Understanding Medicaid Home and Community Services:

A Primer

2010 Edition

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

Office of the Assistant Secretary for Planning and Evaluation

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

ASPE develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating divisions. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

ASPE plans and conducts evaluations and research—both in-house and through support of projects by external researchers—of current and proposed programs and topics of particular interest to the Secretary, the Administration and the Congress.

Office of Disability, Aging and Long-Term Care Policy

The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities—children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared under contract #HHS-100-03-0025 between HHS's ASPE/DALTCP and RTI International.

For additional information about this subject,
you can visit the DALTCP home page at
http://aspe.hhs.gov/_/office_specific/daltcp.cfm

or contact the ASPE Project Officer,
Emily Rosenoff, at HHS/ASPE/DALTCP
Room 424E, H.H. Humphrey Building,
200 Independence Avenue, S.W., Washington, D.C. 20201
Her e-mail address is: **Emily.Rosenoff@hhs.gov**

Understanding Medicaid Home and Community Services: A Primer

2010 Edition

Project Director
Janet O'Keeffe

Co-Authors
Janet O'Keeffe
Paul Saucier
Beth Jackson
Robin Cooper
Ernest McKenney
Suzanne Crisp
Charles Moseley

Managing Editor
Christine O'Keeffe

ASPE Project Officer
Emily Rosenoff

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary
Washington, D.C. 20201

Dear Reader,

We are pleased to present this updated version of the Medicaid Home and Community Services Primer. Over the past 10 years, the Primer has fulfilled its primary purpose of informing key stakeholders about the statutes and regulations governing the financing and provision of Medicaid home and community services. Specifically the Primer was designed:

- 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 authority and control over their services; and
- To encourage a fundamental approach to the support of people with disabilities that minimizes reliance on institutions and maximizes community integration in the most cost-effective manner.

Medicaid policy has continued to evolve over the last 10 years to better support options for community living by people of all ages with disabilities and/or chronic health conditions. The Deficit Reduction Act of 2005 and the Patient Protection and Affordable Care Act of 2010 both created new options for states to provide home and community services without having to secure a federal waiver. In addition, the Centers for Medicare & Medicaid Services (CMS) has made numerous changes to the program to make it easier for individuals to live in the community, such as authorizing coverage of one-time transition expenses for home and community-based services (HCBS) waiver participants.

The current edition of the Primer has been updated to include all relevant statutory, regulatory and other policy changes that have occurred in the last 10 years. Given the significance of the recent changes in Medicaid, I believe the Primer will be an ever more useful tool for all those working to ensure that people with disabilities can live in the most integrated settings appropriate to their needs.

This updated version of the Primer would not have been possible without the commitment and hard work of many people. In particular I want to recognize and thank the CMS staff who took time out of their busy schedules to review each chapter of the Primer to ensure that the content was accurate and consistent with current policy.

As the Medicaid program continues to evolve to better meet the needs of its beneficiaries, new policy and clarifications of existing policy will be made subsequent to the publication of the Primer. Information about policy changes will be disseminated through State Medicaid Director Letters, the Federal Register, and the State Medicaid Manual, which are available on the CMS website.

Richard Frank
Deputy Assistant Secretary for Planning and Evaluation
Disability, Aging, and Long-Term Care Policy

Acknowledgments

ASPE acknowledges with gratitude the assistance of the Centers for Medicare & Medicaid Services in completing the revised Primer. In particular, we would like to thank CMS staff who reviewed each chapter to ensure technical accuracy and consistency: Mary Sowers, Roy Trudel, Dan Timmel, Kathy Poisal, Carey Appold, Peggy Clark, Carrie Smith, Ellen Blackwell, Melissa Harris, Anita Yuskauskas, and Kenya J. Cantwell. We also thank CMS for funding the development of the appendix on quality management systems.

Table of Contents

Introduction
The 2010 Edition of the Primer 13

Chapter 1
Medicaid Coverage of Home and Community Services: Overview 19

Chapter 2
Financial Eligibility Rules and Options 37

Chapter 3
Determining Service Eligibility 63

Chapter 4
Options for Designing Service Coverage: General Considerations 85

Chapter 5
Providing Medicaid Services in Community Residential Settings 123

Chapter 6
Transitioning People from Institutions to the Community 151

Chapter 7
Participant-Directed Services and Supports 175

Chapter 8
Medicaid Authorities for Delivering Home and Community Services through Risk-Based Managed Care Systems 211

Appendix:
Medicaid HCBS Quality 231

Dedication

Gary Smith, the principal author of the original Primer, died in November 2007.

Gary was the preeminent expert on Medicaid Policy and was a resource to hundreds of people all over the country: researchers, policymakers, Centers for Medicare & Medicaid Services staff, state staff, and advocates. He was always generous with his time and his expertise and never let a request for help go unanswered. He is greatly missed—as a colleague and a friend.

Although millions of people with disabilities have never heard his name, his work in public policy has made an ongoing positive difference in their lives.

We dedicate this edition of the Primer to his memory.

Introduction to the 2010 Edition of the Primer

The Primer was first published in 2000—one year after the Supreme Court decision in Olmstead v. L.C. affirmed the right of persons with disabilities to live in the most integrated setting (see Box).[1] A major purpose of the original Primer was to provide information about how the Medicaid program could be used to assist states in meeting the principles set out in the Olmstead decision.

In the 10 years since the Primer was published, Medicaid policy regarding the provision of home and community services has evolved considerably. During this period, the Centers for Medicare & Medicaid Services (CMS) awarded hundreds of grants to support states' efforts to improve access to—and the availability and quality of—home and community services. The grants were also aimed at increasing Medicaid participants' control over their services and supports.[2]

The Olmstead Decision[3]

The Supreme Court ruled 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 Americans with Disabilities Act (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.

The first edition of the Primer emphasized that people of all ages with disabilities want the same opportunities that every American wants: to thrive, not just survive. They want to live in their own homes and make decisions about daily activities; they want to go to school, attend church services, work, and participate fully in recreational and other community activities. People with disabilities have not always been allowed this birthright; society has too often focused on their disabilities rather than their abilities.

Over the past 2 decades, and particularly since the Olmstead decision, progress has been made. 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 with appropriate services and supports. Much remains to be done to enable all persons with disabilities to do so.

Medicaid: An Evolving Program with Considerable State Flexibility

Medicaid is the major source of public funding for long-term services and supports provided in home and community settings. Medicaid was enacted in 1965 as a companion program to Medicare.[4] It was designed as a joint Federal-state entitlement providing primarily medical care to low-income Americans.[5] When first enacted, Federal Medicaid funding for meeting long-term care needs was available mainly when individuals were placed in an institution (e.g., a nursing home), with few avenues for supporting them in their homes and communities. State funds were used to pay for "home care" programs, but only on a limited basis.[6]

In the 45 years since its enactment, Medicaid's "institutional bias" has been steadily diminished through numerous amendments to Federal laws and policy. Since the early 1980s, there has been a steady increase in the options available to states to secure Federal Medicaid funding for comprehensive home and community services. The Deficit Reduction Act of 2005 (DRA-2005) authorized a new optional State Plan authority for states to provide home and community-based services (HCBS) without a waiver, and most recently, the Patient Protection and Affordable Care Act (hereafter referred to as the Affordable Care Act), enacted in 2010, authorized an additional optional State Plan authority to provide "Community-based Attendant Services and Supports"—called the Community First Choice Option.

Over the past two decades, states have greatly expanded the availability of home and community services. The portion of Medicaid long-term care spending directed to home and community services has been increasing steadily by one to three percentage points each year as states continue to invest more resources in alternatives to institutional care. In 2009, home and community services accounted for 45 percent of total Medicaid long-term care spending.[7] Many states are using innovative and fiscally responsible methods to enable more persons with disabilities to receive necessary services in their communities instead of in institutions.

The Medicaid program provides many options to increase the availability of home and community services while controlling costs. As states work toward the goal of integrating people of all ages with all types of disabilities into their communities, they may need to go through a process of fundamentally rethinking how programs serving people with disabilities are structured and how resources are allocated.

The chapters in this Primer stress that when deciding how best to use the Medicaid program to expand the provision of home and community services, states need to consider their unique needs, resources, and social, political, and economic environments. Additionally, all of these factors must be considered in the context of the technological and demographic changes driving the need for publicly funded long-term care services and supports.

Key among these changes are advances in medical technology that have enabled increasing numbers of people with congenital and acquired disabilities to both survive and live longer lives. A second change is that the nation's population is aging. The group most likely to need long-term care—people over age 85—is estimated to grow from 5.3 million in 2006 to nearly 21 million by 2050.[8]

Moreover, the aging population includes individuals who have spent their lives providing informal care for adult children with intellectual disabilities and other developmental disabilities (ID/DD, hereafter referred to as developmental disabilities). Now that many individuals with developmental disabilities are outliving their parents, an increase in the number needing services and support is expected in the coming years.[10] Finally, most assistance to people with disabilities is provided by informal caregivers, typically women. However, continued reliance on this support in the coming years may be unrealistic, given high rates of women's labor force participation, smaller families, and geographic mobility.

Terminology and Definitions

In this Primer, the term "persons with disabilities" includes persons of all ages—young children, adolescents, and working age or older adults—with all types of disabilities due to physical and mental impairments and/or chronic illnesses. Because the Primer's focus is on Medicaid home and community services, the term "people with disabilities" refers primarily to those individuals who need long-term care services. However, not all persons with disabilities need these services.

The service systems for different disability groups use different terms for the same or similar services. For example, the service system for older adults uses long-term care or long-term care services, whereas the service system for people with developmental disabilities uses long-term services and supports or just supports. States also vary in their use of terms: personal care is also called personal assistance or attendant care, which is provided by personal care providers, personal assistants, personal attendants, and direct care workers, among other names.

To eliminate confusion, the Primer uses terms consistently in all chapters and specifically notes when terms are used interchangeably. When discussing a particular state's service system, or Federal statutes and regulations, the Primer uses the specific terms they use. For example, the term home and community-based services is used only when referring to Federal statutes, regulations, or programs that use this term. In general, the Primer uses the term home and community services or just services and supports.

A law enacted in October 2010 amended provisions of Federal law to substitute the term "an intellectual disability" for "'mental retardation," and "individuals with intellectual disabilities" for "the mentally retarded" or "individuals who are mentally retarded."[9] Intermediate Care Facilities for Persons with Intellectual Disabilities (ICF/ID) is the new title for the program formerly known as Intermediate Care Facilities for the Mentally Retarded. The Primer uses these new terms, except when the former terms are used in the titles of previously published books, reports, and articles.

To ensure brevity without excessive use of acronyms when referring to systems of care, the Primer generally uses the shortest term (e.g., long-term care rather than long-term care services and supports).

Finally, many of the Medicaid provisions discussed in the Primer were enacted when the Centers for Medicare & Medicaid Services was known as the Health Care Financing Administration (HCFA). Throughout the Primer, the current name—CMS—will be used, even when referring to actions the agency made when it was named HCFA.

Purpose, Audience, and Organization of the Primer

Medicaid offers a complex and varied set of home and community service options—with similarly complex rules and regulations—that can be bewildering for policymakers, state officials, advocates, and consumers. Even people who have spent years working in Medicaid state agencies do not always understand its many provisions. The extensive flexibility states have to combine these options has resulted in considerable variation among states' Medicaid programs. As some wit has put it, "What state Medicaid programs have most in common is that they are all different."

The Primer is designed to encourage states to use the Medicaid program to minimize reliance on institutions and maximize community integration for people with disabilities in a cost-effective manner. Its intended audience is policymakers, state Medicaid staff, and all stakeholders 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. In addition to providing comprehensive explanations of Medicaid home and community service options, the Primer presents examples of states that have used them to promote greater community integration of people with disabilities.

The service options reviewed address program modifications that states can implement as a State Plan option (without a special waiver of Federal law), as well as those for which Federal waiver approval must be obtained. While each chapter has been written to cover a specific topic, and as such, can be read independently of the rest of the Primer, it also assumes an understanding of basic Medicaid terms and provisions, such as comparability and statewideness, mandatory and optional services, State Plan and waiver services. Those unfamiliar with these basic terms should first read Chapter 1.

When a topic is covered in depth in one chapter, that chapter will be referenced in other chapters that address the topic.

Chapter 1 provides a brief overview of the legislative and regulatory history of Medicaid's coverage of home and community services and current spending on these services.

The next two chapters describe the basic elements of Medicaid's financial and service eligibility criteria.

Chapter 2 provides an explanation of Medicaid's financial eligibility criteria, a complex area of Medicaid law. It first discusses the general eligibility criteria that all Medicaid beneficiaries must meet. It then focuses on the financial eligibility provisions most important for receiving services in home and community settings. The chapter also reviews the options states can select to ensure that people with disabilities can support themselves in home and community settings.

Chapter 3 focuses on Medicaid provisions related to the health and functional criteria states use to determine eligibility for State Plan home health services, State Plan personal care services, State Plan home and community-based services, and HCBS waiver programs. The chapter also discusses how states can design service criteria to ensure that they appropriately and adequately measure the need for services and supports among heterogeneous populations.

Chapters 4 and 5 describe service coverage options.

Chapter 4 presents the major service options for providing home and community services to people with disabilities. The factors states need to consider when choosing among the various options are also discussed.

Chapter 5 describes coverage options for providing services in a wide range of residential care settings that are provider-owned and/or operated, including foster care, group homes, and assisted living.

Chapters 6 and 7 focus on key policy goals related to coverage of home and community services.

Chapter 6 discusses factors states need to consider when developing initiatives to transition institutional residents to home and community settings. It also presents ways in which Medicaid can be used to facilitate transitions.

Chapter 7 describes Medicaid options to increase participants' choice and control of home and community services.

Chapter 8 describes options for states to provide Medicaid home and community services through managed care delivery systems.

An appendix provides an overview of CMS requirements for quality management and improvement systems for HCBS waivers.

To make the Primer as useful as possible, each chapter includes a Resources section that provides information about key publications and links to websites from which the reader can obtain more detailed information about the chapter's topic. The endnotes for each chapter include not just source citations, but additional technical information and—in many cases—web links to these citations and information. Thus, while the Primer can be read either in hard copy or online, the online version enables readers to access a considerable amount of additional information.

This Primer has been prepared by the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services, and reviewed for accuracy by CMS staff. 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 function.

Endnotes

Citations, Additional Information, and Web Addresses

[1] *Olmstead v. L. C.,* 119 S.Ct. 2176 (1999).

[2] The grants were implemented through several programs, primarily the Systems Change Grants for Community Living program.

[3] 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)). Information about the application of the Olmstead decision to the Medicaid program is available from the CMS website in State Medicaid Director Letters. Available at http://www.cms.hhs.gov/SMDL/SMD/list.asp#TopOfPage. Use the word Olmstead to find the relevant letters.

[4] P.L. 89-97, Title XIX of the Social Security Act.

[5] The Federal Government provides matching funds on an open-ended basis for every dollar a state chooses to spend on Medicaid services.

[6] Federal funding through specific programs was sometimes available.

[7] Citation: Eiken, S., Sredl, K., Burwell, B., and Gold, L. (2010). *Medicaid Long-Term Care Expenditures in FY 2009*. Cambridge, MA: Thomson Reuters. Available at http://www.hcbs.org/moreInfo.php/doc/3326.

[8] U.S. Agency on Aging. Statistics available at http://www.aoa.gov/agingstatsdotnet/Main_Site/Data/2008_Documents/Population.aspx.

[9] Called Rosa's Law (Bill S.2781), signed October 5, 2010, by President Barack Obama.

[10] Hubert, J., and Hollins, S. (2002). *People with Intellectual Disabilities and Their Elderly Caregivers*. Available at http://www.intellectualdisability.info/life-stages/people-with-intellectual-disabilities-and-their-elderly-carers/?searchterm=People%20with%20Intellectual%20Disabilities%20and%20Their%20Elderly%20-Caregivers.

Guide to Chapter 1

Introduction 21
Program Evolution and Current Spending Allocations 21
Major Features of Medicaid's Provisions for Home and Community Services 23
Mandatory State Plan Services: Home Health 23
Mandatory State Plan Services: EPSDT 25
Optional State Plan Services: Personal Care 25
Optional State Plan Services: Targeted Case Management 26
Optional State Plan Home and Community-Based Services 27
Optional State Plan Services: Community Choice Option 27
Other Optional State Plan Home and Community Services 27
The HCBS Waiver Authority 28
The Katie Beckett Provision 29
The Program of All-Inclusive Care for the Elderly (PACE) 30
Resources 31
Endnotes: Citations, Additional Information, and Web Addresses 35

Chapter 1
Medicaid Coverage of Home and Community Services: Overview

Long-term care includes a broad range of health and health-related services, personal care, social and supportive services, and individual supports. These services can be provided in institutions, an individual's home, or in community settings. This chapter recounts the legislative, regulatory, and policy history of Medicaid coverage of long-term care services and supports. Both institutional care and home and community services are described, with the latter in greater detail.[1]

Introduction

Medicaid is a needs-based, entitlement program that is designed to help states meet the costs of necessary health care for low-income and medically needy populations. When a Medicaid State Plan is approved by the Centers for Medicare & Medicaid Services (CMS), states qualify to receive Federal matching funds to finance Medicaid services (see Box). States have substantial flexibility to design their programs within broad Federal requirements related to eligibility, services, program administration, and provider compensation.

Federal Medical Assistance Percentage (FMAP)

The Federal government's share of medical assistance expenditures under each state's Medicaid program, known as the Federal medical assistance percentage, 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. States are also reimbursed for 50 percent of administrative costs. For fiscal year 2009, the FMAP ranged from 50 percent in California and several other states to 75.84 percent in Mississippi.[2]

Program Evolution and Current Spending Allocations

When enacted, 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 expanded Medicaid coverage of low-income pregnant women and poor children, and extended coverage to some low-income Medicare beneficiaries who were not eligible for cash assistance. From its beginnings as a health care financing program primarily for welfare recipients, the Medicaid program has been amended and expanded to cover a wide range of populations and services.

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

independently in their homes and in a wide range of community residential care settings.

The Federal Medicaid statute (Title XIX of the Social Security Act) generally 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—called the comparability requirement.

Generally, a State Plan must be in effect throughout an entire state (i.e., the amount, duration, and scope of coverage must be the same statewide—called the "statewideness" requirement). The Social Security Act has some exceptions, notably (1) states operating Section (§)1915(c) home and community-based services (HCBS) waiver programs (hereafter called HCBS waiver programs) are permitted to target services by age and diagnosis and can offer them on a less than statewide basis, and (2) targeted case management services offered as an optional benefit under the State Plan are not subject to the statewideness requirement. (§1115 Research and Demonstration waivers can also operate on a less than statewide basis.)

By 1999, the year of the Olmstead decision, every state was providing home and community services under one or more of the available options except for §1915(i) (which did not become effective until 2007). By then, Medicaid had become the nation's major public financing program for long-term care for low-income persons of all ages with all types of physical and mental disabilities.[3]

Since 1988, Medicaid spending for home and community services has increased dramatically. In that year, expenditures for all long-term care services totaled $23 billion. Nearly 90 percent of those dollars paid for institutional services in nursing facilities and intermediate care facilities for persons with intellectual disabilities (ICFs/ID). Only 10 percent was spent on home and community services (i.e., HCBS waivers, personal care, home health, and targeted case management).[4]

In 2008, total Medicaid spending for all long-term care services had increased to $106.4 billion. Institutional spending had dropped to 57.3 percent and HCBS spending increased to 42.7 percent. The latter percentage, however, masks large variations among states in the share of spending devoted to home and community services and among different populations. For example, in 2008 only 10 states spent 50 percent or more of their long-term care budgets on home and community services. New Mexico and Oregon ranked at the top with over 70 percent; Mississippi was at the bottom with 13.9 percent.[5]

Expansion of home and community services relative to institutional services has been particularly pronounced for individuals with intellectual disabilities and other developmental disabilities (ID/DD, hereafter called developmental disabilities). In 2008, only four states (New Mexico, Washington, Oregon, and California) spent more than 50 percent of their Medicaid long-term care budgets on home and community services for the aged and disabled population, while 42 states spent at least half of their Medicaid long-term care budgets on home and community services for individuals with developmental disabilities. As an example, Oregon's spending on home and community services for the ID/DD population was 100 percent compared with 53.6 percent for the aged and disabled population.

Nationally, in 2008, 35.5 percent of Medicaid's total long-term care expenditures for persons with developmental disabilities were allocated to institutional services and 64.5 percent to home and community services. The allocation for elderly persons and younger persons with physical disabilities was the opposite—68.4 percent of total long-term care expenditures for institutional services and 31.6 percent for home and community services.[6]

Major Features of Medicaid's Provisions for Home and Community Services

The remainder of this chapter presents a brief overview of the Medicaid law, regulations, and policies that give states the flexibility to create comprehensive home and community service systems for people of all ages with all types of physical and mental impairments and/or chronic health conditions. To provide context for the discussion, Table 1-1 lists the major relevant provisions of Medicaid law. This chronological summary illustrates the historical expansion of Medicaid long-term care services away from a primary focus on institutional care.

Key benefits for providing home and community services include both mandatory services such as Home Health and optional services such as Personal Care and Rehabilitation. Additional Medicaid provisions, such as the HCBS waiver authority, enable states to offer a comprehensive range of home and community services.

Mandatory State Plan Services: Home Health

Since 1970, services under the Home Health benefit have been mandatory for people entitled to nursing facility care.[7] States are mandated to cover nursing home care for categorically eligible persons age 21 or older. This mandate entitles persons age 21 or older to nursing facility care. States have the option to cover nursing home care for other Medicaid beneficiaries as well, such as persons under age 21. If a state chooses to cover persons under age 21, they 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.[8] (See Chapter 3 for additional information about eligibility for services under 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 the Home Health benefit—including physical therapy, occupational therapy, and speech pathology and audiology services.[9] States may establish reasonable standards for determining the extent of such coverage using criteria based on medical necessity or utilization control.[10] 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. [11] All Home Health services must be medically necessary and authorized by a physician's order as part of a written plan of care.

In 1998, following the ruling of the U.S. Court of Appeals for the Second Circuit in DeSario v. Thomas, CMS 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 beneficiaries to request items that do not appear on such a list.[12] 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 in Skubel v. Fuoroli 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.[13] (See Chapter 3 for additional information on this ruling.)

TABLE 1-1	Medicaid's Legislative Provisions Regarding Long-Term Care Services
1965	Establishment of Medicaid[14] • Mandatory coverage of SNFs for categorically eligible persons age 21 or older. • Optional coverage of Home Health services and Rehabilitation services.
1967	Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate for children under age 21.[15] States given the option to provide services not covered by their State Plans under EPSDT.
1970	Mandatory coverage of Home Health services for those entitled to SNF services.[16]
1971	Optional coverage of intermediate care nursing facilities and ICFs/ID.[17]
1972	Optional coverage of children under age 21 in psychiatric hospitals.[18]
1973	Option to allow people receiving supplemental security income (SSI) to return to work and maintain their Medicaid benefits.[19]
1981	Establishment of HCBS waiver authority.[20]
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/ID. Also known as the Katie Beckett or Tax Equity and Fiscal Responsibility Act (TEFRA) provision.[21]
1986	Option to cover targeted case management (TCM). States are allowed to cover TCM services without regard to statewideness and comparability requirements.[22] 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.[23]
1988	Establishment of special financial eligibility rules for institutionalized persons whose spouse remains in the community, to prevent spousal impoverishment.[24]
1989	EPSDT mandate amended to require states to cover any service a child needs, even if it is not covered under the State Plan.[25]
1993/94	Removal of requirements for physician authorization and nurse supervision for personal care services provided under the State Plan. States explicitly authorized to provide personal care services outside the individual's home.[26] Personal Care added to the statutory list of Medicaid services. (Personal Care was an option since the mid-1970s, when it was established administratively under the Secretary of Health and Human Services' authority.)
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. Establishment of the Program of All Inclusive Care for the Elderly (PACE) as a State Plan option.
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.[27]
2005	Establishment of a new Medicaid State Plan authority for providing HCBS under §1915(i) of the Social Security Act, under the Deficit Reduction Act of 2005 (DRA-2005), effective 2007. The DRA-2005 also expands options for Medicaid participants to direct their services under HCBS waivers and State Plan Personal Care programs, through §1915(j) of the Social Security Act.
2010	Establishment, under the Affordable Care Act of 2010, of a new authority under §1915(k) of the Social Security Act, effective October 2011. This authority allows states to provide "Community-based Attendant Services and Supports" under the Community First Choice Option.

Mandatory State Plan Services: EPSDT

The Federally mandated Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program for children from birth until they turn age 21 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 Medicaid State Plan. In 1989, Congress strengthened the EPSDT mandate by requiring states to cover all treatment services defined under §1905(a), regardless of whether or not those services are covered in their Medicaid State Plan.[28] As a result, EPSDT programs now cover the broadest possible array of Medicaid services, including personal care and other services provided in the home.

Optional State Plan Services: Personal Care

Since the mid-1970s, states have had the option to offer personal care services under the Medicaid State Plan. This option was first established administratively under the Secretary's authority to add coverages over and above those spelled out in §1905 of the Social Security Act, if such services would further the Social Security 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.[29] (See Chapter 4 for more information about the State Plan Personal Care benefit.)

When the Personal Care benefit option 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 service plan. Moreover, they could be provided only in a person's place of residence. Generally, the personal care services a state offered were for assisting individuals to perform activities of daily living (ADLs)—bathing, dressing, eating, toileting, and transferring (e.g., 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 the 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, when Congress formally incorporated personal care into Federal Medicaid law, it gave states explicit authorization to provide personal care outside an individual's home.[30] Congress went even a step further in 1994, allowing states to (1) use means other than nurse supervision to oversee the provision of personal care services, and (2) establish means other than physician prescription for authorizing such services. In November 1997, CMS issued new regulations concerning optional Medicaid State Plan personal care services to reflect these statutory changes.[31]

In January 1999, CMS released a State Medicaid Manual Transmittal that thoroughly revised and updated guidelines concerning coverage of personal care services. (See the Resources section of this chapter for web links to the Medicaid Manual.) New Manual materials make clear that personal care services may include 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. Additionally, the guidelines 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." It also explicitly recognized that the provision of personal care services may be directed by the people receiving them. Direction by participants includes training and supervising personal care attendants. The ability of participants to direct their 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, participant direction was built into the Massachusetts Medicaid Personal Care program from its inception. Taken together, these ground-breaking

changes in Federal policy can help pave the way for a state to broaden coverage of these services. In order to take advantage of these changes, a state must amend its State Plan. Neither the statutory provisions nor the revised Federal regulations and State Medicaid Manual guidelines dictate that a state must change the scope of its pre-1993 personal care coverage.

In 2005, 36 states covered personal care services under their Medicaid State Plans.[32] The most likely explanation for this less than national coverage is that some states have elected to cover personal care services through more flexible and easy to target HCBS waiver programs instead of adding the benefit to their State Plan. (See Chapter 4 for a discussion of the various options for covering personal care, including their advantages and drawbacks.)

The §1915(j) Authority. The DRA-2005 added §1915(j) to the Social Security Act, effective January 2007.[33] This authority permits a state to institute an option for participants to have individual budgets to purchase non-traditional goods and services other than personal care to the extent that expenditures would otherwise be made for human assistance. It also allows states the option to disburse cash prospectively to participants who direct their services under the State Plan Personal Care benefit or an HCBS waiver program. Participants may also determine rates of pay for their workers, accumulate funds earmarked for the purchase of a specific item designed to increase independence or substitute for human assistance, and work with a fiscal intermediary to perform payroll and tax functions—called the "budget authority." Absent the §1915(j) authority, participant direction of Medicaid State Plan personal care services is limited to hiring, supervising, and dismissing (if needed) their workers—called the "employer authority."

States may use the §1915(j) authority only in programs already offered under its Medicaid State Plan or an HCBS waiver (i.e., states may not offer the specific participant-directed services options under the §1915(j) authority except in an existing State Plan Personal Care program or HCBS waiver program). (See Chapter 7 for a detailed description of this new authority and a discussion of participant-directed service options—also called self- or consumer-directed—that can be offered under several Medicaid authorities.)

Optional State Plan Services: 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 an option for states to cover what were termed "targeted case management" services under their State Plan.[34] 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 optional benefit is exempt from the comparability requirement to make services available to all recipients. A state is permitted to amend its State Plan to cover case management services for one or more specified groups of Medicaid recipients (hence the term targeted). It may also offer these services on a less-than-statewide basis (through a State Plan amendment instead of securing a waiver).[35]

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. In addition to assessment and service/support planning, referrals, and monitoring the delivery of services and supports to ensure they are meeting a beneficiary's needs, covered activities include assistance in obtaining food stamps, emergency housing, or legal services. (See Chapter 4 for more information about this benefit.)

Optional State Plan Home and Community-Based Services[36]

The DRA-2005 added §1915(i) to the Social Security Act, which was amended by the Patient Responsibility and Affordable Care Act of 2010. The §1915(i) authority gives states the option to offer a wide range of home and community-based services without having to secure Federal approval of a waiver. The §1915(i) authority provides states an opportunity to offer services and supports before individuals need institutional care, and also provides a mechanism to provide State Plan HCBS to individuals with mental health and substance use disorders.

Unlike other State Plan services, under §1915(i), states may design service packages without regard to comparability.[37] States may offer HCBS to specific, targeted populations and offer services that differ in amount, duration, and scope to specific population groups, including eligibility groups as authorized under §1915(i)(6)(c), either through one or multiple §1915(i) service packages. Services must be available statewide.

Optional State Plan Services: Community Choice Option[38]

The Affordable Care Act added §1915(k) to the Social Security Act, effective October 2011, which allows states to provide "Community-based Attendant Services and Supports"—called the Community First Choice Option. Under §1915(k), states that provide home and community-based attendant services and supports through their State Plans under this option will receive a six percentage points higher Federal match. Individuals must be eligible for Medicaid under the State Plan and have an income that does not exceed 150 percent of the Federal Poverty Level, or, if their income is greater, they must meet institutional level-of-care criteria. CMS plans to issue a Notice of Proposed Rule Making related to this provision of the Affordable Care Act in early 2011.

Other Optional State Plan 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 provided in home and/or 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 or other licensed practitioner of the healing arts for maximum reduction of physical or mental disability, and restoration of a recipient to his or her best possible functional level.[39] Rehabilitation services can be provided to people with either physical or mental disabilities.

The Rehabilitation 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 serious mental illness. In 2005, 46 states used the Rehabilitation option to provide services for persons with a serious mental illness; 33 states used the Rehabilitation option to provide other services.[40]

Optional Institutional Services

The 1971 addition of the option to cover services provided by intermediate care nursing facilities, called intermediate care facilities (ICFs), and ICFs/ID, moved the Medicaid program into financing additional nursing home care and institutional services for the ID/DD population. States adding optional institutional coverage of ICFs/ID could receive Federal matching funds to help finance services for persons with developmental disabilities, which had previously been supportable only with state funds.

Likewise, states adding optional coverage of ICFs could receive Federal matching funds to help finance a non-skilled level of nursing care (which had previously been supportable only with state funds). Over the next few years, every state and the District of Columbia chose to cover ICFs and ICFs/ID in their State Plan.

The option to cover nursing ICFs and ICF/IDs assumed greater importance after 1981, when the waiver authority was created. This was because §1915(c) waiver services can be provided only insofar as they provide an alternative to institutional care.[41] (In 1987, Congress abolished the distinction between SNFs and ICFs. Nursing facilities were mandated to provide both a skilled and intermediate level of care.)

The Rehabilitation option is not generally used to furnish long-term care to individuals with disabilities or chronic health conditions other than mental illness. During the 1970s and 1980s, a few states secured approval to cover daytime services for persons with developmental disabilities under either the Clinic or the Rehabilitation option. However, CMS ultimately ruled that the services being furnished were habilitative rather than rehabilitative and consequently could not be covered under either option by additional states. The main basis for the ruling was that habilitative services could only be furnished to residents of ICFs/ID under the Medicaid State Plan or through an HCBS waiver program for individuals otherwise eligible for ICF/ID services. States with existing programs serving individuals with intellectual disabilities and other developmental disabilities were grandfathered under the Omnibus Reconciliation Act (OBRA) of 1989.

A few states have maintained their State Plan coverage of these services; others have terminated them in favor of offering similar services through an HCBS waiver program.[42] With the creation of the new HCBS State Plan option under the §1915(i) authority, states may now cover habilitation as a home and community-based service under the State Plan.

The HCBS Waiver Authority

In 1981, Congress authorized the waiver of certain Federal requirements to enable states to provide home and community services (but not room and board) to individuals who would otherwise require institutional services reimbursable by Medicaid (i.e., services in a skilled nursing facility, an intermediate care nursing facility, or an ICF/ID). The waiver programs are often called §1915(c) waivers (named after the section of the Social Security Act that authorized them), but are also called HCBS waivers, the term used in this Primer.[43]

Under the §1915(c) waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are required to prevent institutionalization. Services covered under waiver programs include case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, and "such other services requested by the state as the Secretary of Health and Human Services (HHS) may approve." Services for individuals with a chronic mental illness were added in the late 1980s: "day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility)."

Neither the statute itself nor CMS regulations further specify or define the scope of the listed services. However, the law that created the waiver program expressly permits the Secretary of HHS 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 29 years since the waiver authority became available, CMS has approved a wide range of additional services.

In the early 1990s, CMS first issued a standard HCBS waiver application format for states to submit requests to operate an HCBS waiver program. The standard format included definitions of services states commonly cover in their HCBS waiver programs. The services listed in the standard format appear there because they are included in the listing contained in the statute, or are additional services that states frequently offer.

In 2005, CMS extensively modified its standard §1915(c) application to obtain greater detail about how the proposed program would operate. States must now provide specific information about how their programs comply with Federal standards, as well as detailed information about their quality improvement systems. Beginning in 2006, CMS began offering a web-based version of the application. The conversion to a web-based application streamlines the preparation of waiver applications and amendments, and improves communication between states and CMS about waiver requests.

The Waiver Application Instructions represent the most current guidance related to HCBS waivers. The instructions provide CMS-suggested definitions of services that states may cover under their HCBS waiver programs—identified as Core Service Definitions. The services a state may offer are by no means limited to those that appear in the standard format, nor are the proposed definitions required. (See the Resources section of this chapter for a link to all approved HCBS waivers and a link to the online waiver application and technical guidance document.)

During Federal fiscal year (FFY) 2008, 48 states and the District of Columbia operated 314 HCBS waiver programs. This number includes waivers that CMS had approved but that had not yet been implemented as of September 30, 2008. The two states that did not have HCBS waivers—Arizona and Vermont—provided similar services as part of Research and Demonstration waivers authorized by §1115 of the Social Security Act.[44]

Expenditures for waiver services totaled $30 billion in 2008 and roughly three-fourths was used to purchase services and supports for persons with developmental disabilities, including persons with autism spectrum disorders or intellectual disabilities.[45] Almost all other waiver expenditures in the same year were for older adults and younger adults with physical disabilities; a few smaller population groups accounted for the remaining waiver expenditures.[46]

The Katie Beckett Provision

The Katie Beckett provision is in a statute—the Tax Equity and Fiscal Responsibility Act 134—and was 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. Prior to enactment, 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 obtain medical care for them.

TEFRA 134 amended the Medicaid statute to give states the option to waive the deeming (i.e., counting) 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 them to determine that (1) the child needs the level of care provided in an institution, (2) it is appropriate to provide care outside a 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.

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

The Program of All-Inclusive Care for the Elderly—authorized by the Balanced Budget Act of 1997 (BBA-97)—is a capitated program that features a comprehensive service delivery system that integrates Medicare and Medicaid financing. The BBA-97 established the PACE model of care as a permanent method for organizing service delivery within the Medicare program, and enables states to provide PACE services to Medicaid beneficiaries. Participants must be at least 55 years old, eligible for Medicare or Medicaid or both, and certified as meeting a state's nursing home level-of-care criteria. For most participants, the comprehensive service package permits them to continue living at home rather than be admitted to an institution.

In 2009, 72 PACE programs were operating in 30 states. The State Plan must include PACE as a Medicaid benefit before the state and the Secretary of HHS can enter into program agreements with PACE providers. Participants must be at least 55 years old, live in the PACE service area, and be certified as eligible for nursing home care by the appropriate state agency. The PACE program becomes the sole source of services for persons dually eligible for Medicare and Medicaid who choose to enroll.

An interdisciplinary team, consisting of professional and paraprofessional staff, assesses participants' needs, develops service plans, and delivers all services (including primary and acute health care services, home and community services, and when necessary, nursing facility services). Financing for these services is integrated to promote a seamless system of care. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and other services in accordance with participants' needs. The PACE service package must include all Medicare and Medicaid covered services, and other services determined necessary by the interdisciplinary team for the care of the PACE participant. (See Chapter 8 for more information about the PACE program and other Medicaid managed care options.)

This brief overview of Medicaid's statutory, regulatory, and other policy provisions related to home and community services 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., changing home and community-based services from an optional to a mandatory benefit). 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 waiver services than for institutional care. They also have considerable flexibility to create consumer-responsive systems that facilitate home and community living.

In the next several decades, as already noted, the U.S. population will age dramatically. 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, it is advisable for states to continue working to create comprehensive long-term care service systems that will enable people with disabilities and/or chronic health conditions—whatever their age or the severity of their condition—to live in their homes and community settings rather than in institutions.

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 that they enable people of all ages with disabilities and/or chronic health conditions to retain their independence and dignity.

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key publications and Internet resources regarding Medicaid long-term care generally and home and community services specifically. Most of the publications cite additional resources, and the websites also have links to other sources of information.

Publications

Houser, A., Fox-Grage, W., and Gibson, M. (2009). *Across the States 2009: Profiles of Long-Term Care and Independent Living.* Washington, DC: AARP Public Policy Institute.

This report is the eighth edition of the AARP Public Policy Institute's state long-term care reference report. Published approximately every 2 years, the Across the States series was developed to help inform policy discussions among public and private sector leaders in long-term care throughout the United States. Across the States 2009 presents comparable state-level and national data for more than 140 indicators, drawn together from a wide variety of sources into a single convenient reference. This publication presents the most up-to-date data available at the time of production, and is displayed in easy-to-use maps, graphics, tables, and state profiles.

Available at http://www.hcbs.org/moreInfo.php/doc/2536

Centers for Medicare & Medicaid Services. (2008). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria.* Baltimore, MD: USDHHS.

This publication contains extensive information concerning Federal policies that apply to the operation of an HCBS waiver as well as technical guidance for completing the application.

Available at https://www.hcbswaivers.net/CMS/faces/portal.jsp under links and downloads, entitled §1915(c) Waiver Application and Accompanying Materials.

CMS State Medicaid Director Letter (November 19, 2009). *Implementation of §6087 of the Deficit Reduction Act of 2005 Regarding §1915(j) of the Social Security Act.*

This letter provides guidance on the implementation of §6087 of the Deficit Reduction Act of 2005, Public Law Number 109-171. Section 6087, the "Optional Choice of Self-Directed Personal Assistance Services (Cash

and Counseling)," amended §1915 of the Social Security Act by adding a new subsection (j). The guidance also applies to §1915(c) HCBS waiver programs when states offer a self-direction option and permit participants to purchase "individual directed goods and services." The letter offers information on (1) Background, (2) Medicaid Authorities, (3) Criteria, (4) Support and Monitoring, and (5) Compliance with the Guidance.

Available at http://www.cms.hhs.gov/SMDL/SMD/ItemDetail.asp?ItemID=CMS1230894

The Kaiser Commission on Medicaid and the Uninsured. (2009). *Medicaid Home and Community-Based Service Programs: Data Update.* Washington, DC: Kaiser Family Foundation.

This report presents a summary of the main trends to emerge from an analysis of the 2006 expenditures and participant data for the three main Medicaid home and community service programs: optional §1915(c) HCBS waivers, the mandatory Home Health benefit, and the optional State Plan Personal Care benefit. It also presents survey findings about various features of the three programs, such as eligibility criteria, waiting lists, and provider reimbursement rates for the Home Health benefit and the Personal Care benefit.

Available at http://www.kff.org/medicaid/7720.cfm

National Association of State Medicaid Directors. (2007). *State Perspectives on Emerging Medicaid Long-Term Care Policies and Practices.* Washington, DC: American Public Human Services Association.

The purpose of this survey analysis is to provide states with an overview of state implementation of the DRA-2005 options and other long-term care policies and practices. Findings address a range of issues, including eligibility, Children with Disabilities, Money Follows the Person, HCBS State Plan Amendments, Transition from Institutions, Managed Care, State Plan Amendment for Personal Care Services, Cash & Counseling, Care Coordination, Disease Management, and Long-Term Care Reform.

Available at http://www.hcbs.org/moreInfo.php/doc/2094

Websites

The following websites provide information about Medicaid, long-term care services and supports, 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

Centers for Medicare & Medicaid

General: Links to Programs and Information

Web address: http://www.cms.hhs.gov/default.asp

Specific: Links to Regulations and Guidance

1. Program transmittals are used to communicate new or changed policies and/or procedures that are being incorporated into a specific CMS program manual. The cover page (or transmittal page) summarizes the new changed material, specifying what is changed.
   Available at http://www.cms.hhs.gov/Transmittals/

2. The CMS Online Manual System is used by CMS programs, partners, contractors, and State Survey Agencies to administer CMS programs. It offers day-to-day operating instructions, policies, procedures based on statutes and regulations, guidelines, models, and directives. In 2003, CMS transformed the CMS Program Manuals into a web user-friendly presentation and renamed it the CMS Online Manual System.
   Available at http://www.cms.hhs.gov/Manuals/01_Overview.asp

3. Paper-based manuals are CMS manuals that were officially released in hardcopy. The majority of these manuals were transferred into the Internet-only manual or retired from the manual. The State Medicaid Manual is still an active paper-based manual.
   Available at http://www.cms.hhs.gov/Manuals/PBM/itemdetail.asp?filterType=none&filterByDID=-99&sortByDID=1&sortOrder=ascending&itemID=CMS021927&intNumPerPage=10

4. The State Medicaid Director and State Health Official letters are used to provide states with guidance and clarification on current information pertaining to Medicaid policy, Medicaid data issues, and State Children's Health Insurance Program policy. The intent of these letters is not to establish policy, but to ensure consistency and better serve the states.
   Available at http://www.cms.hhs.gov/SMDL/

5. CMS maintains a database of every state's approved waiver applications under various authorities, for example, §1915(c), §1915(b), and §1115. Users can access fact sheets, copies of proposals, approval letters, and other documents related to specific programs.
   Available at http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/%2008_WavMap.asp

Administration on Aging, Home & Community Based Long-Term Care

Web address: http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/index.aspx

Office of the Assistant Secretary for Planning & Evaluation,
Office of Disability, Aging, and Long-Term Care Policy

Web address: http://aspe.hhs.gov/_/office_specific/daltcp.cfm

State Associations, Other Associations, and Foundations

American Public Human Services Association
Web address: http://www.aphsa.org/Home/home_news.asp

Kaiser Family Foundation
Web address: http://www.kff.org

National Academy for State Health Policy
Web address: http://www.nashp.org/

National Association of State Medicaid Directors
Web address: http://www.nasmd.org/Home/home_news.asp

National Association of State Mental Health Directors
Web address: http://www.nasmhpd.org/

National Association of State Directors of Developmental Disabilities Services
Web address: http://www.nasddds.org/index.shtml

National Conference of State Legislatures
Web address: http://www.ncsl.org/default.aspx?tabid=14489

Robert Wood Johnson Foundation
Web address: http://www.rwjf.org/

State and Local Governments on the Web
Web address: http://www.statelocalgov.net/

The Clearinghouse for Home and Community Based Services promotes the development and expansion of home and community services by gathering resources and tools for research, policymaking, and program development into this one-stop website. The site has over 2,000 resources that users can browse using the site's search engine.
Web address: http://www.hcbs.org

Endnotes: Citations, Additional Information, and Web Addresses

[1] Gary Smith and Janet O'Keeffe co-authored the original chapter. Janet O'Keeffe updated the chapter. In addition to the sources noted in the citations, a major source of historical information for this chapter is the Medicaid Source Book: Background Data and Analysis (1993). Washington, DC: U.S. Government Printing Office.

[2] Overall, the Federal Government finances an average of 57 percent of all Medicaid costs annually. National Health Policy Forum. (January 2009). The Basics, FMAP: The Federal Share of Medicaid Costs. Available at http://www.nhpf.org/library/the-basics/Basics_FMAP_01-15-09.pdf.

[3] The Olmstead Supreme Court decision increased state responsibility to provide a range of home and community service options. The Court ruled that states must provide services in the most integrated setting appropriate to the needs and wishes of people with disabilities. Failure to do so could constitute discrimination under the Americans with Disabilities Act. Information about the application of the Olmstead decision to the Medicaid program is available from the CMS website in State Medicaid Director Letters. Use the word Olmstead to find the relevant letters. Available at http://www.cms.hhs.gov/SMDL/SMD/list.asp#TopOfPage.

[4] Burwell, B. (2000). Memorandum: Medicaid Long-Term Care Expenditures in FY 1999. Cambridge, MA: The MEDSTAT Group.

[5] Burwell, B., Sredl, K., and Eiken, S. (2009). Medicaid Long-Term Care Expenditures in FY 2008. Cambridge, MA: Thomson Reuters. Available at http://www.hcbs.org/moreInfo.php/doc/2793.

[6] Eiken, S., and Burwell, B. (2009). Medicaid HCBS Waiver Expenditures: FY 2003 through FY 2008. Cambridge, MA: Thomson Reuters. Available at http://www.hcbs.org/moreInfo.php/doc/2795.

[7] Section 1902(a)(10)(d) of the Social Security Act. If a state chooses to cover nursing facility care for the medically needy, Home Health services become mandatory for this group as well.

[8] The coverage criterion for Home Health services is often misunderstood because it is linked to the coverage criterion for nursing homes. The confusion 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—that is, they must meet a state's nursing facility level-of-care criteria in order to receive the Home Health benefit. This erroneous interpretation has persisted, notwithstanding its conflict with Federal Home Health regulations prohibiting a state from conditioning eligibility for Home Health services on the need for or discharge from institutional care (42 CFR 441.15(c)).

[9] 42 CFR 440.70(b).

[10] 42 CFR 440.230(d).

[11] 42 CFR 440.230(b)

[12] Health Care Financing Administration. (September 4, 1998). Letter to State Medicaid Directors. Available at http://www.cms.hhs.gov/smdl/downloads/SMD090498.pdf.

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

[14] Social Security Amendments of 1965 (P.L. 89-97).

[15] Social Security Amendments of 1967 (P.L. 90-248).

[16] P.L. 90-248, effective July 1970.

[17] Act of December 14, 1971 (P.L. 92-223).

[18] Social Security Amendments of 1972 (P.L. 92-603). This institutional coverage provides the "institutional alternative" for waiver services for this group.

[19] Section 1619 P.L. 96-265 of the Social Security Act.

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

[21] P.L. 103-66. Section 13601 (a1/5)8. Section 134 of TEFRA contains the amendment.

[22] Consolidated Omnibus Reconciliation Act of 1985 (P.L. 99-272). The provision became effective April 1986.

[23] Ibid.

[24] Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360).

[25] Omnibus Reconciliation Act of 1989.

[26] 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, CMS issued new regulations (42 CFR 440.167) concerning optional Medicaid State Plan personal care services to reflect these statutory changes.

[27] P.L. 106-170.

[28] Omnibus Reconciliation Act of 1989.

[29] The Omnibus Budget Reconciliation Act of 1993 (§13601(a)(5)); Social Security Act (§1905(a)(24)).

[30] Individuals who reside in institutions—nursing facilities, ICFs/ID, hospitals, and institutions for mental disease—cannot receive personal care services through the Personal Care benefit.

[31] 42 CFR 440.167.

Guide to Chapter 2

Introduction 39
Overview of Medicaid Financial Eligibility 39
Medicaid for SSI Beneficiaries 41
General Rule 42
Exceptions to the General Rule 43
State 209(b) Option 43
Medicaid Exceptions to SSI Countable Income and Resources Rules 44
Eligibility Expansion Options Including, but Not Specific to, Home and Community Services 44
100 Percent of Poverty Option 45
Medically Needy Option 45
Eligibility Expansion Options That Can Be Targeted to Persons Needing Home and Community Services 46
State Supplemental Payments (SSPs) 46
300 Percent of SSI Income Option 47
Preventing Spousal Impoverishment 50
Income Protection 50
Resource Protection 51
Provisions Specific to Children with Disabilities 51
Zebley Kids 52
Katie Beckett Option 52
Reducing Financial Barriers to Employment for Persons with Disabilities 53
Federal Provisions 53
State Options 53
Asset/Resource Transfers: Permissions and Penalties 54
Structure of the Penalty 54
Permissible Transfers 54
Estate Recoveries 56
Disqualification for Long-Term Care Medicaid Coverage for Individuals with Substantial Home Equity 56
Resources 57
Endnotes: Citations, Additional Information, and Web Addresses 60

Chapter 2
Financial Eligibility Rules and Options

This chapter describes Federal requirements and state options regarding financial eligibility for Medicaid, with a focus on eligibility for long-term care services and supports.[1]

Introduction

As originally conceived, the Medicaid program was to have served primarily the very poor and near poor who qualified or were close to qualifying for cash welfare programs. It was to have functioned much like private health insurance, with service coverage focused on primary and acute health 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 do not meet the traditional welfare-based definition of "poor." 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'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. As a result, individuals in similar circumstances can be treated differently. The purpose of this chapter is to present the relevant provisions in a way that is most useful to state policymakers and advocates.

Overview of Medicaid Financial Eligibility

Medicaid financial eligibility provisions are deeply rooted in two Federally financed cash assistance programs 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 the "Aged, Blind, and Disabled."[2] (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 program. 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. Individuals needing long-term care services generally fall into one of three Medicaid categories: aged 65 or older, blind, or under age 65 with a disability.

Services for Medicaid-Eligible Persons

The highlights of Medicaid benefits listed here provide a general context for the financial eligibility discussion in this chapter. (For a more detailed discussion, see Chapter 4 and Chapter 5.)

