiver services as a result of their disabilities, and will not include payment for the supervisory activities rendered as a normal part of the business setting.

Supported employment services furnished under the waiver are not available under a program funded by either the Rehabilitation Act of 1973 or P.L. 94-142. Documentation will be maintained in the file of each individual receiving this service that:

1. The service is not otherwise available under a program funded under the Rehabilitation Act of 1973, or P.L. 94-142; and

FFP will not be claimed for incentive payments, subsidies, or unrelated vocational training expenses such as the following:

1. Incentive payments made to an employer to encourage or subsidize the employer's participation in a supported employment program;
2. Payments that are passed through to users of supported employment programs; or
3. Payments for vocational training that is not directly related to an individual's supported employment program.

The State will require prior institutionalization in an NF or ICF/MR before a recipient is eligible for expanded habilitation services (pre-vocational, educational and supported employment).

1. ___Yes 2.___No

Transportation will be provided between the individual's place of residence and the site of the habilitation services, or between habilitation sites (in cases where the individual receives habilitation services in more than one place) as a component part of habilitation services. The cost of this transportation is included in the rate paid to providers of the appropriate type of habilitation services.

1. ___Yes 2.___No

__ Other service definition (Specify):

_____

_____

The State requests the authority to provide the following additional services, not specified in the statute. The State assures that each service is cost-effective and necessary to prevent institutionalization. The cost neutrality of each service is demonstrated in Appendix G. Qualifications of providers are found in Appendix B-2.

_____

_____

_____

h) _____ Environmental accessibility adaptations:

__ Those physical adaptations to the home, required by the individual's plan of care, which are necessary to ensure the health, welfare and safety of the individual, or which enable the individual to function with greater independence in the home, and without which, the individual would require institutionalization. Such adaptations may include the installation of ramps and grab-bars, widening of doorways, modification of bathroom facilities, or installation of specialized electric and plumbing systems which are necessary to accommodate the medical equipment and supplies which are necessary for the welfare of the individual. Excluded are those adaptations or improvements to the home which are of general utility, and are not of direct medical or remedial benefit to the individual, such as carpeting, roof repair, central air conditioning, etc. Adaptations which add to the total square footage of the home are excluded from this benefit. All services shall be provided in accordance with applicable State or local building codes.

__ Other service definition (Specify):

_____

_____

i) _____ Skilled nursing:

__ Services listed in the plan of care which are within the scope of the State's Nurse Practice Act and are provided by a registered professional nurse, or licensed practical or vocational nurse under the supervision of a registered nurse, licensed to practice in the State.

__ Other service definition (Specify):

_____

_____

j) _____ Transportation:

__ Service offered in order to enable individuals served on the waiver to gain access to waiver and other community services, activities and resources, specified by the plan of care. This service is offered in addition to medical transportation required under 42 CFR 431.53 and transportation services under the State plan, defined at 42 CFR 440.170(a) (if applicable), and shall not replace them. Transportation services under the waiver shall be offered in accordance with the individual's plan of care. Whenever possible, family, neighbors, friends, or community agencies which can provide this service without charge will be utilized.

__ Other service definition (Specify):

_____

_____

k) _____ Specialized Medical Equipment and Supplies:

__ Specialized medical equipment and supplies to include devices, controls, or appliances, specified in the plan of care, which enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with he environment in which they live.

This service also includes items necessary for life support, ancillary supplies and equipment necessary to the proper functioning of such items, and durable and non-durable medical equipment not available under the Medicaid State plan. Items reimbursed with waiver funds

shall be in addition to any medical equipment and supplies furnished under the State plan and shall exclude those items which are not of direct medical or remedial benefit to the individual. All items shall meet applicable standards of manufacture, design and installation.

__ Other service definition (Specify):

_____

_____

l) _____ Chore services:

__ Services needed to maintain the home in a clean, sanitary and safe environment. This service includes heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, moving heavy items of furniture in order to provide safe access and egress. These services will be provided only in cases where neither the individual, nor anyone else in the household, is capable of performing or financially providing for them, nd where no other relative, caregiver, landlord, community/volunteer agency, or third party payor is capable of or responsible for their provision. In the case of rental property, the responsibility of the landlord, pursuant to the lease agreement, will be examined prior to any authorization of service.

__ Other service definition (Specify):

_____

_____

m) _____ Personal Emergency Response Systems (PERS)

__ PERS is an electronic device which enables certain individuals at high risk of institutionalization to secure help in an emergency. The individual may also wear a portable "help" button to allow for mobility. The system is connected to the person's phone and programmed to signal a response center once a "help" button is activated. The response center is staffed by trained professionals, as specified in Appendix B-2. PERS services are limited to those individuals who live alone, or who are alone for significant parts of the day, and have no regular caregiver for extended periods of time, and who would otherwise require extensive routine supervision.

__ Other service definition (Specify):

_____

_____

n) _____ Adult companion services:

__ Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise the individual with such tasks as meal preparation, laundry and shopping, but do not perform these activities as discrete services. The provision of companion services does not entail hands-on nursing care. Providers may also perform light housekeeping tasks which are incidental to the care and supervision of the individual. This service is provided in accordance with a therapeutic goal in the plan of care, and is not purely diversional in nature.

__ Other service definition (Specify):

_____

_____

o) _____ Private duty nursing:

__ Individual and continuous care (in contrast to part time or intermittent care) provided by licensed nurses within the scope of State law. These services are provided to an individual at home.

__ Other service definition (Specify):

_____

_____

p) _____ Family training:

__ Training and counseling services for the families of individuals served on this waiver. For purposes of this service, "family" is defined as the persons who live with or provide care to a person served on the waiver, and may include a parent, spouse, children, relatives, foster family, or in-laws. "Family" does not include individuals who are employed to care for the consumer. Training includes instruction about treatment regimens and use of equipment specified in the plan of care, and shall include updates as necessary to safely maintain the individual at home. All family training must be included in the individual's written plan of care.

__ Other service definition (Specify):

_____

_____

q) _____Attendant care services:

__ Hands-on care, of both a supportive and health-related nature, specific to the needs of a medically stable, physically handicapped individual. Supportive services are those which substitute for the absence, loss, diminution, or impairment of a physical or cognitive function. this service may include skilled or nursing care to the extent permitted by State law. Housekeeping activities which are incidental to the performance of care may also be furnished as part of this activity.

Supervision (Check all that apply):

__ Supervision will be provided by a Registered Nurse, licensed to practice in the State. The frequency and intensity of supervision will be specified in the individual's written plan of care.

__ Supervision may be furnished directly by the individual, when the person has been trained to perform this function, and when the safety and efficacy of consumer-provided supervision has been certified in writing by a registered nurse or otherwise as provided in State law. This certification must be based on direct observation of the consumer and the specific attendant care provider, during the actual provision of care. Documentation of this certification will be maintained in the consumer's individual plan of care.

__ Other supervisory arrangements (Specify):

_____

_____

__ Other service definition (Specify):

_____

_____

r) _____ Adult Residential Care (Check all that apply):

__ Adult foster care: Personal care and services, homemaker, chore, attendant care and companion services medication oversight (to the extent permitted under State law) provided in a licensed (where applicable) private home by a principal care provider who lives in the home. Adult foster care is furnished to adults who receive these services in conjunction with residing in the home. the total number of individuals (including persons served in the waiver) living in the home, who are unrelated to the principal care provider, cannot exceed). Separate payment will not be made for homemaker or chore services furnished to an individual receiving adult foster care services, since these services are integral to and inherent in the provision of adult foster care services.

__ Assisted living: Personal care and services, homemaker, chore, attendant care, companion services, medication oversight (to the extent permitted under State law), therapeutic social and recreational programming, provided in a home-like environment in a licensed (where applicable) community care facility, in conjunction with residing in the facility. This service includes 24 hour on-site response staff to meet scheduled or unpredictable needs in a way that promotes maximum dignity and independence, and to provide supervision, safety and security. Other individuals or agencies may also furnish care directly, or under arrangement with the community care facility, but the care provided by these other entities supplements that provided by the community care facility and does not supplant it.

Personalized care is furnished to individuals who reside in their own living units (which may include dually occupied units when both occupants consent to the arrangement) which may or may not include kitchenette and/or living rooms and which contain bedrooms and toilet facilities. The consumer has a right to privacy. Living units may be locked at the discretion of the consumer, except when a physician or mental health professional has certified in writing that the consumer is sufficiently cognitively impaired as to be a danger to self or others if given the opportunity to lock the door. (This requirement does not apply where it conflicts with fire code.) Each living unit is separate and distinct from each other. The facility must have a central dining room, living room or parlor, and common activity center(s) (which may also serve as living rooms or dining rooms). The consumer retains the right to assume risk, tempered only by the individual's ability to assume responsibility for that risk. Care must be furnished in a way which fosters the independence of each consumer to facilitate aging in place. Routines of care provision and service delivery must be consumer-driven to the maximum extent possible, and treat each person with dignity and respect.

Assisted living services may also include (Check all that apply):

__ Home health care

__ Physical therapy

__ Occupational therapy

__ Speech therapy

__ Medication administration

__ Intermittent skilled nursing services

__ Transportation specified in the plan of care

__ Periodic nursing evaluations

__ Other (Specify)

_____

_____

However, nursing and skilled therapy services (except periodic nursing evaluations if specified above) are incidental, rather than integral to the provision of assisted living services. Payment will not be made for 24-hour skilled care or supervision. FFP is not available in the cost of room and board furnished in conjunction with residing in an assisted living facility.

__ Other service definition (Specify):

_____

_____

Payments for adult residential care services are not made for room and board, items of comfort or convenience, or the costs of facility maintenance, upkeep and improvement. Payment for adult residential care services does not include payments made, directly or indirectly, to members of the consumer's immediate family. The methodology by which payments are calculated and made is described in Appendix G.

s) _____ Other waiver services which are cost-effective and necessary to prevent institutionalization (Specify):

t) _____ Extended State plan services:

The following services, available through the approved State plan, will be provided, except that the limitations on amount, duration and scope specified in the plan will not apply. Services will be as defined and described in the approved State plan. The provider qualifications listed in the plan will apply, and are hereby incorporated into this waiver request by reference. These services will be provided under the State plan until the plan limitations have been reached. Documentation of the extent of services and cost-effectiveness are demonstrated in Appendix G. (Check all that apply):

__ Physician services

__ Home health care services

__ Physical therapy services

__ Occupational therapy services

__ Speech, hearing and language services

__ Prescribed drugs

__ Other State plan services (Specify):

_____

_____

_____ Services for individuals with chronic mental illness, consisting of (Check one):

__ Day treatment or other partial hospitalization services (Check one):

__ Services that are necessary for the diagnosis or treatment of the individual's mental illness. These services consist of the following elements:

A individual and group therapy with physicians or psychologists (or other mental health professionals to the extent authorized under State law),

B ccupational therapy, requiring the skills of a qualified occupational therapist,

C services of social workers, trained psychiatric nurses, and other staff trained to work with individuals with psychiatric illness,

D drugs and biologicals furnished for therapeutic purposes,

E individual activity therapies that are not primarily recreational or diversionary,

F family counseling (the primary purpose of which is treatment of the individual's condition),

G training and education of the individual (to the extent that training and educational activities are closely and clearly related to the individual's care and treatment), and

H diagnostic services.

Meals and transportation are excluded from reimbursement under this service. The purpose of this service is to maintain the individual's condition and functional level and to prevent relapse or hospitalization.

__ Other service definition (Specify):

_____

_____

___ Psychosocial rehabilitation services (Check one):

__ Medical or remedial services recommended by a physician or other licensed practitioner under State law, for the maximum reduction of physical or mental disability and the restoration of maximum functional level. Specific services include the following:

A restoration and maintenance of daily living skills (grooming, personal hygiene, cooking, nutrition, health and mental health education, medication management, money management and maintenance of the living environment);

B social skills training in appropriate use of community services;

C development of appropriate personal support networks, therapeutic recreational services (which are focused on therapeutic intervention, rather than diversion); and

D telephone monitoring and counseling services.

The following are specifically excluded from Medicaid payment for psychosocial rehabilitation services:

A vocational services,

B prevocational services,

C supported employment services, and

D room and board.

__ Other service definition (Specify):

_____

_____

__ Clinic services (whether or not furnished in a facility) are services defined in 42 CFR 440.90.

Check one:

__ This service is furnished only on the premises of a clinic.

__ Clinic services provided under this waiver may be furnished outside the clinic facility. Services may be furnished in the following locations (Specify):

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Appendix II

State Medicaid Manual, Section 4480: Personal Care Services

Section 4480: Personal Care Services

A. General.—Effective November 11, 1997, HCFA published a final regulation in the Federal Register that removed personal care services from regulations at 42 CFR 440.170 and added a new section at 42 CFR 440.167, A Personal Care Services in a home or other location. The final rule specifies the revised requirements for Medicaid coverage of personal care services furnished in a home or other location as an optional benefit. This rule conforms to the Medicaid regulations and to the provisions of §13601(a)(5) of the Omnibus Budget Reconciliation Act (OBRA) of 1993, which added §1905(a)(24) to the Social Security Act to include payment for personal care services under the definition of medical assistance

Under §1905(a)(24) of the Act, States may elect, as an optional Medicaid benefit, personal care services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for persons with mental retardation (ICF/MR), or institution for mental disease. The statute specifies that personal care services must be: (1) authorized for an individual by a physician in a plan of treatment or in accordance with a service plan approved by the State; (2) provided by an individual who is qualified to provide such services and who is not a member of the individual's family; and (3) furnished in a home or other location.

B. Changes Made by Final Regulation.—Personal care services may now be furnished in any setting except inpatient hospitals, nursing facilities, intermediate care facilities for the mentally retarded, or institutions for mental disease. States choosing to provide personal care services may provide those services in the individual's home, and, if the State so chooses, in settings outside the home.

In addition, services are not required by Federal law to be provided under the supervision of a registered nurse nor does Federal law require that a physician prescribe the services in accordance with a plan of treatment. States are now permitted the option of allowing services to be otherwise authorized for the beneficiary in accordance with a service plan approved by the State.