- Once determined eligible for Medicaid, beneficiaries are entitled to the full range of health and long-term care Medicaid services covered in their state. To receive long-term care services, however, they must also meet service eligibility criteria.
- Medicaid health 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 these expenses.
- Medicaid services for children can be more extensive than Medicaid services for adults or than services typically covered under private insurance policies.
- Medicare and Medicaid cover many of the same health services (e.g., hospital, physician, and home health services). 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 more extensive coverage of mental health services, 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.[3]
- Nursing facility services are Federally mandated under Medicaid. States may provide other long-term care services at their option, which may be provided either to all eligibles under the Medicaid State Plan or to selected groups under a home and community-based services (HCBS) waiver. Under an HCBS waiver program, states can provide services not viewed as strictly medical (e.g., home modifications, habilitation, and respite care) if the services are required to prevent institutionalization.

Medicaid criteria for determining who is blind or has a disability are generally the same as those used by the Social Security Administration for SSI. 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 2010 in part as earning less than $1,000 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).[4]

Anyone not meeting these criteria cannot receive Medicaid through the disability eligibility category, even if they have extensive medical needs or high medical bills. (Special exceptions—allowing Medicaid eligibility for certain former child beneficiaries of SSI disability benefits and for persons who do not meet one or more of the usual SSI disability criteria because they earn more than $1,000 per month—are discussed later in this chapter.)

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

Medicaid for SSI Beneficiaries

SSI is the Federally-administered program that ensures a nationally uniform income floor for persons who are elderly, blind, or have other disabilities. To be eligible, both income and assets must be low. Thirty-nine states and the District of Columbia 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 that allows them to provide Medicaid to SSI beneficiaries only if they meet the state's eligibility criteria, which may be more restrictive than those for SSI. (The 209(b) option is discussed in more detail below.

New Eligibility Group Established by the Affordable Care Act of 2010[5]

Section (§)2001 of the Patient Protection and Affordable Care Act of 2010 (hereafter, Affordable Care Act) amended the Medicaid statute to create a new eligibility group that all states participating in Medicaid must cover as of January 2014. For the first time since the Medicaid program was established, states will receive Federal Medicaid payments to provide coverage for the lowest income adults in their states, without regard to disability, parental status, or most other categorical limitations, under their Medicaid State Plans.

For this new eligibility group, the Affordable Care Act raises the income eligibility threshold to 133 percent of the poverty line and eliminates the assets test. All rules applicable under the Medicaid program in general apply to this new eligibility group, including rules relating to cost sharing. States can phase in eligibility by income level, but if they do, they must cover individuals with lower incomes before covering those with higher incomes. Parents of children who could be covered under Medicaid but are not cannot be covered under this new group unless their children are also enrolled in Medicaid.

The new group fills in the gaps in existing Medicaid eligibility coverage by making eligible very low-income individuals who are not otherwise eligible under mandatory eligibility categories. Thus, the law describes the individuals eligible under the new group as those who are not

- Age 65 or older,
- Pregnant,
- Entitled to or enrolled in benefits under Medicare Part A,
- Enrolled under Medicare Part B,
- Receiving SSI benefits, or
- Described in any of the other mandatory groups in the statute.[6]

The medical assistance provided to an individual in the new eligibility group must consist of benchmark coverage described in §1937(b)(1) of the Affordable Care Act or benchmark-equivalent coverage described in §1937(b)(2)[7] unless the individual is exempt from mandatory enrollment in a benchmark benefit plan.[8]

Certain states—depending on their income eligibility standards prior to the enactment of the Affordable Care Act—will receive enhanced Federal Financial Participation for services provided for newly eligible individuals: 100 percent in 2014, 2015, and 2016; 95 percent in 2017; 94 percent in 2018; 93 percent in 2019; and 90 percent thereafter.

For more detailed information about this new eligibility group, see the State Medicaid Director Letter issued April 9, 2010 at http://www.cms.gov/smdl/downloads/SMD10005.PDF.

The Centers for Medicare & Medicaid Services (CMS) will be issuing additional guidance on other provisions contained in §2001 of the Affordable Care Act at a later date.

General Rule

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 $674 per month in total income or $2,000 in total resources for SSI) and still qualify for benefits.

The general income rule for SSI specifies the level of "countable income" at or below which an individual is financially eligible for benefits. Countable income includes cash income plus certain in-kind goods or services that an individual receives in a given month, minus certain types of exempted income (discussed more fully below). In the year 2010, the maximum monthly SSI benefit paid to people with no other income is $674 for an individual and $1,011 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 after adjustments for income exclusions. For example, the SSI benefit for an individual with Social Security or pension income of $600 a month would be only $94 per month ($600 minus a $20 disregard on unearned income equals $580, which is deducted from the SSI maximum monthly benefit of $674).

Basic Medicaid Eligibility Rules

- Categorical criteria—Eligible persons must
  - be age 65 or older, or
  - be blind, or
  - be under age 65 and 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; and
  - thresholds must apply statewide except under certain waivers.
- Legal status, residence, and eligibility re-determination—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; and
  - report changes in circumstances and have eligibility periodically re-determined by the state.

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 unearned 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 ($85 if the person has no other income in a month) plus one-half of the remaining earnings amount.[8] However, if earnings exceed $1,000 a month in 2010 then the individual is considered to be engaging in Substantial Gainful Activity, and thus does not meet the statutory definition of being disabled.[9] Since the individual is not considered to be disabled, he or she will probably have their SSI eligibility denied or terminated. However, there are exceptions to this rule, which are

discussed below under "Reducing Employment Barriers for Persons with Disabilities."

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 non-disabled spouse's or parent's income that is left after SSI subtracts amounts used to pay for the basic needs of non-disabled family members. (SSI may apply several other special-purpose reductions also.)

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 pay for current basic living needs. Individuals with up to $2,000 ($3,000 for a couple) in countable resources can qualify for SSI. When determining whether resources are below the SSI $2,000/
$3,000 thresholds, SSI rules reduce gross resources by exempting the home (regardless of value) and (within limits) such things as an automobile, household goods, surrender value of life insurance, burial funds, and property essential to self-support. States often use SSI resource limits when determining eligibility for Medicaid.

Exceptions to the General Rule

There are two major exceptions to the general rule: the 209(b) option and protection for certain 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 similarly large increases in Medicaid enrollment and costs.

Many Medicaid eligibility rules in 209(b) states 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. Eleven states have retained at least some of their pre-SSI rules on countable income or resources, and 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. Spend-down rules for 209(b) states are virtually identical to spend-down rules for the Medicaid medically needy category (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 instead harm this group 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 people 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 could possibly increase 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.

Medicaid Exceptions to SSI Countable Income and Resources Rules

In general, states use SSI rules in determining what is countable income and resources for Medicaid eligibility. However, states have the option to liberalize their Medicaid rules regarding countable income or assets in such a way that the eligibility limits specified in law, while still theoretically required, can be greatly exceeded.[11]

It is important to note that this 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 one or more eligibility groups, those selected must be one of those specifically defined in the part of the Medicaid law that authorizes the use of this option—for example, working persons with disabilities, poverty-related groups, or the medically needy (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, such as residential care facilities).

Examples of Provisions That Can Reduce Countable Income or Resources

- Allow more than the standard SSI income disregard of $20.
- Disregard higher amounts of work earnings.
- 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, and the cash value of life insurance.

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.[12]

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, their cost implications make them unlikely choices for states looking for limited HCBS expansions. However, states may be

encouraged to adopt these eligibility expansions for other sensible reasons. For example, people eligible under any of these expansion options receive the full range of health and long-term care services covered under the State Plan. 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.

100 Percent of Poverty Option

States have the option of raising the income eligibility level for persons over age 65 and persons under age 65 with disabilities as high as 100 percent of the Federal poverty level ($10,830 for one person in calendar year 2010, increasing incrementally for additional family members).[13] The state's eligibility limits on countable resources must be at the SSI levels ($2,000 for one person, $3,000 for a couple), or at the state's option, its medically needy resource levels if they are higher than SSI levels.

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.[14]

Medically Needy Option

States can cover people with too much income to meet financial eligibility criteria through 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 requirements limit the attractiveness of the medically needy option for higher income people needing long-term care, especially home and community services, relative to the more narrowly targeted options discussed in the next section. Requirements include the following:

- Individuals must fit into one of the Medicaid categories for coverage—for example, be age 65 or older or meet the Social Security Administration 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 coverage 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.[15]
- 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 less than the SSI level.
- Medically needy people 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 impediment for higher income people who wish to qualify for home and community services through the medically needy provision. The reason is that medically needy people 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.[16] Until their spend-down limit is reached, they are responsible for their own medical expenses.

General Eligibility Expansion Options

100 percent of the Federal poverty level

- Allows states to provide full Medicaid benefits to all elderly persons or persons with disabilities with countable income up to the Federal poverty level and assets at or below state limits.

Medically needy

- Allows eligibility for those who would qualify except for income.
- Higher income persons must spend down their income to Medicaid eligibility levels.
- States may not cover medically needy who are elderly or have disabilities without also covering medically needy pregnant women and children.

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, people 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.

Hypothetical Spend-Down Situation

Assume the state's medically needy income level for an individual is $450 per month. For individuals with monthly countable income of $950, spend-down liability is $950 minus $450 (= $500), which may be a manageable amount for those with high time-limited medical needs or those in nursing homes who do not need income to maintain a home and pay other community living expenses.

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 community residence; or (c) their income is low enough to result in a spend-down liability that is affordable to them. (Spend-down is discussed in Chapter 5 as it relates to payment of room and board in residential care facilities.)

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 people with higher incomes to qualify—and can be targeted more narrowly to people needing long-term care services in a variety of home and community settings.

State Supplemental Payments (SSPs)

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

The maximum monthly Federal SSI benefit ($674 in 2010) 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 funds to supplement the basic SSI benefit 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.[17] 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.

State Supplemental Payments

- 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.

Few states provide across-the-board state supplements to SSI. Most target them specifically to persons who are unable to live independently but do not need an institutional level of care. The state supplement can be used to help pay for services provided in residential care settings such as foster care, group homes, assisted living, and other settings defined by the state. Services in these settings can vary widely—consisting of as little as housekeeping or general supervision, to various levels of assistance with activities of daily living.

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.

How a State Supplemental Payment Might Work

In the year 2010, the Federal SSI monthly benefit rate is $674 for an individual. Assume a state sets its supplemental benefit at $200 (making the SSP benefit $874). Then,

- a person receiving Federal SSI would receive an additional SSP of $200 per month.
- a person with countable income of $774—from, say, Social Security or a pension—would have $80 ($100 minus $20 disregard) too much income to qualify for SSI, but would still qualify for a $100 SSP benefit, and at the state's option, for Medicaid.

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 Option

The 300 percent of SSI income option (hereafter called the 300 percent 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—$2,022 per month and $24,264 per year in 2010. 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.[18]

Overview of the 300 Percent of SSI Income Rule

- Allows eligibility for persons with gross incomes at or below 300 percent of the current SSI benefit—$2,022 per month in 2010.
- Allows states to use the option for persons residing in institutions, such as a nursing home or intermediate care facility for persons with intellectual disabilities (ICF/ID). If they do so, states can also extend the 300 percent of income rule to eligibility for HCBS waiver applicants.
- Allows states to provide 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 requirement (discussed further below).
- When the 300 percent rule is a state's only option for providing Medicaid to higher income persons in institutions (i.e., the state does not have a medically needy program), allows persons to become eligible by diverting excess income into a Miller trust (discussed below).

When originally created, the 300 percent option was limited to persons in institutions, because home and community service alternatives to nursing homes were extremely limited. However, when the HCBS waiver authority was enacted in 1981, states were allowed to extend the 300 percent option to waiver applicants. The goal was laudable: to enable states to neutralize incentives for individuals to choose a nursing home over home and community services simply because of Medicaid financial eligibility rules.

However, the effectiveness of the 300 percent option in increasing access to home and community services is limited by two important factors. First, it can be used only for HCBS waiver participants, not for those receiving personal care or home and community-based services under the State Plan. Second, individuals eligible under this option, whether in an institutional setting or in an HCBS waiver program, are subject to a post-eligibility share-of-cost obligation (described below).

Miller Trusts

In states where the eligibility of higher income persons is limited to those qualifying under the 300 percent option, individuals with too much income to qualify for Medicaid even under this 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 for services provided under an HCBS waiver. 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. However, 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 may count as income—whether paid directly to the beneficiary or paid to purchase something on their behalf (other than medical care).[19] 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.[20]

Protected Amounts in Calculating Post-Eligibility Share-of-Cost Obligation (an obligation that applies only to certain beneficiary groups)[21]

People who become eligible for Medicaid under the 300 percent option, whether in a nursing home or an HCBS waiver program, are typically expected to pay a share of their income toward the cost of their care, which they pay providers directly.[22] 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 a personal needs allowance and other amounts described below, state waiver programs have greater flexibility to determine how much income HCBS waiver participants can retain; some states require little or no cost sharing. As with the medically needy spend-down provision, Federal rules do not require the individual to actually pay the share-of-cost amount but service providers can ensure payment through their usual bill collection policies.

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/ID 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 groups. The personal needs allowance is set at a low level because the institution provides for most of the individual's basic living needs. The institution receives Medicaid payment for services it provides as part of its daily payment rate.

States establish higher allowance amounts for people eligible under the 300 percent option in HCBS waiver programs, because waiver participants must have sufficient funds to cover their community living expenses. 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 their share of cost, 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 an institution. The amounts protected for spouses of institutionalized persons are governed by the rules designed to protect against spousal impoverishment. States have the option to implement spousal impoverishment protections when one spouse is an HCBS waiver program (discussed in the next section).

Home maintenance allowance (at state option). Persons in an institution can, at state option, retain an additional amount for up to 6 months if needed for maintenance of a home. This allowance is limited to those who can reasonably be expected to return to their homes. This optional allowance is not available to individuals receiving waiver services since their basic needs allowance (discussed above) is intended to include maintenance of a home.

Amounts to cover other medical expenses. States must allow nursing home and ICF/ID residents, as well as HCBS waiver participants, to retain enough income to pay for additional medical costs they incur that are not paid for by Medicare, Medicaid, or any other payer. Long-term care expenses (e.g., home health aides, personal assistants, and adult day care) can be counted toward required medically needy spend-down amounts as long as the individual rather than some third party is responsible for paying the expense.

Preventing 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.

States have the option to implement spousal impoverishment protections when one spouse is an HCBS waiver program. Doing so enables states to protect the income and assets of the spouses of waiver participants to the same extent 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 HCBS waiver participants. 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 $1,821 in the year 2010 (see Table 2-1). Additional amounts, up to a maximum of $2,739, are protected if the spouse has unusually high housing costs or if the state has chosen to protect more than the mini-mum 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 for which the beneficiary is responsible.

Temporary Expansion of Spousal Impoverishment Protections[23]

The Affordable Care Act amended the spousal impoverishment statute to mandate that states include spousal impoverishment protections in their HCBS waiver programs; all spouses of HCBS waiver participants, including those who qualify as medically needy, are covered. The mandate also extends to the spouses of participants in the HCBS State Plan benefit, as well as the new Community First Choice Option State Plan benefit (effective October 2011). The mandate will be effective from January 1, 2014 through December 31, 2019, at which point the current language of the statute will become effective again (i.e., spousal protections will be optional for spouses of HCBS waiver, HCBS State Plan, and Community First Choice Option participants).

Spousal impoverishment protections, at least as they pertain to income, are generally part of the unique Federal post-eligibility income treatment rules applicable to Medicaid-enrolled nursing facility residents and HCBS waiver participants. When applying these rules, states allocate specific portions of an enrollee's monthly income between a personal maintenance allowance, a community spouse maintenance allowance, and the enrollee's share of the cost of the covered services. However, Medicaid enrollees not in a nursing facility or HCBS waiver but receiving other State Plan services, may have co-pays for services they receive but will not be subject to the same income allocations as nursing facility or HCBS waiver participants. Thus, CMS will have to provide guidance to states for applying spousal protections for the spouses of State Plan service recipients.

Table 2-1. Examples of Spousal Income Protection

Assume the minimum protection allowance ($1,821) applies	
Example 1:	
Beneficiary's income	$2,000
Spouse's income	None
Beneficiary income protected for spouse	$1,821
Beneficiary income for calculating share-of-cost obligation	$179 ($2,000 – $1,821)
Example 2:	
Beneficiary's income	$2,000
Spouse's income	$1,000
Beneficiary income protected for spouse	$821 ($1,821 – $1,000)
Beneficiary income for calculating share-of-cost obligation	$1,179 ($2,000 – $821)
Example 3:	
Beneficiary's income	$2,000
Spouse's income	$2,000
Beneficiary income protected for spouse	None
Beneficiary income for calculating share-of-cost obligation	$2,000

Resource Protection

The resource amount protected for the spouse is determined as part of the process of determining Medicaid eligibility of the person needing services. Countable resources belonging to either or both spouses are combined and divided in half. The amount protected for the spouse is either that half, or the level the state has chosen to protect, whichever is higher. In 2010, the amount protected is subject to a Federal minimum ($21,912) and maximum ($109,560).

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, spouses can petition for higher protected assets if the income those assets produce is needed for their reasonable living expenses.

Provisions Specific to Children with Disabilities

Two eligibility provisions—one mandatory and the other at states' option—were enacted specifically to serve children with disabilities. The mandatory provision—sometimes called Zebley Kids or 4913 Children—relates to children rendered no longer eligible by a 1996 change in the SSI definition of disability for children. The Zebley designation comes from a court case, contesting the 1996 change.[24] The optional provision—some-times called the Katie Beckett or Tax Equity and Fiscal Responsibility Act (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 Kids

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 was 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. However, it cannot produce actual eligibility changes 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 might still qualify for Medicaid or for their state's Children's Health Insurance Program, based on the family's income.

Katie Beckett Option

States typically follow Federal SSI rules on whether or not to count (deem) the income and resources of a parent in determining a minor child's financial eligibility.[25] These rules impart a substantial institutional bias by ignoring parental income/resources when assessing eligibility for long-term care services if a minor child is living in an institution, but counting them if the minor child lives at home.[26]

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

States can overcome this institutional bias through two options. The first, the Katie Beckett or TEFRA option, was enacted permanently into law in 1982. This option 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.[27]

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 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 with regard to 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.

Alternatively, states can elect to use institutional eligibility rules when determining a minor's eligibility for an HCBS waiver program. Using institutional eligibility rules means, among other things, choosing not to deem the income and resources of parents available to minor children 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 institution.

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 available 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 Early, Periodic, Screening, Diagnosis, and Treatment benefits provided to all other Medicaid children in the state. However, the HCBS option allows states to offer additional services of a non-medical 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 major 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 for essential health care, 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 as much as they are able 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[28]

Since 1982, certain SSI disability beneficiaries who are able to work and earn more than the SGA amount ($1,000 per month for 2010) have been permitted to keep their SSI and Medicaid benefits, provided their countable income is within SSI qualifying limits. Under this provision, individuals with earnings up to $1,433 per month in 2010 are typically able to continue receiving SSI cash benefits.[29]

Former SSI beneficiaries with even higher earnings may continue to qualify for Medicaid, as long as their earnings are below a state-specified level that is roughly equivalent to the value of the total SSI and Medicaid benefits they would receive if they did not work.[30] 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 to establish the cutoff. The Social Security Administration administers both provisions.

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 6,000. By September 1999, however, the number had risen to nearly 100,000.[31] In December 2008, there were 355,762 SSI disabled beneficiaries who were working—only 5.5 percent of the total SSI blind and disabled caseload—with average earnings of $605 a month; 23 percent earned $65 or less per month.[32]

State Options

Advocates for persons with disabilities argue that the work incentive provisions have not been widely used for several reasons. First, receipt of SSI benefits is the gateway to Medicaid—both for health and long-term care services. Because there is an absolute income cap for Medicaid eligibility—however high that limit may be—there is an absolute drop-off point at which increased additional earning will result in a loss of Medicaid. Second, low asset limits mean that working persons with disabilities are unable to increase their savings without jeopardizing their Medicaid eligibility.

Congress addressed some of these Medicaid access problems with laws enacted in 1997 and in 1999.[33] 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—$27,075 for an individual, $55,125 for a family of four in the year

2010. These individuals need not ever have received SSI but they must—except for the level of their work earnings—meet SSI disability criteria.

The 1999 provision gives states the option to cover individuals with disabilities who currently work without regard to their earnings, and to raise or even eliminate eligibility limits on income from other sources and/or limits on assets. States that have elected this option can also elect to continue coverage for persons (eligible under this 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. For these higher income enrollees, states have the option to impose a monthly premium or other cost-sharing obligations for their Medicaid benefits using a sliding scale based on income. States choosing the 1999 option are required to charge 100 percent of the premium for those with an adjusted gross income (AGI) greater than $75,000 (AGI as defined for Federal income tax purposes).[34] The term "buy-in" is used to describe these options. The state, not the Social Security Administration, makes the eligibility determination for these state work incentive options.

Asset/Resource Transfers: Permissions and Penalties

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) in order to meet Medicaid's financial eligibility criteria. The penalty applies to all eligibility groups in all states.[35] The purpose of the penalty is to preclude the payment of benefits to individuals who can afford to pay for them. States must apply this penalty to people seeking Medicaid coverage for nursing homes, other institutions, and HCBS waiver programs for individuals eligible under what are known as "institutional" rules. The penalty is mandatory for individuals in institutions and those eligible for HCBS waivers under institutional rules, but is optional for those eligible under community rules.

Structure of the Penalty

Both SSI and Medicaid deny benefits for people making uncompensated asset transfers. The nature and effective duration of the penalty, however, differ between the two programs.[36] The following discussion relates to the Medicaid provisions.

Terminology

The terms "assets" and "resources" are used interchangeably to refer to savings, stocks and bonds, and other property. However, Medicaid law specifically related to asset transfers includes "income" in the definition of assets.

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.[37] For assets transferred after February 2006, the Deficit Reduction Act of 2005 (DRA-2005) extended the timeframe to 60 months. If a person did not receive fair market compensation, then states presume the transfer was made to qualify for Medicaid. States are required to have procedures in place that allow applicants to challenge 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.[38]

Transfers by Medicaid applicants/recipients to their blind children or children with disabilities or to a trust for those children's benefit, regardless of the child's age.

Assets transferred into a trust solely for the benefit of a person under age 65 with a disability. Eligible trusts include special needs trusts and pooled trusts established by a nonprofit association that manages multiple accounts.[39] 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 through an HCBS waiver program. Coverage may also be denied at state option for long-term care services such as home health or personal care provided through the State Plan for individuals who are not residing in institutions. For the most part, such penalties do not affect the person's eligibility to receive any other services under the Medicaid State Plan.

States calculate the duration of the penalty based on private pay nursing facility rates—whether the person who has transferred assets is actually in a nursing home or seeking home and community services—even though the monthly cost of services in the community is likely to be substantially lower. 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 people applying for services through an HCBS waiver program.

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. However, Federal law requires that states make exceptions in cases of undue hardship.

Prior to February 2006, the rule regarding the penalty start date—the month the transfer occurred—reduced or eliminated the effect of the penalty, depending on the amount of the transfer and the amount of time that passed between the date of the transfer and the date of application to Medicaid. Thus, if a transfer was modest and occurred relatively early in the 3-year look-back period before the individual applied for Medicaid, it often had no effect.

To correct this situation, the DRA-2005 changed the start date for the penalty period for all transfers made after February 2006 and extended the look-back period from 3 to 5 years. A penalty for transfers made after February 2006 now begins the month an individual becomes eligible for Medicaid and is in a nursing facility or other institution or who is eligible for an HCBS waiver based on institutional rules.[40]

Effect of Transfer on Benefit Loss: Example for Transfers

- A person withdrew $20,000 from savings and gave it to an adult child on January 1, 2005.
- The person is receiving an institutional level of care—that is, she is either in a nursing home or is eligible for waiver services based on institutional rules—on April 1, 2009.
- The monthly cost of nursing facility services is $4,000.
- The penalty period is 5 months ($20,000 divided by $4,000).
- The 5-month penalty period begins on the date the person is eligible for Medicaid; in this example, from April 1 through August 31, 2009. During the 5-month penalty period, a person who is eligible for Medicaid can receive services other than long-term care services. Once the penalty period is no longer in effect (beginning September 1), the person can receive coverage for long-term care as well as other services.[41]

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/ID benefits regardless of age. At a minimum, states must use the same definition of estate used under their probate laws. 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 any type of long-term care services, 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 other 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. States have the option of not pursuing recovery in the case of very small estates, if the cost of doing so is likely to exceed the amount that can be recovered. (See the Resources section of this chapter for links to several publications about states' estate recovery policies.)

Disqualification for Long-Term Care Medicaid Coverage for Individuals with Substantial Home Equity

Under Medicaid, an applicant's home, regardless of its value, is generally an exempt resource for eligibility purposes. The DRA-2005 does not change this basic rule, but for applications filed on or after January 1, 2006, it limits the exemption to individuals whose equity interest in their homes is $500,000 or less, or at state option, a higher amount not to exceed $750,000. For those with home equity above the amount the state has set, the state must deny Medicaid payment for long-term care services (including those provided through HCBS waiver programs). States that choose to use an amount higher than $500,000 need not use this amount on a statewide basis, recognizing potentially wide variations in the cost of housing statewide. Also, states need not apply the higher amount to all eligibility groups.

The new limits on home equity do not apply to an individual if the individual's spouse, child under age 21, or blind or disabled child is living in the individual's home. If the home equity exceeds the maximum amount, individuals may use reverse mortgages or home equity loans to reduce their total equity interest in the home. Beginning in 2011, the limits on equity will increase from year to year based on the percentage increase in the consumer price index for urban areas, rounded to the nearest $1,000.

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key resources relevant to financial eligibility for Medicaid generally and for long-term care services specifically. Most of the publications cite additional resources, and the websites also have links to other sources of information.

Publications

Herz, E.J. (2007). *CRS Report for Congress, Medicaid: A Primer.* Washington, DC: Congressional Research Service.

This report describes the basic elements of Medicaid, focusing on Federal rules governing who is eligible; what services are covered; how the program is financed and how beneficiaries share in the cost; how providers are paid; and the role of special waivers in expanding eligibility and modifying benefits. The Deficit Reduction Act of 2005, as amended by the Tax Relief and Health Care Act of 2006, includes many provisions affecting Medicaid. The DRA-2005 provides states with opportunities to make fundamental changes in Medicaid program design, including covered benefits and beneficiary cost-sharing. This report summarizes these and other major DRA-2005 changes.

Available at http://aging.senate.gov/crs/medicaid1.pdf

Wood, E.F., and Klem, E.M. (2007). *Protections in Medicaid Estate Recovery: Findings, Promising Practices, and Model Notices.* Washington, DC: AARP, Public Policy Institute; American Bar Association; ABA Commission on Law and Aging.

Concentrating primarily on current state practices for clarifying Medicaid beneficiary protections, this study focuses attention on promising practices and model notifications that can be replicated throughout the country for the benefit of both estate recovery programs and the people affected by them. The site includes both the full version and a brief summary of the report.

Available at http://www.aarp.org/health/medicare-insurance/info-2007/2007_07_medicaid.html

Hearne, J. (2005). *CRS Report for Congress: Medicaid Eligibility for Adults and Children*. Washington, DC: Congressional Research Service.

This report describes Federal Medicaid eligibility rules for children and adults under age 65 but does not address eligibility pathways for individuals qualifying on the basis of having a disability or for persons who are age 65 or older. Also, the eligibility provisions pertain to eligibility for all Medicaid benefits, not just home and community services.

Available at http://www.chn.org/pdf/crsmedicaid.pdf

Thomson/MEDSTAT (2005). *Medicaid Estate Recovery*. Washington, DC: U.S. Department of Health and Human Services (HHS), Office of Assistant Secretary for Planning and Evaluation.

This policy brief—one of six commissioned by HHS—provides an overview of state Medicaid Estate Recovery programs, which enable states to recoup public spending from the estates of Medicaid long-term care recipients after their death. The other briefs address the following topics: Medicaid Treatment of the Home, Spouses of Medicaid Long-Term Care Recipients, Medicaid Liens, Medicaid Estate Recovery Collections, and a case study of the Massachusetts Medicaid Estate Recovery Program. These are available through links at the end of the document.

Available at http://aspe.hhs.gov/daltcp/reports/estaterec.pdf

---

Stone, J.L. (2002). *CRS Report for Congress: Medicaid Eligibility for the Aged and Disabled*. Washington, DC: Congressional Research Service.

This report describes Medicaid eligibility rules for persons with disabilities. Many in this group become eligible because they cannot work and are dependent on welfare assistance from SSI. However, Medicaid provides incentives for other disabled persons to work and retain Medicaid coverage.

Available at http://assets.opencrs.com/rpts/RL31413_20020705.pdf

Websites

Centers for Medicare & Medicaid Services

This site provides an overview of Medicaid eligibility (e.g., income and resource guidelines, spousal impoverishment, estate recovery) and includes a link to contact information for state Medicaid offices.

Web address: http://www.cms.hhs.gov/MedicaidEligibility/

The State Medicaid Manual makes available to all state Medicaid agencies informational and procedural material needed by the states to administer the Medicaid program. The material is organized into major parts, which are divided into chapters and sections. (Chapter 3 is about Eligibility). The manual is structured as

closely as possible to the codification of Medicaid regulations. A crosswalk of manual sections and regulations is also included.

Web Address: http://www.cms.gov/Manuals/PBM/itemdetail.asp?filterType=none&filterByDID=-99&sortByDID=1&sortOrder=ascending&itemID=CMS021927&intNumPerPage=10

Kaiser Commission on Medicaid and the Uninsured

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. The Commission is a major initiative of The Henry J. Kaiser Family Foundation and is based at the Foundation's Washington, DC office.

Web address: http://www.kff.org/about/kcmu.cfm

Specific information about Medicaid financial eligibility by state using the latest Kaiser data is available at http://www.kff.org/medicaid/8048.cfm.

Endnotes: Citations, Additional Information, and Web Addresses

[1] Letty Carpenter is the original author of this chapter. Ernest McKenney and Janet O'Keeffe updated the chapter.

[2] This Primer uses person-first language when referring to persons with disabilities and elderly persons, unless referring to the specific language used in statutes, regulations, or programs, as in this instance.

[3] Additional information about the Medicare program can be obtained from the CMS website at http://www.cms.gov/home/medicare.asp.

[4] The amount of monthly earnings considered as SGA depends on the nature of a person's disability. The Social Security Act specifies a higher SGA amount for statutorily blind individuals ($1,640 per month in 2010); Federal regulations specify a lower SGA amount for non-blind individuals ($1,000 per month in 2010). Both SGA amounts generally increase with increases in the national average wage index. Additional information is available at http://www.ssa.gov/OACT/COLA/sga.html.

[5] State Medicaid Director Letter, April 9, 2010 at http://www.cms.gov/smdl/downloads/SMD10005.PDF.

[6] Subclauses (I)–(VII) of §1902(a)(10)(A)(i) of the Social Security Act.

[7] As amended by §2001(c) of the Affordable Care Act.

[8] Benchmark rules apply to the new group whether or not the state has otherwise elected the option to provide benchmark benefit coverage under its State Plan. Individuals in the new group who are exempt from mandatory enrollment in a benchmark benefit plan must receive medical assistance under the state's currently approved plan. Others must be provided with benchmark or benchmark-equivalent coverage, including Secretary-approved benchmark coverage described in §1937(b)(1)(D). Consistent with the provisions of §1937, children covered under the new group must receive all Early and Periodic Screening, Diagnostic, and Treatment services.

[9] If individuals have only work earnings (i.e., they do not have any unearned income), and they do not pay for any work expenses, they can earn up to $1,433 per month in 2010 before their SSI federal cash payments stop. Additional information is available at http://ssa-custhelp.ssa.gov/cgi-bin/ssa.cfg/php/enduser/std_alp.php?p_sid=n6qe7NWj.

[10] See Endnote 4.

[11] Section 1902(r)(2) of the Social Security Act.

[12] 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.

[13] Under §1902(r)(2) of the Social Security Act, a state can elect to disregard more generous amounts. Note: For the first time since the poverty guidelines began to be issued in 1965, the annual average Consumer Price Index has decreased from the figure for the previous year. Therefore, the Department

of Health and Human Services poverty guidelines have been frozen until at least May 31, 2010 at 2009 levels in order to prevent a reduction in eligibility for certain means-tested programs, including Medicaid, Supplemental Nutrition Assistance Program, and child nutrition. Additional information is available at http://aspe.hhs.gov/poverty/09extension.shtml.

[14] This provision applies to §209(b) states as well, which cannot use more restrictive eligibility criteria for this group.

[15] States can use higher levels or additional disregards under the §1902(r)(2) exception.

[16] Typically this is every month. In some states it is every 6 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.

[17] State-by-state information concerning supplements for SSI beneficiaries may be found in State Assistance Programs for SSI Recipients, January 2009. (Released October 2009). Social Security Administration, Office of Policy, Office of Research, Evaluation, and Statistics. Available from Social Security Online at http://www.ssa.gov/policy/docs/progdesc/ssi_st_asst/2009/.

[18] Under §1902(r)(2), described above.

[19] Whether or not the income is counted depends on the specific nature of the transaction; for example, who the payment goes to and what the funds are used to purchase, as determined by additional Medicaid rules.

[20] A recent state survey found that of 43 states (7 did not respond), 19 allow Miller Trusts for institutionalized individuals. Of the 7 states that did not respond, based on 2000 data, 1 allows Miller Trusts; this adds up to 20 states. For states that use the 300 percent rule for HCBS waivers, of the 43 states that responded, 18 allow Miller Trusts. Of the 7 states that did not respond, based on 2000 data, 1 allows Miller Trusts, this adds up to 19 states. Lina Walker, AARP Public Policy Institute. Personal communication, March 24, 2010.

[21] Post-eligibility rules apply to all individuals in institutions, regardless of their eligibility group.

22 Post-eligibility share-of-cost rules also apply to persons in ICFs/ID, 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.

[23] This description is condensed from the analysis provided by Coffey, G. (January 2010). The Medicaid Long-Term Services and Supports Provisions in the Senate's Patient Protection and Affordable Care Act.

[24] In 1990, the Supreme Court ruled in Sullivan vs. Zebley, that in order to meet the standard of equal treatment, the initial disability determination process for children must include a functional limitation component just as it is used for adults. The decision in the case that successfully contested the 1996 definitional change became moot in 1997, when §4913 of the Balanced Budget Act of 1996 (P.L. 105-33) restored Medicaid to the children who had lost eligibility under SSI's 1996 definitional change. See http://www.dhs.state.or.us/spd/tools/crew/blitz/protected/Protected-HO.pdf.

[25] States may also use more liberal rules, such as not counting the parents' income and resources under §1902(r)(2).

[26] 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.

[27] The Tax Equity and Fiscal Responsibility Act of 1982, P.L. No. 97-248, 96 Stat. 324 (September 3, 1982).

[28] Section 1619 and, equivalently, §1905(q) of the Social Security Act.

[29] The amount of the SSI benefit is decreased as earnings increase over the allowable amount. The Social Security Administration has published a rule to adjust the SGA level automatically each year for individuals with impairments other than blindness. The adjustment is based on any increase in the national average wage index. See http://www.ssa.gov/OACT/COLA/sgadet.html.

[30] Section 1619(b).

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

[32] Numbers from "SSI Disabled Recipients Who Work, 2008," available from Social Security Online at http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2008/sect07.html#table44.

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

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

[35] This includes §209(b) states.

[36] The penalty for resource transfers in SSI, 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.

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

[38] Social Security Act, §1917(c)(2)(iii) and (iv).

[39] Unused assets in the trust must revert to the state on the death of the individual, up to the total Medicaid amount spent on the individual's behalf.

[40] The penalty does not apply to individuals who are eligible for HCBS waiver programs under community financial eligibility rules.

[41] The look-back period begins on the date someone applies for Medicaid. The penalty period begins on the date the person becomes eligible for Medicaid, not the date of application. In many instances they are the same date.

Guide to Chapter 3

Introduction 65
Service Criteria: General Considerations. 65
Home Health Services 67
Misperceptions 67
Addressing Cost Concerns. 70
Ensuring Correct Application of Eligibility Criteria 70
Personal Care Benefit. 70
HCBS Waiver Programs 72
Misperceptions About Medical Bias in Nursing Facility Service Criteria 75
HCBS State Plan Benefit 77
Community First Choice Option 78
Major Considerations in Setting Service Criteria: A Recap 78
Resources. 79
Endnotes: Citations, Additional Information, and Web Addresses 82

Chapter 3
Determining Service Eligibility

In addition to categorical and financial eligibility criteria required by Federal Medicaid law, states set additional eligibility criteria to determine who in the large group that is financially eligible and entitled to benefits is eligible to receive specific services, such as nursing home, home health, or personal care. These criteria are based on need and can include an assessment of medical/nursing needs, health and health-related needs, functional limitations, and/or other factors. The goal of these eligibility criteria is twofold: to define medical necessity and to manage overall utilization. This chapter discusses Federal provisions for determining eligibility for four major Medicaid benefits: the mandatory Home Health benefit, the Personal Care benefit, home and community-based services (HCBS) waiver programs, and the State Plan HCBS option (under the Section [§]1915(i) authority). It also discusses factors for states to consider when setting these criteria.[1]

Introduction

Federal law and regulation specify the general eligibility and coverage requirements for mandatory and optional Medicaid home and community services. States use additional criteria to specify who, within the general eligibility group, will receive services. States use a number of different terms to describe these criteria: medical necessity criteria, health and functional criteria, level-of-care criteria, and service criteria. These terms are often used interchangeably, but, in fact, may have specific meanings in state usage, which may differ from usage in Federal requirements. When referring to any of these criteria, this Primer uses the term service criteria. The degree of flexibility states have in setting these criteria depends on whether the service is Federally mandated or a state option and, if optional, whether it is offered under the State Plan or through a waiver program.

Service Criteria: General Considerations

The purpose of service criteria is to define medical necessity and to manage overall utilization. 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.[2] For a Federally mandated service, such as Home Health, states are required to define the service in the State Plan and may specify reasonable limitations to the defined service. States also develop the process by which they determine an individual's medical necessity for a service, a process which is not contained in the State Plan and about which the Centers for Medicare & Medicaid Services (CMS) has historically issued little guidance. Some states have included medical necessity criteria in their State Plan, but these are considered by CMS to be part of the definition of reasonable limitations.

These Federal requirements allow states considerable flexibility, because reasonable limitations and medical necessity are not defined further in Federal law or regulation (although limitations must be approved by CMS in the State Plan). States often interpret the medical necessity criterion to mean that pre-authorization by a medical professional is needed. But medically necessary services do not have to be medical services, that is, services provided by licensed medical personnel; they may be services and supports provided by personal assistants or home health aides to address functional needs. (See discussion of medical necessity under the heading Misperceptions, later in this chapter.)

Service criteria generally include some measures of functioning, such as the ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) without assistance. ADLs include eating, bathing, dressing, toileting, transferring (e.g., from a bed to a chair), and maintaining continence. IADLs include medication management, money management, light housework, laundry, meal preparation, transportation, grocery shopping, and using the telephone.[3] While IADL performance requires higher cognitive functioning than does ADL performance, assistants who provide help with IADLS, other than medication and money management, generally need less training than those who provide help with ADLs. This is particularly true when ADL assistance requires tasks covered by a Nurse Practice Act, such as tube feeding.[4]

Optional benefits provided under the State Plan, such as personal care services, carry no Federal statutory or regulatory provisions regarding the type or level of impairment a person must have to receive benefits. The only Federal rule for optional benefits is that the state must make the service equally available to all beneficiaries who satisfy the service criteria that the state sets as defined and limited in the State Plan.

States are permitted to choose the measures they use to assess the particular level and/or combination of needs a person must have to be eligible. A state may require a person to have 2 out of 5 ADL impairments or 4 out of 12 ADL and IADL impairments. This flexibility has resulted in considerable variation in the service criteria for states' Personal Care programs.

Determining Medical Necessity

Examples of questions that could be relevant in determining medical necessity include

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, or is the service required to assist an individual to perform activities of daily living?
2. Medical reason for treatment: Is the service provided for medical reasons rather than primarily for the convenience of the beneficiary, 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? This question would not apply where Medicaid or the Americans with Disabilities Act require that the beneficiary have a choice among alternate settings.

Source: CMS Office of Counsel.

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 a legitimate need for assistance. On the other hand, states must operate their Medicaid programs in accord with their budgets. Because the number of people served is a major determinant of program costs, setting service criteria is a key financial decision.

Setting service criteria based on a trade-off between coverage and costs can have unintended effects on other parts of the long-term care system.

For example, because nursing homes are expensive, a state may establish stringent level-of-care criteria for Medicaid coverage. Although, the provision of home and community services through an HCBS waiver program can be considerably less expensive, Federal law requires that states use the same level-of-care criteria for nursing homes and HCBS waiver programs. Thus, stringent institutional criteria can be an obstacle to serving people through 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 paid assistance is not available until a person becomes 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 and reimbursement rates. 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 at a greater cost to the state.

Such trade-offs suggest that there is no "correct" decision regarding service criteria. An approach that is appropriate in one state may not work in another. 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 a program's service criteria not only match the policy goals for that program but also fit with and meet the goals of the larger long-term care system. Several states do so 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 for other long-term care programs that have progressively lower need requirements. The waiver program may require three ADL limitations, for example, but the Medicaid Personal Care program may require only two, and a state-funded program for those not eligible for Medicaid may require only one ADL plus one IADL impairment.

The remainder of this chapter provides information about Federal provisions related to the selection of service criteria for four Medicaid benefits: Home Health, Personal Care, HCBS waivers, and State Plan HCBS. The first three benefits account for the vast majority of Medicaid spending on home and community services; State Plan HCBS became an option in 2007. (See Chapter 4 for a more detailed description of these service options.) While the same or similar services may be covered by all three benefits (e.g., assistance with ADLs), states have more flexibility when defining service criteria for optional than for mandatory benefits.

Home Health Services

Home health services are a mandatory benefit for all individuals entitled to nursing facility care under a state's Medicaid State Plan—that is, for categorically eligible persons age 21 or older. 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.6

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, there are no additional Federal requirements.

Misperceptions

Despite the unambiguous nature of Federal coverage and eligibility requirements, misperceptions that additional Federal requirements further restrict who may receive home health services are common. The first misperception is 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 arisen because the word

entitled to nursing facility care has been interpreted to mean eligible for nursing facility care. The Federal requirement specifies the coverage groups entitled to the Home Health benefit. Those entitled include (a) categorically eligible persons age 21 or 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. It also states clearly that eligibility does not depend on the need for institutional care or for skilled nursing or therapy services. Additionally, even if the state does not cover persons under age 21, the Early Periodic Screening, Diagnosis, and Treatment mandate requires that home health services be provided to this group if they are needed.

A second misperception is that states must use Federal eligibility requirements for the Medicare Home Health benefit to determine eligibility for the Medicaid Home Health benefit. In particular, many incorrectly believe that to be eligible for Medicaid home health services, a person has to meet the Medicare home-bound requirement and need skilled nursing or therapy 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).[6]

Additionally, while Federal regulations state that home health services must be provided in the home, there is no requirement that beneficiaries be homebound. A July 2000 State Medicaid Director Letter clarifies that a homebound requirement violates Medicaid comparability requirements.[7]

While Medicaid home health services must be provided by a Medicare-certified home health agency, this requirement is a provider qualification; it does not create an eligibility linkage between the two programs. 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.

Federal Coverage and Eligibility Requirements for Medicaid Home Health Services

Mandatory State Plan 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, speech pathology, and audiology services.
- Services must be ordered by a physician as part of a written plan of care that the physician reviews every 60 days.8
- Once a state defines its Home Health benefit—whether it includes only mandatory home health services or both mandatory and optional services—the benefit must be available to all Medicaid beneficiaries entitled to nursing facility services under the State Plan.
- States may place coverage limits on home health services if the limits are based on considerations related to medical necessity or utilization control.
- Eligibility of beneficiaries to receive home health services does not depend on their need for, or discharge from, institutional care, or their need for skilled nursing or therapy services.

Provision of Services Outside a Beneficiary's Home

A Connecticut lawsuit—*Skubel v. Fuoroli*—challenged CMS's regulation requiring that Medicaid home health care services be provided exclusively in a beneficiary's place of residence. The lawsuit focused on the receipt of nursing services outside the home.

In 1997, 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.[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 beneficiary'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 beneficiary'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 beneficiaries 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.[11]

Addressing Cost Concerns

States can address concerns about the cost of the Home Health benefit without using the impermissible homebound criterion. For example, states may establish criteria to determine who needs the service based on medical necessity, criteria which take account of beneficiaries' unique needs, as described in the following examples.

When a condition—such as quadriplegia—prevents individuals from going to another health care setting to obtain the service.

When going to an outpatient setting for the service would constitute a medical hardship due to an individual's condition, or is contraindicated by a documented medical condition, such as the need to be protected from exposure to infections.

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 services in place will prevent emergency room visits for unscheduled catheter changes due to blockage or dislodgment; and (4) when there is a history of noncompliance with outpatient services that has led to adverse consequences, including emergency room use and hospital admissions.[12]

States can also control costs for the Home Health benefit by limiting the amount, scope, and duration of the services provided—as long as all services listed in the State Plan are sufficient to meet the needs of most persons who need the services. The State Plan must include a list of services that will be provided, as well as their amount, scope, and duration. For example, some states limit the number and duration of daily home health aide visits, and preauthorization is required to exceed these limits. Other states require preauthorization for all services to ensure appropriateness.

The appropriate context for making decisions about limits on a state's Home Health benefit is the state's entire system of home and community services. A state may opt to cover registered nurse and home health aide visits through the Home Health benefit, for example, and not through a waiver program to ensure that all beneficiaries who need these services receive them, not just those who meet the nursing home level-of-care criteria. However, if a state uses institutional rules for the waiver program, doing so will limit services under the Home Health benefit to those who meet the stricter financial eligibility criteria for State Plan services.

Ensuring Correct Application of Eligibility Criteria

States contracting with private managed care organizations to provide the Medicaid Home Health benefit must specify in their managed care contracts who will determine eligibility for the benefit 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 interpreted very differently in a managed health care plan that customarily provides primary and acute health care benefits but not long-term care services.

Home health services can be provided as acute, post-acute, and/or long-term care services. If a state has an HCBS waiver program administered, for example, by an Area Agency on Aging, but the state's capitated health programs control the Home Health benefit, the two systems will need to collaborate to ensure that individuals entitled to and eligible for home health services receive them.

Personal Care Benefit

Personal care services provided through the State Plan are an optional benefit. When personal care services were first authorized in the mid-1970s, they had to be prescribed by a physician in accordance with a treatment plan. In 1993, Congress removed the requirement for physician authorization and gave states the option to use other methods to authorize the benefit in accordance with a state-approved service plan. There are no other Federal

statutory or regulatory requirements regarding eligibility for services. Within the broad parameters of the Federal definition of personal care services, states are free to determine service criteria as well as the amount, scope, and duration of the services.

The State Medicaid Manual definition of personal care services provides the primary guidance for establishing these criteria:

Personal care services . . . 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 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).[13]

The Manual also states that people with cognitive impairments can be offered services through the Personal Care option:

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.[14]

Given the Federal Medicaid definition of personal assistance, 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 research indicates that dependencies in multiple IADLs also indicate a high level of need (e.g., the inability to use the telephone actually indicates a very high level of impairment).[15] Limitations in performing other IADLs, such as meal preparation and medication management, may actually pose a greater health risk than an ADL limitation in bathing and dressing. A number of states use both ADLs and IADLs in their service criteria.

An important consideration when selecting service criteria is that the level of impairment a state requires for eligibility matches the services available. For example, if a state requires applicants to be severely impaired, the maximum number of service hours permitted should be sufficient to enable them to remain in the community. It is also important to ensure that assessment methodologies do not inadvertently exclude certain groups, such as persons with dementia. For example, if the eligibility criteria require that an individual needs "hands-on" assistance with ADLs, a person who needs cueing and supervision to perform ADLs will be excluded.

In effect, states have a very high level of discretion when determining 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.

Given that personal care services are subject to Federal statewideness and comparability requirements, states understandably have cost concerns about increasing access to these services through the use of liberal service criteria. As mentioned, 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 needs through multiple programs).

The Comparability Requirement

With few exceptions (such as the targeted case management benefit), service criteria for any State Plan benefit—mandatory or optional—are subject to the "comparability" requirement. Under this requirement, services must be available on a comparable basis to all Medicaid beneficiaries in an eligibility group in the state who need the service; that is, 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.[16] Additionally, states must use the same eligibility criteria for all applicants, and any limits on service amount, scope, and duration must be applied equally to individuals currently receiving services and those applying for services.

The effect of these requirements is that states cannot have service criteria that target particular groups of people by diagnosis, or condition (e.g., requiring that individuals have a spinal cord injury). Additionally, any changes made in the service criteria—and in the amount, scope, and duration of service—must be applied equally to those currently receiving services and those applying for them. These provisions constitute the "comparability" requirement. HCBS waivers are not State Plan services and not subject to this requirement—they "waive" comparability.

The Statewideness Requirement

States cannot restrict the availability of State Plan services to particular geographic regions.

Some states design programs funded only with state dollars to provide services for people who do not meet Medicaid's eligibility criteria but nonetheless need services. For example, the goal of the Connecticut Home Care Program for Elders is to avoid institutionalization of frail individuals age 65 or older. The program includes both a state-funded component and a Medicaid waiver component. Because many individuals who need services to avoid nursing home placement do not meet Medicaid's financial eligibility criteria and/or the waiver's level-of-care criteria waiver, this population is served in the state program, which has less stringent financial and service eligibility criteria than does the waiver program.

HCBS Waiver Programs

Under HCBS waiver programs, states are permitted to waive Federal comparability and statewideness requirements in order to provide home and community services to people who would otherwise require an institutional level of care reimbursable by Medicaid.

To be eligible for waiver services, individuals must first meet a waiver's targeting criteria, such as age and diagnosis or condition. A state may have a number of waiver programs targeting different groups: people age 65 or older, those age 18 to 64 with physical disabilities, children who are technology dependent, persons with intellectual disabilities and other developmental disabilities (hereafter referred to as developmental disabilities), persons with AIDS, and persons with traumatic brain injury.

Individuals who meet the targeting criteria must then meet service criteria, which for HCBS waiver programs are the level-of-care criteria states use to determine eligibility for either a hospital, nursing facility, or intermediate care facility for persons with intellectual disabilities (ICF/ID)—also called institutional criteria.[17] Level-of-care criteria explicitly describe the type and level (or severity) of functional limitations and/or medical and nursing needs an individual must have to be admitted to an institutional setting.

Illustrative Service Criteria for Personal Care Services: State Examples

Arkansas. To be eligible for State Plan Personal Care services, a person must have physical dependency needs and require assistance performing 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.