C. Scope of Services.—Personal care services (also known in States by other names such as personal attendant services, personal assistance services, or attendant care services, etc.) covered under a State's program may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages which enables them to accomplish tasks that they would normally do for themselves if they did not have a disability. Assistance may be in the form of hands-on assistance (actually performing a personal care task for a person) or cueing so that the person performs the task by him/her self. Such assistance most often relates to performance of ADLs and IADLs. ADLs include eating, bathing, dressing, toileting, transferring, and maintaining continence. IADLs capture more complex life

activities and include personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. Personal care services can be provided on a continuing basis or on episodic occasions. Skilled services that may be performed only by a health professional are not considered personal care services.

1. Cognitive Impairments.—An individual may be physically capable of performing ADLs and IADLs but may have limitations in performing these activities because of a cognitive impairment. Personal care services may be required because a cognitive impairment prevents an individual from knowing when or how to carry out the task. For example, an individual may no longer be able to dress without someone to cue him or her on how to do so. In such cases, personal assistance may include cueing along with supervision to ensure that the individual performs the task properly.

2. Consumer-Directed Services.—A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary 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. The State Medicaid Agency maintains responsibility for ensuring the provider meets State provider qualifications (see E below) and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the State may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving the services.

D. Definition of Family Member.—Personal care services may not be furnished by a member of the beneficiary's family. Under the new final rule, family members are defined to be "legally responsible relatives." Thus, spouses of recipients and parents of minor recipients (including stepparents who are legally responsible for minor children) are included in the definition of family member. This definition necessarily will vary based on the responsibilities imposed under State law or under custody or guardianship arrangements. Thus, a State could restrict the family members who may qualify as providers by extending the scope of legal responsibility to furnish medical support.

E. Providers.—States must develop provider qualifications for providers of personal care services and establish mechanisms for monitoring the quality of the service. Services such as those delegated by nurses or physicians to personal care attendants may be provided so long as the delegation is in keeping with State law or regulation and the services fit within the personal care services benefit covered under a State's plan. Services such as assistance with taking medications would be allowed if they are permissible in States' Nurse Practice Acts, although States need to ensure the personal care assistant is properly trained to provide medication administration and/or management.

States may wish to employ several methods to ensure that recipients are receiving high quality personal care services. For example, States may opt to a criminal background check or screen personal care attendants before they are employed. States can also establish basic minimal requirements related to age, health status, and/or education and allow the recipient to be the judge of the provider's competency through an initial screening. States can provide training to personal care providers. States also may require agency providers to train their employees. States can also utilize case managers to monitor the competency of personal care providers. State level oversight of overall program compliance, standards, case level oversight, attendant training and screening, and recipient complaint and grievance mechanisms are ways in which States can monitor the quality of their personal care programs. In this way, States can best address the needs of their target populations and develop unique provider qualifications and quality assurance mechanisms.

Health Care Financing Administration
Center for Medicaid and State Operations

March 9, 1998

Dear State Medicaid Director:

This letter is one of a series that provides guidance on the implementation of the Balanced Budget Act.

We are writing to alert you to a change in policy on section 4733 of the Balanced Budget Act of 1997 (BBA) from that set forth in our State Medicaid Director letter dated November 24, 1997. Section 4733 created an optional categorically needy group designed to provide Medicaid eligibility to disabled working individuals who, because of relatively high earnings, cannot qualify for Medicaid under one of the other statutory provisions under which disabled working individuals may be eligible for medical assistance.

In an enclosure to the November 24 letter, we described a two-step eligibility process consisting of a family income test of 250 percent of the Federal poverty level, followed by an individual eligibility determination. The family income test required that the family's gross income, essentially without deductions or exemptions, be compared to 250 percent of the poverty level for a family of the size involved.

Since release of the November 24 letter, concerns have been raised about the use of the family's gross income for the family income test. The primary objection is that using the family's gross income limits the amount of income individuals could have and still qualify for eligibility under this group to a point where, in approximately half the States, the income standard under section 4733 is lower than the income standard under section 1619(b) of the Act.

In view of these concerns, and after careful consideration of the options available, we have decided to change our policy on the family income test. Instead of using the family's gross income, States wishing to cover this group should measure the family's net income against the 250 percent family income standard. The family's net income is determined by applying all appropriate SSI income disregards, including the earned income disregard, to the family's total income. The result, i.e., the family's net income, is then compared to the 250 percent income standard.

Use of the family's net, rather than gross, income will have the affect of greatly increasing the amount of income a disabled individual can have and still qualify for eligibility under this group. This in turn will enable States to provide Medicaid to a greater number of disabled individuals, who without such coverage might not be able to work.

The revised enclosure explains use of the net, rather than gross, family income test. It also provides information, which was not included in the earlier version, on use of section 1902(r)(2) more liberal methodologies, as well as use of more restrictive policies in 209(b) States. We also make it clear that the SSI income standard, which is used to determine the individual's eligibility following the family net income test, includes optional State supplementary payments. Finally, the revised enclosure discusses the use of substantial gainful activity (SGA) as a criterion in determining eligibility under this group.

We apologize for any inconvenience issuance of our previous policy may have caused. Any questions about this provision or this letter should be directed to Roy Trudel of my staff at (410) 786-3417.

Sincerely,

Sally K. Richardson
Director, Center for Medicaid and State Operations

Enclosure

Enclosure

Determining Eligibility for Individuals Under Section 4733 of BBA

The eligibility determination for individuals in this group is essentially a sequential two-step process.

1. The first step is a net income test, based on the family's combined income, including all earnings. (A family can also be just one individual; i.e., a family of one.) The family's net combined income must be less than 250 percent of the federal poverty level for a family of the size involved. Family income is determined by applying all appropriate SSI disregards and exemptions, including the earned income disregard, to the family's total income. If the family's income, after all deductions and exemptions have been applied, is equal to or exceeds 250 percent of the appropriate poverty level, the individual is not eligible for Medicaid under this provision.

   It is up to the State to determine what constitutes a "family" in the context of this provision. As one example, a State could choose to consider a disabled adult living with his or her parents as a family of one for purposes of meeting the 250 percent family income standard.

2. Assuming the individual has met the net family income test, the second step is a determination of whether he or she meets the disability, assets, and unearned income standards to receive an SSI benefit. Income of other family members used in Step 1 is not included (unless the individual has an ineligible spouse whose income is subject to the SSI deeming rules). To be eligible under this provision, the individual must meet all SSI eligibility criteria (including categorical requirements).

   SSI methodologies are used in making this determination except that all earned income received by the individual is disregarded. The individual's countable unearned income (e.g., title II disability benefits) must be less than the SSI income standard (in 1998, $494 for an individual), or the standard for optional State supplementary payments (SSP) if the State makes such payments. If unearned income equals or exceeds the SSI/SSP income standard, the individual is not eligible for Medicaid under this provision.

   The individual's countable resources must be equal to or less than the SSI resource standard ($2,000 for an individual).

   Under section 1902(r)(2) of the Act, States may use more liberal income and resource methodologies than are used by the SSI program in determining eligibility for this group. Also, 209(b) States may, but are not required to, apply their more restrictive eligibility policies in determining eligibility for this group.

   There is no requirement that the individual must at one time have been an SSI recipient to be eligible under this provision. However, if the individual was not an SSI recipient, you must do a disability determination to ensure that the individual would meet the eligibility requirements for SSI. A disability determination for an individual who was not previously an SSI recipient should not consider whether the individual engaged in substantial gainful activity (SGA), since use of SGA as an eligibility criterion would in almost all instances result in the individual not being eligible under this group, effectively negating the intent of this provision.

Health Care Financing Administration
Center for Medicaid and State Operations

July 29, 1998

Dear State Medicaid Director:

In the Americans with Disabilities Act (ADA), Congress provided that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." 42 U.S.C. § 12101(a)(8). Title II of the ADA further provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity, or be the subject of discrimination by any such entity." 42 U.S.C. § 12132. Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

We have summarized below three Medicaid cases related to the ADA to make you aware of recent trends involving Medicaid and the ADA.

> In L.C. & E.W. v. Olmstead, patients in a State psychiatric hospital in Georgia challenged their placement in an institutional setting rather than in a community-based treatment program. The United States Court of Appeals for the Eleventh Circuit held that placement in an institutional setting appeared to violate the ADA because it constituted a segregated setting, and remanded the case for a determination of whether community placements could be made without fundamentally altering the State's programs. The court emphasized that a community placement could be required as a "reasonable accommodation" to the needs of disabled individuals, and that denial of community placements could not be justified simply by the State's fiscal concerns. However, the court recognized that the ADA does not necessarily require a State to serve everyone in the community but that decisions regarding services and where they are to be provided must be made based on whether community-based placement is appropriate for a particular individual in addition to whether such placement would fundamentally alter the program.
>
> In Helen L. v. DiDario, a Medicaid nursing home resident who was paralyzed from the waist down sought services from a State-funded attendant care program which would allow her to receive services in her own home where she could reside with her children. The United States Court of Appeals for the Third Circuit held that the State's failure to provide services in the "most integrated setting appropriate" to this individual who was paralyzed from the waist down violated the ADA, and found that provision of attendant care would not fundamentally alter any State program because it was already within the scope of an existing State program. The Supreme Court declined to hear an appeal in this matter; thus, the Court of Appeals decision is final.
>
> In Easley v. Snider, a lawsuit, filed by representatives of persons with disabilities deemed to be incapable of controlling their own legal and financial affairs, challenged a requirement that beneficiaries of their State's attendant care program must be mentally alert. The Third Circuit found that, because the essential nature of the program was to foster independence for individuals limited only by physical disabilities, inclusion of individuals incapable of controlling their own legal and financial affairs in the program would constitute a fundamental alteration of the program and was not required by the ADA. This is a final decision.

While these decisions are only binding in the affected circuits, the Attorney General has indicated that under the ADA States have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. Reasonable steps should be taken if the treating professional

determines that an individual living in a facility could live in the community with the right mix of support services to enable them to do so. The Department of Justice recently reiterated that ADA's "most integrated setting" standard applies to States, including State Medicaid programs.

States were required to do a self-evaluation to ensure that their policies, practices and procedures promote, rather than hinder integration. This self-evaluation should have included consideration of the ADA's integration requirement. To the extent that any State Medicaid program has not fully completed its self-evaluation process, it should do so now, in conjunction with the disability community and its representatives to ensure that policies, practices and procedures meet the requirements of the ADA. We recognize that ADA issues are being clarified through administrative and judicial interpretations on a continual basis. We will provide you with additional guidance concerning ADA compliance as it becomes available.

I urge you also, as we approach the July 26 anniversary of the ADA, to strive to meet its objectives by continuing to develop home and community-based service options for persons with disabilities to live in integrated settings.

If you have any questions concerning this letter or require technical assistance, please contact Mary Jean Duckett at (410) 786-3294.

Sincerely,

Sally K. Richardson, Director
Director, Center for Medicaid and State Operations

Health Care Financing Administration
Center for Medicaid and State Operations

September 4, 1998

Dear State Medicaid Director:

We have received a number of inquiries regarding coverage of medical equipment (ME) under the Medicaid program in light of the ruling of the United States Court of Appeals for the Second Circuit in DeSario v. Thomas. In that case, the court examined the circumstances under which a State may use a list to determine coverage of ME and offered its interpretation of HCFA's policies. We have concluded that it would be helpful to provide States with interpretive guidance clarifying our policies concerning ME coverage under the Medicaid program and the use of lists in making such coverage determinations. This guidance is applicable only to ME coverage policy.

As you know, the mandatory home health services benefit under the Medicaid program includes coverage of medical supplies, equipment, and appliances suitable for use in the home (42 C.F.R. § 440.70(b)(3)). A State may establish reasonable standards, consistent with the objectives of the Medicaid statute, for determining the extent of such coverage (42 U.S.C. § 1396(a)(17)) based on such criteria as medical necessity or utilization control (42 C.F.R. § 440.230(d)). In doing so, a State must ensure that the amount, duration, and scope of coverage are reasonably sufficient to achieve the purpose of the service (42 C.F.R. § 440.230(b)). Furthermore, a State may not impose arbitrary limitations on mandatory services, such as home health services, based solely on diagnosis, type of illness, or condition (42 C.F.R. § 440.230(c)).

A State may develop a list of pre-approved items of ME as an administrative convenience because such a list eliminates the need to administer an extensive application process for each ME request submitted. An ME policy that provides no reasonable and meaningful procedure for requesting items that do not appear on a State's pre-approved list, is inconsistent with the federal law discussed above. In evaluating a request for an item of ME, a State may not use a "Medicaid population as a whole" test, which requires a beneficiary to demonstrate that, absent coverage of the item requested, the needs of "most" Medicaid recipients will not be met. This test, in the ME context, establishes a standard that virtually no individual item of ME can meet. Requiring a beneficiary to meet this test as a criterion for determining whether an item is covered, therefore, fails to provide a meaningful opportunity for seeking modifications of or exceptions to a State's pre-approved list. Finally, the process for seeking modifications or exceptions must be made available to all beneficiaries and may not be limited to sub-classes of the population (e.g., beneficiaries under the age of 21).

In light of this interpretation of the applicable statute and regulations, a State will be in compliance with federal Medicaid requirements only if, with respect to an individual applicant's request for an item of ME, the following conditions are met:

> The process is timely and employs reasonable and specific criteria by which an individual item of ME will be judged for coverage under the State's home health services benefit. These criteria must be sufficiently specific to permit a determination of whether an item of ME that does not appear on a State's pre-approved list has been arbitrarily excluded from coverage based solely on a diagnosis, type of illness, or condition. The State's process and criteria, as well as the State's list of pre-approved items, are made available to beneficiaries and the public. Beneficiaries are informed of their right, under 42 C.F.R. Part 431 Subpart E, to a fair hearing to determine whether an adverse decision is contrary to the law cited above.

We encourage you to be cognizant of the approval decisions you make regarding items of ME that do not appear on a pre-approved list, to ensure that the item of ME is covered for all beneficiaries who are

similarly situated. In addition, your list of pre-approved items of ME should be viewed as an evolving document that should be updated periodically to reflect available technology.

HCFA's Regional Offices will be monitoring compliance with the statute and regulations that are the subject of this guidance. Any questions concerning this letter or the ME benefit may be referred to Mary Jean Duckett of my staff at (410) 786-3294.

Sincerely,

Sally K. Richardson
Director, Center for Medicaid and State Operations

Health Care Financing Administration
Center for Medicaid and State Operations

January 14, 2000

Dear State Medicaid Director:

The recent Supreme Court decision in Olmstead v. L. C., 119 S.Ct. 2176 (1999), provides an important legal framework for our mutual efforts to enable individuals with disabilities to live in the most integrated setting appropriate to their needs. The Court's decision clearly challenges us to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services.