Texas. To be eligible for State Plan Personal Care services, the applicant/client must

1. Meet the minimum functional need criteria as set by the department. The department uses a standardized assessment instrument to measure the client's ability to perform activities of daily living. This yields a score, which is a measure of the client's level of functional need. The department sets the minimum required score for a client to be eligible, which the department may periodically adjust commensurate with available funding.
2. Have a medical need for assistance with personal care:
   - the individual's medical condition must be the cause of the individual's functional impairment in performing personal care tasks;
   - persons diagnosed with mental illness and intellectual disability, or both, are not considered to have an established medical need based solely on such diagnosis. The diagnoses do not disqualify an individual for eligibility as long as the individual's functional impairment is related to a coexisting medical condition;
   - have a signed and dated practitioner's statement that includes a statement that the individual has a current medical need for assistance with personal care tasks and other activities of daily living.
3. Require at least 6 hours of service per week. An applicant/individual requiring fewer than 6 hours of service per week may be eligible if the applicant/individual meets one of the following criteria:
   - requires primary home care or community attendant services to provide respite care to the caregiver;
   - lives in the same household as another individual receiving primary home care, community attendant services, family care, or Community Based Alternatives personal assistance services;
   - receives one or more of the following services (through the department or other resources):
     i. congregate or home-delivered meals,
     ii. assistance with activities of daily living from a home health aide,
     iii. day activity and health services, or
     iv. special services to persons with disabilities in adult day care.
   - receives aid-and-attendance benefits from the Veterans Administration;
   - receives services through the department's In-home and Family Support Program;
   - receives services through the Medically Dependent Children Program; or
   - is determined, based upon the functional assessment, to be at high risk of institutionalization without primary home care or community attendant care services.

These criteria usually include measures of the need for nursing and medically-related services and for assistance with ADLs. 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 an individual applies for services. In the case of ICF/ID services, applicants must have an intellectual disability or a "related" condition, and be found to need various supports necessary to maintain or improve functioning.[18] 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 Federal requirement that states use the same or equivalent service criteria for waiver services that they use for institutional placement stems from the waiver program's primary purpose: to offer an alternative to institutionalization.[19] This statutory requirement was added by Congress in part to address concern about the cost of expanding home and community services: states must demonstrate that they are providing waiver services only to people who are eligible for institutional placement. CMS cannot waive this requirement or lessen its impact by regulation. Congress would have to amend the Federal Medicaid statute to allow states to use substantively different service criteria for a waiver program than for institutional services (i.e., criteria not based on the need for institutional services).

Level-of-Care Criteria for ICFs/ID and HCBS Waiver Programs for People with Developmental Disabilities

Some states use "categorical" level-of-care criteria referencing specific "related conditions" by medical diagnoses or type, such as intellectual disability, spina bifida, or autism. Other states use "functional" criteria, such as that provided by the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000,[20] which are based on a person's adaptive abilities or capacity to perform tasks at a specific level. The majority of states, however, use a combination of the two approaches, referencing both categorical and functional criteria.[21]

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 any one of the following institutions: a Medicaid skilled nursing facility (SNF), an intermediate care facility (ICF) providing nursing services, an ICF/ID, or a hospital that is Medicaid certified as a hospital but provides long-term care services. In 1987, the Omnibus Budget Reconciliation Act eliminated the distinction between mandatory SNFs and the optional ICFs and mandated a new nursing facility benefit, which includes the former SNF and ICF benefits.

The only Federal requirement for persons to receive the former ICF level of care—now the minimum level of care in a nursing facility—is a need on a regular basis for "health-related care and services [provided] to individuals who because of their mental or physical condition require care and services, above the level of room and board, which can be made available to them only through institutional facilities."[25] 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. States vary considerably in the stringency of their minimum level-of-care criteria.[26]

Lawsuit Related to Maryland's Level-of-Care Criteria

On November 30, 2007, Maryland's Court of Special Appeals ruled that Maryland's standard for determining eligibility for nursing facility services and HCBS waiver programs—a need for constant skilled nursing care—was stricter than allowed under Federal law. The Court determined that people should be eligible if they need constant care and supervision provided by health care aides, but not necessarily the level of care that would require licensed or highly skilled nurses.[22]

As a result of the Court's ruling, the State developed new minimum level-of-care criteria for applicants who do not meet the criteria for a skilled level of nursing home care. These criteria include "a need for health-related services above the level of room and board on a regular basis." The State describes such services as

- A need for hands-on assistance to adequately and safely perform two of five ADLs—bathing, dressing, mobility, toileting/continence, and eating—as a result of a current medical condition or disability; or
- Supervision of an individual's performance of two or more ADLs for an individual with cognitive deficits, as indicated by a score of 15 or less on the Folstein Mini-Mental Status Exam (MMSE),23 and who is in need of assistance with at least three or four instrumental activities of daily living—medication management, money management, telephone use, and housekeeping; or
- Supervision of an individual's performance of two or more ADLs combined with the need for supervision and redirection of individuals exhibiting at least two of the following behavior problems: wandering several times a day; hallucinations/delusions at least weekly; abusive/aggressive behavior several times a week; disruptive/socially inappropriate behavior several times a week; and/or self-injurious behavior several times a month.24

Misperceptions About Medical Bias in Nursing Facility Service Criteria

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 how they affect the need for long-term care, or (b) they give greater weight to nursing and medical needs than to functional limitations caused by physical or mental impairments. However, no Federal statute or regulation mandates that states adopt such a medical approach when setting nursing facility level-of-care criteria.

The term medically necessary does not imply a distinction between medical conditions and functional limitations caused by physical or mental impairments. The correct sense of the term is that services need simply to be "necessary" (i.e., needed by the individual). Determining medical necessity is the process states use to determine whether a specific person requires a covered service. States must provide covered services to eligible individuals who require them. States also make medical necessity determinations to control utilization and avoid wasting resources on unneeded services.

There is no Federal definition of medical necessity for specific services, so 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. Oregon, for example, uses only functional criteria.[27] Nor must a state give greater weight to medical and nursing needs than to functional needs.

No clear line separates functional from medical 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., 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 for long-term care is a person's functional limitations.

Another common misperception is that a physical illness or disability is required in order to be eligible for Medicaid coverage of nursing facility care, rather than assistance with ADLs or IADLs due to functional limitations caused by cognitive deficits or mental illness. In fact, §1915(a)(1)(C) of the Social Security Act clearly states that while the overall facility must not be primarily for the treatment of mental diseases, a nursing facility provides health-related care and services to individuals who because of their physical or mental condition require, on a regular basis, care and services (that are above the level of room and board), which can be made available to them only through institutional facilities. However, a Federally required process called Preadmission Screening and Resident Review requires states to ensure that individuals with serious mental illness or an intellectual disability are admitted to a nursing facility only if the facility can meet their needs.

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. In addition to having criteria for a skilled level of care, states' nursing facility benefit must include minimal criteria that comports with the Federal definition of the former ICF criteria: a need, on a regular basis, for health-related care and services by individuals, who because of their mental or physical condition, require care and services (above the level of room and board), which can be made available to them only through institutional facilities.[28]

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 study in Connecticut, for example, found that some people with severe functional limitations (three or more ADL impairments), who met the nursing facility level-of-care criteria, chose to go without nursing home and waiver services rather than spend down to Medicaid eligibility or be subject to estate recovery provisions.[29] States' concerns about increasing the number of people admitted to nursing facilities are understandable. However, states can prevent unnecessary institutionalization by screening people prior to nursing facility admission to determine whether services could be provided in home and community settings (i.e., establish pre-admission screening or nursing facility diversion programs). Other steps that states can take to reduce the number of people in nursing facilities include the establishment of nursing facility transition programs and "money follows the person" policies to allow institutional funds to follow nursing facility residents to home and community settings. Implementation of such programs and policies can help to ensure that only those who truly cannot be served safely and cost-effectively in the community will be admitted to and remain in nursing facilities.[30]

Illustrative Use of Functional Measures to Determine Eligibility for Nursing Facility and Waiver Services: Oregon

Oregon's level-of-care criteria specify 18 functional levels with 1 representing the most impaired and 18 the least impaired. The State does not consider medical or nursing needs to determine eligibility. The State assesses the need for assistance with mobility (ambulation and transferring), eating, and elimination (toileting, bowel and bladder care), and assistance due to impaired mental status (cognition and behavior.) The definitions of ADL assistance recognize that the need for assistance can be the result of a physical impairment, limited endurance, or cognitive impairment.

The State assesses mental status, with measures of memory, orientation, adaptation to change, awareness of needs, and judgment. Memory is defined as the ability to remember and appropriately use current information, which affects an individual's health, safety, and welfare. Behaviors that may affect living arrangements and/or jeopardize the safety of self or others are also assessed; these include wandering, those that pose a danger to self or others, and those that negatively affect living arrangements, providers, and/or others.

Threshold Eligibility Requirement. Depending on available funding, the State sets different levels as the threshold eligibility requirement. In the past 15 years, it has varied from level 13 to level 18.

HCBS State Plan Benefit

The Deficit Reduction Act of 2005 (DRA-2005) added §1915(i) to the Social Security Act, which allows states, at their option, to provide home and community-based services under the Medicaid State Plan without a waiver.[31] Section 1915(i) was subsequently amended by the Patient Protection and Affordable Care Act of 2010 (hereafter, the Affordable Care Act).

The only Federal requirement regarding the needs-based criteria for this optional State Plan benefit is that they be less stringent than a state's level-of-care criteria for institutional services, that is, nursing facilities, ICFs/ID, and hospitals that are Medicaid certified as hospitals but provide long-term care services. However, if a state chooses to use the 300 percent of Supplemental Security Income financial eligibility criteria for this benefit, to be eligible individuals must also be eligible for either a §1915(c), (d), or (e) waiver or a §1115 waiver. For a §1915(c) waiver, this means that individuals must meet the level-of-care criteria for institutional services.

If the state does not have needs-based criteria as part of its level-of-care criteria for these institutions, the state will have to add them.[32] If a state revises its needs-based eligibility criteria, it must continue offering §1915(i) services in accordance with individual service plans to participants who do not meet the new revised needs-based criteria, but continue to meet the former needs-based criteria, for as long as the State Plan HCBS option is authorized.[33]

Needs-Based Level-of-Care Criteria

Because minimum eligibility for the §1915(i) benefit must be set below institutional level-of-care criteria, states may want to use this option to serve individuals with a low level of need and to serve only individuals with a higher level of need in institutions and through HCBS waivers. (However, states could choose not to set such a ceiling, and allow individuals whose needs meet institutional and HCBS waiver criteria to be able to receive State Plan HCBS.)

In order to implement the State Plan HCBS benefit, states may need to add needs-based criteria to their institutional level-of-care criteria requirements, if none presently exist. Section 1915(i) of the Social Security Act does not require that such added needs-based institutional level-of-care criteria necessarily result in excluding individuals who would be served without the added criteria. In fact, the purpose of §1915(i) is to expand access to home and community-based services for individuals who are not at an institutional level of care, rather than to reduce access to institutional and waiver services.

Community First Choice Option

The Affordable Care Act of 2010 also establishes a new State Plan optional benefit—the Community First Choice Option, effective October 2011.[34] The Federal Medical Assistance Percentage rate in the Community First Choice Option will be six percentage points higher than the state's usual matching percentage for Medicaid services. To be eligible for services, individuals must require hands-on assistance, supervision, or cueing with activities of daily living, instrumental activities of daily living, and/or health-related tasks. If their income exceeds 150 percent of the Federal Poverty Level, they must meet the state's institutional level-of-care criteria.

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 select service criteria that best suit 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—both through the Medicaid program and with 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 service 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 services and supports that will meet 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. States, for example, may sometimes impose stringent service criteria for cost containment reasons, which then undermines their ability to promote appropriate access. Careful management of different components 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 (with respect to the institutional/waiver eligibility linkage) will result in higher demand for—and expenditures on—institutional services, seems to be misplaced.

Experience confirms that most individuals want to remain in their homes and in the community. Their ability to do so is strengthened through the provision of home and community services.

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key resources regarding service eligibility for Medicaid long-term care services and supports. Most of the publications cite additional resources and the websites have links to other information sources.

Publications

Centers for Medicare & Medicaid Services. (2008). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria*. Baltimore, MD: Department of Health and Human Services.

This publication contains extensive information concerning Federal policies that apply to the operation of an HCBS waiver, in particular, Appendix B: Participant Access and Eligibility.

Available at https://www.hcbswaivers.net/CMS/faces/portal.jsp under links and downloads, entitled ***§1915(c) Waiver Application and Accompanying Materials***.

Centers for Medicare & Medicaid Services. State Medicaid Director Letter. August 6, 2010. *Improving Access to Home and Community-Based Services*.

The purpose of this letter is to inform states of, and provide guidance on, several changes to §1915(i) of the Social Security Act made by the Affordable Care Act. Under §1915(i), states have the option to amend their State Plans to provide home and community-based services without a waiver. These changes, which become effective October 1, 2010, include revised and new §1915(i) provisions for removal of barriers to offering home and community-based services through the Medicaid State Plan.

Available at http://www.cms.gov/smdl/downloads/SMD10015.pdf**Hendrickson, L., and Kyzr-Sheeley, G. (2008). *Determining Medicaid Nursing Home Eligibility: A Survey of State Level of Care Assessment*. New Brunswick, NJ: Rutgers Center for State Health Policy.**

This study describes the nursing facility level-of-care determination processes for individuals applying for Medicaid coverage of nursing home services. The Appendix provides a brief description of data each state collects, the name of the assessment form, plus contact information for state staff.

Available at http://www.hcbs.org/moreInfo.php/doc/2216

Zaharia, R., and Moseley, C. (2008). *State Strategies for Determining Eligibility and Level-of-Care for ICF/MR and Waiver Program Participants.* New Brunswick, NJ: Rutgers Center for State Health Policy.

This report presents the results of a survey of state developmental disabilities agency officials regarding the determination of initial eligibility/level of care and the "annual level of care" for services furnished under Medicaid waiver and ICF/MR programs. Forty-seven states provided information on state waiver eligibility criteria and practices. The report describes state level-of-care assessment approaches and provides legislative citations and contact information for state staff.

Available at http://www.hcbs.org/moreInfo.php/doc/2305

O'Keeffe, J. (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.

This study investigates whether persons ages 65 or older, with functional limitations caused by cognitive and other mental impairments, can meet states' Medicaid level-of-care criteria for nursing home and HCBS waiver programs. A review of 42 states' Medicaid level-of-care criteria found that many states do not use measures that appropriately assess the need for services among persons with cognitive and other mental impairments. The report includes a state-by-state description of Medicaid level-of-care 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) 434-3840.*

Note: Although this and the following publication are more than 10 years old, more recent reports with this level of detail are not available.

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.* Pub. #9617, Washington, DC: AARP, Public Policy Institute.

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 HCBS waiver programs. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3840.*

Websites

Centers for Medicare & Medicaid Services

Overview of Preadmission Screening and Resident Review (PASRR). Federal law requires that a Medicaid-certified nursing facility may not admit an applicant with serious mental illness (SMI), an intellectual disability (ID), or a related condition, unless the individual is properly screened, thoroughly evaluated, found to be appropriate for nursing facility placement, and will receive all specialized services necessary to meet the individual's unique SMI/ID-related needs. Nursing facility residents with SMI or ID must have a Resident Review when there is a significant change in the resident's physical or mental condition. CMS requires each state and territory to specify the PASRR program in their Medicaid State Plan.

Web address: http://www.cms.hhs.gov/pasrr/

The State Medicaid Manual. This manual makes available to all state Medicaid agencies, in a form suitable for ready reference, informational and procedural material needed by states to administer the Medicaid program. The manual provides instructions, regulatory citations, and information for implementing provisions of Title XIX of the Social Security Act. Instructions are official interpretations of the law and regulations, and, as such, are binding on Medicaid state agencies. The material is organized into major parts, which are divided into chapters and sections. The manual is structured as closely as possible to the codification of Medicaid regulations. A crosswalk of manual sections and regulations is also included.

Web address: http://www.cms.hhs.gov/Manuals/PBM/itemdetail.asp?filterType=none&filterByDID=-99&sortBy DID=1&sortOrder=ascending&itemID=CMS021927&intNumPerPage=10

Endnotes: Citations, Additional Information, and Web Addresses

[1] Janet O'Keeffe and Gary Smith co-authored the original chapter. Janet O'Keeffe updated the chapter.

[2] States may make provision for "outliers"—those individuals whose condition responds less well than expected for their condition, and who, as a consequence, may receive more services for a longer period.

[3] 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. States are not bound by the definitions implied by this developmental model; they can, for example, define ADLs to include whatever tasks/activities they consider important to determine a need for long-term care.

[4] People who work with individuals who have cognitive impairments or behavior issues need specialized training.

[5] Section 1902(a)(10)(d) of the Social Security Act.

[6] 42 CFR 440.230(c) and 42 CFR 440.240.

[7] State Medicaid Director Letter, July 25, 2000. Available at http://www.cms.hhs.gov/smdl/downloads/smd072500b.pdf.

[8] 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.

[9] Skubel v. Fuoroli. (No. 96-6201). United States Court of Appeals, Second Circuit. Decided May 13, 1997. Ruling available at http://openjurist.org/113/f3d/330.

[10] 42 U.S.C. §1396d(a)(7). 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 individuals entitled to skilled nursing facility services under a State Plan.

[11] While CMS has not issued formal guidance on allowing states to provide home health services outside an individual's home, CMS has supported and will continue to support such flexibility when analyzing State Plan amendments related to the Home Health benefit.

[12] These examples are drawn from Colorado's eligibility criteria for the Home Health benefit in the year 2000. At the time of publication, it was not possible to determine if the State still uses these criteria.

[13] State Medicaid Manual, Part 4—Services, §4480.

[14] Ibid.

[15] Kassner, E., and Jackson, B. (1998). Determining Comparable Levels of Functional Disability. Washington, DC: AARP, Public Policy Institute. Spector, W.D., and J.A. Fleishman (1998). Combining activities of daily living with instrumental activities of daily living to measure functional disability. Journal of Gerontology. 53(B):S46-S57.

[16] At §1902(a)(10)(B) of the Social Security Act.

[17] Zaharia, R., and Moseley, C. (2008). State Strategies for Determining Eligibility and Level-of-Care for ICF/MR and Waiver Program Participants. New Brunswick, NJ: Rutgers Center for State Health Policy. Available at http://www.hcbs.org/moreInfo.php/doc/2305; Hendrickson, L., and Kyzr-Sheeley, G. (2008). Determining Medicaid Nursing Home Eligibility: A Survey of State Level of Care Assessment. New Brunswick, NJ: Rutgers Center for State Health Policy. Available at http://www.hcbs.org/moreInfo.php/doc/2216.

[18] Eligibility for ICF/ID services is limited to persons with intellectual disabilities or related conditions (42 CFR 435.1010; 42 CFR 440.150). Eligibility for home and community-based services furnished under §1915(c) or §1915(b)(c) "managed care" Medicaid waivers is directly linked to the ICF/ID level of care. For both ICFs/ID and HCBS waiver programs, states must determine during the level-of-care evaluation process that potential service recipients (a) have a diagnosis of an intellectual disability or a related condition (42 CFR 435.1010; 42 CFR 441.302), and (b) require the level of services provided by an ICF/ID. Intellectual disability (and the former term "mental retardation") are not specifically defined; related conditions are defined functionally. (States have generally interpreted the term "related condition" to mean developmental disabilities other than an intellectual disability. Ernest McKenney, personal communication, December 8, 2009.)

Eligibility for home and community-based services under the waiver program is extended to individuals who, "but for the provision of waiver services," would otherwise require the level of support and assistance furnished by an ICF/ID program (42 CFR 442.302(c)(1)). States are required to use level-of-care evaluation instruments or processes for waivers that yield equivalent outcomes to those used for the ICF/ID program. After a person is admitted to the waiver program, states are required to certify at least annually that he or she continues to need the "level of care provided" (42 CFR 441.302 (c)(2)), during an annual level-of-care determination process." Unless noted otherwise, text above is taken verbatim from Zaharia, R., and Moseley, C. (2008), op. cit.

[19] States may use different evaluation instruments and processes for determining eligibility for 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 "reliable, valid, and fully comparable to the outcome for institutional evaluation. In particular, the state must be able to demonstrate that individuals who meet level of care via the application of the waiver instrument also would meet level of care when the institutional instrument is employed." Appendix B: Participant Access and Eligibility, Item B-6-e in Application for a §1915(c) Home and Community-Based Waiver, [Version 3.5], Instructions, Technical Guide and Review Criteria. See the Resources section of this chapter for the web link.

[20] 42 U.S.C. 15002 Sec. 102.

[21] The term "developmental disability" means a severe, chronic disability of an individual that (i) is attributable to a mental or physical impairment or combination of mental and physical impairments, (ii) is manifested before the individual attains age 22, (iii) is likely to continue indefinitely, and (iv) results in substantial functional limitations in three or more of the following areas of major life activity: (I) self-care; (II) receptive and expressive language; (III) learning; (IV) mobility; (V) self-direction; (VI) capacity for independent living; (VII) economic self-sufficiency; and (VIII) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of life-long or extended duration and are individually planned and coordinated (42 U.S.C. 15002 Sec. 102). Note, this definition is more expansive than the regulatory definition of a "related condition" at 42 CFR 435.1010. The text that this endnote references, and the endnote itself, are taken verbatim from Zaharia, R., and Moseley, C. (2008), op. cit.

[22] Maryland Dept. of Health and Mental Hygiene v. Brown, 177 Md. App. 440, 935 A.2d 1128 (2007), affirmed and opinion adopted, 406 Md. 466, 959 A.2d 807 (2008).

[23] States should not use an MMSE score as an eligibility criterion because the MMSE and similar mental status tests were not designed to determine whether or to what extent an individual needs long-term care services.

These tests were developed as clinical screening tools to determine whether more in-depth assessment is needed to make a diagnosis of dementia. Most importantly, as the Advisory Panel on Alzheimer's Disease has noted, these tests are not correlated with the specific functional limitations or service needs of people with dementia. O'Keeffe, J., Tilly, J., and Lucas, C. (May 2006). Medicaid Eligibility Criteria for Long-Term Care Services: Access for People with Alzheimer's Disease and Other Dementias. Washington, DC: Alzheimer's Association. Additionally, the MMSE is insensitive to the functional limitations common in certain types of dementia. Many individuals with dementia who have extensive functional limitations will never reach the score specified in this eligibility criterion. Donald Royall, M.D., Professor and Chief, Division of Aging and Geriatric Psychiatry, University of Texas Health Science Center at San Antonio. Personal communication, June 28, 2010.

[24] Maryland Department of Health and Mental Hygiene (July 1, 2008). Maryland Medical Assistance Program. Nursing Home Transmittal No. 213. Available at: http://www.msba.org/sec_comm/sections/elder/docs/nursinghometransmittal213.pdf.

[25] Section 1919(a)(1) of the Social Security Act.

[26] 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. Pub. #9617, Washington, DC: AARP, Public Policy Institute.

[27] 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.

[28] Application for a §1915(c) Home and Community-Based Waiver, [Version 3.5], Instructions, Technical Guide and Review Criteria. Glossary, p. 304. See the Resources section of this chapter for a web link to the application, instructions, and appendices.

[29] Most of the people interviewed in this study were able to remain in the community because they had extensive informal care supplemented by small amounts of privately paid care. O'Keeffe, J., Long, S.K., Liu, K., and Kerr, M. (1999). How do They Manage? A Case Study of Elderly Persons Functionally Eligible for Medicaid Waiver Services but Not Receiving Them. Washington, DC: AARP, Public Policy Institute.

[30] 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.

[31] P.L. 109–171. §6086(a).

[32] The lack of functional criteria is more likely to be an issue for ICF/MR level-of-care criteria (which in some states is largely determined by diagnosis) than for nursing facility level-of-care criteria.

[33] State Medicaid Director Letter, August 6, 2010. Available at http://www.cms.gov/smdl/downloads/SMD10015.pdf.

[34] Section 2401 of the Affordable Care Act, amending §1915 of the Social Security Act.

Guide to Chapter 4

Introduction 87
Medicaid Home and Community Services: An Overview 87
Federal Policy Considerations 91
State Policy Goals and Objectives 93
Home and Community Services under the Medicaid State Plan 94
Personal Care/Personal Assistance 95
State Plan Home and Community-Based Services 99
Community First Choice Option 100
Services That May Be Offered Under an HCBS Waiver Program 102
Supports Waivers 105
Supporting Individuals to Live in Their Own or Family Home 106
Medicaid Financing for Supports to Individuals Living in Their Own Home 106
Factors to Consider When Choosing Coverage Options: Two Illustrative Services 107
1. Personal Care/Personal Assistance 107
2. Case Management 111
Resources 116
Endnotes: Citations, Additional Information, and Web Addresses 119

Chapter 4
Options for Designing Service Coverage: General Considerations

To remain in their homes and communities, many people with disabilities and chronic conditions need long-term care services and supports, ranging from personal assistance to more specialized services, as well as assistive technology and environmental modifications. Federal Medicaid law and policy give states great latitude to offer individuals a wide range of home and community services through a state's regular Medicaid program. States can also offer a comprehensive range of services by operating one or several home and community-based services (HCBS) waiver programs. This chapter discusses 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 needs.1

Introduction

Changes in Federal Medicaid statute and policy over the past three decades have made it feasible for states to provide a wide range of home and community services. The many options for furnishing these services can be confusing for policymakers, state officials, advocates, and consumers alike, as they can be funded through one or more of three alternative routes: (1) a state's regular Medicaid State Plan, (2) managed care programs, and/or (3) one or several HCBS waiver programs, each offering a distinct package of services and supports to different groups of individuals.2

Combining these alternatives in creative ways can give states substantial latitude in designing their Medicaid home and community service coverages and customizing benefit packages to meet the needs of particular groups. Use of HCBS waivers also provides considerable flexibility for states to manage service costs and the number of people served. This flexibility explains the considerable variation in the services and supports that states 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 can influence decisions concerning whether to offer a service as a regular Medicaid program benefit or through an HCBS waiver 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—also called personal assistance and attendant care—involves helping individuals perform everyday activities when they have physical or mental impairments that prevent them from carrying out these 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 medication management.

This assistance can be furnished in the home or community settings, as well as to individuals who live in foster care, group homes, and other residential care settings. The terms used for individuals who provide personal care vary, and include personal assistants, personal attendants, personal care aides, and direct care workers. Certified nursing assistants and home health aides also provide personal care.

Individuals with various types of disabilities often require this form of basic assistance throughout their lives. Thus, a need for personal care is a major, if not the primary, reason many individuals seek Medicaid long-term care services and supports. States use several different terms to describe assistance with ADLs and IADLs, which may be provided under the mandatory Home Health benefit, the optional State Plan Personal Care benefit, the optional Section (§)1915(i) HCBS State Plan benefit, and/or a §1915(c) waiver (hereafter called HCBS waiver). In October 2011, an additional State Plan option will be available—the §1915(k) Community First Choice Option benefit, which was authorized by the Patient Protection and Affordable Care Act of 2010 (hereafter called the Affordable Care Act). Personal care can also be provided under the optional §1915(j) Self-directed Personal Assistance Services State Plan benefit. However, only states that offer personal care under either the State Plan Personal Care option or an HCBS waiver may employ the §1915(j) authority. (See Chapter 7 for a detailed discussion of the §1915(j) authority.)

Health-Related Services. Personal care can include assistance with health and health-related tasks, which encompass a wide range of skilled and unskilled nursing services that address chronic conditions and functional impairments (e.g., tube feedings, catheterization, range of motion exercises, and medication administration). However, assistance with skilled tasks may be provided only when delegated by a licensed nurse in accordance with state law.

Specialty Services. This category comprises a wide range of services related to the specific nature of an individual's impairment. These services generally share the common aim of helping individuals to improve their functioning. Adult day health services address both functional and health needs. Psychiatric rehabilitation services address the needs of individuals who have a mental illness that impairs their functioning. Habilitation services enable people with intellectual disabilities and other developmental disabilities (ID/DD, hereafter called developmental disabilities) to acquire or improve skills to help them become more independent. Assistive technology helps people with many types of disabilities become more self-sufficient. States may offer these specialized services through various options, including an HCBS waiver program. Many types of assistive technology (e.g., motorized wheelchairs and 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 and function in the community, many individuals with physical impairments need home and vehicle modifications. Home modifications include the installation of 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 to enable a person to drive or be transported to work and/or community activities. These services can be covered under HCBS waiver programs.

Family and Caregiver Supports. These supports are designed to help family members and friends who support individuals with disabilities. Various Medicaid options are available to maintain and strengthen these supports. Respite care—for unpaid caregivers who are absent or need relief—is one of these services. State Plan personal care services—in addition to those provided on an ongoing basis—can be authorized to temporarily relieve an unpaid caregiver.

States may also provide "caregiver training and education" as a distinct service under an HCBS waiver program to strengthen an unpaid caregiver's ability to meet the needs of the person they are assisting. Training and education can cover a wide range of topics, such as instructions for using equipment specified in the service plan and ensuring compliance with treatment regimens. It may include (a) paying trainers to come into the home to teach skills and techniques for addressing the program participant's (hereafter, the participant's) needs, so that training can be customized to the individual and the caregivers; (b) paying for caregivers to attend special training and education classes; and (c) paying the expenses associated with caregivers attending workshops and conferences where they learn how to better meet participants' needs. (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 participant accompanies the caregiver.)

Caregiver training may also be paid for under the optional Rehabilitation benefit. Rehabilitation services in Kentucky, for example, include home visits to (a) help family members and seriously mentally ill beneficiaries practice effective communication techniques to defuse stressful situations that occur in home settings, and (b) coach family members to improve their skills for managing a severely emotionally disturbed child. Training and supports may also be offered as component parts of other benefits, such as Home Health.

Social Supports. Social supports are intended to help individuals take an active part in both their family and community and can 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 under HCBS waiver and State Plan HCBS programs.

Case Management/Service Coordination helps individuals who need services and supports funded by several sources. Some may be available through the Medicaid State Plan and others through other public programs such as state programs for person with disabilities and programs funded under the Older Americans Act. A common feature of home and community services is the provision of case managers, who may also be called care coordinators, service coordinators, or support coordinators. They frequently prepare—or facilitate preparation of—an individual service plan that describes how all the services and supports a person might need will be identified and delivered. They also play an active role in monitoring the quality and effectiveness of home and community services. Several Medicaid options are available for covering case management/service coordination, which are discussed later in this chapter.

As states consider which home and community benefits to offer, and how to offer them, it is helpful to keep in mind that no bright line distinguishes home and community 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, State Plan coverage of medical equipment and supplies can provide power wheelchairs and other mobility aids. The State Plan may also cover therapeutic services such as occupational and physical therapy, which many

Respite Benefits

Respite benefits encompass whatever services an individual needs (e.g., personal care and nursing services). They are usually furnished on an intermittent basis explicitly to provide relief to primary unpaid caregivers. Respite, for example, can be provided to give parents a night or weekend off periodically from the intense caregiving needed to support children with 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 adults, particularly those with dementia who need around-the-clock supervision. Respite care benefits the individual directly by providing services usually furnished by caregivers, and indirectly by helping avoid caregiver "burnout," which can lead to institutionalization. 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 provided through HCBS waiver programs 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 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 unpaid caregivers. It is not uncommon for states to cap the amount of respite at 30 days during a calendar year. Some states do not impose such caps in their HCBS waiver programs, leaving the amount of respite that will be authorized to be worked out during the individual service planning process based on the needs and circumstances of the particular informal caregivers.

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 participant), caregivers should determine when it is used. States have the option to permit "banked respite" to be carried over from one year to the next.

individuals need to improve or prevent a decline in their functioning. 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 will help to ensure that the coverages chosen address the key needs of those being served.

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

Federal Policy Considerations

While Federal Medicaid law and policy give states considerable latitude in deciding which Medicaid home and community services they will offer, states do not have complete freedom. State choices must be 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 developing effective strategies to support individuals in their homes and communities.

State Plan Requirements. All services covered under a state's Medicaid plan—both mandatory and optional—are subject to two important statutory requirements. First, they must be available on a comparable basis to all state Medicaid beneficiaries (in an eligibility group) who need the service. States must use the same eligibility criteria for all applicants and any limits on service amount, scope, and duration must be equally applied to both individuals currently receiving services and those applying for services. The effect of these requirements is that states cannot have a waiting list and any changes made in the eligibility criteria, as well as service amount, scope and duration, must be applied equally to both those currently receiving services and those applying for them. These provisions constitute the "comparability" requirement.

Second, services must be available statewide (i.e., the state cannot restrict the availability of the service to particular geographic regions). This is called the "statewideness" requirement.[4] There are few exceptions to this statewideness requirement; targeted case management is a major one. Federal regulations also require that each Medicaid service be sufficient in amount, duration, and scope to achieve its purpose. Within this broad requirement, states have the authority to establish reasonable and appropriate limits on the amount, duration, and scope of each service.

Generally, when a state wishes to make home and community services available only to certain distinct groups of Medicaid beneficiaries (e.g., adults with physical disabilities) it must seek Federal approval of an HCBS waiver.[4] This waiver authority permits states to waive both the comparability and statewideness requirements in order to target services to distinct groups of Medicaid beneficiaries. Once eligible for a waiver program, participants must be provided all of the waiver services for which they have a documented need, and the services must be available in all parts of the state covered by the waiver. The Affordable Care Act includes a provision waiving comparability for services provided under the State Plan §1915(i) authority, but services must be provided statewide to everyone who meets the eligibility criteria.[5]

Services That Cannot Be Offered under the State Plan. Some services may not be offered under a Medicaid State Plan because they have not been specified in either the authorizing legislation or implementing regulations. An example is home modifications, which explains why home modifications is one of the most common services offered under HCBS waiver programs.

HCBS Waiver Coverage to Complement or Expand State Plan Coverage. Through an HCBS waiver, a state may augment the services it provides under the State Plan. When a state retains the scope of a State Plan service but increases its amount, duration, or frequency, the service is considered an "extended State Plan" service. For example, a state may allow four home health aide visits each week under the State Plan Home Health benefit and allow three additional visits under an HCBS waiver. States must

have established mechanisms to ensure no duplication of service provision or billing for State Plan and waiver services.[6]

Non-duplication. Federal policy provides that a state may not offer precisely the same service under an HCBS waiver 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. While a waiver service may be similar in scope to a State Plan service, it would be considered an "other" service rather than an "extended State Plan" service if the method of service delivery (e.g., giving participants the ability to direct their services) differs under the waiver. States have added tasks to the scope of services covered under a State Plan in order to create a new waiver service that does not duplicate the State Plan service (see Box).

EPSDT Mandate. When children are served in an HCBS waiver program, states must take account of the mandate to provide enhanced Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services. Federal EPSDT requirements mandate that Medicaid-eligible children receive all medically necessary services (listed in §1905(a) of the Social Security Act) that they require, regardless of whether such services are specifically included in the State Plan. Thus, medically necessary services for children who need them cannot be restricted to children who are waiver participants.

Redefining Services: State Example

Texas provides attendant services through its State Plan Personal Care program. The State expanded the scope of attendant services to be provided in its Community Based Alternatives waiver to include protective supervision as temporary relief for the primary caregiver, extension of therapy services, and the performance of nursing tasks delegated by licensed registered nurses. Because the new service—called Personal Assistance Services—differs from attendant services provided under the State Plan, waiver participants do not have to first obtain attendant services under the State Plan Personal Care program before receiving personal assistance services through the 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 services provided under HCBS waivers, for example, a state may offer only services that are either necessary for people 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; only that Federal 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, utilities, and food) of non-institutionalized persons, except in limited circumstances such as (a) out-of-home respite care, and (b) the room and board costs of a live-in caregiver. Federal financial participation (FFP) is available for room and board provided as part of respite care furnished in a facility that is approved by the state but not in a private residence.

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. The room and board exclusion can complicate the development of strategies to support individuals in their homes and community-based residential care settings. In contrast, room and board expenses are Medicaid-reimbursable in institutions, where individuals receive a significantly reduced SSI payment as a personal needs allowance ($30/month).

Obligations of Other Payers. Medicaid is deemed a payer of last resort. This means that if another public program or private third-party payer—such as a private health insurance plan—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 State 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 requirement can make states wary of offering services under their Medicaid State Plan, because Federal rules prohibit them from reducing services below the amount, duration, and scope needed to achieve their purpose, and from limiting the number of people who receive the service. While states can set the medical necessity criteria for State Plan services, they must serve everyone in the state who requests services and meets the criteria. Because they cannot predict how many individuals will qualify and how much it will cost to serve each person, spending for State Plan services is less predictable than for HCBS waiver programs.

Predictability of costs is the major reason why many states have used HCBS waiver programs to expand the availability of home and community services rather than through State Plan benefits, such as Home Health and Personal Care. HCBS waivers permit states to serve only a set number of beneficiaries that the state itself establishes for the waiver and to set individual cost limits for participants. States may also use an aggregate cost neutrality calculation to determine the total amount of funding available for waiver services. Compared to setting per capita limits for waiver participants, this approach gives states the flexibility to serve individuals with extensive needs who require more services than the average participant.

However, states that limit the provision of home and community services to HCBS waiver programs limit themselves to serving only a high-need population—those who meet institutional level-of-care criteria. By providing State Plan services (e.g., under the Personal Care, Rehabilitation, and/or the §1915(i) benefits), states can serve a population with lower needs and help individuals maintain—and/or slow the decline of—their health and functional status, thereby delaying the need for more costly services and supports.

Inclusiveness. When deciding whether to cover a service under the State Plan or an HCBS waiver program or both, states need to carefully consider how services provided in different programs can complement each other in furnishing people with disabilities the right amount and combination of services.

Target Populations. With a few exceptions, services offered under a Medicaid State Plan must be provided to all eligible individuals on a comparable basis.[7] Thus, it can be difficult to vary services or service delivery approaches based on the needs of individuals who have specific impairments and specialized needs. It also can be 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 states to select an HCBS waiver program as a vehicle for offering

services to defined groups of individuals, because the service package can be designed to meet their distinct needs. The recently enacted §1915(i) HCBS State Plan option also permits states to target services to specific groups.

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, for example, individuals who are elderly, who have a serious mental illness, or who have a developmental disability. One group for which states have historically not developed specific programs or service systems is people 18 to 64 years of age with physical disabilities—a group that is frequently underserved. Some states, such as Connecticut, have programs targeted to people who are financially ineligible for Medicaid but meet the state's institutional level-of-care criteria.[8]

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 an HCBS 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 more individuals living in the community for Medicaid using an HCBS waiver program than it can under its State Plan because it has the option to use the more liberal financial eligibility rules used for institutions when determining eligibility for an HCBS waiver. Some individuals in the community who might not qualify for State Plan Medicaid benefits because they do not meet the income criteria, in particular, may be eligible for services under an HCBS waiver program, if the state uses institutional financial eligibility rules.

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 Health and Human Services (HHS)—operating through the Centers for Medicare & Medicaid Services (CMS)—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 services must be provided by every state that operates a Medicaid program, for example, home health services. These are called mandatory services.[9] Others can be provided at state option—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 four forms: (1) medical/functional need, (2) how often a person may receive a service (amount), (3) for how long (duration), and (4) the exact nature of what is provided (scope). However, Federal law requires that such limitations not undermine a person's receipt of necessary assistance. Any limitations states establish must generally be based on clinical grounds. Although limits must not prevent the state from meeting the needs of most Medicaid beneficiaries most of the time, states are not required to meet all beneficiaries' needs all the time.

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 eligibility, amount, scope, and duration the state has established. This is why Medicaid beneficiaries are said to be "entitled" to State Plan services.[10]

A state has the option of covering under its State Plan four key home and community services that are especially important for people with disabilities: (1) personal care, (2) targeted case management, (3) clinic services, and (4) rehabilitative services. Additionally, the state can cover a wide range of home and community services under the new HCBS State Plan option created by the Deficit Reduction Act of 2005 (DRA-2005) and amended by the Affordable Care Act.

Each of these State Plan options will be discussed next, followed by a brief discussion of services that can be offered under an HCBS waiver program.

Personal Care/Personal Assistance[11]

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—together with implementing regulations effective in November 1997—gave states the option to substantially broaden the scope of personal care services to furnish individuals a wide range of assistance in everyday activities, both in and outside their homes.[12]

In January 1999, CMS released a State Medicaid Manual Transmittal that updated the guidelines concerning coverage of personal care services. In it, CMS made clear that (a) personal care services include assistance with both ADLs and IADLs, and (b) personal care for people 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 the Resources section of this chapter for a link to the Medicaid Manual.)

A state may now extend such services to include supervision and assistance to people with cognitive impairments, which can include people with mental illness, intellectual disabilities, and dementia. However, this supervision and assistance must be related directly to the performance of ADLs and IADLs. 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.

Specific provisions in the Manual are discussed next.

> ***Scope of services****—Personal care services covered under a state's program may include a range of human assistance provided to people 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 the State Plan Personal Care benefit when delegated by a licensed nurse in accordance with state law.

> ***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, CMS further revised the Manual to permit states to offer the option of consumer-directed personal care services (also called self-direction or participant direction). The Manual revisions explicitly recognized that individuals who are receiving personal assistance may direct their workers, that is, train, supervise, manage, and dismiss them (if needed). In particular, the Manual states the following:

> ***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 people with cognitive impairments, who have the ability and desire to manage their own care.*

See the discussion later in this chapter—and in Chapter 7—about the §1915(j) State Plan authority, which expands participant direction service delivery options for both the State Plan Personal Care benefit and HCBS waiver programs.

These Manual materials describe a comprehensive scope of personal care/assistance that a state may choose to cover under its Medicaid State Plan—in keeping with contemporary views concerning the role personal assistance can play in supporting individuals with disabilities in a wide range of everyday activities.

As a result of the changes made in Federal policy, there is now little difference in the scope of personal care services that may be offered under the Medicaid State Plan and those that may be offered under an HCBS waiver program. However, neither the provisions of OBRA 93 nor the revised Federal regulations and CMS State Medicaid Manual guidelines require a state to change the scope of its pre-1993 coverage. In order to take advantage of these changes, a state must file an amendment to its Medicaid State Plan.

Targeted Case Management Services

States have the option of covering case management services for a defined group of Medicaid recipients, or for multiple groups, as long as different provisions apply to each specified group (hence, the term "targeted").[13] Targeted case management services are exempt from the comparability requirement, that is, they do not have to be available to all Medicaid beneficiaries. They can also be offered on a less than statewide basis.[14]

For example, a state may offer one form of targeted case management services to recipients who have a mental illness and another to people who are elderly and have physical impairments. States may use their own definitions to define target groups and may do so broadly (e.g., all Medicaid-eligible individuals with a developmental disability) or more narrowly (e.g., Medicaid-eligible individuals with a developmental disability who also have a mental illness). Other target groups states have established include

- Adults with serious mental illness as defined by the state.
- Children from birth to age 3 who are experiencing developmental delays or behavioral disorders as measured and verified by diagnostic instruments and procedures.
- Pregnant women and infants up to age 1.
- Individuals 60 years of age or older who have two or more physical or mental diagnoses that result in a need for two or more services.
- Individuals with AIDS or HIV-related disorders.
- People being transitioned from nursing homes to the community.
- Individuals enrolled in HCBS waiver programs.

Although the targeting aspects of this case management coverage make it somewhat akin to the HCBS waiver program, there is one important difference. Once a state has established its target population and geographic locations, targeted case management services must be furnished to all eligible individuals. A state may not limit the number of eligible individuals who may receive these services.

States do have the option of limiting the entities that may furnish targeted case management services to individuals with a developmental disability

or a mental illness to enable them to tie provision of these services to the "single point of entry" systems common in state service systems that serve these populations. Doing so enables states to maintain a unified service delivery approach.

The four components of targeted case management include assessment, service plan development, referrals, and monitoring. Targeted case management services can be described as "planning, linking, and monitoring" the provision of direct services and supports obtained from various sources (the Medicaid program itself, other public programs, and a wide variety of private sources), making their scope very broad. Permitted activities can include (1) assistance in obtaining food stamps, housing, and legal services; (2) service/support assessment and planning; and (3) monitoring the delivery of direct services and supports to ensure they are meeting individuals' needs.

Although a range of activities on behalf of beneficiaries can be included within the scope of targeted case management, some cannot. In particular,

- Activities related to authorization and approval of Medicaid services.15
- Activities related to making basic Medicaid eligibility determinations.
- Activities that constitute "direct services" to the consumer (e.g., transporting an individual to and from a doctor's appointment is outside the scope of targeted case management).16
- Activities provided to individuals in institutions. This restriction is based on two Federal provisions: (a) Federal regulations concerning Medicaid institutional services require that facilities provide care coordination services to residents, and (b) Medicaid prohibits duplicate payments for the same service. However, targeted case management services may be provided to residents of institutions in the last 180 consecutive days of a Medicaid-eligible person's institutional stay, if provided for community transition. (See Chapter 6 for a discussion of Medicaid provisions related to transitioning from institutions to the community.)
- Activities that overlap or duplicate similar services a person receives through other means (e.g., development of a service plan by an HCBS waiver case manager).

Other Medicaid options for covering case management services are discussed later in this chapter.

Clinic Services[17]

States have the option of covering specialized treatment services and other supports under several State Plan benefits. The two benefits that states most frequently cover are the optional Clinic benefit and the optional Rehabilitation benefit. States employ the Clinic benefit for a wide variety of purposes in their state Medicaid programs, including paying for services furnished through health care clinics and community mental health centers.

The Clinic benefit also serves as a means of paying for mental health services furnished to Medicaid beneficiaries on an outpatient basis. Mental health clinics may provide mental health therapy and other treatment to Medicaid beneficiaries—services needed by people who have serious and persistent mental illness and need long-term care services and supports to remain in their communities. The clinical services provided through the Clinic benefit must be site-based and supervised by a physician. (See the Resources section of this chapter for a web link to a publication on how to use Medicaid to provide services for adults with serious mental illness.)

Rehabilitation[18]

The Rehabilitation benefit allows states more flexibility to design service packages than does the Clinic benefit, because of its broad definition in Federal regulation: "any medical or remedial services recommended by a physician or other licensed practitioner of the healing arts, within the scope of his practice under state law, for maximum reduction of physical or mental disabilities and restoration of a recipient to his/her best functional level."

Rehabilitation services can include those that are also covered under the Clinic benefit. But unlike services under that option, they are portable (i.e.,

not limited to specific sites under the direct, on-site supervision of a physician). Many other services also fall within the scope of Rehabilitation. Psychiatric rehabilitation services include basic living skills training (including independent living skills and cognitive skills, as well as education regarding medications and medication management), social skills training, counseling and therapy, and collateral services, such as consultation with and training of family members, primary caretakers, providers, legal guardians or other representatives, and significant others. Such training and counseling is limited to activities that directly support the individual.[19]

Collateral services can be covered as a specific stand-alone category or as part of day treatment or intensive in-home services. Through this activity, reimbursement is provided for face-to-face encounters with people who are important in the beneficiary's life, when those encounters are needed to develop or implement the rehabilitation plan. Psychiatric rehabilitation services are furnished in a variety of locations, including homes, partial hospitalization or day programs for adults, day treatment programs in schools or other locations for children, and residential placements (including facilities with fewer than 16 beds, such as group homes or therapeutic foster care homes). Crisis services and early intervention services, including services for very young children exhibiting signs of serious emotional disorders, are also furnished under this option.[20]

These services, along with personal care and targeted case management, can be combined to meet a wide range of service and support needs for people who have a mental illness. Of the 46 states that use the Rehabilitation benefit, many also provide targeted case management services to this population.[21]

The Clinic and Rehabilitation optional benefits are not generally used to provide long-term care services and supports to individuals with disabilities other than mental illness. During the 1970s and 1980s, a few states secured CMS approval to cover daytime services for people with developmental disabilities under either the Clinic or the Rehabilitation benefit. CMS ultimately ruled that the services being furnished were habilitative rather than rehabilitative and consequently could not be covered under either option in additional states.

However, Congress acted in 1989 to permit states that had secured CMS approval of these coverages to continue them but effectively prohibited other states from adding such coverage. The main basis for this ruling was that habilitative services could be furnished only to residents of intermediate care facilities for individuals with an intellectual disability (ICFs/ID) under the State Plan or through an HCBS waiver program for individuals who might otherwise be eligible for ICF/ID services. A few states have maintained their coverage of these services. But many have dismantled their coverages in favor of offering similar services through their HCBS waiver programs. With the creation of the new HCBS State Plan option under the §1915(i) authority, states may now cover habilitation under the State Plan.

State Plan Home and Community-Based Services[22]

The DRA-2005 added §1915(i) to the Social Security Act, which allows states, at their option, to provide a broad range of home and community-based services under the Medicaid State Plan.[23] The Affordable Care Act made a number of significant changes to the §1915(i) authority.

Section 1915(i) allows states to include any or all of the services that are listed in §1915(c)(4)(B) of the Social Security Act. These services include case management, homemaker/home health aide, personal care, adult day health, habilitation, and respite care services. In addition, the following services may be provided to persons with chronic mental illness: day treatment, other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility). States may also offer "such other services…as the Secretary may approve." CMS has drafted an application for states to submit a State Plan amendment to add an HCBS benefit.

All individuals served under §1915(i) must meet the needs-based criteria the state establishes for its HCBS benefit. These criteria must be less stringent than its level-of-care criteria for institutional services, that is, nursing facilities, ICFs/ID, and hospitals that are Medicaid certified as hospitals but provide long-term care services. These criteria cannot be based solely on diagnosis but must be based on an assessed need for a set of supports and services due to functional limitations.

The evaluation process to determine eligibility must be independent and not present a conflict of interest (i.e., service providers may not be involved in the eligibility determination process if

Proposed Changes to Rehabilitation Benefit Withdrawn

On August 13, 2007, CMS published a proposed rule—Medicaid Program; Coverage for Rehabilitative Services—in the *Federal Register* to clarify the definition of Medicaid "rehabilitative services" and to establish new documentation and other requirements.

Due to concerns about the proposed rule expressed by many states and numerous stakeholders, it was subject to a Congressional moratorium that prohibited the Secretary of HHS from taking any action, including publication of a final rule that was more restrictive with respect to coverage or payment for rehabilitative services than the requirements in place as of July 1, 2007.