This decision confirms what this Administration already believes: that no one should have to live in an institution or a nursing home if they can live in the community with the right support. Our goal is to integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice.

The Department of Health and Human Services (DHHS) is committed to working with all affected parties to craft comprehensive, fiscally responsible solutions that comply with the Americans with Disabilities Act of 1990 (ADA). Although the ADA applies to all State programs, Medicaid programs play a critical role in making community services available. As a consequence, State Medicaid Directors play an important role in helping their States comply with the ADA. This letter conveys our initial approach to Olmstead and outlines a framework for us to respond to the challenge.

The Olmstead Decision

The Olmstead case was brought by two Georgia women whose disabilities include mental retardation and mental illness. At the time the suit was filed, both plaintiffs lived in State-run institutions, despite the fact that their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the ADA to live in the most integrated setting appropriate. The Olmstead decision interpreted Title II of the ADA and its implementing regulation, which oblige States to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." (28 CFR 35.130(d)). In doing so, the Supreme Court answered the fundamental question of whether it is discrimination to deny people with disabilities services in the most integrated setting appropriate. The Court stated directly that "Unjustified isolation . . . is properly regarded as discrimination based on disability." It observed that (a) "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and (b) "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Under the Court's decision, States are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) the State's treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services. The Court cautioned however, that nothing in the ADA condones termination of institutional settings for persons unable to handle or benefit from community settings. Moreover, the State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

Under the ADA, States are obliged to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity." (28 CFR 35.130(b)(7)). The Supreme Court indicated that the test as to whether a modification entails "fundamental alteration" of a program takes into account three factors: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the State; and how the provision of services affects the ability of the State to meet the needs of others with disabilities. Significantly, the Court suggests that a State could establish compliance with title II of the ADA if it demonstrates that it has:

- a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and
- a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

Olmstead and the Medicaid Program

Olmstead challenges States to prevent and correct inappropriate institutionalization and to review intake and admissions processes to assure that persons with disabilities are served in the most integrated setting appropriate. Medicaid can be an important resource to assist States in meeting these goals. We want to work closely with States to make effective use of Medicaid support in our planning and implementation of Olmstead. As an example of the interface between Olmstead's explanation of the State's ADA obligation and your Medicaid program we would point to the State's responsibility, under Medicaid, to periodically review the services of all residents in Medicaid-funded institutional settings. Those reviews may provide a useful component of the State's planning for a comprehensive response to Olmstead. States must also be responsive to institutionalized individuals who request that their situation be reviewed to determine if a community setting is appropriate. In such a case the State has a duty to redress the situation, subject to the limits outlined by the Court and the ADA. As another example, States may choose to utilize their Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.

Comprehensive, Effectively Working Plans

As we have noted, the Supreme Court in Olmstead indicated that a State may be able to meet its obligation under the ADA by demonstrating that it has a comprehensive, effectively working plan for placing qualified persons with disabilities in the most integrated setting appropriate, and a waiting list that moves at a reasonable pace not controlled by a State's objective of keeping its institutions fully populated. The Department believes that comprehensive, effectively working plans are best achieved with the active involvement of individuals with disabilities and their representatives in design, development and implementation.

The Court's Olmstead decision regarding the integration requirement applies to all individuals with disabilities protected from discrimination by title II of the ADA. Although Olmstead involved two individuals with mental disabilities, the scope of the ADA is not limited only to such individuals, nor is the scope of Olmstead limited to Medicaid beneficiaries or to services financed by the Medicaid program. In addition, the requirement to provide services in the most integrated setting appropriate applies not only to persons already in institutional settings but to those being assessed for possible institutionalization.

The enclosure to this letter offers some recommendations about key principles and practices for States to consider as they develop plans. We recognize that there is no single plan that is best suited for all States, and accordingly that there are many ways to meet the requirements of the ADA. We certainly hope States and people with disabilities will expand and improve on these ideas. Although these plans

encompass more than just the Medicaid program, we realize the important role played by State Medicaid Directors in this area. As just one example, Federal financial participation will be available at the administrative rate to design and administer methods to meet these requirements, subject to the normal condition that the changes must be necessary for the proper and efficient administration of the State's Medicaid program. Because of your significant role, we have taken this opportunity to raise these issues with you.

The principles and practices contained in the accompanying technical assistance enclosure also serve as an important foundation for the DHHS Office for Civil Rights' (OCR) activities in this area. As you know, OCR has responsibility for investigating discrimination complaints involving the most integrated setting issue. OCR also has authority to conduct compliance reviews of State programs and has already contacted a number of States to discuss complaints. OCR strongly desires to resolve these complaints through collaboration and cooperation with all interested parties.

Next Steps for the Department of Health and Human Services

Consultation: We have begun consultation with States (including State Medicaid Directors and members of the long term care technical advisory group, who share responsibility for Medicaid) and with people with disabilities. We look forward to building on this start. Many States have made great strides toward enabling individuals with disabilities to live in their communities. There is much that we can learn from these States. We are interested in your ideas regarding the methods by which we might accomplish such continuing consultation effectively and economically.

Addressing Issues and Questions Regarding Olmstead and Medicaid: As we move forward, we recognize that States may have specific issues and questions about the interaction between the ADA and the Medicaid program. In response to the issues and questions we receive, we will review relevant federal Medicaid regulations, policies and previous guidance to assure that they (a) are compatible with the requirements of the ADA and the Olmstead decision, and (b) facilitate States' efforts to comply with the law.

Technical Assistance: In response to any issues raised by the States, the DHHS working group will develop a plan to provide technical assistance and information sharing among States and stakeholders. Responses to questions and technical assistance materials will be published on a special website. We are also funding projects in a number of States to assist with nursing home transition. Finally, we seek your ideas on the additional forms of technical assistance you would find most helpful for home and community-based services and conferences for State policy makers. We will use your suggestions to facilitate the implementation of the integration requirement.

We invite all States and stakeholders to submit questions and recommendations to our departmental workgroup co-chaired by the Director of HCFA's Center for Medicaid and State Operations and the Director of the DHHS Office for Civil Rights. Please send such written correspondence to:

DHHS Working Group for ADA/Olmstead
c/o Center for Medicaid and State Operations
HCFA, Room S2-14-26, DEHPG
7500 Security Blvd.
Baltimore MD 21244-1850

Conclusion

The Administration and DHHS have a commitment to expanding home and community-based services and offering consumers choices in how services are organized and delivered. Over the past few years, DHHS has focused on expanding and promoting home and community-based services, offering support

and technical assistance to States, and using the flexibility of the Medicaid program. The Olmstead decision affirms that we are moving in the right direction and we intend to continue these efforts.

We recognize that this interim guidance leaves many questions unanswered; with your input, we expect to develop further guidance and technical assistance. We recommend that States do the following:

- Develop a comprehensive, effectively working plan (or plans) to strengthen community service systems and serve people with disabilities in the most integrated setting appropriate to their needs;
- Actively involve people with disabilities, and where appropriate, their family members or representatives, in design, development and implementation;
- Use the attached technical assistance material as one of the guides in the planning process;
- Inform us of questions that need resolution and of ideas regarding technical assistance that would be helpful.

We look forward to working with you to improve the nation's community services system.

Sincerely,

Timothy M. Westmoreland, Director
Center for Medicaid and State Operations

Thomas Perez, Director
Office for Civil Rights

Enclosure: Developing Comprehensive, Effectively Working Plans
Fact Sheet: Assuring Access to Community Living for the Disabled

Developing Comprehensive, Effectively Working Plans

Initial Technical Assistance Recommendations

In ruling on the case of Olmstead v L.C., the Supreme Court affirmed the right of individuals with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. The Supreme Court indicated that a State can demonstrate compliance with its ADA obligations by showing that it has a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

We strongly urge States to increase access to community-based services for individuals with disabilities by developing comprehensive, effectively working plans for ensuring compliance with the ADA. There is no single model plan appropriate for all States and situations. In developing their plans, States must take into account their particular circumstances. However, we believe there are some factors that are critically important for States that seek to develop comprehensive, effectively working plans. Our intent in this enclosure is to identify some of the key principles, including the involvement of people with disabilities throughout the planning and implementation process. These principles also will be used by the Office for Civil Rights as it investigates complaints and conducts compliance reviews involving "most integrated setting" issues. We strongly recommend that States factor in these principles and practices as they develop plans tailored to their needs.

Comprehensive, Effectively Working Plans

Principle: Develop and implement a comprehensive, effectively working plan (or plans) for providing services to eligible individuals with disabilities in more integrated, community-based settings. When effectively carrying out this principle:

- The State develops a plan or plans to ensure that people with disabilities are served in the most integrated setting appropriate. It considers the extent to which there are programs that can serve as a framework for the development of an effectively working plan. It also considers the level of awareness and agreement among stakeholders and decision-makers regarding the elements needed to create an effective system, and how this foundation can be strengthened.

- The plan ensures the transition of qualified individuals into community-based settings at a reasonable pace. The State identifies improvements that could be made.

- The plan ensures that individuals with disabilities benefit from assessments to determine how community living might be possible (without limiting consideration to what is currently available in the community). In this process, individuals are provided the opportunity for informed choice.

- The plan evaluates the adequacy with which the State is conducting thorough, objective and periodic reviews of all individuals with disabilities in institutional settings (such as State institutions, ICFs/MR, nursing facilities, psychiatric hospitals, and residential service facilities for children) to determine the extent to which they can and should receive services in a more integrated setting.

- The plan establishes similar procedures to avoid unjustifiable institutionalization in the first place.

Plan Development and Implementation Process

Principle: Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up. When effectively carrying out this principle:

- The State involves people with disabilities (and their representatives, where appropriate) in the plan development and implementation process. It considers what methods could be employed to ensure constructive, on-going involvement and dialogue.

- The State assesses what partnerships are needed to ensure that any plan is comprehensive and works effectively.

Assessments on Behalf of Potentially Eligible Populations

Principle: Take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities. When effectively carrying out this principle:

- The State has a reliable sense of how many individuals with disabilities are currently institutionalized and are eligible for services in community-based settings. The plan considers what information and data collection systems exist to enable the State to make this determination. Where appropriate, the State considers improvements to data collection systems to enable it to plan adequately to meet needs.

  1. The State evaluates whether existing assessment procedures are adequate to identify institutionalized individuals with disabilities who could benefit from services in a more integrated setting.

  2. The State also evaluates whether existing assessment procedures are adequate to identify individuals in the community who are at risk of placement in an unnecessarily restrictive setting.

  3. The plan ensures that the State can act in a timely and effective manner in response to the findings of any assessment process.

Availability of Community-Integrated Services

Principle: Ensure the Availability of Community-Integrated Services. When effectively carrying out this principle:

- The plan identifies what community-based services are available in the State. It assesses the extent to which these programs are able to serve people in the most integrated setting appropriate (as described in the ADA). The State identifies what improvements could be accomplished, including in information systems, to make this an even better system, and how the system might be made comprehensive.

- The plan evaluates whether the identified supports and services meet the needs of persons who are likely to require assistance in order to live in community. It identifies what changes could be made to improve the availability, quality and adequacy of the supports.

- The State evaluates whether its system adequately plans for making supports and services available to assist individuals who reside in their own homes with the presence of other family members. It also considers whether its plan is adequate to address the needs of those without family members or other informal caregivers.

- The State examines how the identified supports and services integrate the individual into the

community. The State reviews what funding sources are available (both Medicaid and other funding sources) to increase the availability of community-based services. It also considers what efforts are under way to coordinate access to these services. Planners assess the extent to which these funding sources can be organized into a coherent system of long term care which affords people with reasonable, timely access to community-based services. Planners also assess how well the current service system works for different groups (e.g. elderly people with disabilities, people with physical disabilities, developmental disabilities, mental illness, HIV-AIDS, etc.). The assessment includes a review of changes that might be desirable to make services a reality in the most integrated setting appropriate for all populations.

- The plan examines the operation of waiting lists, if any. It examines what might be done to ensure that people are able to come off waiting lists and receive needed community services at a reasonable pace.

Informed Choice

Principle: Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings. When effectively carrying out this principle:

- The plan ensures that individuals who may be eligible to receive services in more integrated community-based settings (and their representatives, where appropriate) are given the opportunity to make informed choices regarding whether—and how—their needs can best be met.

- Planners address what information, education, and referral systems would be useful to ensure that people with disabilities receive the information necessary to make informed choices.

Implications for State and Community Infrastructure

Principle: Take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan. When effectively carrying out this principle:

- Planners evaluate how quality assurance and quality improvement can be conducted effectively as more people with disabilities live in community settings.

- The State also examines how it can best manage the overall system of health and long term care so that placement in the most integrated setting appropriate becomes the norm. It considers what planning, contracting and management infrastructure might be necessary to achieve this result at the State and the community level.

FACT SHEET

Assuring Access to Community Living for the Disabled

Overview: On June 22, 1999, the U.S. Supreme Court affirmed that policy by ruling in Olmstead v. L.C. that under the Americans With Disabilities Act (ADA) unjustifiable institutionalization of a person with a disability who, with proper support, can live in the community is discrimination. In its ruling, the Court said that institutionalization severely limits the person's ability to interact with family and friends, to work and to make a life for him or herself.

The Olmstead case was brought by two Georgia women whose disabilities include mental retardation and mental illness. At the time the suit was filed, both plaintiffs were receiving mental health services in state-run institutions, despite the fact that their treatment professionals believed they could be appropriately served in a community-based setting.

In accordance with that Court ruling, the U.S. Department of Health and Human Services (HHS) today issued guidance to state Medicaid directors on how to make state programs responsive to the desires of disabled persons to live in appropriate community-based settings. The Administration's goal is to integrate people with disabilities into the social mainstream with equal opportunities and the chance to make choices.

In addition, HHS Secretary Donna E. Shalala wrote to the governor of each state, underlining the Department's commitment to community services for those with disabilities and noting that the Olmstead decision applied to all relevant state programs, not just Medicaid.