Before the expiration of the Congressional moratorium, the American Recovery and Reinvestment Act of 2009, enacted on February 17, 2009, included a "Sense of Congress" that the Secretary should not promulgate a final regulation similar to the August 13, 2007 proposed regulation. In light of clear Congressional concern, as well as the complexity of the underlying issues and of the public comments received, on November 23, 2009 CMS withdrew the proposed rule in order to ensure agency flexibility in re-examining the issues and exploring options and alternatives with Congress and stakeholders.

they have a contract to furnish services under the benefit). Additionally, states must have safeguards in place to ensure there is no conflict of interest in the needs assessment and service planning processes.

States have the option to provide State Plan HCBS to individuals with incomes up to 150 percent of the Federal Poverty Level (FPL) who are eligible for Medicaid under an eligibility group covered under the State Plan without regard to whether they meet institutional level-of-care criteria. They also have the option of providing services to individuals with income up to 300 percent of the SSI Federal benefit rate, but individuals in this new eligibility group must be eligible for a §1915(c), (d), or (e) waiver or §1115 demonstration program.[24] They do not, however, have to be enrolled and receiving services in either waiver program.

States may also make HCBS available to medically needy people if they are covered under the State Plan. For the medically needy group, states may apply income disregards to facilitate their eligibility for HCBS benefits (but not for other State Plan services). States do not have the option to protect spousal income and assets as they can under an HCBS waiver.

Community First Choice Option

The Affordable Care Act added §1915(k) to the Social Security Act to allow states to provide "Community-based Attendant Services and Supports"—called the Community First Choice Option—effective October 2011. Under §1915(k), states that provide home and community-based attendant services and supports through their State Plans will receive a six percentage points higher Federal match. To be eligible for this benefit, individuals must meet Medicaid State Plan eligibility criteria and have incomes that do not exceed 150 percent of the federal poverty level. If their income is greater, they must meet institutional level-of-care criteria.

Services under this option include home and community-based attendant services for the purpose of assisting in "accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands on assistance, supervision, or cueing." Funds can also be spent to provide assistance with "the acquisition, maintenance, and enhancement of skills necessary" for the individual to accomplish such tasks; for "back-up systems or mechanisms to ensure continuity of services and supports (such as the use of beepers or other electronic devices)"; and for "voluntary training on how to select, manage, and dismiss attendants."

This option can also fund transition expenses incurred when moving from an institution to the community, such as security deposits for an apartment or utilities, as well as basic kitchen supplies, bedding, and other necessities required for transition. The law also allows "expenditures relating to a need identified in an individual's person-centered service plan that increase independence or substitute for human assistance, to the extent that expenditures would otherwise be made for the human assistance."

Specific requirements for states that provide these services and supports include the following:

- Collaborate with a Development and Implementation Council established by the state that includes a majority of members with disabilities, elderly individuals, and their representatives.
- Establish and maintain a comprehensive continuous quality assurance system specifically for this service.
- Collect and report information for Federal oversight and the completion of a Federal evaluation of the program.

For the first full fiscal year in which the State Plan amendment is implemented, the state must maintain or exceed the level of expenditures for services provided under the State Plan, waiver programs, or demonstrations.

Table 4-1. Texas Home and Community-Based Waiver Programs

Waiver	Population Served
Medically Dependent Children Program	Children (under age 21) at risk of nursing facility placement because of complex medical needs.
Home and Community-Based Services	People of all ages who qualify for ICF/ID services.
Community Living Assistance and Support Services	People of all ages who have a disability—other than an intellectual disability—that originated before age 22 and that affects their ability to function in daily life.
Deaf-Blind Multiple Disabilities	People age 18 or older who are deaf, blind, and have multiple disabilities who qualify for ICF/ID/Related Conditions (RC) services.
Community Based Alternatives	Adults (age 21 or older) who qualify for nursing facility services.
STAR+PLUS	Adults (age 21 or older) who qualify for nursing facility services and live in designated counties in the State. Services are provided through a §1915(b) waiver and a §1915(c) waiver program.
Consolidated Waiver Program Two waivers: One for ICFs/ID/RC and one for nursing facilities.	People of all ages in Bexar County who qualify for nursing facility services or ICF/ID/RC services.
Texas Home Living	People of all ages, living with their families or in their own home, who qualify for ICF/ID services and meet the SSI income limit.
Youth Empowerment Services	Children between 3 and 18 years of age with Severe Emotional Disturbance who qualify for a Hospital Inpatient Psychiatric Facility for Individuals under 21 as provided for in 42 CFR 440.16.

Services That May Be Offered Under an HCBS Waiver Program[25]

Using the HCBS waiver as authorized under §1915(c) of the Social Security Act, states have great flexibility to design programs that meet the unique needs of individuals with disabilities. Collectively, 48 states and the District of Columbia operate 314 distinct HCBS waiver programs.[26] Some states, such as Texas and Florida have 10 or more waivers for specific populations (see Table 4-1 for a list of Texas's waiver programs).

To assist states in submitting requests to begin waiver programs, CMS issued a standard HCBS waiver application format in the early 1990s. Since November 2006, CMS has offered a web-based version of the application. Conversion to a web-based application streamlined the preparation of waiver applications and amendments, and improved communication concerning waiver requests between CMS and the states. CMS encourages states to employ the web-based application to submit new waivers, waiver renewals, and amendments. The application is linked to specific instructions for completing it and also includes technical guidance regarding its use. (See the Resources section of this chapter for a link to the latest version of the application and accompanying instructions.)

The services a state may offer under the HCBS waiver authority are not limited to those defined in the waiver instructions and technical guidance. States are free to accept the CMS definition, modify it to reflect other features and considerations important to the state, and/or propose a new service entirely and provide its definition. Many states use the CMS definitions—often with modifications—but many others have proposed alternative definitions to ensure that the service description exactly matches the service they want to provide.

Because the CMS service definitions may not be an exact match for what a state wants—and because CMS requires a precise definition of what will be furnished to waiver participants[27]—it is best to begin by developing a clear understanding of what the state intends. This analysis should encompass the types of services and supports to be delivered, as well as how, where, and by whom. Gaining a comprehensive understanding of its objectives puts a state in a good position to decide how well the definitions in the standard format "fit." A good rule of thumb in considering CMS-predefined coverage is, "If it fits, use it. If it almost fits, change it to fit. If it doesn't fit at all, propose a new service." See the Box below for Colorado's definition of Personal Assistant Services provided under its Supported Living waiver for people with developmental disabilities.

HCBS waivers cover many different services, including protective services and home-delivered meals;[28] family counseling to deal with behavioral and other problems; substance abuse counseling/services; training in child and infant care for a parent with a disability; crisis intervention services; behavioral services, generally for individuals with developmental disabilities and acquired brain injuries; community participation supports; and housing coordination to assist individuals in locating and obtaining community housing.

The wide range of services makes it clear that no exact formula exists for deciding which services and supports to include in a particular HCBS waiver program. States' HCBS waiver programs differ in significant ways, but some of the large differences among the 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 several closely related services into one coverage category. For example, Colorado's Supported Living Services waiver program for people with developmental disabilities provides a service it has named "Environmental Engineering," which covers both home modifications and assistive technology. Other states choose to offer them as discrete services. How exactly services and supports are packaged and defined is less important than making sure they are covered in one way or another.

Again, the best starting point for designing and selecting HCBS waiver coverage is for the state to assess the needs of the service population and develop concrete ideas about how those needs can best be met.

Colorado Supported Living HCBS Waiver: *Personal Assistant Services* Definition

Personal assistant services provide necessary personnel and supports to meet the daily living needs of a person with a developmental disability [on a less than 24-hour basis]. These services and supports, including evaluation and assessment, are provided to ensure adequate functioning in the person's own home, someone else's home, in the home of their natural or adoptive family, or for accessing and/or participating in the community.

Personal assistant services may include assistance or training with a wide range of activities necessary to meet the daily living needs of the person in the home and community including

1. Personal care such as hygiene, bathing, eating, dressing, grooming, bowel and bladder care, menstrual care, transferring, basic first aid, giving medications, relief to a family who normally provides personal care, emergency response in the form of human assistance, and operating medical equipment.
2. Household maintenance such as meal preparation, shopping and chores, assistance with money management and personal finances, cleaning, laundry, and household repairs and maintenance related to the person's disability.
3. Mentorship activities such as planning; decision making; assistance with his/her participation on private and public boards, advisory groups, and commissions; person-specific training costs associated with providing unique supported living services to an individual, such as training in child and infant care for parent(s) who themselves have a developmental disability.
4. Supported living consultation such as assistance with decision making, planning daily activities, and direct assistance to access community resources and/or service providers.

A more substantive reason why state waiver services vary so widely is differences among states in the services already covered under the Medicaid State 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. Because the EPSDT mandate requires states to provide the full array of mandatory and optional State Plan services to children, whether or not they are actually covered under the State Plan, HCBS waiver programs for children furnish a more limited array of additional services.

Differences among target populations may also be important. As discussed earlier, several types of waiver services cut across disability categories (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 some 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, because of the nature of their disability.[29] (Indeed, the 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 services and supports

continue to evolve. Approaches that seemed appropriate in the past give way to new approaches, and states vary in how quickly they adopt these changes. One of the most useful features of the HCBS waiver is that it is sufficiently flexible to change over time. States have considerable latitude to modify and/or totally change their HCBS waiver coverages. Each year, states submit numerous amendments to their HCBS waiver programs, which add, delete, and/or modify the services and supports states offer. As a consequence, waiver programs that have been in operation for a relatively long period, usually have changed considerably since they were first approved. Coverages can be fine-tuned based on feedback from waiver participants and service providers concerning problems or gaps.

The "Application for a §1915(c) Home and Community Based Waiver [Version 3.5] Instructions, Technical Guide and Review Criteria" has attached to its instructions—in Appendix C—an excellent description of and guidance on the service options included in the HCBS waiver application format. (See the Resources section of this chapter for a link to the application and to a website where copies of each state's approved waiver applications are available.)

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, 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, and at least two states no longer offer "facility-based" day programming.

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/assistance services. These services can be defined in a way that ties their delivery to a person's living arrangement. But they can also be defined more flexibly, to permit their provision both in and outside the home (as Michigan's HCBS waiver program for people with developmental disabilities allows). Defined in this alternative fashion, these services can be furnished more flexibly and more in accordance with an individual's specific needs and preferences.

HCBS Waivers for Adults with Serious Mental Illness or Children with Severe Emotional Disturbance

Some states provide services for adults with serious mental illness and children with severe emotional disturbance using §1915(c) waivers. Colorado, Montana, and Wisconsin serve adults using nursing facility level-of-care waivers. Indiana, Kansas, Michigan, New York, Texas, Wisconsin, and Wyoming provide services to children and youth using the hospital level of care for an inpatient psychiatric facility for individuals under age 21, as provided in 42 CFR §440.160.

Supports Waivers

States are experiencing extremely high demand for home and community services for people with developmental disabilities. Many states, even those that have substantially expanded their HCBS waiver programs over the past decade, have very long waiting lists for services.[30] Many factors account for this high demand. One factor is the increasing longevity of this population, many of whom now live with parents who themselves are elderly and less able to meet the needs of their adult children.[31] A second and related factor is that many people with developmental disabilities outlive their parents.

As a consequence, many states are rethinking the role that waiver services might play in meeting the needs of people with developmental disabilities—particularly with respect to increasing waiver services and supports for individuals who live with their families or have other informal caregivers who provide support. While requests for services and supports often take the form of families seeking a group home placement, in-home and family support services can often meet individuals' needs so they do not have 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 services in group homes and other residential care settings.[33]

States rethinking is taking various forms. Some states have implemented distinct HCBS waiver programs intended mainly to provide services and supports to meet the needs of individuals who live with their families or on their own, with either informal caregiving available to them or the capacity to live without 24/7 supports. These programs do not offer services in group homes and other residential care settings that provide around-the-clock staffing, such as adult foster care.

These programs—called supports waivers—usually operate under stricter cost caps than the state's parallel HCBS waiver program, which covers service in residential care settings, because the individuals being served have informal caregivers or less intensive support needs. These caps enable the state to avoid imposing service-by-service restrictions on utilization in order to maintain program cost-effectiveness.

Supports waivers also permit the state to give individuals and families considerable flexibility in selecting the mix of services and supports that best meets their needs. However, unlike state-funded family support programs, waiver services and supports must be for the direct benefit of the waiver participant. Although the HCBS waiver does allow for services that support families to give care to a family member with a disability, such as respite and family training, services that are primarily for the benefit of the family can not be covered under a Medicaid HCBS waiver.

The flexibility afforded individuals and families also permits states to reflect many of the principles and values under which developmental disabilities individual support and family support programs have operated for many years: namely, that the individual or the family be in a position to ensure that the services and supports they receive are tailored to meet their needs and preferences.34

The availability of Medicaid funding allows states to offer more comprehensive services and supports to families than has typically been the case with respect to state-funded family support programs, many of which allot only $3,000 to $4,000 to a family each year. Average annual expenditures per participant for all HCBS ID/DD waivers for FY 2008 were

$43,464 per year.[34] In a study of 16 states' supports waivers in 2006, average annual participant expenditures ranged from $4,015 to $24,443.[35]

Operating distinct waiver programs that primarily target individuals who live with their families has both pros and cons. One of the main advantages is that when creating a new program state officials and other stakeholders are often more willing to consider new approaches to furnishing home and community services than when modifying an existing program. 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 those that can strengthen and support informal caregiving.

The main disadvantages appear to be (1) the administrative complications associated with operating multiple HCBS waiver programs for the same general target population, and (2) the CMS requirement that states safeguard participants' health and safety—even if their needs increase beyond what can be addressed within the waiver service cap.[36]

Supporting Individuals to Live in Their Own or Family Home

In-home supports provide an alternative living arrangement to provider-controlled residential programs. In-home supports are individually tailored services that assist individuals to live in their own home or in their family's home. In-home supports may comprise a variety of services such as residential habilitation, personal care, homemaker/chore services, skills training, family training, respite, and housing modifications. In the past, in-home supports for individuals living in their own home (a place they lease or own) were reserved for individuals deemed capable of "independent" living. The model offered intermittent supports to individuals who needed some assistance with activities of daily living or some limited skills training or supervision in order to live independently.

In the ID/DD field, this model has changed dramatically; even individuals who need around-the-clock supports can now live in their own home. The opportunity to own or lease a home (or apartment) is no longer reserved only for those individuals needing minimal supports. Now, individuals live with roommates and have either live-in or come-in support personnel to assist them. This type of arrangement is often referred to as "supported living." The intensity, type, and frequency of supports are based on the person's needs and can be a combination of support, supervision, and skills training based on the person's individual service plan.

For individuals living in their family's home, similar services can be brought in to assist the individual, and other supports, such as respite and caregiver training, can be made available to the family. These supports help families to keep individuals in the family home rather than seeking out-of-home placement in facilities that are provider owned or operated.

Medicaid Financing for Supports to Individuals Living in Their Own Home

Supports for individuals living in their own or family home can be financed through the HCBS State Plan benefit, the HCBS waiver, or both. These supports can be offered under the category of "residential habilitation." States may also offer an array of in-home supports. Common in-home supports include personal care, homemaker chore services, and respite and training for informal caregivers.[37]

Additionally, under the HCBS waiver, states have the option of offering "live-in caregiver" payments that cover services provided by an individual who resides in the home of a waiver participant, and also cover his/her room and board costs (see Box on next page).

Factors to Consider When Choosing Coverage Options: Two Illustrative Services

Every state covers personal care and case management in their Medicaid programs, either through the State Plan, an HCBS waiver, or both. This section will discuss the options for providing these two services, highlighting the advantages and drawbacks of each, which may vary by state depending on a state's configuration of its long-term care system, as well as its policy goals.

1. Personal Care/Personal Assistance

The three major Medicaid options for covering personal care (also called personal assistance) are the Medicaid State Plan Personal Care benefit, the Medicaid State Plan HCBS benefit, and an HCBS waiver. States may also provide personal care under the Community First Choice Option, authorized by the Affordable Care Act, effective October 2011.

Thirty-four states and the District of Columbia cover personal care under their Medicaid State Plans, but only a few states make it broadly available. For example, California, New York, and Texas operate relatively extensive State Plan Personal Care programs; elsewhere, provision of such services is more limited.[38] Many states that offer personal care have strict limitations on its delivery. Some either stringently regulate the amount of personal care services an individual can receive or cap the dollar value of such services at a level well below the annual cost of nursing facility services.[39]

Others limit eligibility for personal care services by identifying a population or level of functional limitation for which they will provide assistance. However, states must be careful not to violate Medicaid comparability requirements by restricting services to those with a particular diagnosis or condition, such as by making benefits available only to people who use wheelchairs. All states are required to provide all §1905(a) services, including personal care, to children under the expanded EPSDT mandate, whether or not the state covers the service under its State Plan.

HCBS Waiver Core Services Definition: Live-in Caregiver

Live-in Caregiver: An unrelated live-in personal caregiver who resides in the same household as the waiver participant. Payment for this service includes the additional costs of rent and food that can be reasonably attributed to the unrelated live-in personal caregiver. Payment will not be made when the participant lives in the caregiver's home or in a residence that is owned or leased by the provider of Medicaid services.

Under the HCBS waiver, states can elect to cover the costs of a live-in caregiver. These costs must be detailed in the cost-neutrality formula in the HCBS waiver application and must be described as a discrete service in the state's waiver application. The Connecticut Department of Developmental Services (DDS) offers "live-in caregiver" as a service under its HCBS waiver for individuals with developmental disabilities using the following definition: "DDS reimburses the waiver participant for the cost of the additional living space and increased utility costs required to afford the live-in caregiver a private bedroom. The reimbursement for the increased rental costs will be based on the DDS Rent Subsidy Guidelines and will follow the limits established in those guidelines for rental costs. The reimbursement for food costs will be based on the United States Department of Agriculture Moderate Food Plan Cost averages. Payment will not be made when the participant lives in the caregiver's home or in a residence that is owned or leased by the provider of Medicaid services."

The principal reason why many states do not cover personal care under the State Plan or, if they do, impose considerable restrictions on its provision, is concern about controlling expenditures for an entitlement benefit. State officials often want to know (1) How many Medicaid beneficiaries will qualify to receive the service? (2) How many service hours will they use once eligible? On the other hand, because HCBS waivers permit states to cap the number of beneficiaries and the cost of services, most states cover personal care or a similar service under an HCBS waiver (or a §1115 waiver in Arizona and Vermont.)

Personal Care and the Medicaid Home Health Benefit

Personal care is also provided by home health aides under the mandatory Medicaid Home Health benefit. However, this benefit is a very costly way to provide personal care because it is subject to the same rules regarding provider conditions for participation as the Medicare Home Health benefit. Under these rules, agencies must be Medicare certified and home health aides must be supervised by a licensed nurse. These requirements significantly increase the costs of a home health aide compared to that of a personal assistant from a non-Medicare certified agency and, of course, personal assistants hired by Medicaid beneficiaries who direct their services.

It is important to note that the Medicaid Home Health benefit *cannot* use the same eligibility criteria that Medicare uses, for example, requiring that individuals need skilled nursing care or be homebound. (See Chapter 3 for a more detailed discussion of the Medicaid Home Health benefit.)

Advocates for personal care point out that this service is usually less costly per person than institutional services and, consequently, that adding this coverage will result in lower institutional expenditures—by avoiding or delaying admission of individuals to institutions, as well as enabling institutionalized persons to return to the community. However, state officials are often concerned that such savings might be offset by the effect of more people overall seeking services once their availability becomes known (i.e., increased demand). The costs of meeting the needs of more people could offset the savings stemming from reduced nursing facility usage. Both are legitimate points and the challenge for state policymakers and disability advocates is to strike a balance between the need to control costs and the need to provide home and community services so that individuals can live in the least restrictive setting.

Expenditure concerns, as noted earlier, have prompted many states to turn to an HCBS waiver program to secure Medicaid financing of personal care assistance services, since the waiver program permits tighter cost and use limits. Table 4-2 summarizes the differences in personal care service coverage between State Plan and HCBS waiver programs.

Personal Care: Issues in Both State Plan and Waiver Programs

Regardless of the Medicaid authority used, states need to consider several issues related to the provision of personal care. Depending on how they are addressed, these issues can either impede or facilitate its provision.

Delegation of Nursing Tasks

Certain health-related personal care tasks (e.g., medication administration and tube feeding) fall under the jurisdiction of states' Nurse Practice Acts. 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, which can significantly increase the cost of serving individuals with medical or health-related needs in the community.

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 may still be provided by personal care workers under HCBS waivers or under the State Plan Personal Care option—as long as the services are provided in conformity with the state's Nurse Practice Act.

A 1999 Medicaid Manual transmittal specifically states that

> *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.*[40]

This policy and its applicability to optional State Plan personal care services and HCBS waiver programs were reaffirmed in a July 2000 letter from CMS to State Medicaid Directors.[41]

Several states, notably Oregon, have amended their Nurse Practice Acts to enable licensed nurses to delegate nursing tasks under specific conditions. Others have amended their Nurse Practice Acts to exempt certain individuals—such as participant-directed personal assistants—from the provisions of the Act, just as most Acts exempt unpaid family members who perform these tasks.

Provider Qualifications

States typically require individuals who would provide personal care services to have completed a basic training course. To ensure proper supervision of personal care workers, some states require that they be employed by agencies that hire the workers and supervise them. More and more states are routinely requiring individuals who would provide personal care services to undergo criminal background checks and checks against abuse/neglect registries.

With the increase in state options for participants to direct their services, however, many states now allow individuals to directly hire the persons they want to provide services and to train and supervise them. States need to determine what provider qualifications will be required and, in so doing, balance concerns about safety with participants' ability to choose who they will hire. (See Chapter 7 for a detailed discussion of various service delivery models for participant-directed services.)

Change in Medicaid Statute to Increase Participant Direction Service Delivery Options

Section 6087 of the DRA-2005 added §1915(j) to the Social Security Act, effective January 2007.[43] This authority permits states to prospectively disburse cash to participants who direct their personal care/personal assistance services using an individual budget. States may not offer participant-directed services under the §1915(j) authority except through an existing State Plan Personal Care program or an HCBS waiver program.

Absent the §1915(j) authority, participant direction of Medicaid State Plan personal care is limited to use of the employer authority. The §1915(j) authority also allows states to permit participants who direct their services under the State Plan Personal Care option to use their individual budgets to purchase non-traditional goods and services other than personal assistance, to the extent that expenditures would otherwise be made for human assistance. (States already have the authority under §1915(c) to allow HCBS waiver participants to purchase a broad range of goods and services.)

Employing Family Members

All of the Medicaid authorities allow participants to hire friends and relatives to provide personal care services. States also have the option under the HCBS waiver authority, and the §1915(j) and §1915(i) authorities, to allow participants to hire legally responsible relatives (i.e., spouses, and parents and

Table 4-2. Key Features of Medicaid Options for Covering Personal Care

Feature	State Plan Personal Care	HCBS Waiver	State Plan HCBS
Entitlement	States can not target services by age or diagnosis. States must provide services to all categorically eligible individuals who meet the eligibility criteria. Services must be provided statewide.	States can target services by age and diagnosis. States can limit the number of people served. States can limit the geographic area in which a waiver program is available.	States can target services by age and diagnosis. States must provide services to all individuals in an eligibility group who meet the eligibility criteria. Services must be provided statewide.
Financial Criteria	Beneficiaries must meet community financial eligibility standards.	States may set financial eligibility criteria up to 300 percent ($2,022 per month) of the Federal SSI benefit ($674 per month in 2010).	States may set financial eligibility criteria at 150 percent of the FPL ($1,354 per month in 2009) or at 300 percent of the Federal SSI benefit ($2,022 per month)[42]
Eligibility Criteria	Beneficiaries must have functional limitations—specified by the state—that result in a need for the services covered.	Beneficiaries must meet the minimum institutional level-of-care criteria and have a medical/functional need for the specific service.	Beneficiaries eligible under 150 percent of the FPL must meet functional eligibility criteria that is less stringent than institutional level-of-care criteria. Beneficiaries eligible under the 300 percent of SSI income eligibility standard must meet institutional level-of-care criteria.
Services	Services include only those specified in the Federal definition of personal care services.	Coverage can include a very broad array of state-defined services, only some of which are specified in statute.	Coverage can include a very broad array of state-defined services, only some of which are specified in statute.
Payment of Relatives	Relatives other than legally responsible relatives may be paid to provide personal care, at the state's option.	Relatives, including those legally responsible, may be paid to provide personal care and other services under specific circumstances determined by the state.	Relatives, including those legally responsible, may be paid to provide personal care and other services under specific circumstances determined by the state.

legal guardians of minor children).[44] Generally, to be a paid personal care provider, a legally responsible relative has to be providing services that a parent or spouse would not be providing for a non-disabled spouse or minor child; for example, feeding a 15-year-old child or bathing a spouse. However, Medicaid still prohibits the hiring of legally responsible relatives under the State Plan Personal Care option.

Within the broad parameters of Federal policy, it is up to states to define the particular circumstances under which relatives will be paid to furnish services to participants. States can take various factors into account, including the availability of other sources for the same services, costs of using family members to provide services versus costs of purchasing such services from conventional sources, and specific circumstances with respect to participants.

2. Case Management

Medicaid gives states three ways to cover case management services: (1) targeted case management, (2) HCBS waiver programs, and (3) administrative claiming.[45] This section discusses the advantages and drawbacks of each option in obtaining Federal financial participation.[46] Some states cover case management services under their HCBS waiver programs and use the targeted case management option for Medicaid beneficiaries not receiving waiver services. For example, some states cover case management services in HCBS waiver programs for adults and children with developmental disabilities, and make targeted case management services available to individuals who have been wait-listed for the waiver services. Targeted case management services can also be made available to people who qualify for a state's HCBS waiver program (in lieu of providing such services under the waiver program), as well as for individuals who do not participate in the waiver program.

Targeted Case Management

Advantages to States of Offering Targeted Case Management Services

- The state is free to define the population that will be targeted.
- The service may be offered to all Medicaid-eligible persons who need home and community services. Consequently, they may be made available without regard to type of service or funding source. This feature makes targeted case management a potentially very useful coverage option in establishing a broad-based coordinated service system.
- The costs of targeted case management services are claimed at the Federal Medical Assistance Percentage, which in many states is significantly higher than the 50 percent matching rate that applies to administrative claiming (see below).47
- 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 unless they are covered under targeted case management, administrative claiming, or under the HCBS waiver if they are begun before waiver participation but completed on the first day the person is enrolled in the waiver program. However, targeted case management services may be furnished irrespective of whether the person is enrolled in an HCBS waiver program, 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 residents of institutions. This limitation arose 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.

- FFP is now available for targeted case management services to assist and arrange for residents' transition to the community for up to 180 days preceding discharge. This policy enables a state to involve case managers 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.48
- If the institutional resident does not transition, FFP can be secured by charging the targeted case management service as an administrative expense. In this case, the activity must be claimed as administrative case management, which is reimbursed at the 50 percent matching rate. (See Chapter 6 for a detailed discussion of Medicaid coverage of transition services, and the Resources section of this chapter for a link to a CMS State Medicaid Director Letter regarding the earliest date of service for which FFP can be claimed.)
- When the targeted groups are those with serious mental illness or developmental disabilities, targeted case management enables a state to strictly limit who may be contracted to provide case management services. This is beneficial when service providers are to be limited to the case management authorities already established in state law, or where counties or other local entities such as Community Centers are responsible for the provision of case management services. It 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 to these populations under an HCBS waiver program, Medicaid freedom of choice of provider rules apply and a state must allow 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.49
- 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). Costs used in the development of the reimbursement rates must take into consideration staff time spent in general administrative activities such as intake, as well as training and travel.
- Service coordinators often support individuals in ways that fall outside the scope of targeted case management activities for which FFP may be claimed. But, 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).50 Having to assign some of the activities case managers routinely conduct on behalf of individuals to other categories creates administrative and billing complexity.

HCBS Waiver Coverage

FFP is available for the costs of case management 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 a waiver service.

Advantages to States of Covering Case Management as a Waiver Service

- Covering case management as a 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 a 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 as an HCBS Waiver Coverage

- The service is limited to individuals enrolled in the HCBS waiver program.
- Under an HCBS waiver, a state may not limit case management service providers to established case management authorities for anyone—including those with serious mental illness and developmental disabilities—as it can under the targeted case management option.
- Claims for FFP may only begin 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 if (a) they are begun before waiver participation, but completed on the first day the person enrolls in the waiver; or (b) 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 to assist recipients to access non-Medicaid services—even though such services might benefit them. 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.

- Because administrative claiming does not have a rule requiring states to contract with "any qualified provider," (as they must with State Plan services) the state can limit which entities can make an administrative claim for case management. This 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. For example, some states use administrative claiming 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).

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

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 to support "inreach" 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—over and above that provided by discharge planners—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 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 a state's Medicaid program. Thus, the costs of activities that assist individuals to access services not available in a state's Medicaid program, such as housing, food, education, and employment, will have to come from state/local dollars. Alternatively, states can use the targeted case management option to cover the activities that relate to the consumer's needs but do not involve Medicaid services.

- 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 Authorities

Federal policy allows 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 waiver services, to help them connect 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.

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key resources relevant to service coverage. Most of the publications cite additional resources and the websites also have links to other sources of information.

Publications

Centers for Medicare & Medicaid Services. (2008). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria*.
This publication contains extensive information concerning Federal policies that apply to the operation of an HCBS waiver, in particular, Appendix C: Participant Services, which includes core service definitions.

Available at https://www.hcbswaivers.net/CMS/faces/portal.jsp under links and downloads, entitled ***§1915(c) Waiver Application and Accompanying Materials.***

Smith, G., Fortune, J., Agosta, J., and O'Keeffe, J. (2007). *Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities: Profiles of State Supports Waivers*. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.

This project was funded to (a) gather descriptive information on HCBS waivers, both comprehensive and supports, operated for people with intellectual and developmental disabilities in 17 states with the supports waivers; (b) determine how supports waivers have emerged as separate and distinct HCBS waivers; (c) better understand the range of participant characteristics and experiences that distinguish supports waivers from other HCBS waivers; and (d) more fully appreciate how states view supports waivers as a way to address demand for home and community services among people with developmental disabilities.

Available at http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.htm

Smith, G., Kennedy, C., Knipper, S., O'Brien, J., and O'Keeffe, J. (2005). *Using Medicaid to Support Working Age Adults with Serious Mental Illnesses in the Community: A Handbook*. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.

This Handbook focuses on working-age adults between the ages of 21 and 64 with serious mental illnesses, whose need for support extends beyond mental health services that can be effectively provided by primary care physicians or periodic visits to outpatient settings. It is designed to improve understanding and provide greater clarity concerning Medicaid's contribution in supporting working-age adults with serious mental ill-

nesses in the community.

Available at http://aspe.hhs.gov/daltcp/reports/handbook.htm

Summer, L.L., and Ihara, E.S. (2005). *The Medicaid Personal Care Services Benefit: Practices in States that Offer the Optional State Plan Benefit*. Washington, DC: AARP, Public Policy Institute.

This paper reports on the eligibility requirements, characteristics of beneficiaries, program expenditures, types of services, and methods of service delivery in 26 states (and the District of Columbia) that offered the optional Medicaid Personal Care Services benefit in 2004. The site includes both the full version and a brief summary.

Available at http://www.aarp.org/health/medicare-insurance/info-2005/2005_11_medicaid.html

---

CMS: State Medicaid Director Letter (July 25, 2000). *Olmstead Update No: 3*.

This letter discusses a policy change regarding the earliest date of service for which Federal financial participation can be claimed, and explains some of the ways that Medicaid funding may be used to help people of all ages with disabilities and chronic illnesses transition from an institution to a community residence.

Available at http://www.cms.gov/smdl/downloads/smd072500b.pdf

Websites

CMS: Medicaid State Waiver Programs and Demonstration Projects

The Social Security Act authorizes multiple waiver and demonstration authorities to allow states flexibility in operating Medicaid programs. Each authority has a distinct purpose, and distinct requirements. This site provides information about these authorities and includes information about state-specific Medicaid waiver and demonstration programs. Users can access fact sheets, copies of proposals, approval letters, and other documents related to specific programs.

Web address: http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/01_Overview.asp

The following site contains approved waiver applications for each state. Clicking on a specific state on the map will lead to a site with a list of all of the state's approved waiver applications with links to view them.

Web address: http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/%2008_WavMap.asp

CMS: The State Medicaid Manual

The State Medicaid Manual makes available to all state Medicaid agencies informational and procedural material to administer the Medicaid program. The material is organized into major parts, which are divided into chapters and sections. (Chapter 4 is about Services.) The manual is structured as closely as possible to the codification of Medicaid regulations. A crosswalk of manual sections and regulations is also included.

Web address: http://www.cms.gov/Manuals/PBM/itemdetail.asp?filterType=none&filterByDID=-99&sortByDID=1&sortOrder=ascending&itemID=CMS021927&intNumPerPage=10

Endnotes: Citations, Additional Information, and Web Addresses

1 Gary Smith and Janet O'Keeffe co-authored the original chapter. Janet O'Keeffe, Ernest McKenney, and Robin Cooper updated the chapter.

2 States may also use §1115 Research and Demonstration waivers to provide long-term care services, as do Arizona and Vermont.

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

4 Section 1915(c) of the Social Security Act. The relevant Federal statute authorizes the Secretary of Health and Human Services to grant these waivers. Medicaid also provides other options for targeting services to specific groups, including the targeted case management benefit and various managed care authorities, and most recently, the §1915(i) authority.

5 State Medicaid Director Letter, August 6, 2010. Available at http://www.cms.gov/SMDL/SMD/itemdetail.asp?filterType=none&filterByDID=0&sortByDID=1&sortOrder=descending&itemID=CMS1238355&intNumPerPage=10.

6 For example, it is increasingly common 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, such as rehabilitation therapies, vision services, and prescription drugs.

7 Exceptions include targeted case management services, among others.

8 Connecticut Home Care Program for Elders. Information available at http://www.ct.gov/dss/cwp/view.asp?a=2353&q=305170 and http://www.ct.gov/dss/lib/dss/documents/fee-for-servicechcp_xls.xls.

9 These services are listed in §1905(a) of the Social Security Act.

10 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 CMS, which reviews the coverage and approves it if it conforms to Federal law and regulations.

11 Section 1905(a)(24) authority.

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

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

14 CMS guidelines concerning targeted case management services are in Sections 4302 et seq. of the State Medicaid Manual. See the Resources section of this chapter for a web link to the manual.

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

[16] 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.

[17] Defined in 42 CFR 440.90 with additional CMS guidelines in §4320 of the State Medicaid Manual.

[18] Defined in 42 CFR 440.130(d).

[19] 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.

[20] Much of the information provided here on the Rehabilitation benefit 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 re-published as two new reports. The reports are available for purchase at the
Bazelon Center's website at http://www.bazelon.org/News-Publications/Publications/CategoryID/20/List/1/Level/a/ProductID/51.aspx?SortField=ProductNumber%2cProductNumber and at: http://www.bazelon.org/News-Publications/Publications/List/1/CategoryID/20/Level/a/ProductID/32.aspx?SortField=ProductNumber%2cProductNumber.

[21] No data are available to determine how many states offer targeted case management to a specific group.

[22] Information about the §1915(i) authority is from the State Medicaid Director Letter, August 6, 2010. http://www.cms.gov/SMDL/SMD/itemdetail.asp?filterType=none&filterByDID=0&sortByDID=1&sortOrder=descending&itemID=CMS1238355&intNumPerPage=10.

[23] P.L. 109–171, Section 6086(a).

[24] Eligibility for a §1915(c) waiver requires that an individual meets the state's institutional level-of-care criteria.

[25] Statutory authority for HCBS waiver programs is contained in §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. CMS guidelines concerning HCBS waiver programs are contained in Sections 4440 et seq. of the State Medicaid Manual. These guidelines are updated periodically.

[26] Eiken, S., and Burwell, B. (2009). Medicaid HCBS Waiver Expenditures: FY 2003 through FY 2008. Cambridge, MA: Thomson Reuters. Available at http://www.hcbs.org/moreInfo.php/doc/2795.

[27] With respect to services a state proposes to cover that depart from those that appear in the waiver application, the definition of each waiver service must describe goods and services in concrete terms, along with any conditions that apply to the provision of the service. The definition of a service cannot use terms such as "including but not limited to . . .," "for example . . .," "including . . .," or "etc." CMS will not approve vague, open-ended, or overly broad service definitions. The service must be defined in a manner to make it clear exactly what will be furnished to the beneficiary.

[28] Although Medicaid cannot pay for food, services such as home-delivered meals and the provision of a meal and snack in adult day health settings are reimbursable because they do not constitute a complete daily diet. (Core service definition. Attachment to the Instructions to Appendix C for the HCBS Waiver Application, Version 3.5. See the Resources section of this chapter for a web link to the applica-

tion and instructions.)

[29] 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 CMS 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 an intellectual disability 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.

[30] 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.

[31] Among individuals with developmental disabilities who live with their families, about 25 percent live with parents who themselves are older than 60.

[32] Smith, G. (1999). Serving and waiting: An update. In 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.

[33] This type of HCBS waiver program is sometimes called 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.

[34] The average is based on the average daily HCBS waiver census. Lakin, K.C., Larson, S., Salmi, P., and Scott, N. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2008. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living. Available at http://rtc.umn.edu/risp08. Print copies may be requested by contacting Naomi Scott at scot0387@umn.edu or 612-624-8246.

[35] Smith, G., Agosta, J., Fortune, J., and O'Keeffe, J. (April 2007). Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities: Final Project Report. Washington, DC: U.S.
Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. Available at http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.htm.

[36] While states must safeguard health and safety under all waivers, it becomes more difficult in a waiver that has a cap that is well below what comprehensive waivers permit. Caps in supports waivers tend to be in the $15-25,000 range and the state must be able to ensure health and safety whatever the cost. If a waiver participant's needs increase but there is no opportunity to move to another waiver and the person does not want to go to an ICF/ID, the state must supplement the services solely with state dollars if the person is to stay enrolled on the supports waiver. The lower cap poses issues, particularly when individuals need only a modest increase above the cap, because for cost containment reasons the state does not want to enroll them in the comprehensive waiver, which opens up the service menu and can lead to much greater increased costs (e.g., residential services instead of in-home supports).

[37] The §1915(j) authority may also be used to provide supports to people in their own home.

[38] Among the states that offered personal care services in 2008, 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 $151.02. Burwell, B., Sredl, K., and Eiken, S. (2009). Medicaid Long-Term Care Expenditures in FY 2008. Cambridge, MA: Thomson Reuters. Available at http://www.hcbs.org/moreInfo.php/doc/2793. (A few of the states included in the 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.)

[39] 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.

[40] Health Care Financing Administration Medicaid Manual Transmittal Part 4, No. 73, September 17, 1999.

[41] State Medicaid Director Letter: Olmstead Update Number 3. July 25, 2000. Available at http://www.cms.hhs.gov/smdl/downloads/smd072500b.pdf.

[42] For the first time since the Federal Poverty Level (FPL) guidelines began to be issued in 1965, the annual average Consumer Price Index has decreased from the figure for the previous year. Therefore, the Department of Health and Human Services poverty guidelines have been frozen until at least May 31, 2010 at 2009 levels in order to prevent a reduction in eligibility for certain means-tested programs, including Medicaid, Supplemental Nutrition Assistance Program, and child nutrition. Additional information is available at http://aspe.hhs.gov/poverty/09extension.shtml.

[43] The text of §1915(j) is located at http://www.paelderlaw.com/pdf/DRA_Provisions.pdf.

[44] They may also do so under a §1115 waiver.

[45] 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.

[46] The amount of FFP for services is called the Federal Medical Assistance Percentage, which cannot exceed 83 percent or go below 50 percent. The FFP for administrative claiming is 50 percent.

[47] The cost of HCBS waiver case management services can also be claimed at the service rate.

[48] 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.

[49] Solutions exist for this problem, but they can involve their own complications.

[50] To the extent that driving a beneficiary to a doctor's appointment is necessary, it could be paid for as a Medicaid State Plan service rather than as a targeted case management service. The person's case manager may certainly transport the individual to a physician's appointment. Although the costs involved cannot be claimed as case management (because the service is direct), they may be reimbursed as a transportation service under the Medicaid State Plan, or as an administrative expense.

Guide to Chapter 5

Introduction 125
Definitions and Terminology 126
Major Types of Residential Care Settings in Which Medicaid Services May be Provided . . . 127
Adult Foster Care 127
Child Foster Care 128
Residential Care Facilities 131
Older Adults and Younger Adults with Physical Disabilities 131
Adults with Developmental Disabilities 132
Medicaid Financing for Services in Residential Care Settings 132
Which Authority to Use 134
Considerations When Using the HCBS Waiver Authority 134
Level-of-Care Criteria and State Regulation of Residential Care Facilities 137
Target Population 137
Licensing and Contracting Issues 137
Enabling Medicaid Beneficiaries to Pay for Room and Board 138
Limiting the Amount Facilities Can Charge for Room and Board 138
Providing State Supplements to the SSI Payment 139
Using the 300 Percent of SSI Standard and Providing an Adequate Personal Maintenance Allowance 139
Income Supplementation by Family Members or Trusts 140
Effect of Medically Needy Rules on the Ability to Pay for Room and Board 142
Service Payment Rates: Adequacy Concerns 143
Bundling Payments 143
Resources 144
Endnotes: Citations, Additional Information, and Web Addresses 147

Chapter 5
Providing Medicaid Services in Community Residential Settings

This chapter provides guidance to states about selecting coverage options for services in a wide range of residential care settings that are provider owned and/or operated, encompassing foster care, group homes, and residential care facilities, including those called assisted living. When a state is faced with different ways of covering services, the tasks of choosing among the coverage alternatives and defining the precise services to be provided in specific settings require a detailed analysis of each alternative in the context of a state's broader service system.1

Introduction

To reduce institutionalization—particularly for individuals who lack housing or cannot be served cost effectively in their own or a family member's home—states offer services in residential care settings. This chapter deals with the provision of Medicaid services only in provider-owned and/or -operated residential care settings that are not institutions.

Using Medicaid to pay for services in residential care settings is of interest to states that want to decrease expenditures on institutional care. Compared to Medicaid-covered institutions—nursing homes, intermediate care facilities for persons with intellectual disabilities (ICFs/ID), hospitals, and some inpatient psychiatric facilities[2]—residential care settings have the potential to be more homelike and to provide residents greater autonomy and privacy. Compared to services delivered in individuals' homes, they may also offer economies of scale as well as the opportunity for socialization.

For many individuals with disabilities and chronic illnesses—such as individuals with dementia who need considerable supervision but little nursing care—residential care settings can provide an alternative to institutionalization. The populations a state chooses to serve in these settings, much like the mix of facilities, depends on the state's overall long-term care system and specific policy goals.

Residential care settings can be owned and/or operated by either individual service providers or agencies offering around-the-clock services. The level of staff support typically relates to the needs of residents as well as applicable state regulations. Staff are employed on either a live-in or come-in basis.[3] They provide assistance with activities of daily living (ADLs), and help individuals to gain access to community activities. Depending on state regulations, individuals may share rooms or may have private rooms and share common public areas (dining and living rooms, and sometimes kitchens).

The size of residential care settings varies widely. In the system serving individuals with an intellectual disability or other developmental disability (ID/DD, hereafter referred to as developmental disabilities), some residential care settings may have more beds than a community ICF/ID.[4] Although Medicaid regulations that apply to the provision of services in residential care settings do not specify an upper size limit for these settings, the Centers for Medicare & Medicaid Services (CMS) defines "larger" facilities as settings serving four or more unrelated individuals.[5] CMS reviews proposed waiver services in residential care settings to ensure that

> *A home-like character is maintained in larger settings, that is, the facility is community-based, provides an environment that is like a home, provides full access to typical facilities in a home such as a kitchen with cooking facilities, small dining areas, provides for privacy, visitors at times convenient to the individual, and easy access to resources and activities in the community.*[6]

Residential care settings and the services they provide are governed by state law and regulations, which vary greatly across states. They can be licensed or certified, or in some instances have only to meet Medicaid requirements if serving Medicaid-eligible persons. States typically license these settings, performing annual reviews to ensure that they meet required standards. Some states choose to use national accreditation bodies to qualify providers, in lieu of or in addition to state standards. While some states license particular settings to serve specific populations (e.g., older adults or individuals with developmental disabilities), some states, such as Minnesota, license facilities to serve many different populations. See Box for Minnesota's definition of a Group Home.

Settings licensed to serve more than one population may choose to serve only one in order to tailor services to meet their needs—and most do. Additionally, if serving participants in Section (§)1915(c) Medicaid home and community-based services (HCBS) waivers (hereafter referred to as HCBS waivers), these settings will also have to meet the standards approved under the waiver for serving this population and be able to serve residents who meet institutional level-of-care criteria. Settings serving specific populations, such as individuals with dementia and those with developmental disabilities, may have specific licensing requirements to ensure that they have the specialized competencies needed to serve these populations.

Minnesota's Definition of Group Homes: Group Residences for Adults with Disabilities

Group Residences for Adults with Disabilities are defined as "Agency-owned or -operated facilities that provide an alternative living environment for adults with developmental disabilities, sensory impairments, physical disabilities, emotional problems, multiple disabilities, or chronic illnesses such as AIDS, who are in need of personal services, supervision, and/or assistance essential for self-protection or for sustaining the ADLs, and consequently are unable to live with their own families or in a more independent setting. Group residences for adults with disabilities may be licensed by the State/province and may be distinguished according to the level of service residents require. Service levels depend on the self-care skills residents possess, their limitations in the areas of physical coordination and mobility, and the presence and extent of behavior problems, including disruptive or self-injurious behavior."[7]

There are no applicable Federal statutes regarding licensing or certification standards for residential care settings other than §1616(e) of the Social Security Act (the Keys Amendment), which requires states to set their own standards for residences where "a substantial number of Supplemental Security Income (SSI) recipients" reside.[8] If states wish to use Medicaid HCBS waivers to fund services in residential care settings, as discussed in more detail below, CMS requires as a condition of approval that they describe how they will ensure compliance with §1616(e).

Definitions and Terminology

The service systems for different populations use very different and sometimes contradictory terms to describe non-institutional provider-operated residential care settings. In the service system for older adults and younger adults with physical disabilities, the generic terms traditionally used for these settings are foster care and residential or congregate care. Consumer preference for the assisted living model of residential care—which provides both privacy and autonomy—has led providers to market

all types of residential care settings as assisted living—whether or not they provide private units or operate with a service philosophy that ensures resident autonomy. Thus, assisted living has become a generic term for many different types of residential care settings for older adults.[9]

Because states regulate residential care settings, the terms they use for them vary considerably. For example, states use 31 different names for adult foster care, including adult family home, family care rest home, adult residential care home, elder group home, and assisted living establishment, to name but a few.

In the service system for people of all ages with developmental disabilities, the generic term residential settings includes the entire range of living options: institutions (ICFs/ID), provider-owned and/or -operated facilities such as group homes, foster care, a family member's home, and a person's own home. The ID/DD system also uses the term community residential program, which may include both community (i.e., small) ICFs/ID as well as group homes. As with the aging services system, states have hundreds of different names for ID/DD residential programs, including residential habilitation facilities, group residences, or residential treatment facilities, among others.

The enormous variability in the terms states use for the same or similar residential care settings can create considerable confusion. Therefore, this Primer will use the terms defined in the Box below.

Major Types of Residential Care Settings in Which Medicaid Services May be Provided

Three major types of residential care settings that are provider owned and/or operated furnish long-term care services and supports to persons of all ages with disabilities and/or chronic illnesses: adult foster care, child foster care, and residential care facilities.

Definitions of Residential Care Settings

Residential care settings. A generic term encompassing all types of state-regulated (licensed or certified) foster care and residential care facilities, regardless of their size or the population they serve.

Foster care. A home owned or rented by an individual or family in which they live and in which they provide care and support for one or more *unrelated* persons. Depending on the state, these homes can serve up to 6 or 8 residents, but typically serve 1 to 3 residents. (In a few states, corporations own and/or operate settings licensed as foster homes and provide staffing 24 hours-a-day.) Foster care providers can serve adults or children.

Residential care facility. A building or residence—other than a foster care home—owned, rented, or managed by the service provider, or the provider's agent, to provide housing, services, and supervision. This term includes many types of facilities—from group homes serving as few as 2 or 3 individuals with developmental disabilities to board and care homes or assisted living facilities serving 100 or more older adults.

When referring to residential care settings in specific states, the Primer will use the terms these states use.

Adult Foster Care

Adult foster care is typically provided in a private home, offering 24-hour support to one or more individuals. Most commonly the support is provided by the owners of the home, although foster care providers may engage other individuals to provide care. In some states, corporate entities oversee and manage foster homes. States may contract with each primary caregiver for the provision of adult foster care services, and/or contract with agencies that, in turn, contract with and supervise individual caregivers. In addition to room and board, foster care providers typically furnish assistance with daily living activities and help in accessing community activities.

Definition of Adult Foster Care in HCBS Waiver Application

"Personal care and supportive services (e.g., homemaker, chore, attendant care, companion, 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. Separate payment is not made for homemaker or chore services furnished to a participant receiving adult foster care services, since these services are integral to and inherent in the provision of adult foster care services."[10]

States may use this definition, or modify or supplement it to reflect the scope of adult foster care to be furnished through a waiver program.

Adult foster care homes serve individuals with a wide range of disabilities, including those with physical and/or cognitive impairments, serious mental illness, and developmental disabilities. Arizona, Maine, Oregon, Washington, and Wisconsin, among other states, offer adult foster care as a means to keep older adults connected to their home communities when they can no longer live alone. Oregon has made efforts to recruit and train foster care providers for older adults specifically to increase the viability of this option as an alternative to nursing homes.[11]

Most foster homes serve a relatively small number of individuals. As an example, in 2007, of the 23,848 family foster homes serving individuals with developmental disabilities, only 652 served four or more individuals, with the maximum number nationally being six individuals.[12] In an HCBS waiver program, adult foster care is considered a residential habilitation service for individuals with developmental disabilities only when habilitation is included in the defined scope of the adult foster care service; it is not considered a residential habilitation service when habilitation services are furnished in the adult foster care setting by a different provider and billed separately.

Adult foster care settings usually are licensed or certified; 17 states regulate these settings for older adults under assisted living regulations.[13] States have flexibility in setting provider standards but most require specialized training to support specific populations, such as adults with developmental disabilities and older adults with dementia.