The Olmstead Decision

The Court based its ruling in Olmstead on sections of the ADA and federal regulations that require states to administer their services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

Under the Court's ruling, certain principles have emerged:

- unjustified institutionalization of people with disabilities is discrimination and violates the ADA;
- states are required to provide community-based services for persons with disabilities otherwise entitled to institutional services when the state's treatment professionals reasonably determine that community placement is appropriate; the person does not oppose such placement; and the placement can reasonably be accommodated, taking into account resources available to the state and the needs of others receiving state-supported disability services; a person cannot be denied community services just to keep an institution at its full capacity; and, there is no requirement under the ADA that community-based services be imposed on people with disabilities who do not desire it.

The Court also said that states are obliged to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity." Meeting the fundamental alteration test takes into account three factors: the cost of providing services in the most integrated setting; the resources available to the state; and how the provision of services affects the ability of the state to meet the needs of others with disabilities.

Olmstead and the Medicaid Program

The Medicaid program can be an important resource to assist states in meeting the principles set out in Olmstead. In its letter/guidance to State Medicaid Directors, the Health Care Financing Administration, which oversees the Medicaid and Medicare programs, reminds states they have an obligation under Medicaid to periodically review the services of all residents in Medicaid-funded institutions.

The letter also reminds states they may chose to utilize their Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.

HCFA urges states to develop comprehensive working plans to strengthen community service systems and to actively involve people with disabilities and their families in the design, development and implementation of such plans. HCFA also encourages states to take steps to prevent future inappropriate institutionalization of persons with disabilities and to assure the availability of community-based services.

Next Steps

Over the past few years, HHS has focused on expanding and promoting home and community-based services, offering support and technical assistance to states and using the flexibility of the Medicaid program. The Olmstead decision affirms that we are moving in the right direction.

To help states comply with the Court ruling, HCFA and the HHS Office for Civil Rights have begun working with states and the disability community toward the goals of promoting home and community-based services; honoring individual choice in service provision; and acknowledging that resources available to a state are limited by the need to serve both community-based and institutionalized persons.

In addition to continued technical assistance to states, HHS will review relevant federal Medicaid regulations, policies and previous guidance to assure that they are compatible with requirements of the ADA and Olmstead decision and that they facilitate states' efforts to comply with the law.

Health Care Financing Administration
Center for Medicaid and State Operations

March 29, 2000

Dear State Medicaid Director:

On December 17, 1999, President Clinton signed the "Ticket to Work and Work Incentives Improvement Act of 1999" into law. In signing this legislation, President Clinton emphasized that it will enable the nation to better ensure that "No one will have to choose between taking a job and having health care." This legislation improves access to employment training and placement services for people with disabilities who want to work. It also offers States unprecedented opportunities to eliminate barriers to employment for people with disabilities by improving access to health care coverage available under Medicare and Medicaid. The Health Care Financing Administration (HCFA) will be providing information on an ongoing basis concerning implementation of this important legislation.

The concern expressed most frequently by people with disabilities who want to work is the fear of losing coverage for health care should their employment cause them to lose eligibility for benefits such as Medicare and Medicaid. Often these individuals cannot get private health insurance. The loss of Medicare and Medicaid would leave them without a way to pay for medical expenses and for basic supports they require to live. Many, therefore, fear working as not in their best interests if it would result in the loss of their Medicare or Medicaid coverage. Others may be employed, but are careful to limit their employment to the very low levels that will not jeopardize such coverage.

Title II of the new legislation entitled "Expanded Availability of Health Care Services" contains five provisions that specifically address the concerns many people with disabilities have about possible loss of health care if they return to work. Three of the provisions affect the Medicaid program, and are described more fully below. The remaining two provisions include: (1) an extension to 78 months (versus the previous 24 month limit) of premium-free Medicare Part A benefits for beneficiaries who lose Title II cash assistance because they return to work; and (2) a consumer protection provision which at the policyholder's request requires suspension of Medigap coverage and premiums for disabled policyholders who are entitled to Medicare Part A benefits if the individual is covered under certain group health plans. The law now requires that the policy be automatically reinstated if the policyholder provides timely notice that he or she lost the group health coverage.

It will take some time to develop detailed guidance on the provisions affecting the Medicaid program. In the meantime, though, I want to provide each of you with a summary of the Medicaid provisions and information on who you can contact for further information and technical assistance. I hope you will begin seriously considering the options available to States to make a real, positive contribution to efforts to assist people with disabilities to gain and sustain competitive employment.

New Eligibility Groups (Section 201 of the legislation). Two new optional categorically needy Medicaid eligibility groups are created by the new statute. Under the subsection (XV) eligibility group, States can cover individuals at least age 16 but less than 65 years of age who, except for earned income, would be eligible to receive Supplemental Security Income (SSI) benefits, regardless of whether they have received SSI cash benefits. This group is similar to the group created by section 4733 of the Balanced Budget Act (BBA), except that there is no 250 percent of the Federal poverty level family income limit, AND under this new group States are free to establish their own income and resource standards, or have no income or resource standards if they choose.

Under what we are calling the "Medical Improvement and Employment Security" group, States can cover employed individuals with a medically improved disability who lose Medicaid eligibility under the subsection (XV) eligibility group described above because their medical conditions have improved

to the point where they are no longer disabled under the SSI definition of disability. If a State wants to cover this group, it must cover the subsection (XV) group described above.

As with the original BBA group, States may impose premiums or other cost-sharing charges on a sliding scale based on income for individuals eligible under both of the new eligibility groups. For individuals with annual adjusted gross income (as defined by the IRS) that exceeds $75,000, States are required to charge 100 percent of the premiums they may impose. However, States can subsidize the premium cost for these individuals, using State funds.

Medicaid Infrastructure Grant Program (Section 203 of the legislation). This eleven year grant program makes $150 million available over the first five years to States to design, establish and operate State infrastructures that:

- implement the Medicaid eligibility group(s) discussed above;
- design and plan a Medicaid demonstration for employed individuals with potentially severe physical or mental impairments;
- plan, design or evaluate improvements to the Medicaid State Plan for purposes of providing more effective employment support; and/or
- create a State-to-State Medicaid Infrastructure Center to serve as a regional technical assistance provider for health care improvements supporting employment.

Funds may also be used to conduct outreach campaigns to educate beneficiaries about the availability of such health care and related coverage for competitively employed individuals with disabilities. Subject to availability of the overall annual amount appropriated for this grant program, the minimum award to States is $500,000 per fiscal year.

To be eligible for grant funds, a State must make personal assistance services available under its State Medicaid plan to the extent necessary to assist individuals with disabilities to maintain employment. The grant program is designed to reward States for their efforts in encouraging individuals with disabilities to be employed, and to give proportionately more funding to States that have elected to cover the eligibility group for working individuals with disabilities.

Medicaid Demonstration (Section 204 of the legislation). This program, which is funded at $250 million over six years, enables States to provide the full Medicaid benefits package to workers with potentially severe disabilities. These workers must be at least 16 but less than 65 years old, and have a specific physical or mental impairment that can reasonably be expected, but for the receipt of Medicaid services, to lead to blindness or disability as defined under the SSI program. Under the demonstration, a State defines the number of people with the physical or mental impairments it chooses to cover. The intention of the demonstration is to measure the effect of providing early intervention in the form of Medicaid benefits and services on the ability of participants to retain competitive employment. States are permitted to operate sub-State demonstrations.

Funds under both the Medicaid Infrastructure Grant Program and the Medicaid Demonstration will be available beginning October 1, 2000. Two requests for proposals (RFPs) will be released this summer with complete details on how States can apply for funds under both the infrastructure grant program, and the demonstration program. We plan to issue State Medicaid Directors letters in advance to alert States to the pending release of the RFPs.

HCFA also is preparing guidance materials for States on the options created by this legislation. Additional letters to State Medicaid Directors will provide more detailed information about the new eli-

gibility groups. A draft State Medicaid plan pre-print for States to use in submitting plan amendments to cover these groups also will be made available.

In addition, we will be providing ongoing technical assistance and education around the new health care programs as well as participating in several public information sessions on the entire Act sponsored by the Social Security Administration. If you have questions about the new eligibility groups created by the Ticket to Work and Work Incentives Improvement Act of 1999, please contact Roy Trudel at 410-786-3417 (e-mail rtrudel@hcfa.gov). If you have questions about the Medicaid Infrastructure Grants or the Medicaid Demonstration, please contact Carey O'Connor at 202-690-7865 (e-mail coconnor2@hcfa.gov).

We are excited about the opportunities presented by the legislation, and look forward to working with you as you begin to consider the options available to your State to really make a difference in the lives of people with disabilities who want to work.

Sincerely,

Timothy M. Westmoreland, Director
Center for Medicaid and State Operations

Olmstead Update No: 2
Subject: Questions and Answers
Date: July 25, 2000

Dear State Medicaid Director:

In our January 14, 2000 letter to you we conveyed our initial approach to compliance with the decision in Olmstead v. L.C., 119 S.Ct. 2176 (1999) and outlined a framework for us to respond to the challenge of crafting comprehensive, fiscally responsible solutions that comply with the Americans with Disabilities Act. As that letter indicated, the Olmstead decision challenges States to prevent and correct inappropriate institutionalization of persons with disabilities and to review intake and admissions processes to assure that persons with disabilities are served in the most integrated setting appropriate. We indicated our willingness to work closely with States to make effective use of Medicaid support in your planning and implementation of Olmstead. In that letter we also recognized that States may have specific issues and questions about the interaction between the ADA and the Medicaid program and we invited you to submit your comments to the DHHS Working Group for ADA/Olmstead.

Since the issuance of that letter we have received numerous questions from States and the disability community. We have begun to review, analyze and develop responses to those questions. Attached to this letter are some of the questions we have received along with our responses.

We urge you to continue to submit your questions and recommendations to us so that we may assist you. Such written correspondence may be sent to:

DHHS Working Group for ADA/Olmstead
c/o Center for Medicaid and State Operations
HCFA, Room S2-14-26, DEHPG
7500 Security Boulevard
Baltimore, MD 21244-1850

or e-mailed to: ADA/Olmstead@hcfa.gov

This letter, as well as future questions and answers, will be posted on the Health Care Financing Administration's ADA/Olmstead website. That site can be found at http://www.hcfa.gov/medicaid/olmstead/olmshome.htm.

We look forward to continuing our work with you to improve the nation's community service system.

Sincerely,

Timothy M. Westmoreland, Director
Center for Medicaid and State Operations

Thomas Perez, Director
Office for Civil Rights

Olmstead / ADA Questions and Answers

On January 14, 2000, the Department of Health and Human Services issued a letter to State Medicaid Directors discussing the Supreme Court's decision in Olmstead v. L.C., 119 S.Ct. 2176 (1999). In Olmstead, the Supreme Court affirmed that the unjustified segregation and institutionalization of people with disabilities constitutes unlawful discrimination in violation of the Americans with Disabilities Act (ADA). The January 14 letter sets out a process for technical assistance and information sharing, and indicated that questions and recommendations sent to the departmental workgroup would be posted on a special website. Accordingly, the following set of Qs&As has been posted on the site (*see* http://www.hcfa.gov/medicaid/olmstead/olmshome.htm).

QUESTIONS ABOUT COMPLAINT INVESTIGATION AND DEVELOPING "COMPREHENSIVE, EFFECTIVELY WORKING" PLANS

Q1. Since the Supreme Court's ruling, the Department of Health and Human Services (DHHS) has received over 150 complaints from individuals and organizations alleging that States are not providing services to qualified individuals with disabilities in the most integrated setting. How is DHHS addressing these complaints?

A. DHHS' Office for Civil Rights (OCR) is responsible for investigating complaints alleging discrimination on the basis of disability by public entities related to health and human services, and by entities receiving funds from DHHS. OCR's first objective is to work promptly and cooperatively with all parties involved, including States and individuals with disabilities, to obtain voluntary compliance whenever possible that reflects the balanced approach outlined in Olmstead.

The Olmstead v. L.C. decision indicates that a court might find a State in compliance with the ADA integration mandate if it can demonstrate that it has a "comprehensive, effectively working plan[s]" for providing services to individuals with disabilities in the most integrated setting, and a waiting list that moves at a reasonable pace not motivated by a desire to keep institutions full. While the court did not require States to undertake planning, we believe planning is a prudent and very practical recommendation for moving forward.

In appropriate cases, therefore, OCR is urging States to bring all relevant stakeholders together to develop and implement comprehensive and effective working plans for providing services to all qualified individuals with disabilities in the most integrated setting. OCR also is working with States to cooperatively resolve complaints filed on behalf of individuals. Only if OCR cannot negotiate a satisfactory resolution will ADA title II complaints be referred to the Justice Department (DOJ) for resolution.

Q2. What is the Federal government doing to aid States in developing these plans, and to help States increase their capacity to provide community-based treatment and supports for people with disabilities?

A. DHHS is providing technical assistance to promote effective implementation of its longstanding policy of facilitating care and service provision in the most integrated setting. Specifically, OCR is working with the Health Care Financing Administration (HCFA) to provide technical assistance regarding individual State's compliance with the ADA. Also, Federal financial participation is available at the administrative rate to design and administer plans to serve individuals with disabilities in the most integrated setting, subject to the normal condition that the changes must be necessary for the proper and efficient administration of the State's Medicaid program.

Even more significantly, DHHS is reviewing its own policies, programs, statutes and regulations to identify ways to enhance and improve the availability of community-based services. The Department recognizes that key programs, such as Medicaid, may sometimes present difficulties for people with disabil-

ities to have access to quality care in the community. The Department is developing and will implement its own comprehensive plan to eliminate these barriers. Recognizing that housing is a critical need, we are also working with the Department of Housing and Urban Development (HUD) to improve affordable, accessible housing opportunities for people with disabilities (see Q17 below). DHHS is committed to working with States to increase community-based alternatives to institutional care.

Q3. What recommendations does DHHS have regarding the elements of a comprehensive, effectively working plan?

A. HCFA and OCR have developed a set of plan recommendations which were attached to the January 14, 2000 State Medicaid Director letter and we encourage States to follow them. Listed below are some of the principles underlying the recommendations contained in the letter. For complete information regarding how to effectively carry out each principle, please consult the January 14 letter.

- **Comprehensive, Effectively Working Plans**

  Principle: *Develop and implement a comprehensive, effectively working plan (or plans) for providing services to eligible individuals with disabilities in more integrated, community-based settings.*

- **Plan Development and Implementation Process**

  Principle: *Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up.*

- **Assessments on Behalf of Potentially Eligible Populations**

  Principle: *Take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities.*

- **Availability of Community-Integrated Services**

  Principle: *Ensure the Availability of Community-Integrated Services.*

- **Informed Choice**

  Principle: *Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings.*

- **Implications for State and Community Infrastructure**

  Principle: *Take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan.*

Q4. Does the Olmstead decision require States to have plans to provide services to people with disabilities in the most integrated setting?

A. The decision does not require a State to have such a plan. However, developing and implementing a comprehensive plan or supplementing existing plans to address unmet needs is an important way States may be able to demonstrate that they are in compliance with ADA requirements and actively address discrimination.

The decision indicates that a court might find a State in compliance with the ADA integration mandate if it can demonstrate that it has a "comprehensive, effectively working plan[s]" for providing services to

individuals with disabilities in the most integrated setting.

Ideally, all people with disabilities would already be provided with services in integrated settings, thereby eliminating the need for planning. As a practical matter, however, many States—including those that have made significant investment in the development of community-based services—still face unmet needs. Developing and implementing the kind of plan described by the Supreme Court in Olmstead is a recommended step towards addressing these needs.

Q5. If a State already has a plan, does it need to develop a new one?

A. It depends on how comprehensive and effective the existing plan is. Ultimately, States must be able to demonstrate that their existing plans are comprehensive and effectively working. States are encouraged to evaluate their existing plans using the Recommendations attached to DHHS' January 14 letter, supplement existing plans as necessary, and monitor them to ensure that they are being implemented.

Q6. Why should a State engage in planning activity undertaken in response to an OCR complaint? Will it protect the State from other investigations or litigation?

A. Regulations issued under title II of the ADA direct OCR to investigate complaints against health and human service-related State and local government entitles. OCR has informed States against which it has received Olmstead-type complaints of its desire to try and resolve complaints by helping the State convene stakeholders to develop a comprehensive, effectively working plan to serve individuals with disabilities in the most integrated setting appropriate to their needs. Where States or other "respondents" (entities against which OCR has received complaints) engage in planning processes in good faith and at a reasonable pace, OCR may determine it is possible to allow plan development to proceed in lieu of investigation. Where a State or other respondent evinces no intent to undertake planning, or where delays in doing so evidence a lack of good faith, or where States or other respondents utterly fail to involve stakeholders in plan development, OCR may determine it necessary to commence full-blown investigation. Following investigation, if a violation is found and no resolution is reached, cases may be referred to DOJ for litigation.

The next question concerns the effect of such planning efforts upon legal claims brought by private litigants, or by non-OCR government actors, such as the DOJ. An agreement between a State and OCR would not have any direct impact on pending and future title II litigation brought by a private party or DOJ unless the private parties or DOJ enter into explicit agreements with the State that incorporate OCR's agreement, either in whole or in part.

That said, although there is no direct linkage between OCR complaint investigations and resolution activities and pending investigations or litigation brought by other private parties and DOJ, there may be situations where creating linkages may result in opportunities to bring all parties to the table to resolve pending claims through negotiation.

Q7. If a State decides to develop a comprehensive plan, what form must it take? Must there be only one plan, or can there be multiple plans?

A. The precise form of the plan is best determined by those who are responsible for developing and implementing it. That said, if OCR has a complaint against a State, and OCR has determined it possible as a preliminary matter to address the complaint by allowing plan development to proceed, OCR may require the State to have a framework that pulls together the essential elements of the various plans. In other words, to address a complaint filed with OCR, the State typically will be asked to demonstrate the pace at which services to people with disabilities are being provided in the most integrated setting, even if more detailed planning documents are developed as "subplans."

Q8. In its letter to State Medicaid Directors dated January 14, 2000, DHHS recommends that States "actively involve people with disabilities in the planning process." Does this mean the Department believes that groups should be involved in medical treatment decisions?

A. The Department strongly encourages States to provide an opportunity for interested persons, including individuals with disabilities and their representatives, to participate in the State's overall plan development process. All stakeholders, including advocacy organizations, should participate in the plan development process to ensure that any plan is comprehensive, works effectively and is designed to meet the needs and concerns of all people with disabilities. Consumer directed organizations, such as independent living centers, often have specific expertise in helping people with disabilities transition from nursing homes and institutions into the community which States may wish to utilize. Decisions regarding the treatment and specific placement of an individual with a disability must be made by that individual in conjunction with the individual's treating professionals.

QUESTIONS ABOUT WHO IS AFFECTED BY OLMSTEAD V. L.C.

Q9. The decision in Olmstead v. L.C. involved two women with mental retardation and mental illness. Is the decision limited to people with similar disabilities?

A. No. The principles set forth in the Supreme Court's decision in Olmstead apply to all individuals with disabilities protected from discrimination by title II of the ADA. The ADA prohibits discrimination against "qualified individual(s) with a disability." The ADA defines "disability" as:

> (A) a physical or mental impairment that substantially limits one or more of an individual's major life activities;
> (B) a record of such an impairment; or
> (C) being regarded as having such an impairment.

To be a "qualified" individual with a disability, the person must meet the essential eligibility requirements for receipt of services or participation in a public entity's programs, activities, or services. For example, if the program at issue is open only to children, and that eligibility criterion is central to the program's purpose, the individual must satisfy this eligibility requirement.

Q10. To meet the definition of disability under the ADA and Section 504, a physical or mental impairment must be serious enough to limit a major life activity. What kinds of life activities are considered "major," and when does an impairment "substantially limit" a major life activity?

A. Examples of major life activities include caring for oneself, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning. They also include such basic activities as thinking, concentrating, interacting with others, and sleeping. An impairment "substantially limits" a major life activity when the individual's important life activities are restricted as to the conditions, manner, and duration under which they can be performed in comparison to most people. Some examples of impairments which may, even with the help of medication or devices, substantially limit major life activities are: AIDS, alcoholism, blindness or visual impairment, cancer, deafness or hearing impairment, diabetes, drug addiction, heart disease, and mental illness. The determination whether an impairment "substantially limits" a major life activity must be made on a case-by-case basis.

Q11. What do the other two prongs of the definition, "record of" or "regarded as having" a disability mean?

A. The ADA also protects people who are regarded by others as having a substantially limiting physical or mental impairment, and people who have a record of a substantially limiting physical or mental impairment. For example, a person who is discriminated against based on his or her history of a serious

seizure disorder is protected by the ADA, even if he or she no longer experiences seizures. Likewise, a person with a very mild seizure disorder that does not substantially limit any major life activity and is completely controlled by medication that has no side effects is protected by the ADA if he or she is discriminated against because he or she is perceived as, or "regarded as," having a disability.

Q12. What about elderly people and children? Are they covered?

A. No matter what specific impairment or group of people is at issue—including elderly people and children—each must meet the same threshold definition of disability in order to be covered by the ADA. The question is: "Does the person have an impairment, have a record of impairment, or is he or she being regarded as having an impairment, that substantially limits a major life activity?"

With respect to elderly people, age alone is not equated with disability. However, if an elderly individual has a physical or mental impairment that substantially limits one of more of his or her major life activities, has a record of such an impairment, or is regarded as having such an impairment, he or she would be protected under the ADA.

Q13. Are people with substance abuse problems covered by the ADA?

A. People with substance abuse problems, except for those currently using illegal drugs, are covered by the ADA if they have a disability that substantially limits a major life activity. This means that people who have alcoholism, people who are addicted to non-controlled substances and people who have a history of drug addiction are covered by the ADA if important life activities are restricted as to the condition, manner, and duration under which they can be performed in comparison to most people. In addition, although current illegal drug users are not covered by the Act, persons who use illegal drugs may still be covered if they are discriminated against based on another disability, such as a mental or physical impairment that substantially limits a major life activity.

Q14. What is the relationship between the ADA and Section 504 definition of a person with a disability and the definition of disability used to establish eligibility for entitlement programs such as SSDI/SSI?

A. The definitions of disability used by entitlement programs are not the same as that used by the ADA and Section 504. Thus, the fact that an entitlement program such as SSDI/SSI or Medicaid has determined that a person is not disabled does not mean that they are not covered by the ADA or Section 504. That said, the fact that someone has been found disabled for purposes of an entitlement program, while not conclusive, is usually good evidence to support a finding of disability under the ADA and Section 504.

ADDITIONAL QUESTIONS [SECTION 504; HUD AND DHHS]

Q15. What, if any, relationship does Olmstead v. L.C. have to Section 504 of the Rehabilitation Act of 1973 (Section 504)?

A. Section 504, which was enacted some seventeen years before the ADA, prohibits discrimination on the basis of disability by entities which receive Federal funding. Section 504 and the ADA use the same definition of disability. Title II of the ADA extends Section 504's prohibition of discrimination in Federally assisted programs to all activities of State governments, including those that do not receive Federal financial assistance. Although the Olmstead decision interpreted the ADA, unjustified segregation by a Federally funded program would also constitute disability discrimination under Section 504. A State program receiving Federal funds must comply with both Section 504 and title II of the ADA.

Q16. What about the Department of Housing and Urban Development? Is HUD involved in the Federal government's Olmstead implementation efforts?

A. Historically, the lack of accessible, affordable housing and necessary community based services has been a major barrier to the integration of people with disabilities. Access to affordable housing is frequently a necessary but missing prerequisite for moving out of a nursing home or other institutional settings. HHS and HUD are strongly committed to assisting States to develop comprehensive working plans to strengthen community service systems and to actively involve people with disabilities and their families in the design, development and implementation of such plans. In some States HUD's "community builders" are aiding plan development, and we urge States to take advantage of the opportunity to call upon the expertise of our Federal partners, including HUD, in developing home and community-based infrastructure. Partnerships among housing, health and human services agencies and other key stakeholders in the disability and aging communities will prove central to a State's success.

Q17. We have many questions regarding the impact of this decision and how we can come into compliance with the law. Who should we talk to at HHS?

A. States should direct any questions or requests for technical assistance regarding their ADA and Section 504 obligations in response to the Olmstead decision to the OCR regional office that handles complaints filed in that State. A list of regional contacts—local staff designated to handle "most integrated setting" issues in each region—may be found at the conclusion of this document. Questions regarding Medicaid or Medicare policy should be directed to your HCFA regional office.

OCR REGIONAL OLMSTEAD CONTACTS

REGION I	Peter Chan	(617) 565-1353 (617) 565-3809 fax
REGION II	Patricia Holub	(212) 264-4997 (212) 264-3039 fax
REGION III	Ed Lewandowski Paul Cushing (Backup)	(215) 861-4445 (215) 861-4441 (215) 861-4431 fax
REGION IV	Mildred Wise Roosevelt Freeman	(404) 562-7866 (404) 562-7886 (404) 562-7881 fax
REGION V	Michael Kruley Al Sanchez	(312) 886-5893 (312) 353-5531 (312) 886-2301 fax
REGION VI	George Bennett Ralph Rouse (Backup)	(214) 767-4546 (214) 767-4056 (214) 767-0432 fax
REGION VII	Jean Simonitsch John Halverson Peter Kemp (Backup)	(816) 426-6513 (816) 426-7236 (816) 426-7236 (816) 426-3686 fax
REGION VIII	Andrea Oliver Jean Lovato Velveta Golightly-Howell	(303) 844-4774 (303) 844-7835 (303) 844-5101 (303) 844-6665 fax
REGION IX	Mario Sagatelian Monica Eskridge	(415) 437-8326 (415) 437-8324 (415) 437-8329 fax
REGION X	Bennett Prows Carmen Rockwell	(206) 615-2621 (206) 615-2288 (206) 615-2297 fax

Olmstead Update No: 3
Subject: HCFA Update
Date: July 25, 2000

Dear State Medicaid Director:

On January 14, 2000, we transmitted the first in a series of letters describing the Supreme Court's decision in the case of Olmstead v. L.C. We observed the fact that Medicaid may be of great assistance to States in fulfilling their civil rights responsibilities under the Americans with Disabilities Act (ADA). We also promised to review federal Medicaid policies and regulations to identify areas in which policy clarification or modification would facilitate your efforts to enable persons with disabilities to be served in the most integrated settings appropriate to their needs.

This letter summarizes some of the recent Health Care Financing Administration (HCFA) efforts to review Federal policies in order to facilitate fulfillment of the ADA. These efforts have been directed towards supporting States' initiatives in the following critical areas:

- Assisting people with disabilities to make a successful transition from nursing homes and other institutions into the community;
- Expanding the availability and quality of home and community-based services; and
- Ensuring that services are comparably available to all.

The attached enclosures consist of policy changes and clarifications that HCFA is making that will give States more flexibility to serve people with disabilities in different settings. These serve as guidance on how States may use the flexibility that Medicaid offers to expand services in a variety of ways.

We appreciate the ideas that you and members of the disability community have contributed so far. Most of the clarifications and policy reforms described in this letter emanate from your communications. We continue to invite new ideas because further policy work is required.

We have established an ADA/Olmstead website that contains questions and answers in response to inquiries received since the January 14th letter. The address is **http://www.hcfa.gov/medicaid/olmstead/olmshome.htm**. The website also contains related letters to State Medicaid Directors and Governors and links to other relevant websites. We encourage you to continue forwarding your policy-related questions and recommendations to the Olmstead workgroup through e-mail at ADA/Olmstead@hcfa.gov or in written correspondence to:

DHHS Working Group for ADA/Olmstead
c/o Center for Medicaid and State Operations
HCFA, Room S2-14-26, DEHPG
7500 Security Boulevard
Baltimore, MD 21244-1850

We look forward to a continuation of our work together to improve the nation's community-based services system.