Child Foster Care

The provision of Medicaid services for children in foster care settings is permissible, typically through an HCBS waiver program. The waiver application does not include a definition for child foster care—it is subsumed under the waiver service called "residential habilitation" (see Box), as are group homes (discussed below).[14]

Definition of Residential Habilitation in HCBS Waiver Application

"Residential habilitation means individually tailored supports that assist with the acquisition, retention, or improvement in skills related to living in the community. These supports include adaptive skill development, assistance with ADLs, community inclusion, transportation, adult educational supports, social and leisure skill development, that assist the participant to reside in the most integrated setting appropriate to his/her needs. Residential habilitation also includes personal care and protective oversight and supervision."

The method by which the costs of room and board are excluded from payment for residential habilitation is specified in Appendix I-5 of the Waiver application.[15]

Children's foster homes are often the private homes of individuals licensed by the state to provide care to one child or a few children. These homes may serve children who are placed voluntarily or those under state protection. In either case, the home must meet the state's licensing criteria. When foster homes serve "special" populations such as children with developmental disabilities, some states require providers to have training above and beyond what is required for a general foster care license. Children with serious emotional disturbances (SED) may also

Moving from Adult Foster Care to Shared Living Arrangements

To better support individuals with developmental disabilities, new, more personalized approaches to adult foster care are being used, such as Shared Living. The purpose of Shared Living is to create a more equal arrangement than is found in traditional foster care—one based on mutual choice. In Shared Living, the individual with a disability and the provider choose to live together. Although the provider furnishes support and supervision, the expectation is that the relationship is more equal and more personal than is typically the case in foster care.

A Shared Living arrangement is usually in the Shared Living Provider's home or apartment, but could also be in the home or apartment of the individual with a disability, in which case it would be considered a home-based supports approach. Many different arrangements can be developed based on individuals' unique needs and situation.

A human services agency in Pennsylvania serving individuals with developmental disabilities offers a foster care approach called Lifesharing Thru Family Living. This approach provides an option for people with developmental disabilities to be active, participating members in a family and the community in which the family lives. This approach emphasizes the importance of matching individuals and families to enable harmony in values, interests, and mutual commitments. Family Living Specialists work closely with the family and the individual, and serve as the primary support to ensure a successful match. For more information, see http://www.skillsofcentralpa.org/public/services/lifesharing.php

be served in child foster care. Detailed information about services for children with SED is the subject of a separate publication listed in the Resources section of this chapter.

Payments under the HCBS waiver cannot supplant funding under Title IV-E of the Social Security Act (hereafter called the Act) that pays for the basic foster home care and services for children in state custody. Waiver services to children in foster care can only supplement the basic services that must be covered under Title IV-E. According to Title IV-E regulations, "Foster care maintenance payments are payments made on behalf of a child eligible for Title IV-E foster care to cover the cost of (and the cost of providing) food, clothing, shelter, daily supervision, school supplies, a child's personal incidentals, liability insurance with respect to a child, and reasonable travel for a child's visitation with family, or other caretakers."[16]

The HCBS waiver application instructions note that

> *Waiver services may be furnished to children in foster care living arrangements but only to the extent that waiver services supplement maintenance and supervision services furnished in such living arrangements and waiver services are necessary to meet identified needs of children. Waiver funds are not available to pay for maintenance (including room and board) and supervision of children who are under the state's custody, regardless of whether the child is eligible for funding under Title IV-E of the Act. The costs associated with maintenance and supervision of these children are considered a state obligation. The costs associated with the treatment of these children may be Medicaid reimbursable [under either the State Plan or an HCBS waiver]. Depending on the nature of the treatment (i.e., habilitation), the costs of treatment may be eligible for Federal financial participation under a waiver.*[17]

Utah and Wisconsin, among other states, cover foster care services under an HCBS waiver for children with "exceptional needs" (i.e., those requiring intensive assistance due to medical or behavioral support needs). See Box for Utah's pro-visions pertaining to coverage of residential services under an HCBS waiver for children in foster care.

Utah's HCBS Waiver Definition of Residential Services for Children in Foster Care

To ensure compliance with CMS payment requirements, Utah has established a prior authorization process and criteria to determine if children in foster care have exceptional needs that can be supported though the HCBS waiver program. In its approved HCBS Residential Services definition, Utah notes that, "For children in the custody of the Division of Child and Family Services (DCFS), the costs of basic and routine support and supervision are not covered as waiver services. Compensation for this routine support and supervision is covered by other funding sources associated with the DCFS. Children in DCFS custody are eligible to receive this service only after the provision of this service has been prior-authorized by the minor's support coordinator. Such prior-authorization will occur only after it has been determined that the minor has exceptional care needs that materially affect the intensity or skill level required of the service provider."

Utah defines a variety of medical and/or behavioral conditions that would qualify a child for this exceptional payment including, among other conditions, "… emotional or behavioral needs such as hyperactivity; chronic depression or withdrawal; bizarre or severely disturbed behavior; significant acting out behaviors; or, the minor otherwise demonstrates the need for 24-hour awake supervision or care in order to ensure the safety of the minor and those around him/her."

The exceptional care criteria also includes a variety of medical needs, such as ostomy care or catheterization; tube feeding or supervision during feeding to prevent complications such as choking, aspiration or excess intake; frequent care to prevent or remedy serious conditions such as pressure sores; suctioning; assistance in transferring and positioning throughout the day; two or more hours of therapy per day; assistance with multiple personal care needs including dressing, bathing and toileting; complex medical treatment throughout the day; or, the minor has a complex and unstable medical condition that requires constant and direct supervision.

Utah further specifies that, "This service is intended to accomplish a clearly defined set of outcomes associated with the child's habilitation that is outlined in their individual support plan. Services provided under this service definition are only those that are over and above the basic routine supports provided for through the DCFS."[18]

Residential Care Facilities

For individuals who live in residential care facilities—whatever their age or type of disability—in order to receive waiver services, the facility must be specifically included as a setting for service provision in the state's waiver program. As noted earlier, states must have licensure, certification, or some other standards for their operation, including required provider qualifications and methods to ensure facility oversight and monitoring. States must include a description of these standards and provider qualifications in the HCBS waiver application.[19] HCBS waiver requirements include "portability," that is, the service funding is an individual benefit for the beneficiary and is not tied to the facility; individuals can move from one type of setting to another as their needs change. States may also use the State Plan Personal Care optional benefit to provide personal care in these facilities, as does North Carolina. However, Medicaid personal care services cannot duplicate or replace services that are part of the residential care facilities' existing service package. They can only be used to supplement existing services.

Older Adults and Younger Adults with Physical Disabilities

For older adults, until the introduction of the private pay assisted living model in the late 1980s, the most frequently used general term for residential care settings other than foster care was board and care. The new assisted living model differs significantly from traditional board and care. According to three of the major assisted living industry trade associations, privacy and flexible services that will meet residents' needs and allow them to age in place are key elements of the assisted living philosophy.[20] The new assisted living model of residential care became popular with older adults because it offered what nursing homes and traditional board and care facilities generally do not: privacy and control over one's daily activities. Another reason for its popularity is that assisted living facilities—many built in the 1990s—have much more desirable physical environments than do most board and care facilities and nursing homes, many of which were built in the 1960s and 1970s.[21]

Due to the popularity of the private pay model of assisted living, many operators of board and care homes and other types of residential care settings believe they will be put at a competitive disadvantage if they cannot market themselves as "assisted living." Consequently, under pressure from the residential care industry, most states have amended their statutes to rename domiciliary care homes, board and care homes, and even adult foster care, as assisted living.[22] Today, virtually all residential care settings for older adults market themselves as assisted living despite the fact that some provide few services and the physical character of a substantial portion of these settings is quite institutional, with two to four persons sharing a bedroom, and as many as 8 to 10 residents sharing a bathroom.[23]

This general use of the term assisted living is also found in the HCBS waiver application, which uses the term assisted living services to cover a wide range of services that can be provided in residential care settings. However, in its guidance, CMS encourages states to use a "more accurate name," noting that the term assisted living describes a setting, not a service and that Medicaid never pays for assisted living in the ordinary sense of a monthly fee to the facility for room, board, and services. Rather, Medicaid may cover, as a waiver service, some of the supportive services provided to beneficiaries in residential care settings.[24]

Core Definition of Assisted Living Services in the HCBS Waiver Application

Personal care and supportive services (homemaker, chore, attendant services, meal preparation) that are furnished to waiver participants who reside in a homelike, non-institutional setting that includes 24-hour on-site response capability to meet scheduled or unpredictable resident needs and to provide supervision, safety, and security. Services also include social and recreational programming, and medication assistance (to the extent permitted under state law). Nursing and skilled therapy services are incidental rather than integral to the provision of assisted living services. Payment is not made for 24-hour skilled care.

CMS guidance notes that when a waiver includes "assisted living services," the locations of service delivery must meet criteria described in Appendix C-2 of the HCBS waiver application with regard to the "home-like" character and community integration of the facility.[25] On June 22, 2009, CMS issued an advance notice of proposed rulemaking in the Federal Register to solicit comments about defining standards for what constitutes "home-like" and "community" under HCBS waivers.

Adults with Developmental Disabilities

The most common type of residential care facility serving adults with developmental disabilities is the group home. Group homes are generally operated by agencies that both own the settings and provide the support staff assisting the residents.

Based on the state's policy goals and the interests and preferences of stakeholders, group homes may also be made available to other populations, such as children with developmental disabilities or serious emotional disturbances. As with adult and child foster care, waiver services provided in group homes and other residential care facilities for persons with developmental disabilities are subsumed under the waiver service category of residential habilitation. CMS provides a general definition of residential habilitation but states have the flexibility to adopt this suggested definition or create a completely different definition crafted to suit the state's services system and array of settings.[26]

States may establish highly specialized group homes to serve specific populations, such as individuals with autism spectrum disorders, intensive medical support needs, or challenging behaviors. These specialized settings may have additional requirements, such as specialized training, and may receive additional reimbursements due to the nature of the services provided.

Medicaid Financing for Services in Residential Care Settings[27]

Medicaid provides several authorities for financing services in residential care settings: HCBS waivers,[28] Section 1115 research and demonstration waivers (hereafter referred to as §1115 waivers), and the Medicaid State Plan. State Plan services include personal care (through the Personal Care optional benefit), rehabilitation services, and services offered under the §1915(i) HCBS benefit, including personal care and habilitation services. Each of these Medicaid authorities has specific eligibility, application, and approval requirements. (See Chapters 1 and 4 for more information about all of these authorities.)

However, Medicaid will pay for services furnished in residential care settings only if a "homelike environment" is preserved. Thus, Medicaid will not pay for services in residential care settings if they are located in the wing of a nursing home or an ICF/ID. As discussed earlier, CMS has provided guidance as to what constitutes a home-like character, particularly in regard to what CMS defines as "larger" facilities—those serving four or more unrelated individuals.

States may provide HCBS waiver services only in residential care settings that are permitted under state regulations to serve individuals who meet institutional level-of-care criteria. Some states, such as Oregon, license both adult foster care providers and residential care facilities to serve persons who meet the state's nursing home level-of-care criteria. Others, such as North Carolina, use the State Plan Personal Care option to provide personal care services to individuals in residential care settings, because these facilities are not permitted to serve individuals who meet the nursing home level-of-care criteria. Some states use both the HCBS waiver and State Plan Personal Care option to provide services in different types of settings.

Table 5-1. Medicaid Authorities States Use to Provide Services in Residential Care
Settings for Older Adults and Younger Adults with Physical Disabilities

Waiver Only[1]		State Plan	State Plan and Waiver
Alaska	Montana	Maine	Arkansas *(AL)*
Arizona *(§1115)*	Nebraska	Massachusetts	Florida *(AL and BW)*
California *(AL)*	Nevada *(AL)*	Michigan	Idaho
Colorado	New Hampshire	New York	Missouri *(AL)*[2]
Connecticut *(AL)*	New Jersey	North Carolina	South Dakota
Delaware *(AL)*	New Mexico	South Carolina	Vermont *(§1115)*
District of Columbia	North Dakota		Washington
Georgia	Ohio *(AL)*		
Hawaii *(§1115)*	Oklahoma		
Illinois *(AL)*	Oregon		
Indiana	Rhode Island *(AL and §1115)*		
Iowa	Tennessee		
Kansas	Texas		
Maryland	Utah		
Mississippi *(AL)*	Virginia *(AL)*		
Minnesota	Wisconsin		
	Wyoming *(AL)*		

AL: Waiver services are provided only in residential care settings (13 states). §1115: Services covered under a §1115 waiver (4 states).

1 Unless indicated as an §1115 or AL waiver, the states provide coverage under a broad HCBS waiver (BW) that covers services in participants' homes and in residential care settings (24 states and the District of Columbia).

2 Missouri's waiver was approved by CMS but had not been implemented by the end of 2009.

In 1981, Oregon was the only state to use the HCBS waiver authority to fund services in residential care settings for older adults. Few states followed suit until the 1990s, when the growth in private pay assisted living focused attention on residential care alternatives to nursing homes. In 2009, 46 of the 50 states and the District of Columbia used either a waiver or State Plan optional services (or both) to provide services in residential care settings for older persons and/or younger persons with physical disabilities.[29] Table 5-1 lists the states that use each authority for these populations. The HCBS waiver is the most frequently used authority and the largest source of financing for Medicaid services in residen-

tial care settings, but more individuals in residential care settings receive personal care services through the State Plan than through an HCBS waiver.

Only four states use a §1115 waiver to cover services in residential care settings for older adults and younger adults with disabilities, and no states currently use the new §1915(i) HCBS authority for this purpose, although it is possible to do so as several of the services under this authority (e.g., personal care and habilitation) can be provided in such settings.

From the inception of the waiver program in 1981, states have used HCBS waivers to pay for services for individuals with developmental disabilities in group homes and foster homes as an alternative to ICFs/ID. As a result, every state now uses the HCBS waiver (or a §1115 waiver as in Arizona and Vermont) to provide services and supports in residential care settings for individuals with developmental disabilities. No states use the State Plan Personal Care option to cover personal care in residential care settings for this population because this benefit is very limited compared to residential habilitation services provided under HCBS waivers.

Because all states use HCBS waivers—and none use the State Plan Personal Care option—to cover services and supports in residential care settings for persons with developmental disabilities, the following discussion regarding which Medicaid authority to use focuses primarily on considerations when serving older adults and younger adults with physical disabilities. However, the discussion regarding considerations when using HCBS waivers is also relevant for the ID/DD population.

Which Authority to Use

The most common choice states face with regard to covering services in residential care settings is whether to use an HCBS waiver program, the State Plan Personal Care option, or both. The primary factor that will determine whether a state can use an HCBS waiver is whether a state's residential care settings are permitted to serve a population that meets institutional level-of-care criteria—nursing home or ICF/ID. States that have several different types of facilities serving different populations—those who meet institutional level-of-care criteria and those who do not—may choose to use the waiver authority to finance services in one type of residential care setting and the State Plan Personal Care option in another.

For facilities serving individuals who meet nursing home level-of-care criteria, the HCBS waiver authority is advantageous in that states can broaden eligibility by using the 300 percent of SSI income rule to reach persons in the community who do not meet Medicaid's community financial eligibility criteria. (The 300 percent rule is explained later in this chapter and in detail in Chapter 2.) The HCBS waiver also offers states considerable flexibility in defining the scope and array of services to be provided as there are no statutory definitions for services. However, since waiver services are available only to beneficiaries who meet the state's nursing home or ICF/ID level-of-care criteria, serving people through a waiver will target a more severely impaired population than can be served through the State Plan Personal Care option.

Because states may set limits on the number of beneficiaries who can be served through waiver programs, waivers also offer the advantage of predictable costs, particularly for states concerned about utilization of a new benefit for older adults. The combination of institutional level-of-care eligibility criteria, a set number of slots, and expenditure caps that are part of the cost neutrality formula required for CMS approval will limit the number of people potentially eligible.

The Boxes below contain examples of how two states—North Carolina and Oregon—use different Medicaid authorities to provide services in residential care settings.[30]

Considerations When Using the HCBS Waiver Authority

The three factors that are important for states considering the HCBS waiver authority are discussed next.

Coverage of Assisted Living through the Personal Care Benefit: North Carolina

North Carolina covers personal care in adult care homes as a Medicaid State Plan service.[31]

Target Population. Adult care homes serve adults of all ages with all types of disabilities, including developmental disabilities and those caused by mental illness. *They are not licensed to serve individuals who need a nursing home level of care*. There are two types of adult care homes: those that serve all populations and those that serve only persons age 65 or older. Adult care homes are divided into different types based on size—family care homes for 2-6 residents and adult care homes for 7 or more residents.

Services. Adult care homes are required to provide three meals a day, transportation, activities, and housekeeping services. The Medical Care Commission may limit what medical and functional care needs can be met in adult care homes; for example, medication may be administered by designated, trained staff but nursing services can only be provided by the residence on a case-by-case exception basis approved by the State's Department of Health and Human Services, or through licensed home care agencies. Unless a physician determines otherwise, adult care homes may not serve people who are ventilator dependent or who require continuous licensed nursing care.

Payment. The payment includes a flat rate for basic personal care services with add-ons for residents with specific ADL impairments. Residents with extensive or total impairments in eating, toileting, or both eating and toileting qualify for a higher rate. In 2009, the basic payment was $17.50 a day for facilities with 30 or fewer beds and $19.17 for facilities with more than 30 beds. The additional daily rate for residents with extensive or total impairments in eating was $10.80 and in toileting was $3.86. Additional payment for residents needing assistance with ambulation/locomotion was $2.76 a day. Eligibility for the additional payment is based on an assessment by the adult care home, which is verified by a county case manager. (The State has a generous SSI state supplement, which is added to the SSI Federal benefit to cover room and board charges for residents of adult care homes: $579 in 2009.)

Coverage of Assisted Living through the Waiver Program: Oregon

Oregon uses an HCBS waiver to cover multiple services in residential care settings. Two settings are licensed: assisted living facilities and residential care facilities. 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 ALFs and Class II RCFs.

ALFs and Class II RCFs can serve the same population. When Oregon first 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 differed somewhat from its RCF rules. The State has since consolidated many requirements for RCFs and ALFs, but maintains separate requirements for living units. *The State does not allow providers to market themselves as assisted living unless they offer residents private apartments and are licensed as assisted living.*

Target Population. The waiver program serves adults age 18 or older. Individuals at risk of nursing home placement and assisted living residents who were formerly private pay but who have spent down and become eligible for Medicaid 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.[32]

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. ALFs must offer individual apartments with lockable doors, kitchen facilities, and private baths.

Services. Services provided by RCFs and ALFs include three meals a day and snacks, personal and other laundry services, a program of social and recreational activities, assistance with ADLs, medication administration, and household services (cleaning and bed making). Facilities must also provide or arrange for social and medical transportation and ancillary services for related medical care (physicians, pharmacy, therapy, podiatry).

Payment. The Medicaid rate pays for the services ALFs provide under the licensing requirements. There are five levels of ALF payments based on residents' acuity, which are based on a service priority score determined through an assessment. The monthly payment rate in 2009 for level 1 was $1,002 and for level 5 was $2,355.

Medicaid also pays for services for persons living in Level II RCFs who meet the nursing home level-of-care criteria. In 2009, the RCF base service rate for all clients was $1,249 per month. Depending on impairment level, there are three add-on payments. The base payment plus one add-on was $1,491; base plus two add-ons was $1,733; base plus three add-ons was $1,975. The add-on is based primarily on individuals' need for assistance with ADLs.

Level-of-Care Criteria and State Regulation of Residential Care Facilities

HCBS waiver regulations require that any facility in which waiver services are furnished must meet applicable state standards regarding provider qualifications and methods to ensure oversight and monitoring of the facilities. As noted above, states must include a description of these standards and provider qualifications in the HCBS waiver application.[33] When services are furnished by a residential care facility, it must meet the standards for service provision that are set forth in the approved waiver documents.

Thus, states planning to cover services in residential care facilities through an HCBS waiver program need to be sure that the admission and retention provisions of state licensing or certification requirements permit facilities to serve individuals who meet Medicaid's nursing home or ICF/ID level-of-care criteria. Licensing must also address a facility's qualifications to provide the services needed by Medicaid beneficiaries.

States that use a waiver program to provide services in residential care settings need to contract with facilities that are willing and able to provide the services needed by individuals who meet the state's Medicaid nursing facility level-of-care criteria, which—if stringent—may be extensive.

Target Population

When determining which population to serve in residential care settings, states need to consider their policy goals and their current long-term care system. Questions to ask include the following: Is the new coverage intended to fill a gap in the current set of options? Will the target population be different from the population usually served in the state's residential care facilities? Is the new coverage 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—those age 65 or older or younger adults with physical disabilities, or both—and whether services will be designed to address the specialized needs of specific populations, for example, persons with dementia or individuals with acquired brain injuries. It is crucial to make certain that the state's licensing and other facility regulations match the needs of the target population. As noted above, if the state wants to target nursing home-eligible beneficiaries, the facilities need to be licensed or certified to serve a population with a nursing home level of need.

When determining the target population for an HCBS waiver serving individuals with developmental disabilities, states may combine the entire eligible population into one HCBS waiver, or may choose to craft "specialty" waivers that target specific populations, such as children or individuals with autism. At least seven states have separate HCBS waivers serving individuals with autism. States may choose to target waivers to specific sub-groups within a larger population of eligible individuals as a means to offer specialized and/or different services to the sub-groups. The choice to use multiple waivers targeting distinct sets of eligible individuals is of course related to state policy goals.

Licensing and Contracting Issues

State licensing rules set the minimum requirements for Medicaid providers; for example, state regulations may establish certain staff-to-resident ratios or may specify awake overnight staff. However, the Medicaid program may set more stringent standards if desired. For example, if licensing rules do not include sufficient provider requirements for residential care settings that serve people with dementia, Medicaid contracting requirements may specify additional training or other requirements. Similarly, while a state may allow residential care facilities to offer rooms shared by two, three, or more residents, the Medicaid programs can choose to contract only with facilities that offer private occupancy unless the resident chooses to share a room or unit.

In states that are considering covering services in "assisted living" facilities for older adults, it is important to recognize that "assisted living" can mean more than just a setting for potentially cost-effective service delivery. It can refer to a philosophical approach to residential care that supports privacy, autonomy, and consumer choice. States that want

to offer residential care services that comport with the assisted living philosophy will need to ensure that their regulations and payment policies support its basic tenets, most notably privacy and autonomy. Several states do so—including North Dakota, Oregon, and Washington—by requiring residential care facilities that call themselves "assisted living," and want to contract with Medicaid, to offer apartment-style units rather than bedrooms.[34]

Enabling Medicaid Beneficiaries to Pay for Room and Board35

Medicaid beneficiaries with limited income may not be able to afford the room and board rates in residential care settings, unless states take specific steps to make them affordable. As noted earlier, Medicaid pays for room and board only in institutions, except in limited circumstances, for example, when providing respite care. For Medicaid purposes, room and board comprises real estate costs (debt service; building maintenance, upkeep, and improvements; utilities; and taxes) and food.[36] The costs of preparing, serving, and cleaning up after meals can be covered as a waiver service.[37]

Although Medicaid beneficiaries are responsible for paying for room and board, states have a range of options to help make the costs affordable.

Limit the amount facilities can charge Medicaid clients for room and board to the Federal SSI benefit, which in 2010 is $674 per month minus a small personal needs allowance.

Provide a state supplement to the SSI payment for persons living in residential care settings, and limit the amount these settings can charge to the combined SSI plus state supplement payment.

Use the 300 percent of SSI standard for HCBS waiver eligibility, and set the maintenance allowance at a level that allows residents to retain sufficient income to pay for room and board.

Allow family supplementation to increase the funds available for room and board, particularly to pay the difference in cost between a shared and a private room.

Each of these options is discussed below.

Limiting the Amount Facilities Can Charge for Room and Board

States can limit the amount that can be charged for room and board by setting a combined "rate" for Medicaid beneficiaries that includes service costs and room and board costs, but the state only pays for services. This approach essentially caps the room and board rate that Medicaid beneficiaries pay. Other states simply limit by policy the amount that facilities can charge Medicaid beneficiaries for room and board, usually capping the charge at the Federal SSI payment for a single elderly beneficiary living in the community, plus a state supplemental payment (SSP), if any. See Box below for a list of states that limit room and board charges.

23 States That Limit Room and Board Charges to the SSI/SSP Benefit Level in One or More Residential Care Settings

Arizona	Nebraska
California	New Jersey
Colorado	North Dakota
Delaware	Ohio
District of Columbia	Oklahoma
Georgia	Oregon
Hawaii	South Carolina
Illinois	Tennessee
Indiana	Texas
Maine	Vermont
Maryland	Washington
Montana	

This approach guarantees that Medicaid beneficiaries can afford room and board costs in facilities that accept Medicaid. However, if providers feel that the room and board rate is too low to cover costs, they

may decide not to admit Medicaid beneficiaries. New Jersey has passed a law requiring that facilities licensed after September 2001 set aside 10 percent of their units to serve Medicaid residents within 3 years after licensing.

Providing State Supplements to the SSI Payment

To increase access to residential facilities for SSI beneficiaries in areas with high housing costs, states can create a special SSI state supplement for residents in these facilities, and limit what providers may charge to the amount of the Federal payment plus the state supplement.[38] Many states have such SSP programs to supplement the Federal SSI payment, which in 2010 is $674 a month; the payment is adjusted each January based on the cost of living index. Individual states may use a specific term to refer to their supplement, and some use the term SSI to refer to both the Federal payment and any state supplement.

States may pay different supplements based on a person's living arrangement. A few states have developed a supplemental payment rate specifically for SSI recipients in residential care facilities to increase the amount of income they have to pay for room and board. State supplements are totally state-determined and vary widely. In 2009, the SSI state supplement payment standards (including the Federal payment of $674) ranged from $722 and $735 a month in Vermont and New Hampshire, respectively, to $1,275 a month in Hawaii and $1,350 in one area of Virginia.[39]

Some policymakers might question the fiscal benefit of providing 100 percent state funding for a state supplement to enable residents to pay for room and board. However, it is important to consider the net state cost for services provided in a residential care facility rather than a nursing home.[40] If the program diverts people from nursing homes or allows nursing home residents to move to a residential care facility, states may be able to fund a fairly substantial supplement to the Federal SSI payment and still reduce their net cost. To determine if such a policy would be budget neutral, states would have to determine the number of people who would receive the increased supplement and the combined cost of the supplement and Medicaid services provided in residential care settings.

Using the 300 Percent of SSI Standard and Providing an Adequate Personal Maintenance Allowance

States have the option to use more liberal income-eligibility criteria for the waiver program—up to 300 percent of the Federal SSI payment—$2,022 per month in 2010. (This option is discussed in detail in Chapter 2.)

This option is attractive for HCBS waiver programs that cover services in residential care settings, because it expands the program to include beneficiaries who are better able to afford room and board costs. To make this option effective, however, states must allow eligible persons to retain enough of their income to cover "maintenance needs," including the room and board charges in residential care settings. Setting a higher maintenance allowance may allow more beneficiaries to be served in residential care settings; however, it will increase Medicaid's service payment since it reduces the "excess income" that is applied to the cost of services.

Under Medicaid's post-eligibility treatment of income rules for HCBS waivers, states are allowed to use "reasonable standards" to establish the maintenance allowance, and may vary the allowance based on the beneficiary's circumstances. For example, states can permit Medicaid beneficiaries to keep sufficient income to pay for the needs of a dependent, health care costs not covered by Medicaid, and other necessary expenses.

States typically set a single maintenance needs allowance for all HCBS waiver participants. Many states set their maintenance needs allowance at 300 percent of the SSI Federal benefit. Since 300 percent of the SSI Federal benefit is the highest amount of income a person can have and still be subject to share of cost requirements, setting the maintenance needs allowance at that level allows waiver participants to keep all of their income to pay for living expenses. It also eliminates the administrative burden for states to calculate cost-sharing requirements.

If a state does not want to set a single maintenance needs allowance, Medicaid rules allow states to set different maintenance allowances for each individual, or for groups of individuals, if they believe that different amounts are justified by the needs of the individuals or groups.

Beneficiaries living in residential care settings may have different income needs depending on the type of facility: private market-rate facility or subsidized housing facility. The rent component of the monthly fee charged by facilities built with low-income housing tax credits will be lower than the rent charged by privately financed facilities. Through tax credits, rents can be reduced to around $400 per month. A lower maintenance amount for individuals with rent subsidies means more income is available to share the cost of services.

Setting the maintenance allowance based on the area's average monthly charge for room and board may be overly generous when applied to residents in subsidized units. On the other hand, setting the maintenance allowance based on the amount paid by residents in subsidized units may be too low for private market facilities and create access barriers. If a state wants to improve access to both private and subsidized residential care facilities, it can set a separate maintenance allowance for each setting.

Income Supplementation by Family Members or Trusts

Family members may be able and willing to help with room and board costs when the beneficiary is unable to pay them. While this discussion focuses on payments by family members, 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.

Since Medicaid does not pay for room and board in residential care settings, Federal rules regarding supplementation in nursing homes do not apply (i.e., families of nursing home residents may not supplement Medicaid payments, which cover room and board and services).

As presented in Table 5-2, 24 states and the District of Columbia reported that they allow family supplementation for individuals in residential care settings, 14 states do not allow supplementation, and 2 states have no policy. The remaining states either do not cover services in residential care settings or did not report whether they have a supplementation policy.[41] States are not allowed to require supplementation.

In states that allow supplementation, family members need to understand that the amount of the supplement is considered in determining financial eligibility for SSI. Federal SSI regulations contain provisions for treating unearned income during the eligibility determination process, and, because Medicaid income and resource rules for the "Aged, Blind, and Disabled" follow SSI rules, the SSI rules for treating unearned income apply to Medicaid eligibility determinations as well, even if an "elderly, blind, or disabled" person is not receiving SSI.[42] The application of SSI rules is not required for individuals eligible for Medicaid through another categorical group, such as pregnant women.

Under SSI rules, the entire amount of a family contribution paid directly to an individual is counted as unearned income. As a result, supplementation can lead to a reduced SSI payment or the loss of SSI altogether, and with it, potentially Medicaid as well. Even if an individual is not receiving SSI, this unearned income could cause him or her to lose Medicaid if it raises countable income above the Medicaid income limit.

If, however, the family contribution is paid directly to a residential care facility on the beneficiary's behalf, it is treated somewhat differently (i.e., as an "in-kind" payment). Under SSI (and therefore Medicaid) rules, in-kind support and maintenance—no matter how much—is valued at only one-third of the monthly SSI benefit, or approximately $225 in 2010. This amount is also considered to be unearned income, just as a direct payment from the family to the individual would be, with similar potential consequences. The difference is that an in-kind payment cannot be valued at more than one-third

Table 5-2. Family Supplementation Policy

Allow Supplementation		No Policy	Prohibit Supplementation	
Alaska	New Hampshire	Indiana	California	New York
Arizona	New Jersey	Massachusetts	Hawaii	Ohio
Colorado	New Mexico		Illinois	Oregon
Connecticut	North Carolina		Maryland	South Carolina
Delaware	North Dakota		Michigan	South Dakota
District of Columbia	Oklahoma		Montana	Texas
Florida	Rhode Island		Nebraska	Vermont
Georgia	Tennessee			
Kansas	Utah			
Maine	Washington			
Minnesota	Wisconsin			
Missouri	Wyoming			
Nevada				

of the SSI benefit, whereas the entire amount of a direct payment to the individual is countable.

Another point worth noting is that if the family can document that the actual amount of an in-kind payment is less than one-third of the SSI monthly payment, the actual amount of the payment will be used instead of the higher one-third amount. Finally, some states have elected to not count in-kind support and maintenance at all when determining eligibility for Medicaid. The Medicaid state agency should be able to provide information on whether a state has elected to not count such support.

Because the Federal rule states that the maximum reduction to an SSI payment is only one-third of the benefit, there is no limit on the amount of money that can be paid to a facility on behalf of an SSI beneficiary. If a family chooses, they could pay for a private room and board in a more expensive facility without jeopardizing an individual's eligibility for SSI. However, the payment could result in the loss of Medicaid eligibility.

To prevent beneficiaries from losing Medicaid eligibility, states could amend their State Plan, with approval from CMS, to exempt in-kind income that supports a person's accommodations or services not covered by the Medicaid payment in residential care settings. Section 1902(r)(2) of the Social Security Act allows states to use less restrictive income and resource methodologies than are used by SSI when determining eligibility for most Medicaid eligibility groups. States can elect to disregard different kinds or greater amounts of income and/or resources than SSI, giving states more flexibility to design and operate their Medicaid programs.

However, although a state may limit its less restrictive methodologies to eligibility groups it selects,

the group(s) must still be one of those specifically listed in §1902(r)(2); for example, buy-in groups for working persons with disabilities, most poverty-related groups, and the medically needy. States are not permitted to carve out a subgroup of their own definition (e.g., one based on place of residence).

Effect of Medically Needy Rules on the Ability to Pay for Room and Board

States have the option of covering medically needy beneficiaries under their Medicaid programs. The medically needy are persons who, except for income, would qualify under one of the other Medicaid eligibility groups covered under the State Plan (such as people receiving SSI or the optional aged and disabled poverty level group). Medicaid payments can begin for medically needy persons 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 level. As discussed in the previous section, any family supplementation is considered part of the excess income that must be spent down. If it is paid to a residential care facility, the one-third rule applies and it is still treated as unearned income.

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 beneficiaries in residential care settings.

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 residential care 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 residential care settings. First, these individuals may find it more difficult to incur sufficient medical expenses to meet the spend-down requirements while living in the residential care setting than they would in a nursing home. The higher their "excess" income, the higher the amount of their spend-down, which means that only beneficiaries with extremely high medical expenses may become eligible for Medicaid.

Second, community providers are less willing to deliver services during the spend-down period, since payment cannot be guaranteed and collection may be difficult. Third, 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 room and board. Permitting spend-down to a higher amount—such as 300 percent of SSI instead of a state's medically needy standard for HCBS waiver eligibility—requires a change in the Medicaid statute.

In summary, room and board costs may present an access barrier to residential care settings for Medicaid beneficiaries unless states take specific steps to make these costs affordable. Several observers have suggested that the Medicaid program be allowed to pay for room and board in residential care settings as it does in nursing homes. To do so, Congress would have to amend the Medicaid statute. It is possible that states would not welcome this change because currently the SSI benefit, which pays for room and board, is 100 percent Federal funding. If Medicaid were to pay for room and board in residential care settings, states would be responsible for part of the cost under Federal Medical Assistance Percentage provisions. (See Chapter 2 for a detailed discussion of Medicaid's financial eligibility rules.)

Service Payment Rates: Adequacy Concerns

Unless service rates are considered reasonable by residential care settings, they will not be willing to contract with Medicaid, particularly in states where private pay rates are very high. It is important for states to recognize that payment levels will likely need to vary based on residents' current needs (called tiered rates). Doing so will enable people whose condition deteriorates to stay in the setting rather than having to move to a nursing home. A number of states use tiered rates (including Arizona, Delaware, Ohio, Oregon, Vermont, 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.

Many states use tiers or levels of payment in group homes for individuals with developmental disabilities to account for individual needs within a single setting, allowing increased payments for individuals who have intensive medical or behavioral support needs requiring a higher staffing ratio or specialized expertise. For example, Ohio uses payment rates that account for the size of the setting, the staffing ratio, and residents' specialized needs. This allows for individualized services that are tailored to the support needs of persons in group settings. Alabama and Utah use an assessment process that costs out the hours of support an individual needs, while Missouri establishes rates by "category" of facility, with higher payment rates going to settings serving individuals with more intensive support needs. As payment rates are set, consideration should be given to what aspects of the supports are included in the rate versus other supports that are billed outside the rate.

Whatever the specific process, states will want to allow for individualization of rates to ensure that individuals receive the level of support appropriate to their needs. This type of individualized rate can also be applied to foster homes as well. For example, some states operate "medical" foster homes that support children with intensive medical needs. The costs for operating these specialized homes—and their highly specialized personnel—are reflected in the payment rates.

Payments to licensed foster care settings may be tax exempt. If so, individualizing rates allows states to adjust the payment rate to account for the increased revenue to the provider because they may not have to pay Federal income taxes. As with larger residential care settings, the foster care payment rates can be individualized and tailored to meet the needs of the individuals and/or target group served.

Bundling Payments

Bundled rates are permitted for services that are by design multi-component or, as a practical matter, very difficult to break down into separate billing components; for example, rates for a single worker who supervises several residents and engages in one-on-one interactions with them for varying lengths of time. States are expected to have effective means to verify that bundled services are in fact providing the claimed components. Monthly rates are not as useful for this purpose as are daily or, in some cases, hourly bundled rates, which can account for resident absences from a facility for varying amounts of time for other services, such as offsite vocational programs.

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key resources relevant to the use of Medicaid to pay for services in residential care settings. Most of the publications cite additional resources, and the websites also have links to other sources of information.

Publications

Mollica, R. (2009). *State Medicaid Reimbursement Policies and Practices in Assisted Living.* Washington, DC: National Center for Assisted Living, American Health Care Association.

This report presents and updates information on state coverage of Medicaid services in assisted living/residential care settings and includes the source of coverage, the number of participating facilities, number of people served, payment rates, and other data.

Available at http://www.ahcancal.org/ncal/resources/Documents/MedicaidAssistedLivingReport.pdf

Mollica, R.L., Simms-Kastelein, K., Cheek, M., Baldwin, C., Farnham, J., Reinhard, S., and Accius, J. (2009). *Building Adult Foster Care: What States Can Do.* Washington, DC: AARP, Public Policy Institute.

This report examines the role of adult foster care within the long-term care system and offers guidance to policy makers interested in developing or expanding this type of residential care.

Available at http://www.aarp.org/health/doctors-hospitals/info-09-2009/2009_13_building.html

CMS. (2008). Application for a §1915(c) *Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria.* Baltimore, MD: U.S. Department of Health and Human Services.

This publication contains extensive information concerning Federal policies that apply to the operation of an HCBS waiver, including a section on paying for services in residential facilities. (Appendix C-2-c: Facilities Subject to §1616(e) of the Social Security Act.)

Available at https://www.hcbswaivers.net/CMS/faces/portal.jspunder links and downloads, entitled §1915(c) Waiver Application and Accompanying Materials.

Mollica, R., Sims-Kastelein, K., and O'Keeffe, J. (2007). *Residential Care and Assisted Living Compendium: 2007*. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.

This report provides information about regulations covering residential care/assisted living facilities in all 50 states and the District of Columbia. It also discusses Medicaid policy regarding coverage of services in these facilities.

Available at http://aspe.hhs.gov/daltcp/reports/2007/07alcom.htm

---

Ireys, H.T., Pires, S., and Lee, M. (2006). *Public Financing of Home and Community Services for Children and Youth with Serious Emotional Disturbances: Selected Strategies*. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.

This report describes important system-of-care principles that have shaped services for youth with serious emotional disturbances, the role of the various agencies that serve these children, and the financing mechanisms many states use to fund services for this population. It covers the strengths and weaknesses of major financing mechanisms, including HCBS waivers, the Medicaid rehabilitation option, and provisions in the Tax Equity and Fiscal Responsibility Act, also known as the Katie Beckett provision. The report also presents information that can inform legislative efforts to strengthen the financing of intensive home and community services for youth with serious emotional disturbances and their families.

Available at http://aspe.hhs.gov/daltcp/reports/2006/youthSED.htm

---

Stancliffe, R.J., and Lakin, C. (2004). Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities. *Policy Research Brief 14(1)*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

This Policy Research Brief reviews available research on the costs and outcomes of community service provision for people with intellectual disabilities and developmental disabilities, with a particular emphasis on residential services. It focuses on a number of key issues related not only to public expenditures, but also to funding systems, related policies and regulations, and their impact on service systems, on specific service types, and on service users.

Available at http://ici.umn.edu/products/prb/151/151.pdf

Websites

Assisted Living Federation of America (ALFA)

The Assisted Living Federation of America is the largest national association exclusively dedicated to professionally operated assisted living communities for seniors. ALFA's member-driven programs promote business and operational excellence through national conferences, research, publications, and executive networks. In addition, ALFA works to influence public policy by advocating for informed choice, quality care, and accessibility for all Americans. The website includes links to publications and information about Federal and state policy.

Web address: http://www.alfa.org/alfa/Default.asp

Center for Excellence in Assisted Living

The Center for Excellence in Assisted Living is a non-profit collaborative of 11 national organizations that builds upon the work of the Assisted Living Workgroup, which was formed to work with the U.S. Special Committee on Aging on a range of assisted living issues. The Center's purpose is to promote high-quality assisted living and to serve as a national clearinghouse for information about assisted living, including research findings, exemplary practices, training and education materials, and consumer materials.

Web address: http://www.theceal.org

The Clearinghouse for Home and Community Based Services

This site promotes the development and expansion of home and community-based services by gathering resources and tools for research, policymaking, and program development into this one-stop website. The site has over 2,000 resources that users can browse using the site's search engine. For example, using the search words "Medicaid" and "assisted living" yields 17 results, including several of the publications listed above.

Web address: http://www.hcbs.org/

Endnotes: Citations, Additional Information, and Web Addresses

1 Janet O'Keeffe and Robin Cooper co-authored this chapter. Some sections of this chapter draw liberally from other published sources, which are referenced in the endnotes.

2 Medicaid-covered "institutional" services refer to specific services and settings as authorized in the Social Security Act. While the term "institutional" is also commonly used to describe specific characteristics of a facility—such as structuring its operation to accommodate the facility's needs rather than the residents' choices—in Federal Medicaid statute and regulations the term institutional generally has the following meanings:

(1) The service is institutional, that is, a provider accepts responsibility for residents' overall care, and furnishes food and shelter in addition to services; (2) the setting is institutional—subject to state licensure requirements and survey and certification process; (3) payment is made through separate provisions for institutional services; and (4) eligibility rules may be specific to institutional services.

Taken together, these requirements mean, among other things, that an institutional service such as Medicaid nursing facilities can only be provided in a Medicaid-certified nursing facility, and only reimbursed under the Medicaid nursing facility benefit. It is important to note that a facility does not have to have many beds to be considered an institution, despite the popular image of institutions as being large. (See endnote 5 regarding the minimum size of an ICF/ID.)

3 Come-in staff generally work 8-hour shifts (day, evening, night) but can also work 12-hour day or night shifts.

4 ICFs/ID are considered institutions under Federal regulations. Although some ICFs/ID are large state-operated facilities, the majority are now smaller. CMS regulations provide for a "community size" ICF/ID option. Facilities that have 15 or fewer beds are considered "community" ICFs/ID, and facilities with 16 or more beds are considered to be "large." A number of states operate community ICFs/ID, many of which have few beds.

For example, California, Texas, Illinois, Indiana, and Louisiana, among other states, all have ICFs/ID that serve six or fewer individuals. Thus, a state could potentially provide services under the HCBS waiver in group homes that serve the same number of residents (or more) than an ICF/ID, so that the two settings are the same in size. The difference is that the ICF/ID setting provides the ICF/ID institutional service, must comply with numerous Federal regulations, and receives the comprehensive institutional reimbursement, which includes payment for room and board.

5 CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, Appendix C-2-c-ii, p. 117. See the Resources section of this chapter for a web link to the application, instructions, and appendices.

6 Ibid.

7 Found at http://www.minnesotahelp.org/Public/taxonomy_glossary.aspx?code=BH-840.600-28.

8 Section 1616(e) of the Social Security Act requires that the state must "establish, maintain, and insure

the enforcement of standards for any category of institutions, foster homes, or group living arrangements in which a significant number of SSI recipients resides or is likely to reside. The standards must be (a) appropriate to the needs of residents and the character of the facilities involved; and (b) govern such matters as admission policies, safety, sanitation, and protection of civil rights."

Section 1616(e) also requires states to maintain records of information concerning standards, procedures available to ensure enforcement of the standards, and a list of waivers of standards and violations of standards by specific facilities. These records must be made available annually to the public. States must certify annually to the Commissioner of Social Security that they are in compliance. Office of the Inspector General (March 31, 1997). Review of the Social Security Administration Procedures to Ensure State Compliance with §1616(e) of the Social Security Act – A-01-96-62001. Available at http://www.ssa.gov/oig/ADOBEPDF/audit_htms/96-62001.htm.

9 Mollica, R., Sims-Kastelein, K., and O'Keeffe, J. (2007). Residential Care and Assisted Living Compendium: 2007. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. Available at http://aspe.hhs.gov/daltcp/reports/2007/07alcom.htm.

10 CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, pp. 168-169, and 265-266. See the Resources section of this chapter for a web link to the application, instructions, and appendices.

11 Mollica, R., Booth, M., Gray, C., and Sims-Kastelein, K. (2008). Adult Foster Care: A Resource for Older Adults. New Brunswick, NJ: Rutgers Center for Health Policy, p. 7. Available at http://www.hcbs.org/moreInfo.php/doc/2273.

12 Alba, K., Prouty, R.W., and Lakin, K.C. (2007). Chapter 4: Number of Residential Settings and Residents by Type of Living Arrangement on June 30, 2007. In Prouty, R.W., Alba, K., and Lakin, K.C. (Eds.). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2007. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, p. 45. Available at http://www.hcbs.org/moreInfo.php/doc/2312.

13 Mollica, R.L., Simms-Kastelein, K., Cheek, M., Baldwin, C., Farnham, J., Reinhard, S., and Accius, J. (2009). Building Adult Foster Care: What States Can Do. Washington, DC: AARP, Public Policy Institute, p. 9. Available at http://www.aarp.org/health/doctors-hospitals/info-09-2009/2009_13_building.html.

14 Supported living in an individual's own home and any other type of residential supports a state wants to cover are also subsumed under residential habilitation.

15 CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, pp. 151-152. See the Resources section of this chapter for a web link to the application, instructions, and appendices.

16 45 CFR 1355.20.

17 CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, p. 131. See the Resources section of this chapter for a web link to the application, instructions, and appendices.

18 Utah's Community Supports Waiver for Individuals with Intellectual Disabilities and Related Conditions, Waiver # 0158.90.r#.02.

[19] States do not have to include citations of state rules, which can change over time. The application must also include the state's quality assurance plans.

[20] Hawes, C. (2001). Introduction. In Zimmerman, S., Sloan, P.D., and Eckert, K. (Eds.). Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly. Baltimore, MD: The Johns Hopkins University Press.

[21] The supply of older residential care facilities that serve individuals eligible for SSI and Medicaid is much larger than the supply of private pay assisted living facilities. Robert Newcomer, University of California at San Francisco. Personal communication, November 25, 2009.

[22] Mollica, R., Sims-Kastelein, K., and O'Keeffe, J. (2007), op. cit.

[23] Mollica, R. (2009). State Medicaid Reimbursement Policies and Practices in Assisted Living. Washington, DC: National Center for Assisted Living; American Health Care Association. Available at http://www.ahcancal.org/ncal/resources/Documents/MedicaidAssistedLivingReport.pdf. Hawes, C., Rose, M., and Phillips, C.D. (1999). A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. Available at http://aspe.hhs.gov/daltcp/reports/facres.pdf.

[24] The Guidance also notes that states may modify or supplement the core definition to reflect the scope of assisted living services furnished under the waiver.

[25] CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, pp. 117, 170. See the Resources section of this chapter for a web link to the application, instructions, and appendices.

[26] Ibid. Appendix C, Attachment: Core Service Definition, pp. 151-153.

[27] This section draws liberally from Mollica, R., Sims-Kastelein, K., and O'Keeffe, J. (2007), op. cit.

[28] An HCBS waiver may cover services provided in participants' homes or in residential care settings. Some states have implemented specialized assisted living waivers, which provide services only in residential care settings.

[29] Mollica, R. (2009), op. cit. Individuals with developmental disabilities who meet a state's nursing home level-of-care criteria may also be served in Aged or Aged/Disabled HCBS waiver programs. But only persons with developmental disabilities can be served in ID/DD waiver programs, because the level-of-care criteria for ICFs/ID require a specific diagnosis of developmental disabilities to be eligible.

[30] Information in the Boxes is mainly from Mollica, R. (2009), op. cit., and Mollica, R., Sims-Kastelein, K., and O'Keeffe, J. (2007), op. cit.

[31] Licensing requirements adopted in 1995 and 1996 established the umbrella term of "assisted living residences" for two types of residential care facilities: (1) licensed adult care homes and (2) multi-unit assisted housing with services (which are not licensed, but must be registered with the State).

[32] 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 or poses a danger to self and others; (c) the resident has a medical or nursing condition that is complex, unstable or unpredictable and exceeds the level of health services the facility provides; or (d) the facility is unable to accomplish resident evacuation in accordance with OAR 411-054-

0090 (Fire and Life Safety).

[33] As noted, above, states do not have to include citations of state rules, which can change over time. The application must also include the state's quality assurance plans.

[34] Oregon and Washington also allow other types of residential care settings that contract with Medicaid to have shared rooms.

[35] The information in this section is taken verbatim from Mollica, R., Sims-Kastelein, K., and O'Keeffe, J. (2007), op. cit.

[36] Medicaid will pay for food costs in specific situations, such as meals served as part of an adult day health program.

[37] CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, Appendix I-5: Exclusion of Medicaid Payment for Room and Board, pp. 265-266. See the Resources section of this chapter for a web link to the application, instructions, and appendices.

[38] Many states have a state supplement for residential care settings that may be too low to cover more intense services needs and higher capital costs in some residential care settings.

[39] Mollica, R., (2009), op. cit.

[40] The net cost to the state will depend on Medicaid payment rates for both nursing homes and services in residential care facilities.

[41] Mollica, R. (2009), op. cit.

[42] Family contributions that do not affect SSI eligibility—and therefore do not affect Medicaid eligibility—might have an affect in 209(b) states because Medicaid eligibility in these states is not linked to SSI eligibility. (When SSI replaced state-only programs of aid for elderly persons and persons with disabilities, the change 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 limit large increases in Medicaid enrollment and costs.

[43] See IRS Code Section 131b1 that defines a qualified foster care payment as "a payment made pursuant to a foster care program of a state or a political subdivision of the state: that is paid by a political subdivision of a state, or a qualified foster care placement agency; and that is paid to the foster care provider for caring for a qualified foster care individual in the foster care provider's home, or a difficulty of care payment."