Sincerely,

Timothy M. Westmoreland, Director

Enclosures

HCFA POLICY CHANGES AND CLARIFICATIONS

ATTACHED TO THIS LETTER

Policy	Clarification/Interpretation/Policy Change:
Purpose: Assisting people with disabilities to make a successful transition from nursing homes and other institutions into the community.	
Attachment 3-a: Earliest Eligibility Date in HCBS Waivers.	Discusses a policy change regarding the earliest date of service for which Federal financial participation (FFP) can be claimed.
Attachment 3-b: Community Transition	Explains some of the ways that Medicaid funding may be used to help elderly people and individuals with a disability transition from an institution to a community residence.
Attachment 3-c: Personal Assistance Retainer.	Discusses a HCFA policy change indicating that a State may make payment for personal assistance services under a Medicaid HCBS waiver while a waiver participant is temporarily hospitalized or away from home.
Purpose: Expanding the availability and quality of home and community-based service.	
Attachment 3-d: Habilitation.	Clarifies that habilitation services, including prevocational, educational, and supported employment services, are available under an HCBS waiver to people of all ages, in all target groups, if so specified by the State.
Attachment 3-e: Out-of-State Services.	Clarifies the circumstances under which Medicaid HCBS waiver services may be provided out-of-state.
Purpose: Ensuring that services are comparably available to all.	
Attachment 3-f: Services Provided Under a Nurse's Authorization.	Clarifies that States may receive FFP for services provided at the authorization of a nurse, if the providers meet qualifications specified under the State Plan or Medicaid waiver for these services.
Attachment 3-g: Prohibition of Homebound Requirements in Home Health.	Notifies that the use of a "homebound" requirement under the **Medicaid** home health benefit violates Federal regulatory requirements at 42 CFR 440.230(c) and 440.240(b).

Attachment 3-a
Subject: Earliest Eligibility Date
In HCBS Waivers
Policy Change
Date: July 25, 2000

Timely home and community-based services (HCBS) waiver eligibility determinations are particularly important to ensure that individuals awaiting imminent discharge from a hospital, nursing home, or other institution are able to return to their homes and communities.

Consequently, we have been asked to clarify the earliest date of service for which Federal financial participation (FFP) can be claimed for HCBS and other State plan services when a person's Medicaid eligibility is predicated upon receipt of Medicaid HCBS under a waiver.

Under current Health Care Financing Administration policy, States must meet several criteria (described below) before they can receive FFP for HCBS waiver services furnished to a beneficiary who has returned to the home or community setting. For example, section 1915(c)(1) of the Social Security Act (the Act) requires that HCBS waiver services be furnished pursuant to a written plan of care.

Policy Change: To facilitate expeditious initiation of waiver services, we will accept as meeting the requirements of the law a provisional written plan of care which identifies the essential Medicaid services that will be provided in the person's first 60 days of waiver eligibility, while a fuller plan of care is being developed and implemented. A comprehensive plan of care must be in place in order for waiver services to continue beyond the first 60 days.

The following chart summarizes the above and other requirements.

Earliest Date of HCBS Waiver Eligibility =
The Last Date All of the Following Requirements Have Been Met

1. Basic Medicaid Eligibility: The person is determined to be Medicaid-eligible if in a medical institution.	The eligibility group into which the person falls must be included in the State plan.
2. Level of Care: The person is determined to require the level of care provided in a hospital, nursing facility, or ICF/MR.	Level of care determinations must be made as specified in the approved waiver.
3. Special Waiver Requirements: The person is determined to be included in the target group and has been found to meet other requirements of eligibility specified in the State's approved waiver. These requirements include documentation from the individual that he or she chooses to receive waiver services.	The person must actually be admitted to the waiver.
4. Plan of Care: A written plan of care is established in conformance with the policies and procedures established in the approved waiver.	**Policy Change:** For eligibility determinations we will initially accept a provisional written plan of care which identifies the essential Medicaid services that will be provided in the person's first 60 days of waiver eligibility, while a fuller plan of care is being accomplished. A comprehensive care plan, designed to ensure the health and welfare of the individual, must be developed within this time.
5. Waiver Service: The plan of care must include at least one waiver service to be furnished to the individual, and the State must take appropriate steps to put the plan of care into effect.	

When the eligibility determination has been made finding the individual eligible for the Medicaid HCBS waiver, the State may make a claim for FFP for services furnished beginning on the date on which all of these criteria are met. In subsequent attachments, we provide for special procedures to accommodate reimbursement for certain transition expenses that enable an individual residing in an institution to transition to community residence.

Any questions concerning this attachment may be referred to Mary Jean Duckett at (410) 786-3294 or Mary Clarkson at (410) 786-5918.

Attachment 3-b
Subject: Community Transition
Policy Change
Date: July 25, 2000

Medicaid home and community-based services (HCBS) waivers are statutory alternatives to institutional care. Many States have found HCBS waivers to be a cost-effective means to provide comprehensive community services in the most integrated setting appropriate to the needs of the individuals enrolled.

Nursing facilities and intermediate care facilities for the mentally retarded (ICFs/MR) likewise play important roles in our long term care system. They are particularly important for short-term rehabilitation, sub-acute care, and crisis management that enable timely hospital discharge. However, short-term stays often become long term residence when complicated planning is required for a return home, special housing or housing modification needs to be arranged, or exceptional one-time expenses must be paid.

This attachment explains several means by which Medicaid may assist States to overcome these barriers to community transition. It addresses the following:

A. Case Management

1. Targeted Case Management Under the State Plan
2. HCBS Case Management
3. Administrative Case Management

B. Assessments for Accessibility

C. Environmental Modifications

D. Modifications Interrupted due to Death

A. Case management. Case management services are defined under section 1915(g)(2) of the Social Security Act (the Act) as "services which will assist individuals, eligible under the plan, in gaining access to needed medical, social, educational, and other services." Case management services are often used to foster the transitioning of a person from institutional care to a more integrated setting or to help maintain a person in the community. There are several ways that case management services may be furnished under the Medicaid program:

1) Targeted case management (TCM), defined in section 1915(g) of the Act, may be furnished as a service to institutionalized persons who are about to leave the institution, to facilitate the process of transition to community services and to enable the person to gain access to needed medical, social, educational and other services in the community. We are revising our guidelines to indicate that TCM may be furnished during the last 180 consecutive days of a Medicaid eligible person's institutional stay, if provided for the purpose of community transition. States may specify a shorter time period or other conditions under which targeted case management may be provided. Of course, FFP is not available for any Medicaid service, including targeted case management services, provided to persons who are receiving services in an institution for mental disease (IMD), except for services provided to elderly individuals and children under the age of 21 who are receiving inpatient psychiatric services.

2) HCBS Case Management may be furnished as a ***service*** under the authority of section 1915(c) when this service is included in an approved HCBS waiver. Persons served under the waiver may receive case management services while they are still institutionalized, for up to 180 consecutive

days prior to discharge. However, Federal financial participation (FFP) is available on the date when the person leaves the institution and is enrolled in the waiver. In such cases, the case management service begun while the person was institutionalized is not considered complete until the person leaves the institution and is enrolled in the waiver. In these cases, the cumulative total amount paid is claimed as a special single unit of transitional case management. To claim FFP for case management services under the waiver, the State may consider the unit of service complete on the date the person leaves the facility and is enrolled in the waiver, and claim FFP for this unit of case management services furnished on that date. The cost of case management furnished as a HCBS waiver service must be estimated in factor D of the waiver's cost-neutrality formula.

3) Administrative Case Management may be furnished as an ***administrative*** activity, necessary for the proper and efficient administration of the State Medicaid plan. When case management is furnished in this fashion, FFP is available at the administrative rate, but may only be claimed for the establishment and coordination of Medicaid services that are not services funded by other payors for which the individual may qualify. Case management furnished as an administrative expense may be eligible for FFP even if the person is not eventually served in the community (e.g., due to death, the individual's choice not to receive waiver services, loss of Medicaid eligibility, etc.). This is because the service is performed in support of the proper and efficient administration of the State plan.

When a State elects to provide case management as both an administrative and a service expense (either under the targeted case management State plan authority, or as a service under a HCBS waiver), the State must have a policy on file with HCFA that clearly delineates the circumstances under which case management is billed as either an administrative or a service expense. This information must be included in the supporting documentation that the State forwards with its State plan or waiver request.

B. Assessments for Accessibility. Environmental modifications are often crucial to a State's ability to serve an individual in the most integrated setting appropriate to his/her needs. The State may assess the accessibility and need for modification in a person's home or vehicle at any time. FFP may be available in the costs of this assessment under several categories:

1) Administrative Expense: FFP may be claimed at the administrative rate for assessments to determine whether the person's home or vehicle may require modifications to ensure the health and welfare of the HCBS waiver participant. When the assessment is performed to determine whether the individual's needs can be met under an HCBS waiver, the administrative costs of the assessment may qualify for FFP regardless of whether or not the person is eventually served under the waiver;

2) Included in Environmental Modifications: The cost of environmental assessment may be included in the cost of environmental modification under an HCBS waiver; or

3) Included in a Relevant Service: The assessment may be performed by another service provider, such as a home health agency or an occupational therapist. FFP would be available at the service match rate when these providers perform assessments in addition to their other duties.

When a State elects to provide assessments for accessibility as a service expense under a HCBS waiver, the State must have a policy on file with HCFA that clearly delineates the circumstances under which these assessments are billed as either an administrative or a service expense. This information must be included in the supporting documentation that the State forwards in support of its HCBS waiver request.

The cost of reassessment may also be found eligible for FFP. Reassessment may be performed to deter-

mine whether new or additional modifications are needed, or whether existing (or newly installed) arrangements continue to be sufficient to meet the individual's needs.

C. Environmental Modifications: It may be necessary to make environmental modifications to an individual's home before an individual transitions from an institution to the community. For example, a wheelchair ramp may need to be built and doors may need to be widened to permit the individual to access his/her home. In such cases, the home modification begun while the person was institutionalized is not considered complete until the date the individual leaves the institution and is enrolled in the waiver. A State may claim FFP for home modifications (including actual construction costs) furnished as a waiver service for up to 180 days prior to discharge when (a) these modifications have been initiated before the individual leaves the institution and enrolls in HCBS waiver, (b) home modifications are included in the approved HCBS waiver. The claim for FFP must indicate the date the individual leaves the institution and enrolls in the waiver as the date of service for allowable expenses incurred during the previous 180 days.

D. Policy Change: Modifications Interrupted by Recipient's Death: The HCBS waivers serve a vulnerable population. Individuals who have chosen to relocate from an institutional to a community residence sometimes die before the relocation can occur. We believe that it would have a chilling effect if States were denied FFP for environmental assessments or modifications for individuals who died before their transition to home or community-based services. Therefore, we will allow the State to claim FFP at the administrative rate for services which would have been necessary for relocation to have taken place when the person has:

1) applied for waiver services,
2) been found eligible for the waiver by the State (but for the person's status as an inpatient in an institution), but
3) died before the actual delivery of the waiver services.

Any questions concerning this attachment may be referred to Mary Jean Duckett at (410) 786-3294 or Mary Clarkson at (410) 786-5918.

Attachment 3-c
Subject: Personal Assistance Retainer
Policy Change
Date: July 25, 2000

Medicaid regulations at 42 CFR 447.40 permit States to make payment to "hold" an institutional bed open for a resident while that individual is hospitalized or away from the facility for a short period. States which make this payment must indicate their intentions (and applicable time limits) in their State plans. We are writing this guideline to inform you that you may choose to implement a similar policy to allow payment for personal assistance services (such as personal care or attendant services) under HCBS waivers. This would enable beneficiaries to have parity between nursing home care and HCBS care in terms of assuring continuity of care and services.

Individuals with disabilities utilize personal assistance services provided under a HCBS waiver to support various activities of daily living. These services are furnished by individuals employed by community-based agencies, or by persons who are self-employed or employed directly by the waiver participant. Typically low payment rates make it unlikely that a provider could afford to give up a day's or week's salary because the waiver consumer is hospitalized or otherwise absent. Rather than wait for the waiver consumer to return, providers are more likely to find permanent employment elsewhere. Those who are employed by agencies are often reassigned to other agency clients - and may not return. Lack of providers can be catastrophic for an individual with disabilities.

Personal assistance retainer payments, as described in this attachment, are limited to services furnished under HCBS waivers. To enable waiver participants to continue to receive services in the most integrated setting appropriate to their needs, we will permit continued payment to personal caregivers under the waiver while a person is hospitalized or absent from his or her home. If a State chooses to make such payments, it must clearly indicate this in its HCBS waiver request.

States that choose to make payments to be made for personal assistance retainers must also specify the limits that will be applied to this service. The personal assistance retainer time limit may not exceed the lesser of 30 consecutive days or the number of days for which the State authorizes a payment for "bed-hold" in nursing facilities.

Any questions concerning this attachment may be referred to Mary Jean Duckett at (410) 786-3294 or Mary Clarkson at (410) 786-5918.

Attachment 3-d
Subject: Habilitation in HCBS Waivers
Clarification
Date: July 25, 2000

Section 1915(c)(4)(B) of the Social Security Act (the Act) permits States to offer habilitation services under a Medicaid home and community-based services (HCBS) waiver. Habilitation services are defined in 1915(c)(5) of the Act as "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." The definition includes expanded services such as prevocational, educational, and supported employment services, if not otherwise excluded by law or the terms of a State's approved waiver.

Clarification: States have historically provided habilitation services under an HCBS waiver to individuals with mental retardation or related conditions which occurred before age 22. However, neither the law nor implementing regulations restrict who may receive habilitation services in an HCBS waiver. Other individuals who do not have mental retardation or related conditions, such as persons with traumatic brain injury or other physical disabilities that occurred after age 22, may also benefit from habilitation services under the waiver. Accordingly, States may provide habilitation services - including the expanded habilitation services of educational, prevocational and supported employment services - under an HCBS waiver to people of all ages who qualify for the waiver.

To receive services under a HCBS waiver, an individual must meet all targeting criteria set forth in the approved waiver. These criteria must include the institutional level or levels of care to which the waiver services provide an alternative. We believe that this clarification will expand a State's choices of services which can be provided to persons with disabilities in home and community-based waiver programs. It may also assist States in fulfilling their responsibilities under the Americans with Disabilities Act.

States continue to have the flexibility to target waivers to specific populations and age groups within statutory allowances and to determine what services are provided under the waiver. Any questions concerning this attachment or the home and community-based waiver program may be referred to Mary Jean Duckett at (410) 786-3294 or Mary Clarkson at (410) 786-5918.

Attachment 3-e
Subject: Out-of-State Services
Clarification
Date: July 25, 2000

Out-of-State services have been provided by several States for many years, with excellent results in quality of service and quality of life for the waiver participants. Regulations at 42 CFR 431.52 prescribe the conditions under which a State is required to provide out-of-State services. Section 1902(a)(23) of the Social Security Act (the Act) provides that an individual may receive Medicaid services (including home and community-based services (HCBS) waiver services) from any qualified provider willing to furnish the services.

Historically, out-of-State services have been used to support some individuals attending college, and enabled others to visit family members. In addition, there are some areas near State borders where the closest (or most convenient) provider is located in an adjacent State. When convenience or necessity make it advisable for services to be provided outside the State, there is no restriction to in-State services.