Guide to Chapter 6

Introduction 153
Lessons from the Transitioning Experience with ICFs/ID 154
Nursing Home Transition Grants Program 156
General Factors to Consider for Transition Initiatives 157
Identifying and Addressing Administrative and Legal Barriers 157
Ensuring the Availability of a Comprehensive Range of Home and Community Services 158
Developing Methods to Circumvent HCBS Waiver Waiting Lists 158
Identifying and Educating Residents with the Desire and Potential for Transition 159
Involving and Collaborating with Key Stakeholders 161
Developing and Implementing Case Management/Service Coordination Systems That Support Transition 162
Identifying and Addressing Housing Needs and Rental Assistance 163
Providing Flexible Funding Mechanisms 165
Preventing Unnecessary Admissions and Avoidable Long Stays 166
Establishing a Quality Assurance System That Effectively Balances Risk and Autonomy 166
Resources 168
Endnotes: Citations, Additional Information, and Web Addresses 171

Chapter 6
Transitioning People from Institutions to the Community

The realization that many people with long-term care service and support needs can thrive in integrated community settings and the requirements of the Supreme Court's Olmstead decision have increased states' commitment to transition residents of intermediate care facilities for persons with intellectual disabilities (ICFs/ID), nursing facilities, and other long-term care institutions to the community. This chapter begins with a brief overview of how states have used Medicaid home and community-based services (HCBS) waiver programs to enable ICFs/ID residents to transition to the community. It then discusses important factors states need to consider when planning transition programs for persons in nursing facilities and options for using Medicaid to help cover certain transition costs.1

Introduction

After Medicaid's enactment, the following decades saw an increase in the number of states developing alternatives to institutional care for persons with disabilities, in order to provide services and supports in the most integrated setting appropriate to their needs. The Supreme Court decision—Olmstead v. L.C., finding that unnecessary segregation of people with disabilities in institutions constitutes a form of discrimination under the Americans with Disabilities Act (ADA)—gave legal weight and new urgency to this policy direction.[2] The Centers for Medicare & Medicaid (CMS) guidance, issued to states in January 2000, underscores the importance of states' efforts to move people out of nursing homes and other long-term care institutions into community settings as a part of a state's "comprehensive effectively working plan" for providing services to qualified persons in the most integrated settings. (See the Resources section of this chapter for a link to 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 people with intellectual disabilities and other developmental disabilities (ID/DD, hereafter called developmental disabilities) were inappropriately placed in large public facilities and institutions. 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 ID/DD service systems from institutionally dominated to community-centered.

The first section of this chapter provides a brief overview of the transition process for residents of ICFs/ID, distilling the lessons learned from this experience that apply to transition initiatives more generally. The second section focuses on current Medicaid options for supporting transitions and discusses major factors states need to consider when setting up transition programs—focusing primarily on the transition of nursing home residents—but also applicable to transitions from ICFs/ID and other institutions.

Lessons from the Transitioning Experience with ICFs/ID[3]

Medicaid funding for home and community services and supports for persons with 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.[4] Between 1970 and 2008, 40 states closed or initiated plans to close more than 140 large public institutions.[5] Alaska and Oregon have closed all of their state and non-state ICF/ID programs and Vermont supports a single private facility of six residents. Additionally, many states ceased sponsoring additional ICF/ID development.

Terminology

In the developmental disabilities service system, ICFs/ID that serve a small number of residents—from 15 to as few as 4—are called community ICFs/ID, and the term "institution" is used only for ICFs/ID with 16 or more residents. However, for Medicaid purposes, ICFs/ID are considered to be institutions, irrespective of the number of people they serve.

Not all institutions that serve persons with developmental disabilities are ICFs/ID. Prior to coverage of ICFs/ID under Medicaid in the early 1970s, institutions were exclusively state funded. While states converted virtually all of these institutions to ICFs/ID to take advantage of Federal funding, a few privately funded institutions may still be operating, as well as former ICFs/ID that have lost their certification and are not receiving Federal finding.

By the end of 2009, 10 states and the District of Columbia had closed all of their large public institutions for people with developmental disabilities.[6] In the private sector as well, the number of residents of both large and small ICFs/ID nationwide has declined steadily since 1997. The decline in ICF/ID 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 1992 and 2007, the number of individuals participating in HCBS waiver programs for people with developmental disabilities grew by 703 percent.[7] A major reason for the 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.

The successful transitioning of people with developmental disabilities from institutions to the community demonstrates that waiver services can be cost-effective substitutes for institutional services for this population.[8] States that have been especially successful in closing large public facilities and reducing reliance on ICFs/ID have taken many other important steps to ensure that the needs of individuals with developmental disabilities can be met in the home and community. Many of these steps are equally applicable to beneficiaries with other disabilities being transitioned from nursing homes and other institutions. These steps are

- ***Developing community-based crisis and quick-response capabilities.*** In many states, institutions provide backup services and supports for persons who are in crisis and need emergency services. In the 10 states that have closed all of their public institutions (as well as the District of Columbia), each has addressed the need for emergency support in different ways. 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, which 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. Vermont established the Vermont Crisis Intervention Network in 1992 to provide community-based emergency support and assistance statewide. New Mexico and Hawaii developed similar programs using the same organizational model. The development of an effective crisis response capability

was instrumental in Oregon's closing its Fairview facility in February 2000 and the Eastern Oregon Training Center in 2009.

- ***Expanding community services to meet the needs of individuals with multiple disabilities and challenging conditions who require particularly intensive support and assistance.*** People with significant needs are often described as "requiring" institutional services. States that have closed their institutional programs have demonstrated that people with even the most intensive support requirements can lead productive and successful lives in home and community settings when afforded person-centered services and supports tailored to their strengths and needs.[9] Many states have found that the costs of community services for people being transitioned from institutional services can be higher on average than the costs of waiver services furnished to persons who have not been institutionalized. This cost differential may result because as institutional populations have declined, the proportion of institutionalized residents with significant and multiple disabilities has increased, and these individuals require more intensive services wherever they are served—in an institution or the community. To ensure sufficient capacity to support these individuals, many states must enhance the infrastructure of community agencies.[10]

- ***Providing higher than average funding allocations for individuals transitioning to the community.*** States have taken steps to provide needed services and supports in community settings by permitting the development of HCBS waiver service plans that allow an individual's costs to rise 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 an individual expenditure limit or cap.[11]

- ***Developing waivers targeting specific populations and groups.*** 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. 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 waiver services to 180 individuals in addition to the persons transitioned from Brook Run. The Washington State Division of Developmental Disabilities developed and implemented five separate waiver programs designed to support individuals at differing levels of need. Four types of waivers—Basic, Basic Plus, Core, and Community Protection—furnish a variety of supports at increasing intensity. A fifth provides intensive in-home behavioral support to children with significant needs.

- ***Developing specialized "supports" waivers.*** An increasing number of states to date have developed and implemented distinctive HCBS waiver programs—called supports waivers—which offer a limited menu of specific services that operate in tandem with previously existing comprehensive waiver programs. Designed to limit Medicaid costs by preventing out-of-home placement in 24-hour residential programs or ICFs/ID, these waivers offer a variety of flexible in-home supports. Supports waivers impose specific expenditure limits on the amount of services provided and per-person costs are significantly less than those found in comprehensive waivers. Supports waivers typically emphasize participant direction and are intended to promote the use of non-traditional, "natural supports" provided by family, friends, and neighbors.[12] (See Chapter 4 for additional information about supports waivers.)

- ***Expanding supports offered to individuals and families.*** Family support services are crucial for preventing unnecessary out-of-home placements and are used by many states to reduce reliance on institutional services. In

addition to supports waivers, states furnish assistance to families through state general fund programs and the provision of cash subsidies or stipends. As a result of these and other efforts, increasing numbers of individuals with developmental disabilities are able to avoid institutional placement by receiving the assistance they need in the home of a family member. In 2007, the majority (55.8 percent) of persons with developmental disabilities receiving publicly funded services lived in the home of a family member.[13] Michigan, for example, reduced the number of individuals served in large public facilities from over 6,000 in 1977 to fewer than 300 in 1998—in large part by implementing and sustaining family support programs.

- ***Developing strong and locally centered community service systems.*** In developmental disabilities services, creating a strong infrastructure at the community level has proven to have a significant impact on the ability to avoid institutionalization and promote quality services. An important component of Michigan's transition activities was its strengthening of the State's network of local governmental Community Mental Health Service Programs through its Section (§)1915(b)(c) managed care waiver program. 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 to train 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.

- ***Expanding investments in quality assurance and quality improvement capabilities.*** The Medicaid HCBS waiver application requires each state to submit a comprehensive quality management strategy outlining the approaches the state intends to use to assess, improve, and safeguard the health and welfare of waiver program participants.[14] Several states are responding by improving current practice through the utilization of standardized outcome measurement tools such as the National Core Indicators (NCI), which permit state-to-state comparisons, or other instruments such as the Participant Experience Survey. Pennsylvania launched a comprehensive quality measurement system for community-based services, which relies on information obtained from individuals receiving support and their families. The data are collected by individuals who have no connection to entities delivering services. The Independent Monitoring for Quality project combines both state-specific and the NCI national outcome measurement tools. (See the appendix for an overview of CMS requirements for quality management and improvement systems.)

Nursing Home Transition Grants Program

During the 1990s, the system serving individuals with developmental disabilities gained considerable experience transitioning individuals from institutions to the community. In contrast, most states had little experience transitioning nursing home residents to the community. To encourage states to develop and implement nursing home transition programs, in 1998 and 1999 the U.S. Department of Health and Human Services (HHS) provided grants to eight states through the Nursing Home Transition Program.

By 1999, the Olmstead decision had increased state interest in nursing home transition, and in Federal fiscal year (FFY) 2001 and FFY 2002, under its Systems Change for Community Living Grants program, CMS provided 33 Nursing Facility Transition (NFT) grants to help states develop a sustainable transition infrastructure, and to promote partnerships between state agencies and Independent Living Centers (ILCs) to facilitate transitions.[15] In FY 2004, CMS awarded nine Systems Change Money Follows the Person (MFP) grants to states to continue working on NFT initiatives with a specific focus on developing and implementing MFP initiatives.[16]

Many of the lessons learned through this grants program, and Grantees' recommendations for addressing continuing transition barriers, have been incorporated into the discussion that follows.

General Factors to Consider for Transition Initiatives

Successful transitions depend fundamentally on the ability to provide services and supports in the community that meet the needs of the person transitioning. Persons leaving ICFs/ID have varying types and levels of need. Residents of nursing facilities are an even more heterogeneous group. Nursing facility residents can 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 (TBI). While those transitioning will have some needs in common, they will also require services and supports tailored to their specific situations.

Whether a person currently resides in a nursing facility or in an institution serving primarily those with a developmental disability or mental illness, the steps in planning or arranging for home and community services are the same. In either case, solid transitional planning is essential.[17] Because each person has unique needs, the complexity and cost of each individual's transition process will vary. For this reason, it is crucial that states design their transition programs to operate with maximum flexibility. In addition to the numerous options for providing home and community services, Medicaid also provides options to facilitate and support transitions.

The remainder of this chapter will discuss the key factors essential to implementing successful transition programs, along with related Medicaid policies and service options. The key factors are

- Identifying and addressing administrative and legal barriers to transition.
- Ensuring the availability of a comprehensive range of home and community services.
- Developing methods to circumvent HCBS waiver waiting lists.
- Identifying and educating residents with the desire and the potential for transition.
- Involving and collaborating with key stakeholders.
- Developing and implementing care management/service coordination systems that support transition.
- Identifying and addressing housing needs and rental assistance.
- Providing flexible funding mechanisms.

States generally undertake many of these activities simultaneously. The chapter ends with a brief discussion of how states can prevent unnecessary admissions to institutions and avoidable long stays.

Identifying and Addressing Administrative and Legal Barriers

States need to analyze their Medicaid regulations and administrative policies 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. For example, if a state does not use the 300 percent of SSI income rule for its HCBS waiver program, some institutional residents will not meet the financial eligibility criteria for waiver services, even though they can be appropriately served in the community. (See Chapter 2 for a discussion of Medicaid's financial eligibility rules.)

In addition, if Medicaid's maintenance needs allowance is too low to permit individuals to pay for room and board costs in the community, nursing home residents may be unable, simply for financial reasons, to transition to the community—whether to an independent living arrangement or a residential care facility. (See Chapter 2 for a discussion about financial criteria and Chapter 5 for a discussion of state policies to help Medicaid beneficiaries afford room and board costs.)

Ensuring the Availability of a Comprehensive Range of Home and Community Services[18]

Since persons transitioning from institutions have widely varying needs, the transition process presupposes that a broad range of home and community services and supports is available. Yet, Medicaid HCBS waiver programs vary greatly in the comprehensiveness of services they provide, and in many states the home and community services system does not provide the amount, duration, and scope of services needed to enable people with severe disabilities or extensive nursing needs to live safely in the community.

New Service Developed to Enable Transition

During implementation of its Systems Change NFT grant, state staff in Rhode Island found that lack of day services was a transition barrier for persons with traumatic brain injury. Under a contract with an adult day services provider, grant staff established an adult day services program for adults with severe cognitive disabilities, many with traumatic brain injury. The new program is now funded as a Medicaid State Plan service under the Rehabilitation services option.

Some Systems Change NFT Grantees cited a lack of services for specific populations as a transition barrier; for example, when a state does not have a TBI waiver and the services available in other waiver programs do not meet the needs of persons with traumatic brain injury. Other barriers Grantees cited were (1) insufficient funding for home modifications and assistive technology; (2) HCBS waiver programs that do not provide all of the services a person needs; (3) lack of mental health and substance abuse services and supports; and (4) lack of agreement among state agencies about who is responsible for providing services for people with both physical and mental impairments, making it difficult to ensure adequate services for this population. The lack of nurse delegation provisions that enable individuals with complex medical needs to be served cost-effectively in the community can also be a barrier as can the lack of experience of HCBS providers in serving this population, which may make them reluctant to do so.

Lack of home and community services prevents diversion as well as transition. One NFT Grantee noted that timely access to in-home services is essential for diverting persons being discharged from hospitals. In the absence of these services, hospital staff will not discharge patients to their homes, sending them instead to a nursing facility. Clearly, before spending resources on transition activities, states need to ensure that a comprehensive range of services and supports are available in the community, particularly for individuals with severe disabilities and/or extensive nursing needs.

Developing Methods to Circumvent HCBS Waiver Waiting Lists[19]

Waiting lists for HCBS waiver services are a major transition barrier. States have several options available to deal with this problem. First, states can prioritize their waiver waiting lists so that individuals wanting to transition are placed at the top of the list (generally, after individuals who are at immediate risk of nursing home admission).

Second, states can increase the number of waiver slots and designate them solely for people who are transitioning. For example, Michigan authorized new waiver slots for persons who are transitioning if they have been in a nursing facility for more than 6 months. Exceptions to the 6-month rule may be granted in a limited number of circumstances (e.g., if individuals are at risk of losing their housing). Additionally, for each successful move to the community, the State provides transition costs and waiver services for one additional Medicaid nursing facility resident without regard to their length of stay.

Third, if states are reluctant to increase the number of waiver slots, they can appropriate state funds to cover home and community services. When Georgia's Systems Change NFT grant ended, the State appropriated $7.25 million for non-Medicaid covered transition expenses and the first year of home and community services for transitioning individuals for whom there were no waiver slots. The legis-

Money Follows the Person Demonstration[20]

To further encourage states to implement nursing facility transition programs and MFP policies, the Deficit Reduction Act of 2005 authorized the Secretary of HHS to award up to $1.75 billion in special MFP demonstration grants to states over a 5-year period to support the transition of individuals from institutional settings to the community.[21] All states were eligible to participate in the 5-year demonstration program and had to commit to provide demonstration services for at least 2 years. As of 2009, 29 states and the District of Columbia had MFP grants. The Patient Protection and Affordable Care Act of 2010 extended the demonstration program until 2016.[22]

The MFP demonstration has four major objectives:

- Increase the use of home and community services in place of institutional services.
- Eliminate barriers or mechanisms that prevent Medicaid-eligible individuals from receiving appropriate and necessary services and supports in the settings of their choice.
- Increase the ability of state Medicaid programs to ensure continued provision of services and supports to eligible individuals who choose to move from an institutional to a community setting.
- Ensure that procedures are in place to ensure the quality of Medicaid home and community services, and to provide for continuous quality improvement in the furnishing of these services.

As an incentive to states to participate, CMS will increase Federal Medicaid matching funds for home and community services for each person transitioned for a 1-year period, after which the state must ensure that individuals transitioned will continue to receive HCBS as long as they are Medicaid eligible and need the services.

To qualify for the enhanced Federal match, individuals must transition to community living arrangements that they own or lease, their family home, or a community-based residential setting where no more than four unrelated people reside.

The MFP program is being rigorously evaluated and CMS is offering an ongoing series of reports completed as part of the MFP national evaluation.[23]

lature specified a maximum of $50,000 per person for up to 145 individuals. Only when individuals have been supported with these funds for 1 year does the State create a new waiver slot to continue services.

Fourth, states can enact a global budget or an MFP policy to allow Medicaid funds budgeted for institutional services to be spent on home and community services when institutional residents move to the community.

Identifying and Educating Residents with the Desire and Potential for Transition

States must first establish the target population: all individuals or specific groups, such as those under age 60 who do not need a skilled level of care or those who at admission are at risk of losing their housing. Once the target population has been selected, states must then develop feasible and effective referral, screening, and assessment procedures to identify individuals who have the desire and the potential to be transitioned successfully to the community.

Money Follows the Person Policies: State Examples

Texas was one of the originators of the MFP concept. The State's MFP policy enables individuals residing in nursing facilities to move back to a community setting and to utilize their entitlement dollars to receive HCBS, primarily through the Community-Based Alternatives waiver program. The Texas Health and Human Services Commission implemented the program September 1, 2001, and the policy was subsequently codified into law. The MFP policy has been highly successful in relocating individuals from nursing facilities to the community. As of December 31, 2007, 12,461 individuals had transitioned from nursing facilities.[24]

Maryland enacted the Money Follows the Individual Act, which requires admission to an HCBS waiver program if (1) an individual is living in a nursing home at the time of the application for waiver services, (2) the nursing home services for the individual were paid by Medicaid for at least 30 consecutive days immediately prior to the application, (3) the individual meets all of the eligibility criteria for participation in the waiver program, and (4) the home and community services to be provided to the individual will qualify for Federal matching funds.

There is no single profile of a nursing facility resident who would be considered a good candidate for transition. Individuals of all ages with many different diagnoses and varying disability levels have successfully transitioned. However, some factors are considered essential for an individual's successful transition: motivation for discharge, community supports, and available housing. People who lost their home during a nursing home stay and those whose home is not accessible can find it difficult to transition.

Some states have used the nursing home minimum data set (MDS) or other screening and assessment tools to identify potential candidates.[25] The MDS is a core set of screening and assessment elements that forms the foundation of the comprehensive assessment for nursing facility residents. By looking at factors captured in these data sets—such as medical needs, functional status, desire to transition, and length of stay—transition programs can screen for potential candidates, who can then be further assessed for transition.

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, and some of those who do may face insurmountable transition barriers. Therefore, programs should not rely solely on screening tools but should work with persons and groups who know the nursing home residents. Such knowledge can make them invaluable sources of information to identify appropriate transition candidates.

Minnesota enacted legislation in 2005 requiring its Department of Human Services to develop a methodology for sharing MDS data with Independent Living Centers to assist them in identifying institutional residents who want to live in the community.[26]

North Carolina added a transitions protocol to the Medicaid Uniform Screening and Assessment Tool, and obtained a Data Use Agreement Amendment that allows the State to use MDS data to identify those wanting to transition.[27]

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. A number of states use Independent Living Centers to both assist in the identification of individuals and with the transition process. The expertise and capabilities of such community organizations should be tapped early on to ensure effective collaboration.

Based on the experience of Systems Change NFT Grantees, the following methods have proved to be most effective in identifying individuals with the highest potential for community living: (1) targeted outreach and education by local transition coalitions to nursing facility staff, including administrators, social workers, discharge planners, and directors of nursing; (2) outreach activities for residents of nursing facilities; and (3) education of and collaboration with regional nursing facility ombudsmen.[28]

Use of Peers to Facilitate Transition

Utah developed a statewide network of trained ILC transition coordinators and peer mentors who can provide information to any nursing home resident contacting an Independent Living Center for transition services.

State transition program staff should anticipate some resistance to transition activities among nursing home staff and family members. Several Systems Change NFT Grantees considered such resistance to be a major transition barrier. Some nursing facility staff do not believe that individuals with extensive functional limitations or medical and nursing needs can be safely served in the community. In addition, some nursing facilities may actively resist transition efforts, believing that such efforts will decrease their occupancy rates and profitability. Even if families do not oppose their relative's transition, their ability to support it and/or provide informal care depends on a wide range of factors, including work commitments, available time and money, distance from their home, and the age of any dependent children. In some instances, family members may not want to provide informal care, particularly if the relative's admission to a nursing facility followed many years of informal care at home and caregiver "burnout."

Dealing with resistance can require considerable time and effort, and in some cases such resistance may pose an insurmountable transition barrier, particularly if the individual seeking transition has extensive needs and no family or friends willing or able to provide informal care. (See the Resources section of this chapter for publications describing nursing facility transition programs.)

Involving and Collaborating with Key Stakeholders[29]

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 stakeholders. Stakeholders include consumers, families, consumer advocates, nursing facility administrators and discharge planners, HCBS providers, Independent Living Centers, housing authorities, and state agency staff.

A good way of taking these interests into account, and thus increasing an NFT program's chance of success, is to develop relationships and partnerships with these key stakeholders, particularly at the direct service level (e.g., the community organizations that provide services and supports), which can facilitate effective coordination of transition activities. Involving nursing facility provider associations in one project's work group helped the project to succeed by allaying providers' fears and gaining their support. Project staff also made presentations to individual nursing facilities to introduce the program and answer questions from administrators, directors of nursing, and social services staff; this strategy proved to be valuable, as about 85 percent of the project's referrals came from nursing facilities.

Some stakeholders can assist the state Medicaid program with identifying the home and community service infrastructure necessary for a successful transition, and can help design service and support systems. It is important that the key stakeholders involved include individuals or groups with experience in moving people out of nursing facilities and that they be involved at the earliest feasible point in the process.

In general, states need to use two approaches to develop a successful and sustainable transition program: (1) a "top-down" approach that elicits the involvement and support of the leadership of key agencies to reduce barriers and urge cooperation; and (2) a "bottom-up" approach of fostering cooperative staff relationships in the field to facilitate referrals and address specific transition issues. Although efforts to involve stakeholders can be time consuming, the resulting goodwill and improved communication ultimately contribute to successful transitions.

Collaborating with Key Stakeholders: State Examples

New Jersey's Community Choice counselors work in all of the State's nursing homes and have developed invaluable collaborative relationships with nursing home social workers and admission staff. This collaboration enables dialogue and cooperation, thereby facilitating the transition process.

North Carolina established 16 regional coalitions to work on nursing facility transitions, and the Divisions of Medical Assistance and Vocational Rehabilitation Services, as well as Independent Living Centers, use state, local, and private resources to provide transition services.

Nebraska created transition partnerships statewide among all the State's Area Agencies on Aging (AAAs) and nursing facilities to identify residents who were likely candidates for transition and to facilitate successful transitions for those candidates. The State also established a statewide toll-free number for nursing facility transition assistance that routes callers to the appropriate AAA.

Developing and Implementing Case Management/Service Coordination Systems That Support Transition[30]

The primary service needed to ensure a successful transition is case management, also called care management, service coordination, transition coordination, or relocation assistance. In general, individuals with severe disabilities and medical needs who have no informal care will require more intensive case management than those with lesser needs. Individuals without their own or family housing in the community will also require assistance in finding affordable and accessible housing.

Transition case management is an intensive process that includes a range of activities: identifying and coordinating services, motivating participants, working with participants' families or friends, assisting participants in finding housing and other resources, and assessing participants' living arrangements for health and safety issues. The use of a person-centered planning format—one that involves all stakeholders in the transition—enables the development of a cohesive transition and service plan, which is essential to successful and safe transitions. With regard to specific case management practices, having transition staff present on the day of relocation can help to ensure a smooth transition.

Medicaid allows states to pay for case management services related to transitioning an individual from an institution, as long as they do not duplicate regular discharge planning services paid for through Medicaid or another source. Medicaid-reimbursable case management services that help to ensure a successful transition include the following:

- Discussing options with the resident.
- Arranging visits to potential settings and assisting the resident to obtain essential furniture and household items.
- Providing education and training for the resident prior to discharge.
- Arranging transportation on moving day.
- Implementing a plan of care so that services are available immediately when the individual moves.

Three options are available for obtaining Medicaid reimbursement for case management services: case management as a waiver service, the targeted case management option, and administrative claiming.[31] (The advantages and drawbacks of each of these payment methods are described in Chapter 4.)

The targeted case management option is likely to offer the most flexibility because it can be targeted specifically to persons who are being transitioned. 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, which are necessary for the optimal functioning of a Medicaid beneficiary in the community. State Plan targeted case management services must

include the following four components: assessment of need, plan of care development, referrals and linkages, and monitoring and follow up activities. States desiring to provide transition 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.

CMS policy regarding case management services specifically recognizes that some individuals may require a considerable amount of time to transition to the community. It is 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 case management services are provided under the targeted case management option, states may specify a shorter time period or other conditions under which the services may be provided.[32]

Case management furnished as a service under an HCBS waiver program may also be provided to institutionalized persons during the last 180 consecutive days prior to discharge. However, Federal financial participation (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 the Resource section of this chapter for a link to CMS State Medicaid Director letters providing guidance on this topic.)

Although Medicaid policy regarding case management is flexible and allows payment for services over a 6-month period, states need to ensure that the amount of case management it covers is sufficient—particularly for nursing home residents who lack housing, have weakened community connections, or are dependent on the institutional environment. In such instances, the individual's needs may exceed case managers' ability and time to provide the services needed. States need to ensure both a sufficient number of case managers and sufficient time for them to complete complex transitions.

Connecticut funds six full-time transition coordinators to provide outreach and transition services, and a toll-free line for nursing facility residents that gives them direct access to a transition coordinator.

Ensuring adequate transition capacity may require education and training for hospital and nursing home discharge planners, nursing facility staff, and community case managers about home and community services, generally, and nursing facility transition, specifically.

Identifying and Addressing Housing Needs and Rental Assistance

Lack of accessible, affordable, and safe housing is a major transition barrier. Waiting lists for both services and rental assistance present a major coordination challenge. Individuals may receive a rental assistance voucher after waiting a year but be unable to use it because a waiver slot is not yet available. Only those individuals with informal support may have the option of transitioning and then waiting for waiver services. In some cases, individuals may remain in nursing facilities solely because there are no other housing alternatives.

Housing requirements 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/long-term care 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.

Successfully addressing housing issues often requires considerable time and effort. The services of a dedicated housing coordinator are invaluable in helping nursing facility residents find suitable housing. This individual can also work at the policy level to increase awareness of the need for housing for persons relocating and to address the need for affordable, accessible housing for all persons with disabilities.

If dedicated staff are not feasible, one way of finding affordable, accessible housing is to call housing unit managers and developers to let them know of unmet need and to impress on them the importance of notifying transition counselors of available units. Once potential housing has been identified, it is beneficial to have nursing home residents visit the prospective residence or apartment in order to identify any potential problems or barriers in advance—for example, a physical layout that does not accommodate their needs.

Some states are using Housing and Urban Development (HUD) Section 8 rental vouchers for individuals who are transitioning to help them secure affordable, accessible housing. Housing authorities in some Maryland counties changed their priority criteria on housing voucher set-asides to allow persons in a nursing facility who are on the housing voucher list to move to the top of the list when they become eligible for waiver services. Similarly, the Spokane Housing Authority in Washington State has designated individuals leaving nursing facilities as "homeless," enabling them to bypass a 2-year waiting list for rental assistance vouchers. An Independent Living Center in Spokane now has an ongoing process for assisting nursing facility residents with housing voucher applications. Waiver transition funds or state general funds pay for this service.[33] Other states have created rental assistance programs for individuals seeking diversion or transition from nursing facilities, such as Arkansas's Bridge Rental Assistance Program, which bridges the gap between income and the cost of affordable apartments for persons transitioning or being diverted from nursing homes.[34]

Arkansas's Bridge Rental Assistance Program

The Arkansas Supported Housing Office and the Governor's Task Force on Supported Housing recommended the creation of a rental assistance program for individuals who are being diverted or are transitioning from nursing homes. Under the State's Nursing Facility grant initiatives, Spa Area Independent Living Services, the Arkansas Development Finance Authority, and Arkansas Rehabilitation Services developed and implemented the Bridge Rental Assistance Program. Individuals who apply for Section 8 vouchers and are on a waiting list are provided a monthly rental stipend for up to 2 years, while case managers work with them to create and execute a plan for housing self-sufficiency. The Bridge Rental Assistance Program is being sustained through funding from the Arkansas Development Finance Authority.[35]

Assessments for Accessibility

Environmental modifications are often crucial to a state's ability to serve an individual in the community. Federal financial participation 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 safeguard 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; if so, FFP is available at the service match rate for these providers when they perform the assessment in addition to their other duties. (See the Resource section of this chapter for the link to the

State Medicaid Director letter regarding payment of assessments for accessibility and environmental modifications.)

Providing Flexible Funding Mechanisms

Many resources are needed to help individuals relocate from nursing facilities to community settings, including but not limited to subsidized accessible housing, transition funds, services and supports, and a wide range of local community resources, including transportation. To provide adequate services for individuals who are transitioning, it may be necessary to combine services from multiple funding sources, for example, HCBS waiver services, home health services, and state-funded programs. Inflexible funding streams and a lack of mechanisms to coordinate funding can pose transition barriers.

Because Medicaid-eligible residents in institutions have only a small monthly personal needs allowance, they lack the financial resources to pay for one-time transition expenses, such as security deposits for rent, utilities, and phone service, and essential furniture and household items. CMS permits coverage of these one-time transition expenses under HCBS waiver programs. The CMS HCBS waiver application defines these expenses as Community Transition Services:

> *Community Transition Services are non-recurring set-up expenses for individuals who are transitioning from an institutional or other provider-operated living arrangement to a living arrangement in a private residence where the person is directly responsible for his or her own living expenses.*
>
> *Allowable expenses are those necessary to enable a person to establish a basic household that do not constitute room and board and may include* ***(a) security deposits*** *that are required to obtain a lease on an apartment or home;* ***(b) essential household furnishings*** *required to occupy and use a community domicile, including furniture, window coverings, food preparation items, and bed/bath linens;* ***(c) set-up fees or deposits*** *for utility or service access, including telephone, electricity, heating and water;* ***(d) services necessary for the individual's health and safety*** *such as pest eradication and one-time cleaning prior to occupancy;* ***(e) moving expenses; (f) necessary home accessibility adaptations;*** *and,* ***(g) activities to assess need, arrange for and procure needed resources.***
>
> *Community Transition Services are furnished only to the extent that they are reasonable and necessary as determined through the service plan development process, clearly identified in the service plan, and the person is unable to meet such expense or when the services cannot be obtained from other sources. Community Transition Services do not include monthly rental or mortgage expense; food, regular utility charges; and/or household appliances or items that are intended for purely diversional/recreational purposes.*

States are permitted to supplement or modify this definition to reflect the specific expenses they want to include in their waiver program and may also list expenses that are specifically excluded. While Federal law prohibits Medicaid payment for room and board, payment of a security deposit to a landlord is not considered rent. Medicaid Community Transition Services may not be used to pay for furnishing living arrangements that are owned or leased by a waiver service provider where the provision of these items and services are inherent in the service they are already providing.

One-time transition expenses for waiver participants can be billed when the individual leaves the institutional setting and becomes a waiver participant. For these expenses to be reimbursable, the individual must be reasonably expected to be eligible for and to enroll in the waiver. If for any reason the individual does not enroll in the waiver (e.g., due to death or a significant change in condition), transition expenses may be billed to Medicaid as an administrative cost.

Some states have chosen to use state funding for transition expenses. New Jersey began covering transition expenses under the Enhanced Community Options and Assisted Living waiver programs. For persons ineligible for these waivers, transition expenses can be covered through a special fund established under the State's Systems Change NFT

grant. Two other states—Ohio and Wyoming—have also appropriated funds to cover one-time transition expenses not covered by Medicaid.[36]

South Carolina added a nursing facility transition services package to the Elderly and Disabled waiver that covers housing and utility deposits and basic furniture and appliances. All items must be required by the service plan, and total expenditures are capped at $1,000. The State also enhanced coverage for environmental modifications for all waiver participants, and now covers bath safety items and door widening.[37]

Individuals who are receiving Medicaid-funded institutional services have had to spend down their assets and some may have credit issues that prevent them from obtaining phone, utility, and other services that require a good credit history. Transition coordinators need to address this potential barrier early in the planning process.

Preventing Unnecessary Admissions and Avoidable Long Stays

Although transitioning people out of institutions can save money over the long term, the process can incur major costs, and not all may be reimbursable by Medicaid. Given this, it makes sense for states to consider strategies that will divert people from entering institutions in the first place and ensure a quick return to the community if placement is unavoidable.

The ICFs/ID experience illustrates that the best transition program is one that makes sure that very few people will need to be transitioned. In the ID/DD field, this is known as the front door/back door connection. Little progress with transitioning can be made as long as the front door to the institution remains open; intervention before inappropriate placement (i.e., diversion) is easier than intervention after placement.

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 in the immediate period after transition and for the first few months. 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 participant direction model allow individuals to assume more responsibility and accountability than those that use an agency-directed model. (See Chapter 7 for a full discussion of participant direction service delivery models).

The assurances CMS requires from states for approval of HCBS waiver services include "necessary safeguards" to safeguard 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. (See the Appendix for an overview of CMS requirements for quality management and improvement systems.)

Diversion Strategies: State Examples

Several states have recognized the need to prevent both unnecessary nursing facility admissions and unnecessarily long stays that result in a loss of housing.

Rhode Island developed a protocol for the State's long-term care nurses—who conduct level-of-care determinations and Level I Preadmission Screening and Resident Review (PASRR)[38]—to identify and refer individuals who do not appear to be at risk for a long stay when admitted. Based on the success of this protocol, in 2005 the State enacted a statute requiring that registered nurses (RNs) reevaluate all new nursing facility admissions 45 days after admission. The RNs who perform level-of-care and PASRR determinations flag individuals who appear to require only a short stay, and a computer-generated letter to this effect is sent to the resident and the nursing facility. A computer-generated reminder is sent to the RNs 45 days after admission, instructing them to evaluate the most recent MDS assessment to determine whether a continued stay is required.[39]

Rhode Island also enacted a statute in 2004 requiring the Department of Human Services (DHS) to inform nursing facility residents about home and community services that may enable them to live in a less restrictive community setting or their own home. The law requires DHS to mail a brochure describing the range of available services to all nursing facility residents whom the state long-term care nurses have identified as likely candidates for discharge within several months of admission.[40]

Nebraska operates a nursing facility preadmission program—Senior Care Options (SCO)—to ensure that Medicaid applicants in need of nursing facility care receive information on alternative choices appropriate to their level of care. SCO staff, located throughout the State, are trained to use the Blaylock Risk Assessment Scoring System (BRASS) screening tool, an instrument that identifies patients at risk for prolonged hospital stays at admission and in need of discharge planning services; BRASS can also be used to identify individuals at risk for long nursing home stays.

As a result of positive experience with the tool, the State changed its preadmission screening procedures. Every AAA now employs the BRASS tool for preadmission screening to identify individuals who should be reassessed in 3 to 6 months. For these individuals, Medicaid provides only a short-term authorization to enter a nursing home so that they will have to be reassessed to remain there. This change has led to active discharge planning to return new admissions to the community, and has resulted in shorter nursing home stays.[41]

Nebraska also allows service coordinators to authorize waiver services for individuals who will likely be eligible for Medicaid coverage. Based on basic financial information provided by the applicant, the service coordinator consults with a Medicaid eligibility worker who can judge whether it appears that the applicant will be eligible for Medicaid. If, ultimately, the applicant is not eligible, the State uses funds from the Social Services Block Grant to pay for services, which has occurred only twice over a 2-year period.[42]

New Jersey's preadmission screening process for all nursing home admissions designates Medicaid beneficiaries as "Track One" or "Track Two" depending on whether they are likely to remain in the facility for a long or short period of time. All short-term residents receive a letter indicating that they are certified for 6 or fewer months and are contacted by Community Choice counselors who work with them to develop a relocation plan.[43]

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key resources relevant to transitions. Most of the publications cite additional resources and the websites also have links to other information sources.

Publications

Centers for Medicare & Medicaid Services. (2008). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria*.

This publication contains extensive information concerning Federal policies that apply to the operation of an HCBS waiver, in particular, Appendix C-3: Waiver Services Specifications, and C-3H: Services to Facilitate the Transition of Institutionalized Persons to the Community.

Available at https://www.hcbswaivers.net/CMS/faces/portal.jsp under links and downloads, entitled §1915(c) Waiver Application and Accompanying Materials.

O'Keeffe, J., O'Keeffe, C., Greene, A.M., and Anderson, W. (2008). *Enduring Changes of the FY 2001 and FY 2002 Nursing Facility Transition Grantees*. Baltimore, MD: Centers for Medicare & Medicaid Services.

This issue brief provides a summary overview of the accomplishments and enduring changes brought about by all of the Systems Change NFT Grantees. Despite achieving many enduring systems improvements, Grantees reported that many transition barriers remain. Grantees made recommendations to help states address continuing barriers to nursing facility transition and diversion.

Available at http://www.hcbs.org/moreInfo.php/doc/2353

O'Keeffe, J., O'Keeffe, C., Osber, D., Siebenaler, K., and Brown, D. (2007). *FY 2002 Nursing Facility Transition Grantees: Final Report. Baltimore, MD: Centers for Medicare & Medicaid Services.*

This report provides an overview of the 16 FY 2002 Systems Change NFT Grantees' initiatives to either establish or improve NFT programs or to help develop some components of an NFT infrastructure. The report includes lessons learned and recommendations that can guide states that are undertaking similar initiatives.

Available at http://www.hcbs.org/moreInfo.php/doc/2060

O'Keeffe, J., O'Keeffe, C., Siebenaler, K., Brown, D., Anderson, W., Greene, A.M., and Osber, D. (2006). *FY 2001 Nursing Facility Transition Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services.

This report provides an overview of the 17 FY 2001 Systems Change NFT Grantees' initiatives to either establish or improve NFT programs or to help develop some components of an NFT infrastructure. The report includes lessons learned and recommendations that can guide states that are undertaking similar initiatives. The report was referenced on page 48 of the CMS MFP Demonstration Solicitation Document.

Available at http://www.hcbs.org/moreInfo.php/doc/1678

Siebenaler, K., O'Keeffe, J., Brown, D., and O'Keeffe, C. (2005). *Nursing Facility Transition Initiatives of the Fiscal Year 2001 and 2002 Grantees: Progress and Challenges.* Baltimore, MD: Centers for Medicare & Medicaid Services.

This report provides an overview of the NFT initiatives implemented by 18 of the FY 2001 and FY 2002 Systems Change Grantees. It describes their differing approaches to nursing facility diversion and/or transition within a framework of the key steps needed to create NFT programs that are integrated into a state's long-term care system. This report also identifies the transition challenges and policy issues facing states and Independent Living Centers, discusses lessons learned from grant initiatives, and recommends programmatic and policy changes needed to support transitions.

Available at http://www.hcbs.org/moreInfo.php/doc/1308

Eiken, S., Holtz, D., and Steigman, D. (2005). *Medicaid HCBS Waiver Payment for Community Transition Services: State Examples.* Cambridge, MA: Thomson Reuters.

This topic paper summarizes how states can use Medicaid to pay for most institutional transition program costs. It also describes how states are currently using Medicaid HCBS waivers to pay for Community Transition Services—temporary supports people need when trying to move, such as housing deposits, utility set-up fees, and furniture.

Available at http://www.hcbs.org/moreInfo.php/doc/1192

Summer, L. (2005). *Strategies to Keep Consumers Needing Long-Term Care in the Community and Out of Nursing Facilities.* Washington, DC: Kaiser Commission on Medicaid and the Uninsured.

In recent years, states have been trying to shift resources from institutions to home and community services. This report examines transition and diversion policies and practices in eight states. It provides a sense of what state Medicaid programs are doing or could be doing to promote diversion. The report has a 10-page executive summary.

Available at http://www.hcbs.org/moreInfo.php/doc/1442

Websites

Centers for Medicare & Medicaid Services

CMS issues State Medicaid Director letters to clarify Medicaid policy and provide guidance to states to ensure consistency in its application. The initial Olmstead decision letter, dated January 14, 2000, and subsequent updates, can be accessed at the following website by using the word "Olmstead" in the search criteria. In particular, Olmstead Update #3, July 25, 2000, includes Attachment 3-b, Community Transition, which discusses policy changes related to case management services, assessments for accessibility, and environmental modifications.

Web address: http://www.cms.hhs.gov/SMDL/SMD/list.asp#TopOfPage

In 2007, CMS awarded MFP grants to 30 states and the District of Columbia, proposing to transition 37,731 individuals out of institutional settings over a 5-year demonstration period. The MFP demonstration is the most ambitious program to date aimed at helping Medicaid enrollees transition from long-term care institutions to the community. A series of reports are being completed as part of the MFP national evaluation and are available at the following website.

Web address: http://www.cms.hhs.gov/DeficitReductionAct/20_MFP.asp#TopOfPage

The Clearinghouse for Home and Community Based Services

This site promotes the development and expansion of HCBS by gathering resources and tools for research, policymaking, and program development into this one-stop website. Under the topic Transition/Diversion from Institutions, there are 302 publications and other resources, including all of the publications listed above, and also many states' promising practices for facilitating nursing facility to community transitions.

Web address: http://www.hcbs.org/

Endnotes: Citations, Additional Information, and Web Addresses

1 Gavin Kennedy, Gary Smith, and Janet O'Keeffe co-authored the original chapter. Janet O'Keeffe and Charles Moseley updated the chapter.

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 Prouty, R.W., Alba, K., and Lakin, K.C. (Eds.). (2008). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2007. Minneapolis, MN: University of Minnesota Research and Training Center on Community Living, Institute on Community Integration. Available at http://rtc.umn.edu/docs/risp2007.pdf. Additional print copies may be requested by contacting Naomi Scott at scot0387@umn.edu or 612-624-8246.

4 HCBS waiver programs are authorized under Section (§)1915(c) of the Social Security Act.

5 Braddock, D., Hemp, R., and Rizzolo, M.C. (2008). The State of the States in Developmental Disabilities, 2008. Boulder, CO and Washington, DC: Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, and American Association on Intellectual and Developmental Disabilities.

6 New Hampshire, Vermont, Rhode Island, West Virginia, Maine, New Mexico, Alaska, Hawaii, Indiana, and Oregon.

7 Prouty, R.W., Alba, K., and Lakin, K.C. (Eds.). (2008), op. cit.

8 Institutional services for persons with developmental disabilities are generally much more costly than nursing home services.

9 Although the need for such intensive services may continue indefinitely for some persons, for others, the level of support required may decrease over time.

10 Additional Federal matching funds were provided to states transitioning people from institutions to community services under the Federal MFP state demonstration grants to assist them with developing the necessary community infrastructure, among other objectives.

11 While per capita service plans may exceed the average cost of institutional services, the aggregate costs for the waiver program must meet Medicaid cost neutrality requirements.

12 Smith, G., Fortune, J., and Agosta, J. (2006). Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities: Profiles of State Supports Waivers. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. Available at http://aspe.hhs.gov/daltcp/reports/2006/gauging.htm.

[13] Prouty, R.W., Alba, K., and Lakin, K.C. (Eds.). (2008), op. cit.

[14] Version 3.5. See the Resources section of this chapter for a web link to the waiver application, instructions, and technical guidance.

[15] NFT grants were provided to state agencies—called State Program grants—and to Independent Living Centers—called Independent Living Partnership (ILP) grants. The purpose of the ILP grants was to capitalize on ILC expertise to develop outreach materials, identify and support nursing facility residents who want to transition, provide technical assistance, and supplement state transition infrastructure.

[16] These are not the grants awarded through the MFP demonstration authorized under the Deficit Reduction Act of 2005 (DRA-2005).

[17] Additional challenges are involved when downsizing or closing an institutional facility, including ensuring that any special services provided in the facility will be available to individuals after they have left the institution, maintaining the quality of facility services and worker morale, assisting workers to find other employment, and addressing the "dual funding" problem (i.e., meeting the costs of maintaining facility operations while underwriting the costs of community placement).

[18] Information in this section draws liberally from O'Keeffe, J., O'Keeffe, C., Greene, A.M., and Anderson, W. (2008). Enduring Changes of the FY 2001 and FY 2002 Nursing Facility Transition Grantees. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at http://www.hcbs.org/moreInfo.php/doc/2353.

[19] Information in this section draws liberally from O'Keeffe, J., O'Keeffe, C., Greene, A.M., and Anderson, W. (2008), op. cit.

[20] See CMS Press Release, available at http://www.hcbs.org/moreInfo.php/doc/1909. See also CMS website about the MFP demonstration at http://www.cms.hhs.gov/DeficitReductionAct/20_MFP.asp#TopOfPage.

[21] Section 6071 of DRA-2005.

[22] P.L. 111-148 (signed on March 23, 2010) and the Health Care and Education Reconciliation Act of 2010 (signed on March 30, 2010).

[23] The reports and other information concerning the MFP demonstration can be found at http://www.cms.hhs.gov/DeficitReductionAct/20_MFP.asp.

[24] Texas Health and Human Services Commission. Medicaid Reform Strategies for Texas. February 2007.

[25] Federal law mandates use of the MDS for all residents of facilities that are certified to participate in Medicare or Medicaid skilled nursing facilities 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, and Triggers.

[26] O'Keeffe, J., O'Keeffe, C., Greene, A.M., and Anderson, W. (2008), op. cit.

[27] Ibid.

[28] O'Keeffe, J., O'Keeffe, C., Osber, D., Siebenaler, K., and Brown, D. (2007). FY 2002 Nursing Facility Transition Grantees: Final Report. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at http://www.hcbs.org/moreInfo.php/doc/2060.

[29] Information in this section draws liberally from O'Keeffe, J., O'Keeffe, C., Osber, D., Siebenaler, K., and Brown, D. (2007), op. cit.

[30] Ibid.

[31] Case management can also be provided as an integral and inseparable part of another covered service.

[32] Medicaid funding is not available for targeted case management services provided to persons who are receiving services in an institution for mental disease, except for services provided to elderly individuals and children under the age of 21 who are receiving inpatient services.

[33] O'Keeffe, J., O'Keeffe, C., Greene, A.M., and Anderson, W. (2008), op. cit.

[34] Ibid.

[35] O'Keeffe, J., O'Keeffe, C., Osber, D., Siebenaler, K., and Brown, D. (2007), op. cit.

[36] Ibid.

[37] Ibid.

[38] Medicaid regulations require states to maintain a program to screen nursing facility applicants and residents for serious mental illness and intellectual disability. The program's intent is to ensure that individuals are placed in the most appropriate setting and have access to specialized mental health services where appropriate. To do this, the program uses a progressive screening process to assess whether applicants for nursing facilities have a mental illness or an intellectual disability, and if the nursing facility is an appropriate placement.

The first test, Level I, screens for potential mental illness. All those who test "positive" must receive a more in-depth screen—Level II—that more accurately identifies mental illness and assesses whether the individual needs specialized services and nursing facility level of care. Linkins, K., Lucca, A., Housman, M., and Smith, S. (2006). PASRR Screening for Mental Illness in Nursing Facility Applicants and Residents. Report prepared for the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. Available at http://download.ncadi.samhsa.gov/ken/msword/SMA05-4039.doc.

[39] O'Keeffe, J., O'Keeffe, C., Greene, A.M., and Anderson, W. (2008), op. cit.

[40] O'Keeffe, J., O'Keeffe, C., Osber, D., Siebenaler, K., and Brown, D. (2007), op. cit.

[41] O'Keeffe, J., O'Keeffe, C., Greene, A.M., and Anderson, W. (2008), op. cit.

[42] Example taken verbatim from the Executive Summary of Summer, L. (2005). Strategies to Keep Consumers Needing Long-Term Care in the Community and Out of Nursing Facilities. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. Available at http://www.hcbs.org/moreInfo.php/doc/1442.

[43] Ibid.

Guide to Chapter 7

Introduction 177
Evolution of Participant Direction of Medicaid HCBS 178
Basic Features of Participant Direction of Medicaid HCBS 179
Federal Medicaid Statutory Authorities 180
1. State Plan Coverage of Personal Care 181
2. HCBS Waiver Authority 183
3. State Plan Coverage of HCBS 185
4. State Plan Coverage of Participant-Directed Personal Assistance Services 186
5. State Plan Community First Choice Option 188
Service Planning and Authorization 189
Use of Representatives 190
Individualized Backup Plans 190
Building Flexibility into the Service Plan While Ensuring Equitable Budgets 191
Employing Family Members 192
Non-Personal Care Services 192
Furnishing Assistance to Individuals in Managing and Directing Services 193
Information and Assistance 193
Financial Management Services 195
Performance of Skilled Nursing Tasks 199
Resources 200
Endnotes: Citations, Additional Information, and Web Addresses 203

Chapter 7
Participant-Directed Services and Supports

Like those without disabilities, 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 and the individuals who provide them. Virtually every state now has at least one participant direction program under Medicaid that provides options for individuals to direct and manage their own services and supports, with the assistance of family members when needed. Participant-directed services are an alternative to—and can be offered alongside—the traditional service delivery model. This chapter describes the main features of participant-directed home and community services, and the interplay between participant direction options and Medicaid policy. It focuses on services furnished through five Medicaid authorities, including Section (§)1915(c) waivers, the §1915(i) Home and Community-Based Services (HCBS) State Plan benefit, and §1915(j) Participant-Directed Personal Assistance Services. Medicaid gives states the authority to provide a full range of options for participant direction—on a continuum from less to more control and responsibility.[1]

Introduction

Participant direction, referred to alternatively as consumer direction, self-direction, and participant-driven supports, is a service model that offers individuals and their families the opportunity, support, and authority to choose the services they need and direct the individuals who provide them.[2] Participant direction principles have broad applicability for individuals of all ages who need long-term care services and supports (hereafter called services and supports) due to physical or cognitive impairments, including those caused by serious mental illness, a developmental condition, or dementia.