When residential out-of-State services are recommended by a State because services within the State are unavailable or insufficient to meet the person's needs, careful consideration must be given to the reason for providing the services, as well as alternatives which may contribute more to an individual's ability to receive quality supports in a community based setting. Services provided in a location remote from the individual's family and friends may not provide appropriate support for the person to live in the most integrated setting appropriate to his or her needs.

When services are provided out-of-State, the standard waiver requirements must continue to be met. Examples include the following:

> ***Written Plan of Care:*** The services must be in the person's written plan of care (section 1915(c)(1) of the Act). The plan of care must identify the services to be provided, the amount and type of each service, and the type of provider. The requirement that the type of provider be included in the care plan does not mean that the name of the actual provider must be listed in the plan of care. The plan of care is subject to the approval of the Medicaid agency. The actual provider is subject to the approval of the individual receiving services.
>
> ***Waiver-Qualified Provider:*** Services must be furnished by a qualified provider (section 1902(a)(23) of the Act). The provider must meet the standards for service provision that are set forth by the State in the waiver and approved by HCFA. Any standards of licensure or certification which are applicable to the provision of the service must also be met (42 CFR 441.302(a)(2)). This means that any standards applicable to the provision of the service in the State in which the service is furnished must be met, as well as those standards set forth in the approved waiver. If one State were to pay for a service furnished in another, the provider must be qualified under the standards in the waiver, and the service must also meet any applicable requirements in the State in which it is provided.
>
> ***Quality Assurance:*** The State operating the waiver remains responsible for the assurance of the health and welfare of the beneficiary (section 1915(c)(2)(A) of the Act). Oversight may be performed directly by the home State or by the host State in which services are actually received. If it is done by the host State, there must be an interstate compact or agreement setting forth the responsibilities of each party. Under an interstate compact, the State in which services are provided can agree to take over monitoring responsibilities. Some States have compacts which recognize each other's provider agreements. Others recognize each other's provider standards. States have the opportunity to be quite creative in their utilization of these compacts to foster efficient and responsive HCBS programs. We recognize this as an opportunity to expand Medicaid

services to meet the needs of individuals in the most integrated settings appropriate.

Choice of Provider: The provider must be chosen by the individual (section 1902(a)(23) of the Act). The provider of out-of-State services must be chosen just as freely as the provider of in-State services. We realize that in some cases, out-of-State services are much closer and more easily obtained than in-State services. This is particularly true when a neighboring State has a large city on or near a State border.

Provider Agreements: The provider must have a provider agreement with the Medicaid agency (section 1902(a)(27) of the Act); and Medicaid payment must be made directly to the provider (section 1902(a)(32) of the Act).

Any or all of the above requirements may be met directly by the State which operates the waiver, or indirectly through an interstate compact in which the second State attends to provider agreement and payment activities.

Any questions concerning this attachment may be referred to Mary Jean Duckett at (410) 786-3294 or Mary Clarkson at (410) 786-5918.

Attachment 3-f
Subject: Services Provided Under a Nurse's Authorization **Clarification**
Date: July 25, 2000

This attachment provides policy guidance regarding Medicaid coverage of services provided pursuant to a nurse's authorization by other providers and the availability of Federal Financial Participation (FFP) for those services. States have referred to these services as "nurse-delegated services" or "services provided under a nurse's delegation of authority." This guidance clarifies that States may enable individuals to receive services in the most integrated setting by permitting providers, such as personal care and attendant care providers, to furnish these services.

State Medicaid programs may cover any services authorized by a nurse that fit within a category of services covered under the Medicaid State plan, a home and community-based services (HCBS) waiver, a managed care waiver, or an approved demonstration project. FFP for the services must be claimed under the category appropriate for the service that was furnished. Under this interpretation, health-related services provided at the authorization of a nurse, which would otherwise be classified as nursing services, are billed in the category of the actual provider. For example, the health-related component of personal care services authorized by a nurse, which are provided by a personal care provider, would be billed and reimbursed as personal care services (Medicaid State plan, HCBS waiver, or other waiver).

As with all Medicaid services, the service for which FFP is claimed must meet the definition provided in the approved Medicaid State plan or HCBS waiver, and the actual provider must meet applicable provider qualifications and requirements. For example, if a State includes personal care services under its Medicaid State plan, FFP would be available for activities authorized by a nurse but furnished by a personal care provider who meets the provider qualifications and standards established by the State. States may wish to impose a requirement for authorization for any covered service when such a requirement would further the objective of ensuring appropriate high quality services. Of course, services provided under the authorization of a nurse must also be consistent with State law and regulations.

States may choose to design their payment methodologies to take into consideration the complexity of authorized tasks, and may impose reasonable provider qualifications applicable to particular tasks. For example, States may choose to have two levels of provider qualifications and payment methodologies for personal care providers under its State plan: a basic level applicable to all personal care providers, and a higher level with additional qualifications for personal care providers who provide more complex tasks, such as those authorized by nurses. Qualifications may include additional training and/or demonstrated competency related to tasks authorized by a nurse that would not be required for providers who do not furnish such tasks. As States also establish the qualifications and payment methodologies for waiver providers, these requirements and rates for waiver personal care services or attendant care services may also reflect the same multi-level approach.

Any questions concerning this attachment or Medicaid coverage of services authorized by a nurse may be directed to Mary Jean Duckett at (410) 786-3294 or Mary Clarkson at (410) 786-5918.

Attachment 3-g
Subject: Prohibition of Homebound Requirement in Medicaid Home Health **Clarification**

Date: July 25, 2000

The Medicaid home health benefit is an important tool for serving persons with disabilities in integrated settings. Medicaid regulations at 42 CFR 440.70(a)(1) require that home health services be provided to an individual at his or her place of residence. An individual's place of residence for purposes of home health services does not include a hospital, nursing facility, or intermediate care facility for the mentally retarded. Home health services must include part-time or intermittent nursing services, home health aide services, and medical supplies, equipment, and appliances suitable for use in the home. Physical or occupational therapy and speech pathology and audiology services are optional.

While current regulations specify that these services must be provided to an individual at his place of residence, it is not necessary that the person be confined to the home for the services to be covered under the Medicaid home health benefit. The "homebound" requirement is a Medicare requirement that does not apply to the Medicaid program. Imposing a homebound requirement on receipt of Medicaid home health benefits as explained below violates Medicaid regulations related to "amount, duration, and scope of services" at 42 CFR 440.230 and "comparability of services" at 42 CFR 440.240. However, States may still limit the home health benefit in the manner allowed by statute and regulation.

Section 42 CFR 440.230(c) indicates that "the Medicaid agency may not arbitrarily deny or reduce the amount, duration, or scope of a required service under sections 440.210 and 440.220 to an otherwise eligible recipient solely because of the diagnosis, type of illness, or condition." Sections 440.210 and 440.220 relate to required services for the categorically needy and to required services for the medically needy, including home health services. If a State limits home health services to persons who are homebound, while not providing medically necessary home health services to persons who are not homebound, it is arbitrarily denying the home health service based on the individual's condition (i.e., whether or not the individual is homebound) in violation of regulations at 440.230(c).

Section 42 CFR 440.240(b) indicates that "the plan must provide that the services available to any individual in the following groups are equal in amount, duration, and scope for all recipients within the group: (1) The categorically needy. (2) A covered medically needy group." Thus, if a State limits the provision of Medicaid home health services to individuals who are homebound, the State violates Federal requirements at 440.240(b) by providing the services to some individuals within the eligibility group and not to others within the group. However, States may still limit the home health benefit in the manner allowed by statute and regulation.

The restriction of home health services to persons who are homebound to the exclusion of other persons in need of these services ignores the consensus among health care professionals that community access is not only possible but desirable for individuals with disabilities. New developments in technology and service delivery have now made it possible for individuals with even the most severe disabilities to participate in a wide variety of activities in the community with appropriate supports. Further, ensuring that Medicaid is available to provide medically necessary home health services to persons in need of those services who are not homebound is an important part of our efforts to offer persons with disabilities services in the most integrated setting appropriate to their needs, in accordance with the Americans with Disabilities Act.

For purposes of receipt of Medicaid home health services, a person's place of residence continues to be defined by the requirements of 42 CFR 440.70(c).

Any questions concerning this attachment or the home health benefit may be referred to Mary Jean Duckett at (410) 786-3294 or Mary Clarkson at (410) 786-5918.

Health Care Financing Administration
Center for Medicaid and State Operations

August 29, 2000

Dear State Medicaid Director:

This is the second in a series of letters that provide guidance on the implementation of the "Ticket to Work and Work Incentives Improvement Act of 1999" (TWWIIA). This legislation improves access to employment training and placement services for people with disabilities who want to work. It also offers States unprecedented opportunities to eliminate barriers to employment for people with disabilities by improving access to health care. Our first letter, dated March 29, 2000, provided (a) general information about the legislation, (b) an overview of our plans for implementing the two new Medicaid eligibility groups created by the legislation, and (c) a description of our plans for issuing grants to assist States with the infrastructure and for demonstration projects.

This letter provides more detailed information about the two new Medicaid eligibility groups. Those groups are briefly described below, with particular emphasis (as discussed in the enclosure to this letter) on how eligibility is determined for those applying for coverage under these groups.

New Eligibility Groups Related to Employment (Section 201 of the legislation). TWWIIA created two new optional categorically needy Medicaid eligibility groups.

Under what we are calling the **"Basic Coverage Group"** (otherwise known as the subsection (XV) eligibility group), States can cover individuals who are age 16 or over, but under age 65, and who, except for earned income, would be eligible to receive Supplemental Security Income (SSI) benefits, regardless of whether they have ever received SSI cash benefits. This group is similar to the group created by section 4733 of the Balanced Budget Act (BBA), except that eligibility is not limited to people with family income below 250 percent of the Federal poverty level family income limit, AND under this new group States are free to establish their own income and resource standards (including the option to have no income or resource standards at all).

Under what we are calling the **"Medical Improvement Group,"** States can cover employed individuals with a medically improved disability who lose Medicaid eligibility under the Basic Coverage Group described above because their medical conditions have improved to the point where they are no longer disabled under the SSI definition of disability. If a State wants to cover this group, it must cover the Basic Coverage Group described above.

As with the original BBA group, States may impose premiums or other cost-sharing charges on a sliding scale based on income for individuals eligible under both of the new eligibility groups. For individuals with annual adjusted gross income (as defined by the IRS) that exceeds $75,000, States are required to charge 100 percent of the premiums they may impose. However, States can subsidize the premium cost for these individuals, using State funds.

Both of these new eligibility groups become effective on October 1, 2000.

I enclose a detailed explanation of how eligibility is determined under the two new groups. We have also developed draft State plan preprint pages which States can use, if they wish, when submitting Medicaid State plan amendments to implement either or both of these groups. The draft preprint pages are available from your HCFA regional office eligibility contact or State Representative, from the HCFA Central Office contact shown below, or they can be downloaded from HCFA's Work Incentives website at www.hcfa.gov/medicaid/twwiia/twwiiahp.htm.

If you have questions about the new eligibility groups created by the Ticket to Work and Work Incentives Improvement Act of 1999, please contact Roy Trudel of my staff at 410-786-3417 (e-mail: rtrudel@ hcfa.gov).

We look forward to working with you as you consider the options available to your State under this legislation, which has the remarkable potential to assist people with disabilities to work in competitive employment.

Sincerely,

Timothy M. Westmoreland, Director
Center for Medicaid and State Operations

Enclosure: Explanation of Eligibility Groups

ENCLOSURE

EXPLANATION OF ELIGIBILITY GROUPS

The "Ticket to Work and Work Incentives Improvement Act of 1999" (TWWIIA) created two new Medicaid eligibility groups to allow States to provide Medicaid to certain individuals with disabilities who want to work, or who are already working but want to increase their earnings. Both groups are optional categorically needy groups. Following is detailed information about these groups, including how eligibility is determined and your options for charging premiums and other cost-sharing expenses.

I. BASIC COVERAGE GROUP

A. Key Elements Under Section 1902(a)(10)(A)(ii)(XV) of the Act

To be eligible under this group, an individual must:

- Be at least 16 but less than 65 years old;
- Be disabled as defined under the SSI program (except for earnings);
- Have income and resources that do not exceed a standard established by the State.

You have sole discretion to establish income and/or resource standards for this group, including the choice not to have any income and/or resource standard at all if you wish.

The following rules and requirements apply to this group:

- If you choose to establish an income and/or resource standard, SSI methodologies apply in determining eligibility, including the SSI earned income disregard of $65 plus one-half of the remainder. Unlike the BBA Group, all earned income is not automatically disregarded in determining eligibility under this group. However, you can use section 1902(r)(2) of the Act (described below) to disregard additional earned income beyond the SSI earned income disregard, including a total disregard of earned income.
- Section 1902(r)(2) of the Act (optional use of more liberal income and resource methodologies than are used by the SSI program) applies to this group.
- The limitations on Federal Financial Participation (FFP) at section 1903(f) of the Act do not apply to this group. This means that States can use more liberal income methodologies under section 1902(r)(2) without the usual FFP restrictions.
- If a State exercises its option not to establish an income and resource standard for this group, the above requirements are not applicable.
- Section 1902(f) (209(b) States) applies to this group. 209(b) States may (but are not required to) apply their more restrictive eligibility criteria in determining eligibility for this group.
- There is no requirement that an individual must at one time have been an SSI recipient to be eligible under this group. However, if the individual is not currently an SSI or SSDI recipient, you must do a disability determination to ensure that the individual would meet the definition of disability under the SSI program. NOTE: The disability test must be identical to the SSI/SSDI disability test except that employment activity, earnings, and substantial gainful activity (SGA) must not considered in determining whether the individual meets the definition of disability.

- Because this is an optional categorically needy eligibility group, the benefits and services available to individuals eligible under the group are the same as are available to the categorically needy under your State plan.

You may provide services under a home and community-based services (HCBS) waiver to individuals eligible under this group. To do so, you must amend an existing waiver (or apply to HCFA for a new waiver) to cover the group. Individuals receiving services under an HCBS waiver must meet the level of care requirement (i.e., would require the level of care provided in a medical institution if not for receipt of waiver services). NOTE: Individuals eligible for Medicaid under the Basic Coverage Group are eligible under community, not institutional rules. Therefore, institutional rules under HCBS waivers (including spousal impoverishment, institutional deeming of income and resources, and post-eligibility treatment of income) do NOT apply to this group.