Participant direction has been demonstrated to promote positive outcomes for individuals and their families, improve participant satisfaction, and increase access to needed services.[3] Participant direction service models can be a means to involve individuals and families in quality assurance and improvement efforts, promote effective service delivery, and improve participant satisfaction with services.[4]

For individuals with intellectual disabilities and other developmental disabilities (hereafter referred to as developmental disabilities), participant-directed services are considered an essential element of self-determination, the philosophy that continues to reshape the provision of services and supports for this population. A key principle of self-determination is that individuals should have the authority to direct and manage their own lives, including their services. Individuals may invite and enlist friends and family members to assist them in directing and managing services.[5] An individual's legal representative or surrogate decision maker may also provide assistance and advice and perform some service management tasks (as they can for all individuals who need assistance to direct their services).

Participant direction models can operate side by side with traditional service delivery models, so individuals and families can choose the extent to which they wish to manage their services. Those who want to exercise a high level of control can select participant direction options, while others can have services and supports managed by a provider agency.

Evolution of Participant Direction of Medicaid HCBS

Participant direction of Medicaid home and community services began in the 1970s when a few states launched Medicaid personal assistance/attendant services programs that authorized Medicaid participants to hire, train, supervise, and dismiss their workers.[6] During the 1980s and 1990s, the number of states that authorized Medicaid participants to manage their workers grew—both through the Medicaid State Plan Personal Care optional benefit and, starting in 1981, through §1915(c) home and community-based services waivers (hereafter referred to as HCBS waivers). In 1997, the Centers for Medicare & Medicaid Services (CMS) released formal guidance (discussed in more detail below) acknowledging that states could employ a "participant-directed service delivery model" for the delivery of personal care/assistance services under the Medicaid State Plan.

In 1995, the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services (HHS) launched the National Cash and Counseling Evaluation Demonstration.[7] Its aim was to test a broader approach to participant direction that gave participants the authority to manage an individual budget and the latitude to use this budget to purchase goods and services to meet their service and support needs. The demonstration also gave participants the option of receiving allowances in cash to purchase services and supports, or have their funds deposited with an entity that would perform financial transactions under their direction.[8]

In the same year, RWJF also launched its Self-Determination for People with Developmental Disabilities Program.[9] RWJF awarded grants to 18 states to create pilot programs that gave individuals and families a leadership role in the design of person-centered service plans along with choice and control over an individual budget to carry out the service plan. These pilots also featured the provision of independent counseling services (specifically referred to as Support Broker services) to assist participants in selecting and managing services, along with fiscal intermediaries to serve as their agents to handle employment-related tasks. The Self-Determination pilots operated within the regulatory confines of the HCBS waiver program and, therefore, did not permit individuals or their representatives to receive any benefits directly as "cash."

In response to the favorable early evaluation results from the Cash and Counseling Demonstration, experience garnered through the Self-Determination pilots, and rapidly growing state interest in offering participant direction options, CMS launched its Independence Plus initiative in 2002, which provided guidance to the states about incorporating employer and budget authority into a waiver program.[10] CMS also issued separate templates for Independence Plus programs operating under the HCBS and §1115 waiver authorities.

In 2005, CMS extensively modified its standard HCBS waiver application so that states could include a participant direction option in any HCBS waiver, eliminating the need for a separate Independence Plus waiver. The new waiver application built upon the predecessor Independence Plus waiver template and further clarified the Federal policies that apply when a participant direction option is implemented in an HCBS waiver. To date, at least 37 states have a participant direction option in one or more HCBS waivers.[11] However, some states offer only the employer authority and some have experienced slow enrollment in participant direction options.

In the Deficit Reduction Act of 2005 (DRA-2005), Congress added two statutory provisions that offer states additional options to incorporate participant direction into the delivery of Medicaid HCBS without having to seek Federal waivers.[12] These provisions are discussed in more detail below.[13] In the space of about 10 years, Federal Medicaid policy has evolved to provide states with several options to afford Medicaid participants wide-ranging authority

to direct their services and supports, including the option to direct an individual budget.

Basic Features of Participant Direction of Medicaid HCBS

The sections below describe in detail the legal authorities that permit incorporation of participant direction into the delivery of Medicaid HCBS. While each authority has unique elements, certain basic features of participant direction cut across the authorities. These features are described next.

Individual Election of Participant Direction. The various authorities have different requirements regarding the provision of alternatives to participant direction.

- When a state offers participant direction through an HCBS waiver program, it must provide that participants may opt into or out of directing their services, that is, a state must offer a "provider-managed" service delivery option alongside the participant direction option and ensure there are no service breaks during transition periods.
- Participant direction programs operated under the State Plan Personal Care benefit are not required to use a particular service delivery model or to offer more than one service delivery model; nor are they required to specify policies for voluntary or involuntary transition from participant-directed services to other types of service delivery, such as agency-provided services.
- If a state chooses to use the §1915(j) authority to permit self-direction of State Plan personal care services, it must ensure that participants may opt into or out of directing their services and that a traditional service delivery option is available. Because traditional service delivery models vary, they are not specified here. If a state uses the §1915(j) authority in conjunction with the HCBS waiver authority, the requirements of the latter authority must be met.
- Under §1915(i), CMS requires states to have policies to facilitate voluntary or involuntary transitions from participant-directed services to non-participant-directed service delivery models.

Participant-Led Service Planning Process. Another important feature is positioning the participant (or a personally-selected personal representative) to lead the person-centered service planning process. This includes giving participants the authority to select who participates in the process (e.g., family members and friends), and ensuring that participants' service plans reflect their preferences and goals. Participants are expected to have the authority to select their services and supports, in addition to exercising free choice of provider, a long-standing right under Federal Medicaid law.[14]

Managing Workers. All of the pertinent Medicaid authorities allow participants to select, hire, supervise, and manage their workers—called the *Employer Authority*. Under this authority, a state may recognize Medicaid participants (or their representatives) as the legal ("common law") employers of their workers and provide for the use of Fiscal/Employer Agents (F/EAs) to pay workers and file payroll taxes on their behalf. A state also may elect to use a "co-employer" model whereby an organization serves as the primary or legal employer of participant-hired workers, while the individual or their representative serves as the *secondary* or managing employer.[15] This co-employer model is commonly referred to as the Agency with Choice model.

Individual Authority Over Service Delivery. Participant direction of Medicaid services and supports also allows participants to determine how and when services are delivered. This includes specifying the elements of services that will be delivered (within the approved scope of the service(s) that the state offers), scheduling the delivery of services, and establishing any additional special qualifications for the workers or agencies that provide services.[16]

Individual Budget. Under the §1915(c) and §1915(j) authorities, participants may be provided an individual budget that includes some or all of their service and support funding and the ability to exercise decision-making authority and manage-

ment responsibility to purchase goods and services authorized in the service plan—called the *Budget Authority*.[17] Participants, with the aid of counselors (i.e., information and assistance providers) and the financial management services entity, assume responsibility for managing their individual budgets.

Supports for Participant Direction. The §1915(c) and §1915(j) authorities specifically require states to provide certain key supports to participants who direct their services: financial management services and information and assistance. The proposed rule for the §1915(i) authority also addresses the provision of these two support services. However, its requirements are not included here because at the time of publication, the rule had not yet been finalized.

- **Financial management services.** These services include performing financial transactions on behalf of participants (e.g., paying workers that participants employ, deducting payroll taxes, and under the §1915(c) and §1915(j) authorities, facilitating the purchase of other goods and services) along with tracking expenditures against the individual budget.
- **Information and assistance in directing services and supports.** Medicaid funding is available to reimburse the costs of personalized assistance to participants in directing their services. Such assistance may include (a) counseling participants about available services and supports, (b) helping them to acquire the skills to create and manage the individual budget and to manage their individually employed workers, (c) assisting them in locating workers and services, and (d) accessing other benefits and community resources. States use various terms for this type of assistance, including counseling, supports brokerage, supports coordination, or consulting.

Safeguards. Finally, states are expected to provide safeguards on behalf of participants who direct their services. These include ensuring that services are not interrupted when an individual elects to transition from participant direction to provider-managed services, guarding against the premature depletion of the individual budget, and ensuring that participants have an individualized backup plan to handle breakdowns in service delivery.

Under the applicable authorities, states have considerable latitude in how they implement each of these participant direction features.

Federal Medicaid Statutory Authorities

There are five principal Medicaid authorities under which states may implement participant direction of home and community services. (A sixth authority—a §1115 waiver—is available under certain conditions[18] [see Box].)

Four of the five are Medicaid State Plan authorities. A state can add participant direction options under the State Plan by submitting a State Plan amendment to CMS for review and approval. Once approved, it becomes part of the state's Medicaid program unless subsequently altered by the state. The fifth is a waiver authority, that is, states can request waivers of Federal statutory provisions in order to furnish services in a fashion not otherwise permitted under the Medicaid State Plan.

Section 1115 Waivers[19]

Before the enactment of the §1915(j) authority, Federal law did not easily accommodate the incorporation of the full range of participant direction options into the delivery of personal care services furnished through the Medicaid State Plan. As a consequence, the §1115 authority had to be invoked when a state was interested in implementing a wide-ranging participant direction option (including budget authority) for State Plan personal care services.[20]

With the availability of the §1915(j) and other authorities for implementing participant direction options, states now have little or no reason to invoke the §1115 waiver authority solely to initiate a participant-directed services option for Medicaid HCBS except in so far as participant direction is a component of a broader Medicaid reform proposal. As a general matter, §1115 waivers may only be used to test service delivery approaches that are not otherwise feasible under Medicaid law.

Table 7-1 summarizes the key features of participant direction programs under four of the five principal Medicaid authorities. The remainder of this section describes the basic scope of each authority and how it can be applied with respect to participant direction.

1. State Plan Coverage of Personal Care

Under §1905(a)(24) of the Social Security Act, a state has the option to cover personal care services under its Medicaid State Plan. (See Chapter 1 and Chapter 7 for more information about this authority.) Thirty-two states cover personal care under their Medicaid State Plans.[21] When personal care is covered under the Medicaid State Plan, it must be provided to all Medicaid participants who require such services. Because Personal Care is an optional State Plan benefit, a state may impose limitations on the amount, frequency, and duration of the services that it provides to eligible participants.

Participant Direction of Personal Care

In 1997, CMS issued revised guidance concerning the provision of personal care under the Medicaid State Plan.[22] In this guidance, CMS confirmed that states have the option to use a participant direction model, where "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." States may also permit family members or others specified in the service plan to direct the provider on behalf of the individual receiving the services.

Many states that cover personal care under the Medicaid State Plan authorize participant-directed services.[23] In some states (e.g., Maine and Massachusetts), third-party entities (often Independent Living Centers) facilitate participant direction by performing payroll and related employment functions on behalf of program participants (hereafter, called participants) who select and manage their workers. Elsewhere (e.g., California and Michigan), the state itself or its claims payment contractor performs payroll and tax-filing functions as the participant's employer-agent.

There are two main limitations concerning the extent to which participant direction can be used in conjunction with the delivery of personal care under the Medicaid State Plan.

- When personal care is covered under §1905(a)(24), the budget authority may not be used and personal care dollars may not be redirected or cashed out (i.e., converted to a budget) to purchase other types of goods and services. Medicaid dollars may only be used to pay for the provision of personal care.
- Legally responsible relatives (i.e., parents of minor children and spouses) may not be paid to provide personal care. However, other relatives (at a state's option) can be paid to provide personal care.

Table 7-1. Participant Direction Features of the Optional Medicaid Authorities

Features	§1905(a)(24) State Plan Personal Care Services	§1915(c) Home and Community-Based Services Waiver	§1915(i) State Plan Home and Community-Based Services	§1915(j) Self-Directed Personal Assistance Services
Employer Authority	Allowed	Allowed	Allowed	Required
Budget Authority	Not allowed	Allowed	Allowed	Required
Cash Payments to Participants	Not allowed	Not Allowed	Not allowed	Allowed
Direction by Representative	Allowed	Allowed	Allowed	Allowed
Hiring of Legally Responsible Individuals	Not allowed	Allowed	Allowed	Allowed
Information & Assistance	Not required	Required	Required	Required
Financial Management Services	Fiscal employer agent services only are required	Required	Required	Required, except for those receiving the cash option
Limitation on services that can be directed	Not applicable; personal care is the sole service	Allowed	Allowed	Not allowed
Availability of Non-Traditional Goods and Services	Not allowed	Allowed	Allowed	Allowed
Comparability	Cannot be waived	Can be waived	Can be waived	Can be waived
Statewideness	Cannot be waived	Can be waived	Cannot be waived	Can be waived
Availability of Non-Participant-Directed Services	Not required	Required	Not Required	Required[24]

These limitations may be overcome when a state elects to furnish participant-directed personal care under provision §1915(j) of the Social Security Act (described below).

2. HCBS Waiver Authority

Under the provisions of §1915(c) of the Social Security Act, a state may obtain Federal waivers to furnish home and community services to participants who require the level of care that is provided in a Medicaid-reimbursable institutional setting but choose to be supported in the community. All states except Arizona and Vermont operate HCBS waivers.[25] (For more information about this authority, see Chapter 1 and Chapter 4.)

Participant Direction of Waiver Services

Since the inception of the HCBS waiver program in 1981, some states allowed participants to exercise the employer authority (e.g., Oregon, Wisconsin, Washington). As previously noted, in 2002 the CMS Independence Plus initiative spelled out for the first time the essential features for incorporating participant direction into the delivery of waiver services.[26] As part of the initiative, CMS issued a stand-alone Independence Plus HCBS waiver application template for states interested in implementing participant direction of waiver services[27]

In 2004, CMS undertook a major revision of the standard HCBS waiver application.[28] The revised application, released in 2005 (and the most recent update, released in 2008), requires states to describe in detail the critical operational features of their HCBS waivers and places a stronger emphasis on waiver service quality assurance/quality management than did the previous application.[29] In conjunction with the release of the new application, CMS also released comprehensive technical guidance to states concerning various dimensions of the design and operation of HCBS waivers.[30]

An important feature of the revised HCBS waiver application is the inclusion of a distinct part (Appendix E) that is devoted to participant direction of waiver services.[31] Appendix E is designed to permit a state to incorporate participant direction into the operation of any HCBS waiver.

When states elect to include a participant direction option in an HCBS waiver, they have the latitude to shape the option along several dimensions, including

- **Limited Implementation of Participant Direction.** A state may elect to offer the participant direction option in all parts of the state or limit it to specific areas or regions, for example, to create a pilot in a specific geographic area to evaluate the program design before expanding it statewide.
- **Availability of Participant Direction by Types of Living Arrangement.** A state may decide to make its participant direction option available to all waiver program participants (hereafter called participants) or limit the option to specified groups of participants, such as persons who live with their families or in their own homes[32]
- **Direction by a Representative.** A state may allow services to be directed by a representative selected by the participant.
- **Limitation of Services That May Be Participant Directed.** A state may specify which waiver services—some or all—may be directed by participants.
- **Election of Employer and/or Budget Authority.** A state may elect to offer participants the employer authority or the budget authority—or both—over the services they may direct. In each instance, a state may limit the extent of the authority that participants may exercise.
- **Employer Authority.** A state has the option to offer two models of the employer authority: (1) "co-employer" model—also known as the "agency with choice" model, where a third party serves as the primary or legal

employer of workers that the participant selects to furnish services and the individual or representative serves as the secondary or managing employer; and/or (2) a "common law employer" model, where the participant or his/her representative is the legal employer of workers.[33] Regardless of the employer authority model used, the state may not permit payment to individuals who are ineligible to participate as providers in the Federal Medicaid program.[34]

- **Budget Authority.** A state has the option to allow participants to exercise decision-making authority and management responsibility for an individual budget to purchase goods and services authorized in the service plan. When a state offers budget authority, it may specify whether participants are afforded the flexibility to shift funds among authorized services within the total amount of the budget without prior review and approval; desired purchases that are not in the service plan, however, must be formally added.

- **Coverage of Individual Directed Goods and Services.** A state may elect to include the coverage of non-traditional "individual directed goods and services" in its waiver.[35] Under this service coverage, participants may identify and purchase goods and services from their individual budgets that are not otherwise covered under the HCBS waiver or the Medicaid State Plan; for example, appliances that substitute for or reduce the need for paid assistance, such as a microwave oven. Coverage of non-traditional goods and services is only an option for waiver participants who exercise budget authority.[36] The criteria for allowable goods and services is articulated in a State Medicaid Director Letter.[37]

As part of its design of an HCBS waiver participant direction option, a state must also address the following topics:

- **Information About Participant Direction.** A state must describe how it will inform waiver participants about the benefits, responsibilities, and potential risks of directing their services as compared to continuing to receive services in the traditional service system.[38]

- **Financial Management Services.** A state must provide for the provision of financial management services on behalf of participants who direct their waiver services. The HCBS waiver statute does not permit the payment of Medicaid dollars directly to waiver participants through the use of a "cash option." Thus, the use of an intermediary to perform financial transactions on behalf of participants is required under the HCBS waiver authority. States have the latitude to contract for financial management services as a Medicaid administrative function or to offer them as a waiver service.[39]

- **Information and Assistance to Support Participant Direction.** Similarly, a state must make information and assistance available to participants who direct their services and wish to avail themselves of such assistance. This assistance may take the form of a distinct waiver service or it can be covered as an administrative activity.[40] For example, assistance might be provided to help participants locate workers or to develop the service plan. The type and extent of the supports that must be available to participants depends on the nature of the participant direction opportunities provided under the waiver.

- **Budget Safeguards.** A state must put mechanisms in place to flag situations when a waiver participant might overspend and prematurely deplete the individual budget, and intervene as appropriate. It is also important that states monitor budgets to identify under-spending, as this may be an indication of inadequate service delivery.

- **Transition.** A state must allow waiver participants who voluntarily decide to discontinue participant direction to transition to traditional models of service delivery, which can include agency-delivered services.

In particular, a state must ensure that such participants continue to receive critical services during the transition period.

- **Termination from Participant Direction Option.** Finally, a state must describe the circumstances under which it will terminate participants' use of the participant direction option and provide for their transition to traditional modes of service delivery. As with voluntary transitions, a state must ensure the participants continue to receive critical services during the transition period.

States have considerable latitude in determining how they will address these requirements.

Additional HCBS waiver operational dimensions relate to participant direction of waiver services. These include service planning (and associated risk assessment processes) and some elements of quality management. CMS does not require states to develop processes concerning these generic dimensions of waiver operations that are specifically keyed to participant direction. However, when a state offers a participant-directed services option, CMS expects that such processes will take into account any special considerations related to participant direction. For example, when participants assume the role of employer and a professional service provider is no longer overseeing service delivery, participants themselves must assume the responsibility of managing staff and assessing quality.

Some states have elected to deliver HCBS in tandem with the provision of State Plan services by operating a §1915(b)/§1915(c) concurrent waiver program.[41] Such waivers use a managed care model to coordinate the provision of services to Medicaid participants. Participant direction may be incorporated into this type of waiver program.[42] (See Chapter 8 for a discussion of Medicaid managed care authorities.)

3. State Plan Coverage of HCBS

Section 6086 of the DRA-2005 added §1915(i) to the Social Security Act, effective January 2007.[43] This provision permits a state to offer HCBS under its Medicaid State Plan without having to secure Federal approval of a waiver. Section 1915(i) was subsequently amended by the Patient Protection and Affordable Care Act of 2010 (hereafter called the Affordable Care Act). The amendments only affect one of the DRA-2005 provisions related to participant direction: states may now offer "other" services (as they can in §1915(c) waivers), which means that participants will have the flexibility to purchase a wide range of "goods and services" to reduce their dependence, as long as they are included in the service plan. CMS has not yet published a final rule for the §1915(i) authority.

Participant Direction of State Plan HCBS

The §1915(i) authority specifically allows states to incorporate a participant direction option for the delivery of State Plan HCBS.[44] Under the statute, participant-directed services are defined as HCBS "which are planned and purchased under the direction and control of such individual or the individual's authorized representative."

States that elect to incorporate a participant direction option in the provision of State Plan HCBS must address the following:

- **Assessment.** The state must provide for a process to assess the "needs, capabilities, and preferences" of the individual.
- **Service Plan.** The state must have a person-centered service plan development process that is directed by the individual or the individual's authorized representative. The process must (1) build upon the individual's capacity to engage in activities that promote community life; (2) respect the individual's preferences, choices, and abilities; and (3) involve families, friends, and professionals as desired or required by the individual or his/her authorized representative. The service plan must also include appropriate risk management techniques that recognize the roles and sharing of responsibilities in obtaining services in a participant-directed manner and ensure the appropriateness of the service plan based on the resources and capabilities of the individual or the individual's authorized representative.

- **Limitation of Services That May Be Participant Directed.** A state must specify which of the services it offers under its §1915(i) benefit may be directed by participants. The service plan must specify the services that participants or their representatives will self-direct, the methods by which they will self-direct, and the supports that are available to the participant.
- **Methods of Participant Direction.** A state must also specify the methods by which participants may direct their services. States may elect to offer participants the employer and/or budget authority along similar lines as allowed under the HCBS waiver authority.
- **Participant-Directed Budget.** States may offer participants a participant-directed budget that identifies the dollar value of the services and supports under the control and direction of the individual or the individual's authorized representative. When a state offers a participant-directed budget, it must specify the methods by which the budget is calculated and provide for a process to adjust the budget based on changes in an individual's assessment and service plan.[45]
- **Financial Management Services.** A state may provide financial management services as an administrative activity to support participants who elect to direct their services or contract with an outside entity to provide these services.

In most respects, the elements of a participant direction option under §1915(i) closely parallel those in HCBS waivers.

4. State Plan Coverage of Participant-Directed Personal Assistance Services

Section 6087 of DRA-2005 added §1915(j) to the Social Security Act, effective January 2007.[46] This authority permits a state to institute a participant-directed services option that includes the disbursement of cash prospectively to participants who direct their personal assistance services.[47] (While specific statutes use different terms—personal care and personal assistance—the service provided is the same.) Absent the §1915(j) authority, participant direction of Medicaid State Plan personal care services is limited to use of the employer authority, as previously discussed.

The §1915(j) authority also allows states to permit participants who direct their services under the State Plan Personal Care benefit to use individual budgets to purchase non-traditional goods and services other than personal care/assistance, to the extent that expenditures would otherwise be made for human assistance. (States already have the authority under §1915(c) to allow HCBS waiver participants to purchase a broad range of goods and services.)

States may use the §1915(j) authority only in a State Plan Personal Care program or in HCBS waiver programs already in operation (i.e., states may not offer participant-directed services under the §1915(j) authority except through an existing State Plan Personal Care program or an HCBS waiver program).

Especially with respect to Medicaid State Plan personal care services, this authority is specifically intended to relieve states of the need to operate §1115 waivers in order to offer participants wide-ranging authority to direct their personal care services, including using their personal care budget to purchase other goods and services, as long as they substitute for or reduce the need for paid personal assistance.

In September 2007, CMS issued a State Medicaid Director Letter that provides guidance to states concerning this Medicaid State Plan option.[48] The letter is accompanied by a Medicaid State Plan amendment pre-print that states may submit in order to invoke this authority.[49] The rule was finalized on October 3, 2008.[50] So far, seven states—Alabama, Oregon, Florida, Texas, New Jersey, California, and Arkansas—have secured CMS approval of a State Plan amendment under this authority, and several other states have submitted their draft amendments to CMS and requested technical assistance.

Key Features of the §1915(j) Authority

The authority has the following major features:

- **Disregard of Statewideness and Comparability**. A state may elect to make its participant direction option available statewide or in specified parts of the state, and may limit the number of persons who direct their services under this option.
- **Limitations on Participants Who May Self-Direct.** The participant direction option may only be offered to participants who live with their families or in housing that they own or lease, not to those whose living arrangement is owned, operated, or controlled by a service provider. States also have the latitude to make participant direction available to all participants (subject to the preceding limits) or only to specified groups of participants.
- **Election of Participant Direction.** A state must provide information and counseling regarding participant direction to individuals so they can make an informed choice about whether to direct their services and supports. A state also must allow participants to voluntarily terminate participant direction and return to receiving provider-managed services. When a person voluntarily ends participant direction (or the state determines that participant direction should be terminated involuntarily), the state must ensure that the individual continues to receive critical services during the transition period.
- **Use of a Representative.** A state may permit the individual to appoint a representative to direct services, but the person acting as a representative is prohibited from providing personal assistance services to that individual.
- **Service Plan.** The state must fashion a person-centered service planning process that includes an assessment of the individual's needs, strengths, and preferences and that "… (a) builds upon the participant's capacity to engage in activities that promote community life and that respects the participant's preferences, choices, and abilities; and (b) involves families, friends, and professionals in the planning or delivery of services or supports as desired or required by the participant."
- **Quality Assurance and Risk Management.** The state must develop appropriate quality assurance methods and employ processes that identify and address risks. The risk management plan must be developed in concert with the participant.
- **Individual Budget.** The state must provide an individual budget to each participant who elects to direct his/her services. The amount of this budget must be determined through the uniform application of a methodology developed by the state.
- **Cash Option.** A state may elect to disburse cash prospectively to self-directing participants to directly purchase services. Participants who elect this option are also permitted to pay their workers and file the employer share of payroll taxes, subject only to retrospective oversight to ensure compliance with labor and tax law requirements. There is no comparable cash option available under the State Plan Personal Care option, the HCBS waiver program, or Medicaid State Plan HCBS coverage.[51]
- **Purchase of Non-traditional Goods and Services.** A state may elect to permit participants who self-direct to "to acquire items that increase independence (such as a microwave oven or an accessibility ramp) or substitute for human assistance, to the extent that expenditures would otherwise be made for the human assistance." In other words, participants may be given the authority to use their individual budgets to purchase goods and services other than personal assistance, as long as they substitute for or reduce the need for paid personal assistance. On November 19, 2009, CMS issued a State Medicaid Director Letter to provide guidance on this provision. Among other clarifications, the Letter stated that "the services, supports, and items that are purchased with a service budget must be

linked to an assessed participant need or goal established in the service plan."[52]

- **Availability of Ongoing Assistance in Participant Direction.** The state must make ongoing training, assistance, and counseling available to participants who direct their personal assistants through the use of a counselor and other information and assistance methods.
- **Providers.** Under this authority, participants can "choose as a paid service provider, any individual capable of providing the assigned tasks including legally liable relatives," as long as they meet applicable state requirements, such as those related to training and criminal background checks.
- **Financial Management Services.** A state must arrange for the provision of financial management services on behalf of self-directing participants (except those who have elected the cash option, if available).[53] The state may obtain such services from vendors or elect to provide the services itself. The costs of these services are eligible for Federal financial participation only as an administrative expense. As noted above, under an HCBS waiver, they can be reimbursed as either a service or an administrative expense.

While this authority shares some of the features of participant direction that are available under the HCBS waiver and Medicaid State Plan HCBS options, it goes beyond those options by permitting states to offer an individual the option to receive some or all of the benefit directly in cash.

5. State Plan Community First Choice Option

Section 2401 of the Affordable Care Act amends §1915 of the Social Security Act by adding a new subsection (k), effective October 2011, to allow states to provide "Community-based Attendant Services and Supports"—called the Community First Choice Option.

Under this new benefit, services and supports may be provided through an agency-provider model or "other" model, both of which require that participants or their representatives select, manage, and dismiss workers. An "other" model is defined as methods, other than an agency-provider model, for the provision of consumer-controlled services and supports. Such models may include the provision of vouchers, direct cash payments, or the use of a fiscal agent to assist in obtaining services, as long as the model allows for the services to be "selected, managed, and dismissed by the individual, or, as appropriate, with assistance from the individual's representative," and to be "controlled, to the maximum extent possible, by the individual…regardless of who may act as the employer of record." Services must be provided by qualified individuals, although the law allows providers to be "family members," and gives the Secretary of HHS latitude to define the term.

Employers must adhere to the provisions of the Fair Labor Standards Act of 1938 and applicable Federal and state laws regarding income and payroll taxes, unemployment and workers compensation insurance, general liability insurance, and occupational health and safety.

Key Participant Direction Features of the §1915(k) Authority

The authority has the following major features:

- **Use of a Representative.** Participants may appoint a representative to direct services.
- **Service Plan.** The state must fashion a person-centered service planning process based on a functional needs assessment.
- **Purchase of Non-Traditional Goods and Services.** In addition to assistance with Activities of Daily Living and Instrumental Activities of Daily Living, permissible services may include… "the use of beepers or other electronic devices" and "voluntary training on how to select, manage, and dismiss attendants." Expenditures for transition costs involved in moving from an institution to the community, including deposits for the first month's payment for rent and utilities,

bedding, basic kitchen supplies, and other necessities, can also be funded through this authority. The authority also allows "expenditures relating to a need identified in an individual's person-centered plan of services that increase independence or substitute for human assistance, to the extent that expenditures would otherwise be made for the human assistance."

Service Planning and Authorization

Participant direction service models use the needs assessment and service planning processes as fundamental activities to safeguard participants' health and welfare, and to ensure that the services and supports provided enable participants to meet their individual community living goals. The participant direction model differs from professional-directed service models by affirming that the participant is the center of—and leads—the service planning process. Person-centered planning (PCP) is a critical component of participant-directed service planning, which enables and helps the individual to identify and access a personalized mix of paid and non-paid services and supports. While PCP methods used to be associated only with service planning for persons with developmental disabilities, these methods are now employed for individuals with any type of disability, and CMS encourages and supports the use of person/family-centered planning methods in service plan development.

With the exception of home health services, Medicaid policy does not dictate that service plans must be prepared by medical, clinical, or case management professionals. Whether for waiver services authorized in a plan of care or personal care services under the optional State Plan benefit, states have considerable latitude with regard to empowering the individual to manage authorized services. Under the Personal Care option, for example, many states already allow participants to determine when authorized service hours are to be furnished and to alter the schedule to meet their needs.

In an HCBS waiver program, states may also permit participants to manage the service schedule or alter the mix of authorized services to meet their changing needs without having to develop an entirely new service plan. However, the statutory requirement that "services be provided pursuant to a written plan of care" must continue to be met.

Federal law requires that the services individuals receive through an HCBS waiver program be provided pursuant to a plan of care.[54] Neither Federal law nor regulations specify the process by which this plan of care is to be developed. The plan of care must meet the requirements spelled out in the State Medicaid Manual and the Technical Guide for HCBS waivers, as well as requirements included in the state's approved HCBS waiver request. Effective service plan development processes are essential to ensure that waiver participants will receive the services and supports they need and want in order to successfully live and thrive in the community. States must specify in their waiver application how the participant-centered plan will be developed as well as how the state will monitor the service planning process to ensure that it is person centered.

At one time, Federal regulations dictated that the §1905(a) optional State Plan Personal Care benefit 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. This policy change enables states to adopt alternative approaches to personal care service planning. A common approach is to delegate this task to case managers who are responsible for assessing eligibility and authorizing services.[55]

Section 1915(i) highlights service planning as a fundamental component of participant direction, intended to both safeguard health and welfare, as well as ensure meaningful involvement of participants in identifying and selecting the services and supports they need. Section 1915(j)(5)(B) emphasizes the assessment and service planning process by requiring an assessment of the participant's "needs, strengths, and preferences" for personal assistance services.

Use of Representatives

All individuals, regardless of their impairments, can be successful in directing their services with the proper supports. People with serious illnesses and those with cognitive impairment—including impairment due to dementia, stroke, traumatic brain injury, and developmental disabilities—are capable of expressing preferences, but may need assistance to manage their services and budget. Most participant direction programs permit participants to designate a representative to assist them in these tasks. Representatives can ensure that participants' preferences are known and respected and can manage tasks that participants would perform if they were able.

Some programs allow participants to use representatives without formally designating them as such, but have criteria that individuals must meet to be a representative, such as demonstrating a strong commitment to the participant's well-being and being interested in and able to carry out program responsibilities and requirements.[56] Although formal designation requires individuals to complete a form acknowledging acceptance of the duties and responsibilities of a representative, there is no legal transfer of authority or responsibility with respect to personal decision making or financial matters from the participant to the representative (as would be the case if an individual were to grant power-of-attorney or a court were to appoint a guardian.)

Program requirements for person-centered planning also apply to representatives, who must re-present the best interests of participants and ascertain and act in accordance with their preferences—unless they are impractical.[57]

The use of a representative under the §1915(j) authority is at the option of the state. This authority provides that representatives include "(1) a minor child's parent or guardian; (2) an individual recognized under state law to act on behalf of an incapacitated adult; (3) a state-mandated representative, after approval by CMS of the state criteria, if the participant has demonstrated, after additional counseling, information, training, or assistance, the inability to self-direct personal assistance services."[58]

The statutory language of §1915(i) gives states the option to allow an individual *or the individual's representative* to elect to receive self-directed HCBS.[59] An issue intrinsic to the use of representatives is avoiding a conflict of interest. Most programs that allow representatives generally do not permit them to be paid either as workers or for serving as representatives. However, exceptions can be made under extraordinary circumstances (e.g., lack of workers in isolated areas or the inability of workers to understand individuals with speech impairments). The final rule for §1915(j) stipulates that a person acting as a representative for a participant directing their personal assistance services is prohibited from acting as a provider of such services.[60] The HCBS waiver application (version 3.5) instructions provide guidance on the use of representatives. (See the Resources section of this chapter for a link to the application.)

Individualized Backup Plans

A key component of person-centered service planning is a risk assessment process to identify issues or situations that can jeopardize health and welfare and to develop an individualized backup plan that specifies actions to prevent them or address them if they occur. For example, a backup plan should designate individuals to be called—and in which order—if workers do not arrive when scheduled. Backup plans should also address methods for handling any critical incidents that may occur, such as a serious injury, abuse, neglect, or exploitation.

Every participant receiving home and community services—whether through the traditional agency-delivered service system or a participant direction program—should be educated about the availability of backup resources and have a backup plan individually tailored to their needs and preferences.

Appendix D-1(e) of the HCBS waiver application (version 3.5) requires states to specify how potential risks to participants will be assessed during the development of the service plan and how strategies to mitigate risk will be incorporated into the service plan, subject to participants' needs and preferences. In addition, states must describe how the service

plan development process will address the need for backup plans and the arrangements that are used for backup must be included. These requirements apply to both traditional and participant direction programs.

Section 1915(j) regulations also emphasize the importance of developing backup plans. Identifying actual and potential risks—and determining how they will be handled—should be accomplished through discussion and negotiation among persons involved in the service planning process.

If the backup plan includes calling individuals who are willing and able to work at short notice, such as neighbors, all of their payroll paperwork must be on file in advance. Similarly, if it includes calling a traditional service agency, the agency should be informed that they are listed on a participant's backup plan and should be provided with information about the participant's needs.

Typically, backup plans include the names and contact information of individuals or entities to be called in a specific order; for example, family and friends may be called first, and a counselor or case manager called only if family and friends are unable to provide backup. Some states have developed an Emergency Backup Person Designation Form to identify individuals as emergency backup personnel; individuals designated are required to sign the form demonstrating their willingness to serve in this capacity. The effectiveness of backup plans should be tested periodically and changes made as needed.

Building Flexibility into the Service Plan While Ensuring Equitable Budgets

In programs that allow participants to exercise budget authority, purchases must be clearly linked to an assessed need that is identified in the service plan.[61] Typically, purchases either increase independence or address a personal care need. While some programs only allow participants to purchase personal care services, others allow them to purchase a range of services, including skilled nursing, rehabilitative therapies, and supported employment services.

The flexibility afforded to participants to purchase goods and services varies by program. Programs may require pre-approval of non-traditional services, such as purchase and maintenance of a service dog, or they may develop a list of allowable items and a prior authorization process to approve the purchase of items not on the list. Other programs allow participants significant flexibility and consider any purchase that fosters community inclusion as allowable.

States also can build flexibility into the service menu and individual service plans by combining certain services (e.g., personal care, homemaker, respite, non-medical transportation, and companion services) into one service category in the waiver application. This could allow participants to use their budgets to purchase the specific services they need to address their needs without having to formally alter the service plan.

Programs that allow participants broad discretion to purchase goods and services—within Federal parameters—must ensure that financial accountability is maintained through the application of consistent methods to determine both needs and allowable purchases to meet those needs. States must demonstrate to CMS that statewide procedures are in place to assess need and ensure access to services, even in states where counties or local entities play a strong role in the operation of the waiver.

Uniform use of a standardized assessment process—and training to ensure its consistent use—will enable states to ensure equitable funding of individual budgets and help them to determine whether budgets are being calculated accurately using a consistent method. It is also important that states implement procedures to ensure that funds go to enrolled or otherwise eligible providers.

The methods states use to perform the assessment vary greatly and often differ within a state according to the population being served. In programs serving persons with developmental disabilities, many states use standardized assessment processes and instruments that are nationally tested and accredited, such as the Supports Intensity Scale. In programs serving elderly persons and younger adults with physical disabilities, assessment instruments

are generally state specific, but typically assess ADLs and IADLs, as well as nursing needs, cognitive impairment, and behavioral issues.[62]

A few states use the comprehensive Minimum Data Set–Home Care assessment instrument, which assesses multiple factors that determine the need for services, including cognition; vision; hearing and communication; mood/behavior; social functioning; informal support services; physical functioning (including IADLs and ADLs); continence; medical conditions and medications; and the living environment.[63]

Employing Family Members

All of the participant direction Medicaid authorities allow participants to hire friends and relatives to provide personal care services. States also have the option under the HCBS waiver authority, and §1915(i) and §1915(j), to allow participants to hire legally responsible relatives (i.e., spouses, and parents and legal guardians of minor children) within certain parameters.[64] Generally, to be a paid personal care provider, a legally responsible relative has to be providing services that a spouse or parent would not be providing for a non-disabled spouse or minor child; for example, feeding a 15-year-old child or bathing a spouse. Medicaid prohibits the hiring of legally responsible relatives in participant direction programs under the Medicaid State Plan Personal Care benefit.

Non-Personal Care Services

Relatives—including legally responsible relatives—may be hired to provide non-personal care services when they 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. For example, if a minor child has extensive medical needs and requires skilled nursing services, a parent who is a licensed nurse could provide the service as long as she or he meets the state's provider qualifications.

Within the broad parameters of Federal policy, it is up to states to define the particular circumstances under which relatives will be paid to furnish services to participants. States can take various factors into account, including the availability of other sources for the same services, costs of family member services versus costs of purchasing such services from conventional sources, and specific circumstances with respect to participants. See Box for Minnesota's provisions regarding payment of family members.

Minnesota's Family Payment Policies[65]

Minnesota does not allow legally responsible relatives (i.e., spouses or parents of minor children) to be reimbursed for personal care, which they are legally obligated to provide to a spouse or child.

Additional provisions are available under the consumer-directed community supports waiver service to allow spouses and parents of minor children to provide "personal support services"—within state-set limits in hours, rate of pay, and scope of tasks.

The State allows services provided by other relatives or friends to be reimbursed only if:

(1) they meet the qualifications for providers of care,

(2) the State has strict controls to ensure that payment is made to the relative or friend as providers only in return for specific services rendered, and

(3) adequate justification exists for the relative or friend to provide the service (e.g., lack of qualified providers in remote areas). Medicaid payment may be made to qualified parents of minor children or to spouses for extraordinary services requiring specialized nursing skills that they are not legally obligated to provide.

Furnishing Assistance to Individuals in Managing and Directing Services

Participants who are interested in directing their services may need or want assistance to do so. The §1915(c) HCBS waiver authority and the §1915(j) State Plan authority require states to furnish two support services to participants directing their services: (1) information and assistance, and (2) financial management services. (The proposed rule for §1915(i) also addresses the provision of these two support services. However, it is not included here because at the time of publication, it had not yet been finalized.)

These support services are necessary to ensure that individuals have a support system to ensure they are able to manage their services and budgets. The extent to which such supports are utilized depends on the capacity, preferences, and needs of each individual and may vary in scope and timing. While their main purpose is to facilitate participant direction, these supports also provide important protections and safeguards for those directing their own services. Financial management services also provide fiscal accountability for state budget staff, by helping participants to manage the individual budget and by issuing payments on behalf of the state.

Information and Assistance

Many terms are used to describe the provision of information and assistance, including counseling, supports brokerage, service coordination, and service consultation. This Primer uses the term counseling. States have broad flexibility to design counseling services in a manner that suits their program, as long as they meet the intent of the service: to provide detailed information to enable individuals to make informed decisions about whether participant direction is right for them, and if it is, to assist them in obtaining and managing their services.

CMS views the roles and responsibilities of the counselor as fundamentally different from those of a case manager. See Table 7-2 for a comparison of services provided by counselors and traditional case managers.

The case manager's role to oversee and monitor service delivery is often required to ensure that Medicaid or other public programs meet state and Federal health and welfare requirements, and the case management system is often a key component of states' quality management systems. Consequently, many programs use both case managers and counselors to assist participants, and in such cases it is essential that they understand each other's respective roles and responsibilities, work collaboratively, and avoid duplication of services. Participants also need to understand the difference between the two roles.

Some programs have one person perform the responsibilities of both roles—either transferring case management functions to counselors, or having case managers assume the counselor role. Whichever approach a state uses, the individuals providing these services—whether counseling, case management, or both—need to meet all applicable job requirements. Prior to approval of a participant direction waiver program, Federal reviewers will ask, at a minimum, the following questions:

1. Does the program provide participants with information about (a) its benefits, (b) their responsibilities under the program, and (c) their liability if employment-related taxes and workman's compensation insurance premiums are not paid?
2. Who provides the above information and what is the process for providing it?
3. Who oversees the provision of information and assistance?
4. Is the information provided in a timely manner to permit informed decision making?
5. If both counselors and traditional case managers are involved, how will their functions be coordinated and how does the program prevent duplication of services?

Table 7-2. Examples of Typical Activities of Counselors and Traditional Case Managers

Counselors	Traditional Case Managers
Provide information about • the person-centered planning process • participants' rights • resources, choices, and options • responsibilities, risks and/or liabilities associated with participant direction and decision making • program limitations or restrictions • how to report changes in condition and needs • recognizing and reporting critical events, abuse, or neglect • the availability of criminal background checks and processes for conducting reference checks Provide assistance with • defining needs, preferences, and goals • developing and managing the individual budget • developing a backup plan • identifying and obtaining services, supports, and resources • recruiting, hiring, and managing workers • obtaining training in practical skills related to personnel management (e.g., negotiating rates, arranging schedules, training workers, and making changes) • assessing the quality of services received	• Explain the program process, and eligibility criteria • Present information about various settings for service delivery: institutional, home, or community-based; and service options: traditional agency or participant direction • Conduct an assessment to determine eligibility for services and to develop a service plan, and match needs with resources • Implement the service plan • Monitor the provision of services • Assess the quality of services • Ensure cost/budget neutrality, if required • Revise the service plan when changes occur • Perform periodic assessments and eligibility determinations

For detailed information about counseling services, see the Resources section of this chapter for a link to the chapter on Counseling in the Self-Direction Handbook.

Financial Management Services[66]

CMS defines Financial Management Services (FMS) as follows:

> *Service/function that assists the family or participant to (a) manage and direct the distribution of funds contained in the participant-directed budget; (b) facilitate the employment of staff by the family or participant by performing as the participant's agent such employer responsibilities as processing payroll, withholding and filing Federal, state, and local taxes, and making tax payments to appropriate tax authorities; and (c) performing fiscal accounting and making expenditure reports to the participant and/or family and state authorities.*[67]

The provision of financial management services is essential when implementing participant direction programs for several reasons.

- Under the §1905(a) State Plan Personal Care benefit, the HCBS waiver authority, and the §1915(i) authority, payments for services can not be made directly to participants, either to reimburse them for expenses incurred or to enable them to directly pay a service provider. Rather, payments on the participant's behalf must be made by an intermediary organization (i.e., either a qualified Medicaid provider or an entity under administrative contract with the state).[68]
- Under the §1915(j) authority, CMS does not require states to mandate the use of financial management services for participants who elect the "cash" option. Instead, these participants may choose to retain responsibility for some or all of their fiscal and employer-related responsibilities. However, even if participants choose to receive some benefits in cash and distribute workers' payroll checks directly, they may still choose to have an FMS organization manage the Federal and state tax filings and deposits and generate payroll checks for their workers.[69]
- Some FMS organizations may act as a neutral bank for receiving and disbursing public funds (i.e., Fiscal/Employer Agents).[70]
- Financial management services provide fiscal accountability for state and local government agencies, and safeguards for individuals enrolled in participant direction programs and their workers, by ensuring that payroll,[71] workers' compensation insurance policy management, and vendor payment tasks are performed accurately and in accordance with Federal, state, and local rules and regulations, and in a timely manner.
- Some FMS organizations (i.e., Fiscal/Employer Agents) assist program staff and participants by providing a variety of financial reports related to the receipt of public funds, service use, and payments. These reports inform participants about their service use and related expenditures and also act as a fiscal and/or fraud monitoring tool for them and for program staff.
- At the request of participants who are acting as their workers' managing employer, an FMS provider who has a joint/co-employment arrangement with participants (as in the Agency with Choice or Public Authority/ Workforce Council models) can also provide worker-related services (e.g., recruitment, training, and supervision, and the provision of emergency backup staff).[72]

FMS Models

States principally use two FMS models to implement Medicaid and state-funded participant direction programs: the Fiscal/Employer Agent (F/EA) model and the Agency with Choice model. The F/EA model includes two specific types: Government F/EA and Vendor F/EA. All of these models are described below.

1. Fiscal/Employer Agent Model

Fiscal/Employer Agents are most effective for implementing participant direction programs, particularly those that allow participants to have individual budgets, for several reasons. First, using an F/EA provides participants a high degree of choice and control over their workers as their common law employers, while reducing their employer-related burden by managing the payroll and bill payment tasks. Second, using an F/EA provides safeguards for participants by ensuring that all required taxes are paid and all Department of Labor and workers' compensation insurance requirements are met. Third, using an F/EA can provide fiscal accountability for states. Both the Government and Vendor F/EA models operate under §3504 of the Internal Revenue Service (IRS) code.[73]

Government Fiscal/Employer Agents. When states implement participant direction programs using a Government F/EA, the costs associated with providing financial management services must be billed as an administrative expense for the purpose of claiming Federal Medicaid matching funds because participants' freedom of choice of provider is limited.[74] Thus, when evaluating the feasibility of implementing a Government F/EA, a state's Medicaid agency and program staff should assess the economic impact of using this model on the receipt of Federal Medicaid matching funds and the administrative costs to the state associated with monitoring multiple F/EA providers.

Vendor Fiscal/Employer Agents. When states implement participant direction programs using a *Vendor* F/EA, states may engage vendor entities–either under contract or as qualified Medicaid service providers, or both—who have the knowledge, experience, resources, and the infrastructure necessary to provide effective fiscal services. This model enables states to negotiate cost-effective fees for F/EA services rendered, rather than providing these services in-house. States also have the option to (1) select a discrete number of Vendor F/EAs, using a competitive solicitation process, and bill F/EA costs as an administrative expense (at a uniform Federal matching funds rate of 50 percent); or (2) develop Medicaid F/EA provider standards and provide freedom of choice of provider to participants, and bill F/EA costs as a service expense for the purpose of claiming Federal matching funds (at a Federal matching funds rate that ranges from 50 to 83 percent).[75]

For Vendor F/EA services to be reimbursed as a waiver service, states must meet a number of Federal requirements. States must develop a service definition that includes a set of provider qualifications and the tasks that will be performed by the Vendor F/EA and any reporting agent. States must verify a provider's qualifications before services are initiated, and must provide a detailed description of the frequency and methods by which provider qualifications will be re-verified and ongoing performance will be monitored.

States must treat Vendor F/EAs as they would any Medicaid service provider. States may not arbitrarily limit the number of Vendor F/EAs available to participants as this would restrict their freedom of choice of provider and disqualify the state from claiming Vendor F/EA expenses as a waiver service for Federal matching funds purposes. Finally, states must monitor Vendor F/EAs and any reporting agents' performance on an ongoing basis.

A significant number of states limit the number of Vendor F/EA providers and forgo the receipt of Federal service matching funds, called Federal Medical Assistance Percentage (FMAP), in order to obtain the cost efficiencies from working with and monitoring fewer F/EA providers.[76] The majority use some type of competitive solicitation process to select one or more Vendor F/EA providers.

However, some states report challenges related to this strategy, such as (1) the need to write an effective solicitation document that accurately and completely reflects F/EA requirements; (2) the need to evaluate F/EA knowledge and experience for proposal review and vendor selection purposes; (3) interruptions in the continuity of F/EA providers because a satisfactory F/EA provider must rebid at the end of each contract period and may not be reselected (e.g., if they are not the lowest bidder, which may be a priority for a state's purchase and property department responsible for managing the solicitation process); (4) the resources and time required to complete a solicitation, including address-

ing any bidder challenges; and (5) developing and executing effective performance-based contracts.

Other states provide freedom of choice of F/EA service providers for participants in order to receive Federal service matching funds.[77] Again, some of these states have experienced challenges, such as (1) having sufficient knowledge of Federal and state F/EA requirements and operations to prepare Medicaid standards and execute Medicaid provider agreements effectively; (2) preparing effective protocols for certifying F/EA providers as Medicaid providers and monitoring their performance through periodic re-certification; (3) having the staff and financial resources necessary to conduct F/EA certifications and recertification/performance monitoring in a timely and effective manner; and (4) having the cost of monitoring F/EA performance exceed the additional amount a state may receive in Medicaid service match versus administrative match. Given this last challenge, *states should determine how much it will cost them to monitor the performance of significant numbers of F/EAs, as this amount may well exceed the funds they would receive through FMAP.*

Establishing Reimbursement for F/EA Services. States need to establish reasonable and adequate reimbursement for Vendor F/EA services (and Government F/EA services that are subcontracted to a subagent or reporting agent) that reflect the costs of providing these services. CMS has approved a variety of methods for determining reimbursement for financial management services, including the basic transaction-based reimbursement method and the modified transaction-based (per member per month or per member per day) reimbursement method. A method that is not approved by CMS is the percent of budget reimbursement method, which reimburses on the basis of a percentage of the total dollar volume of services that an FMS entity processes. This approach is not approved because it does not reflect the actual cost of providing the F/EA service. 78

For a detailed description of the various F/EA models and their advantages and challenges, see the Resources section of this chapter for a link to the chapter on Fiscal/Employer Agent Services in the Self-Direction Handbook.

2. Agency with Choice Model

In contrast to the F/EA models described above, the Agency with Choice FMS model operates under a co-employment arrangement whereby employer status is shared by the participant and an agency. For IRS purposes and other considerations, the agency is the primary or legal employer and officially hires the worker(s), processes human resource forms, and manages the payroll tasks. They also monitor the participant's health and welfare, ensure that intended services are provided, and may provide guidance on recruiting, training, managing, and discharging workers. The participant or his/her representative is the secondary or managing employer. In this role, the participant or representative recruits, interviews, and selects workers, and then refers them to an agency for the completion of employment/payroll paperwork. In addition, the participant or representative trains, manages, and discharges workers (to the extent they wish to).