B. Limitations on Defining Employment Under the BBA and Basic Coverage (Subsection (XV)) Groups

We are aware that many States, concerned about the potential costs of covering one or more of the eligibility groups created by TWWIIA and the BBA, would like to define "employment" or "work" in a manner similar to the definition of employment discussed later for the Medical Improvement Group. We appreciate States' concerns, but must make it clear that under the statute, defining employment for the Medical Improvement Group applies only to the Medical Improvement Group. There is no authority under the statute to apply that definition (or any similar definition) to the Basic Coverage Group (subsection (XV)) described previously, nor can it be applied to the existing eligibility group created by section 4733 of the BBA (section 1902(a)(10)(A)(ii)(XIII) of the Act).

For both the BBA group and the Basic Coverage Group, you:

- Must require that an individual have earned income; i.e., that the individual be working;
- May require that the individual provide evidence of employment or work; for example, pay stubs, evidence of FICA taxes paid, or other evidence of employment that the State finds appropriate and necessary.
- May use your options under the premium and cost-sharing process (described in more detail below) to encourage substantive work efforts while discouraging participation by individuals with high levels of unearned income (e.g., SSDI or other benefits) who do not intend to engage in a substantive work effort. For example, you can establish a two-tiered cost-sharing structure that charges a low amount on earned income, but a high amount on unearned income above a personal maintenance level.

However, under the law a State cannot establish a definition of work or employment for the Basic Coverage Group (or the BBA Group) that sets a minimum standard for number of hours worked during a period of time, or a minimum level of earnings. Any such definition is inherently more restrictive than permitted under the applicable provisions of the Medicaid statute, and as such would be out of compliance with the statute.

NOTE: See section III. below for information concerning State options for requiring payment of premium or other cost-sharing charges. See section IV. below for information on maintenance of effort requirements.

II. MEDICAL IMPROVEMENT GROUP SECTION 1902(a)(10)(A)(ii)(XVI) OF THE ACT

NOTE: TO COVER THIS GROUP, YOU MUST ALSO COVER THE BASIC COVERAGE GROUP DISCUSSED ABOVE.

A. Key Elements

To be eligible under this group, an individual must:

- Be at least 16 but less than 65 years of age;
- Be employed and have a medically improved disability (see below for further explanation);
- Have been eligible under the Basic Coverage Group discussed above, but lost that eligibility because the individual, by reason of medical improvement, is determined at the time of a regularly scheduled continuing disability review to no longer meet the definition of disability under the SSI or SSDI programs;
- Have income and resources that do not exceed a standard established by the State.

You have sole discretion to establish income and/or resource standards for this group, including the choice to not have any income and/or resource standard at all if you wish. The following rules and requirements apply to this group:

- If you choose to establish an income and/or resource standard, SSI methodologies apply in determining eligibility, including the SSI earned income disregard of $65 plus one-half of the remainder. Unlike the BBA Group, all earned income is not automatically disregarded in determining eligibility under this group. However, you can use section 1902(r)(2) of the Act (described below) to disregard additional earned income beyond the SSI earned income disregard, including a total disregard of earned income.
- Section 1902(r)(2) of the Act (optional use of more liberal income and resource methodologies than are used by the SSI program) applies to this group.
- The limitations on Federal Financial Participation (FFP) at section 1903(f) of the Act do not apply to this group. This means that States can use more liberal income methodologies under section 1902(r)(2) without the usual FFP restrictions.
- If a State exercises its option not to establish an income and resource standard for this group, the above requirements are not applicable.
- Section 1902(f) (209(b) States) applies to this group. 209(b) States may (but are not required to) apply their more restrictive eligibility criteria in determining eligibility for this group.
- There is no requirement that an individual must at one time have been an SSI recipient to be eligible under this group. A disability test, different from the SSI/SSDI disability test, will apply and is discussed below in Part II.C. below.
- Because this is an optional categorically needy eligibility group, the benefits and services available to individuals eligible under the group are the same as are available to the categorically needy under your State plan.
- You may provide services under a home and community-based services (HCBS) waiver to individuals eligible under this group. To do so, you must amend an existing waiver (or apply to HCFA for a new waiver) to cover the group. Individuals receiving services under an HCBS waiver must meet the level of care requirement (i.e., would require the level of care provided in a medical institution if not for receipt of waiver services). NOTE: Individuals eligible for Medicaid under the Medical Improvement Group are eligible under community, not institutional rules.

Therefore, institutional rules under HCBS waivers (including spousal impoverishment, institutional deeming of income and resources, and post-eligibility treatment of income) do NOT apply to this group.

Employed Individual with a Medically Improved Disability

To be eligible under the Medical Improvement Group, an individual must be employed, and have a medically improved disability. In the interest of clarity, the following addresses the definitions of "employed individual" and "medically improved disability" as separate topics.

B. Employed Individual

For purposes of determining eligibility under the Medical Improvement Group, an employed individual is one who:

- Is at least age 16 but less than 65 years of age; and
- Is earning at least the Federally required minimum wage AND is working at least 40 hours per month; OR is engaged in a work effort that meets an alternate definition of substantial and reasonable threshold criteria for hours of work, wages, or other measures as defined by the State and approved by the Secretary.

State-Defined Work Effort

As noted above, a State may establish its own definition of employment that differs from the minimum level of earnings and hours worked per month set forth in the statute. A State's alternative definition of work effort must be approved by HCFA. If a State wishes to establish an alternative definition of work effort, it should do so as part of an amendment to its Medicaid plan to cover the Medical Improvement Group.

At this time HCFA does not plan to approve alternative definitions of work effort that involve an across-the-board change in the statutory number of hours worked per month or level of earnings described above. We believe that Congress intended those levels to serve as the reasonable baseline for work effort for the Medical Improvement Group as a whole, and thus should serve as the standard most individuals eligible under the group should be expected to meet.

However, we recognize that there is considerable diversity among people with disabilities, including relative degrees of disability, the employment opportunities available to them, and many other considerations that can affect types and amounts of work people with disabilities do, and consequently how work effort can be measured. Therefore, we will consider alternative definitions of work effort involving different levels of earnings and/or hours worked for identifiable groups of individuals with disabilities provided the State can clearly define the group involved and explain why the proposed alternative definition is in fact reasonable and necessary for members of that group.

We will also consider alternative definitions of work effort using threshold criteria (and ways of determining if those criteria are met) that do not necessarily rely on measuring earnings levels and/or hours worked. It is quite possible that people with disabilities have access to employment and work opportunities where the number of hours worked or level of earnings is not the best or most valid measurement of the quality of the work effort. An example might be people who are self-employed. We believe States are in the best position to identify such situations and address them through alternative definitions and measurements of work effort. Therefore, we will definitely consider such alternative definitions, where appropriate, as part of an amendment to your Medicaid plan to cover the Medical Improvement Group.

C. Defining "Medically Improved Disability"

For purposes of determining eligibility under the Medical Improvement Group, an individual with a medically improved disability is one who:

- Was eligible for Medicaid under the Basic Coverage (subsection (XV)) Group discussed above;
- Continues to have a medically determinable severe impairment, but
- Whose disability, impairment, or condition has, by reason of medical improvement, improved to the point where the individual has lost eligibility under the Basic Coverage (subsection (XV)) Group because it was determined, at the time of a regularly scheduled continuing disability review, that he or she no longer met the definition of disability under the SSI and SSDI programs.

It is important to emphasize that the loss of eligibility under the Basic Coverage Group must be the direct and specific result of loss of disability status because of medical improvement. Loss of disability status for a reason unrelated to medical improvement would not qualify as loss because of medical improvement.

Under the statute, the Secretary is required to define the term "medically determinable severe impairment." Information concerning how that term is defined, as well as information on other related disability issues in the context of the work incentives legislation, will be forthcoming in a separate letter to State Medicaid Directors.

NOTE: See section III below for information concerning State options for requiring payment of premiums or other cost-sharing charges. See section IV below for information on maintenance of effort requirements.

III. PREMIUMS AND COST-SHARING CHARGES

Under the existing eligibility group created by section 4733 of the BBA (section 1902(a)(10)(A)(ii)(XIII) of the Act), States may (but are not required to) require eligible individuals to pay premiums or other cost-sharing charges. If States require such payments, the amount must be set on a sliding scale based on income.

TWWIIA also permits States to require payment of premiums or other cost-sharing charges by individuals eligible under both the Basic Coverage Group and the Medical Improvement Group. While some aspects of the premium and cost-sharing requirements under TWWIIA are similar to those under the BBA, many are different.

A. Key Elements of TWWIIA Premiums and Cost-Sharing

The rules applicable to payment of premiums or other cost-sharing charges under TWWIIA are discussed below. The same basic rules apply to both the Basic Coverage (subsection (XV)) Group and the Medical Improvement Group, and your requirements for payment of premiums or other cost-sharing charges must apply equally to all individuals eligible under either of the two groups.

It should also be emphasized that while you have the option to require payment of premiums or other cost-sharing charges, you are not required to do so. A State can elect to impose no premium or cost-sharing charges at all on individuals eligible under either or both of these groups.

For individuals eligible under the Basic Coverage (subsection (XV)) Group and the Medical Improvement Group you may, in a uniform manner for all individuals eligible under those groups:

a. Require individuals to pay such premiums or other cost-sharing charges, set on a sliding scale based on income, as the State may determine;

b. For any individual whose annual family income is less than 450 percent of the Federal poverty level, you can require payment of premiums only to the extent that the amount of the premiums does not exceed 7.5 percent of the individual's income.

c. For any individual whose (IRS) adjusted gross income exceeds $75,000 annually, you must charge 100% of premiums.

B. Sliding Scale Based on Income

The requirement under (a.) above that payments be on a sliding scale based on income applies to both premiums and other cost-sharing charges. While the degree to which such premiums and charges increase with increasing levels of income is up to the State, the underlying principle is that individuals with higher levels of income should contribute more toward the cost of services they receive than those with less income. A percentage premium or cost-sharing charge (e.g., 5 percent of income) is, by definition, on a sliding scale based on income because the actual amount paid increases as income increases.

For purposes of this provision, premiums are defined as fees (usually monthly) that are charged to secure coverage under one of the work incentives Medicaid eligibility groups. Premiums would normally be paid by the individual directly to the State Medicaid agency. By contrast, cost- sharing charges are defined as any other charges that the State may establish through which an individual eligible under one of the work incentives groups shares in the cost of the care and services provided to him or her under the Medicaid program. Cost-sharing charges can either be paid by the individual directly to the State Medicaid agency, or paid by the individual to providers of services in the form of co-pays, deductibles, or co-insurance payments.

A flat cost-sharing or co-payment charge (e.g., $5.00 for each doctor's visit) does not, if applied alone, meet the requirement that charges be on a sliding scale based on income. However, you can use a flat cost-sharing charge system provided that premiums charged to eligible individuals rise with increasing income, either because the premium is a percentage of income or the specified dollar amount of the premium increases as the individual's income increases. A flat cost-sharing charge in conjunction with a sliding scale premium produces an aggregate premium/cost-sharing charge that would meet the requirement that such charges be on a sliding scale based on income.

This means, for example, that a State's normal cost-sharing requirements, when used in conjunction with a sliding scale premium structure, would meet the sliding scale based on the income requirement. So long as there is a sliding scale premium structure, there is no need for a State to incur the added administrative expense of establishing a cost-share system which is different from that used in the rest of its Medicaid program.

It is important to emphasize that while under (a.) above you may require payment of premiums and other cost-sharing charges, the limitation of 7.5 percent of annual income described in (b) above applies only to premiums. The restrictions and requirements outlined in items (b.) and (c.) do not apply to cost-sharing charges that are not premiums.

Regardless of whether or not you exercise your option to require payment of premiums and other cost-sharing charges for the individuals described above you are required, under the statute, to charge 100 percent of premiums for certain other individuals. Individuals subject to payment of 100 percent of premiums are those whose adjusted gross annual income (as determined under the IRS statute) exceeds $75,000. This amount will increase each year after 2000 by the percentage of the annual Social Security cost-of-living increase.

If you exercise the option described above to require individuals eligible under these groups to pay premiums, "100 percent of premiums" would be the highest amount of premiums that an individual would be required to pay under your premium structure. For individuals with income below $75,000, you can require payment of the same amount of premiums, or a lower amount, provided the total premium for individuals with income below 450 percent of the poverty level does not exceed 7.5 percent of the person's income.

You may, if you wish, subsidize payment of premiums for individuals whose income exceeds $75,000. However, any such subsidy must be made solely with State funds. No Federal matching funds are available for such subsidies.

C. Private Health Insurance and TWWIIA Premiums or Other Cost-Sharing Charges

In some instances an individual eligible under the Basic Coverage Group or the Medical Improvement Group may have access to private health insurance coverage; for example, through employment or membership in an organization. If the individual could be covered under such private health insurance at no cost to him or her you may require, under your premium and cost-sharing rules, that the individual take advantage of that insurance. Where private insurance in the form of a group health plan is available to the individual, although at some cost, section 1906 of the Act allows States to enroll individuals in such plans provided such enrollment is cost-effective AND the State pays the cost of enrollment in the plan, including premiums, deductibles and co-insurance

Unless the State pays the full cost of enrollment in the private health insurance plan (including all premiums, deductibles and co-insurance) you may not require individuals to take advantage of the availability of private health insurance. Section 1906 of the Act does not permit mandatory enrollment in private health insurance when that insurance involves a cost to the individual.

IV. MAINTENANCE OF EFFORT REQUIREMENT

Under the statute, States are not permitted to supplant State funds directed toward programs to enable working individuals with disabilities to work with Federal funds used to provide benefits under the Basic Coverage Group and the Medical Improvement Group. If a State covers either or both of the eligibility groups discussed above, Federal Financial Participation (FFP) will not be available for services provided to individuals eligible under those groups for any fiscal year unless the State establishes, to the satisfaction of the Secretary, that its expenditures for those programs are not less than its expenditures for such programs for the fiscal year ending before December 17, 1999.

We will provide additional information concerning this requirement, including procedures to follow to establish and submit to HCFA baseline expenditure levels and annual reports on State expenditures, as well as HCFA's review and determination process, in a separate letter to State Medicaid Directors.