To be considered a bona fide participant direction model, agencies operating under this model must give participants meaningful choice and control over their workers—the authority to select, train, manage, and dismiss, as well as directing the tasks they perform. Key elements of an effective Agency with Choice program include (1) a strong commitment to the philosophy of participant direction; (2) a high level of choice and control afforded participants and their representatives; and (3) comprehensive support services, such as employer-related skills training that covers worker recruitment, selection, management, evaluation, and discharge; assistance with recruiting, hiring, and discharging workers when requested; and guidance on conducting criminal background checks, if not required by a participant-directed services program.

Each of the five Medicaid participant direction authorities acknowledge the Agency with Choice model as an option for participant direction programs and it may be used to fulfill FMS responsibilities for participants exercising employer authority, budget authority, or both. CMS provides some basic information on Agency with Choice models in the Waiver Application Instructions and Technical Guidance.[79] Some states have established specific

requirements for this model (e.g., New Hampshire and Pennsylvania).

In 2003, New Hampshire implemented regulations for "Other Qualified Agencies" that outline the requirements for entities to be certified as such in the State.[80] This is the name the State uses for Agency with Choice FMS providers that furnish financial management services to participants in the State's Choices for Independence HCBS waiver who are directing their personal care services. Effective July 1, 2008, Pennsylvania published an Office of Developmental Programs Administrative Bulletin entitled, *Agency with Choice Financial Management Services*. Among other things, the Bulletin outlines the requirements for agencies to operate as Agency with Choice FMS providers for individuals enrolled in the State's Medicaid Consolidated and Person/Family-Directed Supports waivers.

Consumer Choice and Provider Qualifications

Section 1902(a)(23) of the Social Security Act requires that Medicaid enrollees must be free to choose among all willing and qualified providers. This statutory requirement applies to all Medicaid-funded services, including services furnished through HCBS waiver programs. The Act allows the Secretary of HHS 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 providers is absolutely necessary for individuals to direct their own services and supports (with the exception of FMS providers and counselors).[81] However, the Medicaid freedom of choice statutory requirement extends only to "qualified" providers, and therein lies the source of limitations and/or complications when seeking to implement participant direction programs. Federal Medicaid law (whether under the Medicaid State Plan or through an HCBS waiver program) requires that a state establish required provider qualifications and agree to enroll all willing providers who meet such qualifications.

These qualifications must be reasonable (i.e., they 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 greater will be the number of people who 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 participant-directed services.

Some of these barriers arise from state Nurse Practice Acts provisions, which sometimes dictate that even non-health care related personal assistance be provided under the supervision of a nurse (and, not atypically, nurses who themselves must be employees of a licensed home care or home health agency). Thus, a central task for states interested in promoting participant-directed 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 home and community services may be furnished by friends, neighbors, and family members—including spouses and parents of minor children under some authorities, at the state's option. In various states, families are encouraged to seek out individuals in their communities who can provide some types of services and supports for people with developmental disabilities.

Revising provider qualifications can be vital not only in promoting participant-directed services but also in expanding the potential sources of services and supports for people with disabilities more generally. However, no providers on the Office of the Inspector General excluded provider lists may furnish Medicaid services, whether directed by participants or provided by agencies.

Performance of Skilled Nursing Tasks

Although the principles underlying participant direction support a social rather than a medical service model, avoiding the medical model 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 participant direction service models. Liability concerns—particularly when participants have extensive medical and nursing needs—can also stand in the way of promoting participant direction.

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 may still be provided by personal care workers under HCBS waivers or under the State Plan Personal Care benefit—as long as the services are provided in conformity with the state's Nurse Practice Act. A 1999 CMS State Medicaid Manual transmittal specifically states that

> *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.*[82]

This policy and its applicability to State Plan Personal Care programs and HCBS waiver programs were reaffirmed in a July 2000 State Medicaid Director Letter.[83]

Most states restrict performance of medical or skilled nursing tasks to licensed medical professionals, although most physician and nurse licensing laws do permit individuals to be trained to perform these tasks for themselves or for close family members. Federal Medicaid law references state licensing laws by requiring that Medicaid State Plans comply with all "applicable" state and local statutes. Under the Nurse Practice Acts in most states, tasks that require nursing judgment—such as medication administration—and tasks considered to be invasive procedures—such as catheterization and injections—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. (See the Appendix for an overview of CMS requirements for quality management and improvement systems.)

See the Resources section of this chapter for a link to the chapter on Self-Direction and Health Care in Developing and Implementing Self-Direction Programs and Policies: A Handbook, which includes a detailed discussion of liability issues related to the performance and delegation of skilled nursing tasks, and ways in which states have addressed them.

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key resources relevant to participant direction. Most of the publications cite additional resources and the websites also have links to other sources of information.

Publications

Crisp, S., Doty, P., Flanagan, S., Smith, G., O'Keeffe, J., et al. (2009). *Developing and Implementing Self-Direction Programs and Policies: A Handbook*. Chestnut Hill, MA: National Resource Center for Participant-Directed Services.

This publication was developed to provide state staff, policymakers, service providers, program participants, and other stakeholders with a single comprehensive source of information about participant direction programs and policies.

Available as the full handbook at http://www.cashandcounseling.org/resources/handbook

Available as individual chapters using the following links:

Chapter 1: Self-Direction
http://www.cashandcounseling.org/resources/pdf/cc-01.pdf

Chapter 2: Legal Authority
http://www.cashandcounseling.org/resources/pdf/cc-02.pdf

Chapter 3: Involving Participants
http://www.cashandcounseling.org/resources/pdf/cc-03.pdf

Chapter 4: Enrollment
http://www.cashandcounseling.org/resources/pdf/cc-04.pdf

Chapter 5: Individual Budgeting
http://www.cashandcounseling.org/resources/pdf/cc-05.pdf

Chapter 6: Counseling
http://www.cashandcounseling.org/resources/pdf/cc-06.pdf

Chapter 7: Fiscal/Employer Agent Services
http://www.cashandcounseling.org/resources/pdf/cc-07.pdf

Chapter 8: Quality Management in Self-Direction Programs
http://www.cashandcounseling.org/resources/pdf/cc-08.pdf

Chapter 9: Self-Direction and Health Care
http://www.cashandcounseling.org/resources/pdf/cc-09.pdf

Chapter 10: Looking Ahead
http://www.cashandcounseling.org/resources/pdf/cc-10.pdf

Appendix I: Using Strategic Communications
http://www.cashandcounseling.org/resources/pdf/cc-app1.pdf

Appendix II: The Consumer Direction Module
http://www.cashandcounseling.org/resources/pdf/cc-app2.pdf

Appendix III: History of Self-Direction
http://www.cashandcounseling.org/resources/pdf/cc-app3.pdf

CMS State Medicaid Director Letter (November 19, 2009). *Implementation of §6087 of DRA §1915(j).*

This letter provides guidance on the implementation of §6087 of the Deficit Reduction Act of 2005, Public Law Number 109-171. Section 6087, the "Optional Choice of Self-Directed Personal Assistance Services (PAS) (Cash and Counseling)," amended §1915 of the Social Security Act by adding a new subsection (j). The guidance also applies to §1915(c) HCBS waiver programs when states offer the self-direction opportunity and permit participants to purchase "Individual Directed Goods and Services." The letter offers information on (1) Background, (2) Medicaid Authorities, (3) Criteria, (4) Support and Monitoring, and (5) Compliance with the Guidance.

Available at http://www.cms.hhs.gov/SMDL/SMD/ItemDetail.asp?ItemID=CMS1230894

CMS. (2008). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria.*

The Application contains extensive information concerning Federal policies that apply to the operation of an HCBS waiver, in particular, Appendix E: Participant Direction of Services, which addresses how the waiver affords participants the opportunity to direct some or all of their waiver services. The addition of Appendix E to the waiver application recognizes that participant direction is an increasingly common feature of waivers.

Available at https://www.hcbswaivers.net/CMS/faces/portal.jsp under links and downloads, entitled ***§1915(c) Waiver Application and Accompanying Materials***.

Brown, R., Lepidus Carlson, B., Dale, S., Foster, L., Phillips, B., and Schore, J. (2007). *Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services.* Princeton, NJ: Mathematica Policy Research, Inc.

This report summarizes the findings from 5 years of research by Mathematica Policy Research, Inc. on how each of the three Cash and Counseling Demonstration states implemented its program, and on how the programs have affected participants, their paid and unpaid caregivers, and Medicaid costs.

Available at http://www.cashandcounseling.org/resources/20070910-145713/index_html

Websites

National Association of State Medicaid Directors

This website contains information about the Medicaid program, including all State Medicaid Director Letters issued since 2004, links to state Medicaid websites, information about Medicaid statutory and regulatory issues, and current Federal legislative and policy initiatives.

Web address: http://www.nasmd.org/Home/home_news.asp

Cash and Counseling National Program Office

This website contains extensive, wide-ranging resources concerning participant direction.

Web address: http://www.cashandcounseling.org/

National Resource Center for Participant-Directed Services (NRCPDS)

Drawing on over a decade of experience with participant direction and experience as a National Program Office for the Cash and Counseling project, the NRCPDS provides technical assistance to develop and improve participant direction programs, regardless of funding source. The website contains extensive resources on participant direction.

Web address: http://www.bc.edu/schools/gssw/nrcpds/

The Clearinghouse for Home and Community Based Services

This site promotes the development and expansion of HCBS by gathering resources and tools for research, policymaking, and program development into this one-stop website. Under the topic Consumer/Participant Direction, there are 520 publications, including policy alerts and briefs, promising practices, and reports.

Web address: http://www.hcbs.org/

Endnotes: Citations, Additional Information, and Web Addresses

[1] The original chapter was co-authored by Gary Smith, Pamela Doty, and Janet O'Keeffe. The information in this chapter is drawn from several sources. The section on consumer choice and provider qualifications is from the original Primer chapter. The sections on Basic Features of Participant Direction of Medicaid HCBS and Federal Medicaid Statutory Authorities, authored by Gary Smith, are taken verbatim from Chapter 2 of the publication Developing and Implementing Self-Direction Programs and Policies: A Handbook. (See the Resources section of this chapter for the full citation, including web links to the entire document and to the individual chapters.) The section on Financial Management Services (FMS) is a brief condensation of information in Chapter 7, Fiscal/Employer Agent Services, authored by Susan Flanagan in the same publication. Suzanne Crisp and Janet O'Keeffe updated all other sections.

[2] Family involvement is not always needed or appropriate, but many participants desire or require it.

[3] Brown, R., Lepidus Carlson, B., Dale, S., Foster, L., Phillips, B., and Schore, J. (2007). Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services. Princeton, NJ: Mathematica Policy Research, Inc. Available at http://www.cashandcounseling.org/resources/20070910-145713/index_html.

[4] Phillips, B. et al. (2003). Lessons from the Implementation of Cash and Counseling in Arkansas, Florida and New Jersey. Washington, DC: Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. Available at http://aspe.hhs.gov/daltcp/reports/cclesson.htm.

[5] In the developmental disabilities field, the term "circle of support" is used to describe such informal supports.

[6] Doty, P., Kasper, J., and Litvak, S. (1996). Consumer-Directed Models of Personal Care: Lessons from Medicaid. The Milbank Quarterly, 74(3):377-409. Available at http://aspe.hhs.gov/daltcp/reports/lessons.htm.

[7] CMS collaborated with Arkansas, Florida, and New Jersey to design programs under the §1115 Research and Demonstration waiver authority (hereafter referred to as the §1115 waiver authority) to implement the demonstration and to evaluate the benefits of this approach. The demonstration was launched in the three states between 1998 and 2000, using a random assignment social experimental design to address selection bias, which yielded robust data about the positive benefits of the Cash and Counseling approach to participant direction. Phillips, B. et al. (2003), op. cit. Several more reports about the results of the demonstrations are located at http://aspe.hhs.gov/_/topic/topic.cfm?topic=Consumer%20Choice.

[8] Notably, fewer than a dozen participants in all three states selected the cash option. Pamela Doty, Office of the Assistant Secretary for Planning and Evaluation. Personal communication, July 2008.

[9] More information about this program is available at http://www.rwjf.org/reports/npreports/sdpdd.htm.

[10] A few states offered employer authority prior to the Independence Plus initiative.

[11] CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5] Instructions, Technical Guide and Review Criteria. See the Resources section of this chapter for a web link to the application instructions.

[12] P.L. 109-171.

[13] The DRA-2005 also provides that states may offer participants in Money Follows the Person (MFP) demonstrations the authority to direct their services and supports. Section 6071 of DRA-2005 also authorized the Secretary of HHS to award $1.75 billion in special MFP demonstration grants over a 5-year period to states to support the transition of individuals from institutional settings to the community. These grant funds may be used to pay for special transition services to facilitate community placement. States are also eligible to receive an enhanced Federal Medical Assistance Percentage (FMAP) for a 1-year period for the costs of HCBS furnished to persons who move to the community.

After 1 year, the state must ensure that individuals will continue to receive HCBS through the Medicaid State Plan and/or an HCBS waiver. In order to qualify for the enhanced FMAP, individuals must transition to community living arrangements that they own or lease, their family home, or a community-based residential setting where no more than four unrelated people reside. CMS has awarded MFP grants to 31 states to support the transition of individuals from nursing facilities, intermediate care facilities for persons with intellectual disabilities, and other institutional settings to the community.

Section 6071(c) of DRA-2005 specifically provides that a state may offer MFP demonstration participants the authority to direct their HCBS. The participant direction elements of the MFP authority closely parallel the participant direction provisions contained in the §1915(i) HCBS State Plan authority. These elements include providing for a person-centered service plan development process and the option for the state to give participants choice and control over an individual budget. More information concerning MFP is located at http://www.cms.hhs.gov/DeficitReductionAct/20_MFP.asp

[14] As provided in §1902(a)(23) of the Social Security Act, participants may select any qualified and willing provider to furnish services. A significant number of states restrict freedom of choice of FMS provider because the cost of monitoring large numbers of FMS providers often outweighs the benefit of receiving a higher FMAP matching payment.

[15] The terms primary and secondary employer are often used in states' unemployment statutes to describe the role of employers under a "co-employer" model.

[16] Individuals may establish additional qualifications as long as they do not contradict those that the state has established. For example, a person may require that the worker can communicate in sign language.

[17] CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5] Instructions, Technical Guide and Review Criteria, p. 195. See the Resources section of this chapter for a web link to the application instructions.

[18] Home and community services may be delivered under additional authorities and through various service delivery arrangements. For example, the delivery of Medicaid health and long-term care services may be integrated under the §1915(a) authority. HCBS also may be included in managed care programs offered under the provisions of §1932 of the Social Security Act. The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 created a new type of Medicare coordinated care health plan, the Medicare Special Needs Plan (SNP). SNPs may be created to "wrap around" the

delivery of health and long-term care services for persons who are dually eligible for Medicare and Medicaid. Section 6044 of the DRA-2005 gives states the option to create alternative Medicaid benefit packages, including tailored benefits to meet participants' special health needs. As a general matter, participant direction options may be employed in conjunction with these other authorities or service delivery arrangements.

[19] Section 1115 of the Social Security Act gives the Secretary of HHS wide-ranging authority to grant states waivers of Federal Social Security Act provisions for the purpose of demonstrating and evaluating alternative approaches to service delivery. When a state is interested in testing such alternative approaches, this waiver authority provides states with a means to obtain relief from statutory requirements that stand in the way of implementing them. A state is required to develop a research strategy to assess the extent to which its alternative approach results in improved or more efficient delivery of services to participants. In recent years, states principally have employed this authority to restructure the delivery of Medicaid health care services rather than long-term care services. The authority also has been employed to expand eligibility for Medicaid services. Section 1115 waivers operate under "budget neutrality" requirements (i.e., expenditures can be no higher under the waiver than they would otherwise have been).

[20] It was necessary to use this authority in the Cash and Counseling demonstrations, which offered participants a cash option, permitted participants to redirect personal care/assistance funds to purchase other goods and services, and allowed payment of legally responsible relatives for services.

[21] Source: Mary Sowers, CMS. Personal communication, December 11, 2009.

[22] Centers for Medicare & Medicaid Services. (2005). Medicaid-At-A-Glance: 2005. Available at http://www.cms.hhs.gov/MedicaidGenInfo/downloads/MedicaidAtAGlance2005.pdf.

[23] The exact number of states is not known.

[24] Must provide option to transition to traditional services under §1905(a)(24) and §1915(c) authorities.

[25] These two states furnish HCBS to Medicaid participants under the §1115 waiver authority.

[26] CMS stressed the use of person-centered planning, provided guidance to states on establishing individual budgets, defined requirements for supporting participants who direct their services (e.g., through the provision of financial management services and information and assistance services), and provided guidance on how states could permit waiver program participants to exercise choice and control over the selection of workers and their individual budgets.

[27] CMS also issued a §1115 waiver template for the same purpose.

[28] CMS worked in collaboration with several state agency associations that have operational responsibility for HCBS delivery: the National Association of State Directors of Developmental Disabilities Services, the National Association of State Units on Aging, the National Association of State Medicaid Directors, the National Association of State Head Injury Administrators, and the Alliance of Cash and Counseling States.

[29] The Version 3.3 HCBS waiver application was released in November 2005 but has since been replaced by subsequent versions. Version 3.5 was issued in January 2008. CMS continually updates the waiver application and the current version is also being updated. Version 3.6 is expected to be released in late 2010 or early 2011. With respect to participant direction, there are no substantive differences in the treatment of participant direction among the various versions of the application.

[30] CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5] Instructions, Technical Guide and Review Criteria. See the Resources section of this chapter for a web link to the application instructions.

[31] Appendix E built upon the participant direction elements that were contained in the predecessor Independence Plus waiver application template.

[32] Waiver of comparability has traditionally been interpreted to mean that states can have multiple waivers offering different kinds of services for different populations. However, there has also been a legal interpretation by General Counsel that there can be no waiver of comparability within waivers. Unlike the §1915(j) authority, HCBS waiver rules do not have an explicit prohibition on self-direction for group home residents. However, as a practical matter, group home residents can not direct their services if they are provided by facility staff or outside staff through arrangements with the facility. Basically, if waiver participants choose to live in a group residential service setting, by definition they are choosing to use services they can not direct. However, it is technically possible that "some" services not provided by the facility could be self-directed.

[33] It is important to specify that a representative may be the common law or managing employer because in both cases, the employer must be someone who can successfully participate in an unemployment or worker's compensation appeal.

[34] State Medicaid Director Letter regarding how to check for excluded providers, available at http://www.cms.gov/smdl/downloads/SMD061208.pdf.

[35] In the Instructions, Technical Guide, and Review Criteria that accompanies the HCBS waiver application, p. 172, CMS has defined Individual Directed Goods and Services as "services, equipment or supplies not otherwise provided through this waiver or through the Medicaid State Plan that address an identified need in the service plan (including improving and maintaining the participant's opportunities for full membership in the community) and meet the following requirements: the item or service would decrease the need for other Medicaid services; AND/OR promote inclusion in the community; AND/OR increase the participant's safety in the home environment; AND, the participant does not have the funds to purchase the item or service or the item or service is not available through another source. Individual Directed Goods and Services are purchased from the participant-directed budget. Experimental or prohibited treatments are excluded. Individual Directed Goods and Services must be documented in the service plan."

[36] A few states extend the coverage of Individual Directed Goods and Services to waiver participants who do not formally self-direct. More commonly, the coverage is confined to individuals who self-direct and exercise budget authority. For example, West Virginia includes this coverage in its Personal Options participant direction program in its Medicaid HCBS waiver for older persons and individuals with disabilities. Waiver participants may save up to $1,000 from their budget to purchase participant-directed goods and services. For more information, go to http://www.cashandcounseling.org/resources/20070611-111748.

[37] Issued on November 19, 2009. Available at http://www.cms.hhs.gov/SMDL/downloads/SMD111909.pdf.

[38] Participant direction programs pose different risks than do traditional service delivery programs. In both programs, a risk always exists that workers will not show up. But when participants assume the role of employer and a professional service provider is no longer overseeing service delivery, participants themselves must assume the responsibility of managing staff and assessing quality. Participants

who employ their workers may also be liable if employment-related taxes and workers compensation insurance premiums are not paid. Consequently, CMS requires states to (1) institute safeguards and supports to minimize participants' potential liability (including the use of strong fiscal employer agent models), and (2) develop quality management and improvement systems sufficient to safeguard the health and welfare of individuals in participant direction programs. States must also continue to meet all other statutory assurances required when operating a waiver program.

39 When financial management services are furnished as a Medicaid administrative activity, costs are reimbursable at the standard 50 percent administrative claiming rate for federal financial participation. Under this option, a state may limit the number of FMS entities, for example, by selecting them through a competitive process. When financial management services are furnished as a waiver service, the costs are reimbursable at the state's services claiming rate, which may be higher than 50 percent and any willing and qualified provider must be permitted to furnish financial management services.

When the services are covered as a waiver service, a state also may designate the FMS provider as an "organized health care delivery system." Such a designation may simplify compliance with Medicaid provider agreement requirements. There is an extensive discussion of the provision of financial management services as an administrative activity or as a covered waiver service in the CMS HCBS Waiver Application Instructions, Technical Guide, and Review Criteria, including managing provider agreements. See the Resources section of this chapter for a web link to the Application Instructions.

40 Another option for providing counseling services to self-directing HCBS waiver participants is the use of targeted case management services (paid as a State Plan service). See the Resources section of this chapter for additional information on counseling services and Chapter 4 for information on the targeted case management option.

41 The §1915(b) waiver authority permits a state to obtain a freedom of choice waiver in order to limit the providers of Medicaid State Plan services. Some states (e.g., Michigan and Wisconsin), and sometimes jurisdictions within a state, operate programs under concurrent §1915(b)/§1915(c) waivers. For example, the North Carolina Piedmont Cardinal Health Plan operates under concurrent §1915(b)/§1915(c) waivers to provide mental health and developmental disabilities services in a five-county area.

See also Chapter 9: Incorporating Self-Direction Options in Managed Care Plans from the publication Developing and Implementing Self-Direction Programs and Policies: A Handbook. See the Resources section of this chapter for the full citation and web link to the chapter.

42 A state can restrict freedom of choice of financial management services entities and information and assistance providers in a (b)(c) waiver program and receive Federal matching funds under the service rate rather than the administrative rate, as long as the service is included in the approved §1915(b)(4) request.

43 The text of §1915(i) is located at http://www.paelderlaw.com/pdf/DRA_Provisions.pdf.

44 Section 1915(i)(1)(G)(iii) of the Social Security Act.

45 See Chapter 5, Individual Budgeting from the publication Developing and Implementing Self-Direction Programs and Policies: A Handbook. See the Resources section of this chapter for the full citation and web link to the chapter.

46 The authority defines participant direction as follows: "The participant (or in the case of a participant who is a minor child, the participant's parent or guardian, or in the case of an incapacitated adult, another individual recognized by state law to act on behalf of the participant) exercises choice and

control over the budget, planning, and purchase of participant-directed personal assistance services, including the amount, duration, scope, provider, and location of service provision." The text of §1915(j) is located at http://www.paelderlaw.com/pdf/DRA_Provisions.pdf.

[47] Different Medicaid authorities use different terms to describe the same service. As noted previously, the terms personal assistance, personal care, and attendant services encompass the same service: assistance performing activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

[48] Available at http://www.cms.hhs.gov/SMDL/downloads/SMD091307.pdf. The letter provides guidance on the implementation of Section 6087, Optional Participant Direction Personal Assistance Services Program of the Deficit Reduction Act of 2005.

[49] Available at http://www.cms.hhs.gov/SMDL/downloads/SMD091307Encl.pdf.

[50] On October 3, 2008, CMS published a final rule in the Federal Register (73 Fed. Reg. 57,854) providing guidance to states that choose to administer self-directed personal assistance services through their Medicaid State Plan, as authorized by the DRA-2005. Available at http://edocket.access.gpo.gov/2008/E8-23102.htm.

[51] A cash option would be allowed under a §1115 waiver, but CMS is no longer approving the use of this authority solely to implement participant-directed services options. However, if a participant direction program is a component of a broader Medicaid reform proposal, the authority could be used.

[52] Available at http://www.cms.hhs.gov/SMDL/downloads/SMD111909.pdf.

[53] Under the §1915(j) authority, CMS does not require states to mandate the use of financial management services for participants who elect the "cash" option. Instead, these participants may choose to retain responsibility for some or all of their fiscal and employer-related responsibilities. Individuals who receive cash benefits have the option to hire an FMS provider or a private accountant to perform employer tasks, such as payment of payroll taxes. Participants who choose to perform these tasks themselves must comply with all applicable employment and tax laws.

[54] 42 CFR Subpart G—Home and Community-Based Services: Waiver Requirements. Available at http://law.justia.com/us/cfr/title42/42-3.0.1.1.10.7.html.

[55] The service plan is based on a needs assessment that determines how many hours of aide services will be authorized for payment. Some states also require specification of tasks the aide will perform, and in some of these states the number of hours authorized is determined by the time allocated for particular tasks, such as bathing, dressing, and meal preparation.

[56] Some states require the representative to be a legal entity, such as a guardian, which limits participants' choice of representatives.

[57] If representatives serve their own interests rather than those of participants, the counselor may advise a change of representative.

[58] At §441.480.

[59] Statute available at http://www.ssa.gov/OP_Home/ssact/title19/1915.htm.

[60] Federal Register, 73(193):57885 (444.480).

[61] CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions,

Technical Guide and Review Criteria. p. 173. See the Resources section of this chapter for a web link to the application instructions.

62 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.

63 Available at http://www.hhsc.state.tx.us/Contract/529060406/final/Attachment_H.pdf.

64 They may also do so under the §1115 waiver authority.

65 Kathy Kelly, Minnesota Department of Human Services, Disability Services Division, Supervisor of Policy Implementation in the Home & Community Living Services Group. Personal communication, January 27, 2010.

66 This section is condensed from Chapter 7 on Fiscal/Employer Agent Services, authored by Susan Flanagan, Ph.D., M.P.H., from the publication Developing and Implementing Self-Direction Programs and Policies: A Handbook. See the Resources section of this chapter for the full citation and web link to the chapter.

67 CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria. Appendix C: Participant Services, Attachment: Core Services Definitions, Section D, Services in Support of Participant Direction, #2 Financial Management Services, p. 176. See the Resources section of this chapter for a web link to the application instructions.

68 Ibid. Appendix E, Overview: Financial Management Services, p. 201.

69 Medicaid funds may also be disbursed directly to participants in programs under the §1115 authority. However, as stated above, CMS will generally not approve a §1115 waiver solely to offer a participant direction program.

70 The term "neutral bank" is used because the F/EA is not providing direct care services to participants so it is "neutral" about which providers they use. Prior to the use of F/EAs, some participants with developmental disabilities found it difficult to move between/among agency service providers because their Medicaid benefit was often allocated to one service organization for the fiscal year, which had a financial interest in who provided services to participants.

71 Payroll includes, but is not limited to, the collection and processing of worker timesheets; making sure that workers are paid in accordance with Federal and state labor laws; the withholding, filing, and payment of Federal and state income tax withholding and employment taxes, and locality taxes; processing of the advanced Federal earned income credit, when applicable, and any garnishments, liens, or levies against workers pay, as required; and generating and distributing payroll checks.

72 When participants are not able or willing to act solely as their workers' employer, their representatives can assume this role if they are willing to do so.

73 Flanagan, S.A., and Green, P.S. (2000). Fiscal Intermediaries: Reducing the burden of consumer-directed support. Generations, 24(111):94-95. This publication describes the development of Fiscal/Employer Agents and various issues regarding their use.

74 Participants' choice of provider is limited because, per IRS regulations, only one entity (a Government F/EA, or its reporting agent or subagent if it chooses to use one) can file and deposit the required Federal taxes for participants and their workers under the same entity name and Federal Employer

Identification Number on the required IRS Forms.

[75] However, if a state implements a Medicaid State Plan participant direction program in accordance with §1915(j) of the Social Security Act, the costs associated with Vendor F/EA services must be billed as an administrative expense for the purpose of claiming Federal matching funds.

[76] States that limit the number of Vendor F/EA providers available to participants include, but are not limited to, Alabama, Arkansas, Arizona, Connecticut, Florida, Idaho, Iowa, Illinois, Maryland, Massachusetts, Kansas (WORK Program), Missouri, Nevada, New Jersey, New Mexico, Pennsylvania, Tennessee, Virginia, Vermont, and West Virginia. States that restrict participant choice of F/EA provider, including states that implement Government F/EAs or Medicaid State Plan amendments in accordance with §1915(i) and §1915(j) of the Social Security Act, are reimbursed for F/EA costs at the Federal administrative matching rate.

Alabama has implemented a pilot participant direction program under its Medicaid State Plan by using the §1915(j) authority. New Jersey converted its Personal Preference Program from operating under a Medicaid §1115 waiver to the §1915(j) authority effective July 1, 2008. The Missouri Division of Developmental Disabilities has implemented a Government F/EA and performs all tasks internally. Nevada plans to implement a participant-directed services pilot for individuals with developmental disabilities living in rural areas sometime in 2010. West Virginia's Bureau of Medical Services and Florida's Department of Elder Affairs and Agency for Persons with Disabilities have implemented a Government F/EA and use a subagent.

[77] States include, but are not limited to, Pennsylvania (53 percent Medicaid service match rate), Michigan (58.10 percent Medicaid service match rate), Minnesota (50 percent Medicaid service match rate), and Rhode Island (52.35 percent service match rate).

[78] CMS. (2008). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria. Appendix E, Item E-1-i: Provision of Financial Management Services, p.205. See the Resources section of this chapter for a web link to the application instructions.

[79] Ibid.

[80] Chapter He-P600, Part He-P601, Certification of Other Qualified Agencies.

[81] The administrative burden for states of having multiple FMS providers is significant and the cost often exceeds the funds a state receives through the receipt of FMAP. In addition, the potential liability associated with poor performance by FMS providers increases when they do not have enough business to stay current with Federal and state requirements. For example, if a state has 75 FMS providers, but only 25 are regularly serving clients and 50 are not serving anyone, those without clients are at risk of not staying up-to-date with Federal and state requirements. A similar situation can occur with having too many counselors (i.e., information and assistance providers). New Jersey's Personal Preference Program found that only a small number of counseling agencies were serving the majority of consumers while the others were serving very few consumers and were not keeping up with requirements.

[82] Medicaid Manual Transmittal Part 4, N. 73, September 17, 1999. Available online as part of the State Medicaid Manual, Chapter 4: Services, 4444 to 4658, at http://www.cms.hhs.gov/Manuals/PBM/itemdetail.asp?filterType=none&filterByDID=-99&sortByDID=1&sortOrder=ascending&itemID=CMS021927&intNumPerPage=10.

[83] Available at http://www.cms.hhs.gov/smdl/downloads/smd072500b.pdf.

Guide to Chapter 8

Evolution of Medicaid Long-Term Care in Managed Care Systems 213
Early Growth of Medicaid Managed Care 214
Recent Trends 214
Reasons for Developing MLTC Programs 215
Challenges to Implementing MLTC Programs 216
Medicaid Authorities 216
Section 1115 Waivers 219
Concurrent §1915(b) and §1915(c) Waivers 220
Section 1915(a) 221
Section 1932(a) 222
Section 1934 222
Medicare Special Needs Plans 223
Section 1915(i) 224
All Quality and Other Requirements of Each Authority Must Be Met 224
Resources 225
Endnotes: Citations, Additional Information, and Web Addresses 229

Chapter 8
Medicaid Authorities for Delivering Home and Community Services through Risk-Based Managed Care Systems

Managed care is an approach to financing and delivering health care that aims to enhance value by controlling costs while improving quality. Risk-based managed care is defined as a financing and delivery system in which a contractor is paid a set monthly fee per person enrolled (called a capitation rate), and bears financial risk for providing a defined package of services to the enrolled population. Forty-six states use risk-based Medicaid managed care; it is the most commonly used approach for organizing and financing primary and acute health care. But, apart from the Program of All-inclusive Care for the Elderly (PACE) model, only 11 states have applied risk-based managed care approaches in the delivery of long-term care—either institutional or home and community services and supports. Recently, however, the number of people receiving these services and supports through managed care delivery systems has grown significantly.

This chapter discusses the Medicaid authorities that states can use to provide home and community services through risk-based managed care delivery systems. It briefly decribes the history of programs that include long-term care services in managed care arrangements, and discusses how Medicaid authorities have evolved over time. Because the majority of Medicaid-eligible individuals who need long-term care also have Medicare coverage—known as people who are dually eligible—some programs are designed to integrate Medicaid and Medicare funding for these beneficiaries. Thus, this chapter also briefly discusses the Medicare authority for integrated service delivery models.[1]

Evolution of Medicaid Long-Term Care in Managed Care Systems

Prototype Medicaid managed care programs that include long-term care services and supports go back to the 1980s, when the PACE demonstration grew out of San Francisco's innovative On Lok program, and the Arizona Long-Term Care System (ALTCS) was implemented. Both of these programs were implemented under the Section (§)1115 Research and Demonstration waiver authority (hereafter referred to as a §1115 waiver).

PACE and ALTCS are very different programs, but they have one important feature in common: their contractors receive a monthly capitation fee per member regardless of the amount of services their members use. This contrasts with the usual fee-for-service approach used to pay for home and community-based services (HCBS).

Thirty states now operate PACE sites under a §1934 State Plan amendment, and ALTCS continues to operate as a statewide demonstration program under a §1115 waiver. (More information about these programs and the authorities under which they operate is provided later in this chapter.) Despite the early efforts of these enduring programs, it was several years before a few other states began fashioning managed long-term care (MLTC) models of their own.

Early Growth of Medicaid Managed Care

In the 1980s, many states were implementing Medicaid managed health care. Their efforts were focused on the largest groups of beneficiares: families and children who qualified for Medicaid based on their eligibility for cash assistance through Aid to Families with Dependent Children (now Temporary Assistance to Needy Families). Individuals eligible for Medicaid through Supplemental Security Income (SSI) typically were excluded from managed health care, or included on a voluntary basis.[2] When SSI-related groups were included, their long-term care services were almost always "carved out" and continued to be delivered through the traditional fee-for-service system. This was in part because early Medicaid managed care programs were building on the experience of commercial managed care organizations (MCOs) that provided only primary and acute health care.

Growth of Medicaid managed health care accelerated in the 1990s. By 1998, state survey data showed that a majority of Medicaid beneficiaries were enrolled in some form of Medicaid managed care. About two-thirds of Medicaid managed care enrollment was in risk-based commercial or Medicaid-only MCOs.[3] The remaining third were enrolled in primary care case management, which assigns primary care providers to members but does not capitate payments.

In the 1990s, a number of states began applying risk-based managed care strategies to the provision of long-term care services. These included both Medicaid-only models, which focused exclusively on Medicaid-funded services, and integrated models, which included both Medicaid and Medicare services for persons who were dually eligible. New integrated programs were implemented in two states: the Wisconsin Partnership Program (1995) and Minnesota Senior Health Options (1997). Three Medicaid-only programs were launched in the same period: New York Managed Long-Term Care (1997), Texas Star+Plus (1998), and Florida Diversion (1998).[4]

The Balanced Budget Act (BBA) of 1997 included significant changes to Federal Medicaid managed care policy. For the first time, Federal law allowed states under certain conditions to implement mandatory Medicaid managed care programs without the need for Federal waivers (i.e., a state could require certain Medicaid participants to enroll in a new managed care program). However, individuals eligible for both Medicaid and Medicare (hereafter called dually eligible persons) and children with special health and/or long-term care needs were specifically excluded from those provisions. The change in Federal policy recognized that managed care had become the dominant delivery system for families and children, but was still relatively untested among SSI-eligible groups.

Recent Trends

Facilitated by the policy changes in the BBA, Medicaid managed care for families and children has continued to grow in the past decade. By June 2008, the Centers for Medicare & Medicaid Services (CMS) reported that 71 percent of Medicaid enrollees were in managed health care of some type in 48 states, including risk-based arrangements and primary care case management.[5] As about two-thirds of the managed care enrollment is in risk-based arrangements in 46 states, risk-based arrangements are the dominant form of Medicaid managed care.[6] However, populations receiving long-term services have largely continued to be excluded from states' Medicaid managed care initiatives. For example, one survey showed that 90 percent of states with managed care service delivery models excluded persons in

long-term institutional settings, 73 percent excluded dually eligible persons, and 71 percent excluded persons receiving home and community services.[7]

As a percentage of overall Medicaid managed care programs, MLTC continues to be small, but a number of new Medicaid-only and integrated MLTC initiatives have been implemented since 2000 and some of the early MLTC programs have grown substantially. In 2000, Wisconsin piloted its Medicaid-only Family Care Program in five areas of the State and by 2009 had almost completed its statewide expansion. In 2001, building on its experience with Senior Health Options, Minnesota launched its Disability Health Options, an integrated Medicaid-Medicare program for adults with physical disabilities, and in 2005, expanded Senior Health Options statewide. Texas has also engaged in a multi-region expansion of Star+Plus.

In 2004, Massachusetts implemented the integrated Senior Care Options program, and in 2008, New Mexico began implementing its Coordinated Long Term Services program, a mandatory, statewide Medicaid managed care program with an estimated 38,000 persons enrolled. Hawaii implemented Quest Expanded Access in 2009, adding an estimated 39,000 persons to the national MLTC enrollment.

As of 2009, 11 states were providing long-term care services and supports through risk-based managed care arrangements outside of PACE programs, and one additional state has been approved to implement an MLTC initiative.[8] So, although MLTC continues to be the exception rather than the rule, it is slowly being adopted by additional states.

Reasons for Developing MLTC Programs

The key feature of risk-based managed care is that a contractor bears financial risk for services provided over time and across settings. The contractor is paid a capitation rate per enrollee and is responsible for providing all contracted benefits under this rate. If the actual cost of providing services exceeds the aggregate capitation amount, the contractor experiences a loss, but if services can be provided at or below the capitation amount, the contractor profits. As applied to long-term care, this approach creates an incentive to avoid institutional care whenever possible through the provision of cost-effective home and community services.

States commonly cite the following goals as reasons to develop MLTC.

- **Strengthen accountability for quality.** When bolstered by a robust quality improvement component, MLTC can hold contractors accountable for consumer outcomes over time and across service settings. Given that many individuals who receive long-term care services have complex, multi-service needs, the ability to hold contractors accountable for a broad range of services across multiple service settings is critical to quality improvement. Absent a single, accountable contractor, it is very difficult to work on preventing avoidable hospitalization or institutionalization.
- **Streamline and coordinate access to services.** A good care management system can help address the lack of coordination across primary, acute, and long-term services. Such coordination is particularly important in integrated programs for dually eligible persons. Care management is also critical in traditional HCBS waiver programs, but care managers are limited to managing waiver services and have little or no interaction or influence with primary and acute health care providers.
- **Complement state efforts to better balance their long-term service systems.** States see MLTC as an effective vehicle for reducing the unnecessary use of institutional services and increasing the use of home and community services. In the fee-for-service system, such balancing efforts often face a financing obstacle: states need to increase resources for home and community services while maintaining funding for institutional care. The flexibility of capitation addresses this problem when community and institutional services dollars are blended in a single capitation rate. The contractor has the flexibility to use the capitation rate in the most appropriate way that meets

the needs and preferences of the consumer. In essence, the capitation becomes a flexible, portable, and global budget.[9]

Challenges to Implementing MLTC Programs

Implementing MLTC programs has proven to be more challenging than traditional Medicaid managed primary and acute health care for families and children. Major issues are summarized below.

- **Consumers and advocates worry about underservice and loss of control.** Despite efforts to emphasize person-centered concepts in MLTC programs, many consumers and their advocates worry that contractors will be financially motivated to reduce access to services, limit consumer choice, and provide service plans that are less tailored to members' individualized needs. To address these and related concerns, states must engage consumers early on and throughout program development, implementation, and evaluation, recognizing that a meaningful engagement process with consumers requires a substantial commitment of time and resources.
- **Entities involved in delivering HCBS resist role changes.** In particular, organizations to whom the state has delegated case management of waiver services, such as counties, Area Agencies on Aging, and Independent Living Centers, generally do not want to cede that responsibility to MCOs. States must work with these entities to help them redefine their roles, and in some programs, to forge formal partnerships with MCOs.
- **Infrastructure is lacking at the state and service delivery levels.** Commercial MCOs generally lack experience providing long-term care services, while state Medicaid agencies and traditional HCBS providers lack experience managing risk. Additionally, because state legislatures often equate managed care with privatization, they may expect to reduce state administrative positions when MLTC is implemented. A major education effort may be needed for the state legislature to understand that implementing a managed care program does not result in a need for fewer state agency staff.
- **Rate setting is complex.** Considerable variation in the needs of the population served presents a major challenge to the rate setting process. One person may need only a few hours of personal assistance per day, while another might need several months of nursing facility care; also, an individual's needs can vary over time. Determining a capitation rate to pay appropriately for this potential range of services, while also building appropriate incentives to provide HCBS instead of institutional services, is a complex task.
- **High incidence of dually eligible persons.** One of the greatest challenges is the high incidence of dually eligible persons among the population in need of long-term care. While a state may conclude that a Medicaid-only program will have too few participants—particularly in small states—and so is not worth the effort, on the other hand, finding a contractor that can provide the entire range of Medicaid and Medicare services may not be feasible or may require too much effort.

Medicaid Authorities

Medicaid authorities for MLTC have evolved considerably since the early programs of the 1980s and 1990s. ALTCS and the first generations of Minnesota's Senior Health Options and Wisconsin's Partnership Program all operated under §1115 waivers, which are intended to promote research and demonstration initiatives that test new ideas. Since then, additional statutory authorities have been enacted, and CMS has helped states to assess whether or not they need the §1115 authority to achieve their goals. The result has been a marked movement away from §1115 waivers.[10]

Medicaid authorities that states may consider alone or in combination are described below and their key features are summarized in Table 8-1 (on the next page). The authority or combination of authorities that a state selects depends primarily on the program features desired. Ideally, the choices made will enable the desired program features with the least

administrative burden. The major program features are listed in the first column of Table 8-1 and are discussed below.

- **Managed care** authority is used to pay a limited number of contractors to serve a population on a capitated basis. The contractor is responsible for a group of services, which it offers through a network of providers. States may select contractors through a competitive process, or may simply set the participation requirements and contract with any organization meeting the requirements.

- **Selective contracting** allows the state to limit the number of participating providers. This feature differs from the normal practice in Medicaid, in which provider qualifications are set by the state and all providers who meet them may participate as Medicaid providers.

- **Mandatory enrollment** into Medicaid managed long-term care requires a §1115 or a §1915(b) waiver. Mandatory enrollment is also possible under the §1932(a) and §1937 authorities, except for dually eligible persons. Because persons dually eligible are at risk for needing long-term care, exempting them from mandatory enrollment makes these authories impractical for mandatory MLTC. Regardless of the authority used, dually eligible persons may never be subject to mandatory enrollment for Medicare services.

- **HCBS beyond the State Plan, institutional level-of-care requirement, and waiver of comparability.** Traditionally, states have provided a wide range of home and community services—including those not available under the Medicaid State Plan, such as environmental modifications—on a fee-for-service basis in a §1915(c) waiver program. States can offer a capitated MLTC program using a §1915(c) waiver in com-bination with a managed care authority. However, the program will be limited to individuals who meet the state's institutional level-of-care criteria.

  With the passage of the Deficit Reduction Act of 2005 (DRA-2005)—as amended by the Patient Protection and Affordable Care Act of 2010 (hereafter called the Affordable Care Act)—states may now offer HCBS under their State Plan through the §1915(i) authority, freeing them from the requirement to use institutional level-of-care criteria—unless the state uses the 300 percent of SSI income eligibility criteria. (See Chapter 4 for more information about this authority.)

- **Limit geographically.** Except for the §1915(i) authority, all of the authorities listed in Table 8-1 allow a state to limit a program geographically, referred to as waiving Medicaid's "statewideness" requirement. States often do so to gradually phase-in a pro-gram or because a limited supply of MLTC contractors in rural areas makes it impractical to offer a program except in highly populated areas.

- **HCBS financial** eligibility. In general, a state may not deviate from the financial eligibility criteria included in its State Plan, with the exception of institutional financial eligibility criteria, an option states may elect to use for institutional services and for §1915(c) waiv-ers. Institutional financial eligibility criteria include (1) the special income rule, which allows states to expand financial eligibility to cover individuals in institutions (and §1915(c) waivers) who have incomes up to 300 percent of the Federal SSI benefit level; (2) the ap-plication of spousal impoverishment rules; (3) non-deeming of parental income for de-pendent children living at home; and (4) var-ious exclusions from countable income (such as a home maintenance allowance) in the determination of financial eligibility for home and community services.

  This option to use 300 percent of the Federal SSI benefit to determine financial eligibility is also possible with a §1115 waiver, in a PACE program under §1934, and with the §1915(i) authority. However, if a state uses the special income rule in its §1915(i) program, then participants must meet institutional level-of-care criteria. It is not possible to use institu-tional financial eligibility criteria under a §1915(b) waiver or under the §1915(a) statutory authority alone.

Table 8-1. Features of Medicaid Authorities That May Be Employed in Managed Long-Term Care Programs

Features	Waivers			Statutory Authority			
	§1115	§1915(b)	§1915(c)	§1915(a)	§1915(i) (ACA)	§1932(a) (BBA)	§1934 (BBA)
Managed care	✓	✓		✓		✓	PACE model only
Selective contracting allowed	✓	✓				✓	✓
Mandatory enrollment	✓	✓				Yes, but not for dually eligible persons	
Offer HCBS beyond State Plan	✓		✓		✓		✓
Institutional level-of-care requirement			✓		Only if state uses the 300% of SSI income rule		✓
Waive comparability	✓	✓	✓		✓	✓	✓
Limit geographically	✓	✓	✓			✓	✓
Expand HCBS financial eligibility	✓		✓		✓		✓
Budget and cost requirements	Budget neutral	Cost effective	Cost neutral				Less than upper payment level
Includes Medicare							✓
State Plan amendment required					✓	✓	✓
Renewal requirement	Usually every 5 years	2 years	5 years	None	—[1]	None	None

ACA = The Affordable Care Act; BBA = Balanced Budget Act.

[1] If a state's §1915(i) program targets a specific population, the State Plan amendment will only be approved for 5 years, with the option for the state to renew for additional 5 year periods if CMS determines, prior to the beginning of the renewal period, that (1) the state met Federal and state requirements and (2) the state's monitoring is in accordance with the Quality Improvement Strategy in the state's approved State Plan Amendment.

- **Budget and cost requirements** are important when selecting an authority for implementing an MLTC program, especially a §1115 waiver. The test for a §1115 waiver demonstration program is that it be budget neutral, which means that the total costs of the program can not exceed what they would have been under the state's regular Medicaid program. Because the state needs to stay within a total expenditure cap, if enrollment is greater than projected, the state is at risk for any additional costs. A state may manage this risk by capping enrollment, but may not want to do so if the policy objective is to expand coverage.[11]

  Section 1915(b) waivers require cost effect-iveness, which applies to the average per-person costs, which may not exceed the average per person costs of the comparable fee-for-service group. These costs must be calculated in an actuarially sound manner, based on actual expenditures in a base year. A state is at risk if average per person costs exceed fee-for-service costs, but not for unanticipated enrollment of additional per-sons.[12]

  Section 1915(c) waivers require cost neutrality, which means the average per person cost for waiver services may be no greater than the average cost of the institutional services that the waiver services are an alternative to, determined on a per capita basis or in the aggregate. The budget requirement for PACE sites under §1934 is similar to that for §1915(c). It requires that the cost of PACE services must be less than the upper payment limit—defined as the average amount that would have been spent on a comparable population in fee-for-service arangements.[13] Finally, if proposing a benchmark plan under §1937, a state must demonstrate that the proposed plan is actuarially equivalent to the selected benchmark.

- Renewal requirements. When determining which authority to use, states may want to consider the associated administrative burdens of each option. A clear advantage of using the §1932(a) and §1934 authorities is that once approved, they become a permanent feature of the state's Medicaid program unless subsequently altered by the state. Section 1915(b) waivers are approved for 2-year per-iods and may be renewed for up to 2 years. Section 1915(c) waivers are approved initially for a 3-year period with a 5-year renewal period. Section 1115 demonstration programs are initially approved for a 5-year period and can be renewed for a 3-year period. Section 1915(i) benefits that include targeted pop-ulations can only be approved for a 5-year period, with the option to renew for additional 5-year periods.

  Under a new provision of the Affordable Care Act, the Secretary of HHS may allow waiver programs for individuals who are dually eligible to be approved for an initial period of up to 5 years and renewed for up to 5 years, at the State's request.[14] CMS will be issuing guidance on this provision in the near future.

The features a state wishes to include in its MLTC program should drive the state's decision about what specific authorities to use. In general, a state wants to achieve the greatest number of desired features with the least administrative burden. A summary of each authority follows.

Section 1115 Waivers

Of all the Medicaid authorities that states can use to offer MLTC, §1115 waivers offer the greatest flexibility. However, they also have the most rigorous approval criteria and generally take longer to obtain than other waivers. Section 1115 allows the Secretary of Health and Human Services to waive any of the requirements of §1902 of the Social Security Act for purposes of researching innovative approaches to delivering Medicaid benefits and services, including both managed care and fee-for-service innovations. Section 1902 includes the basic requirements for operating a Medicaid program, making the §1115 waiver the most comprehensive available.

To be approved, a §1115 demonstration must test a new idea to improve the Medicaid program. The budget test is more rigorous than those for other waivers and the Federal Office of Management and Budget reviews for budget neutrality. There is

no limit on the amount of time CMS may take to review the application. In short, this waiver can do the most, but can only be used to test a true innovation. See Table 8-2 for an example of the use of this authority.

Concurrent §1915(b) and §1915(c) Waivers

Section 1915(b) waivers are used to create mandatory managed care programs. They may not be used to offer benefits that are not included in the Medicaid State Plan, nor may they be used to expand financial eligibility for HCBS beyond State Plan eligibility levels. An exception is that a managed care plan can offer expanded or additional services with program savings. Section 1915(b) waivers provide the opportunity for states to offer to enrollees additional services paid for through savings achieved under the waiver. In order to provide these §1915(b)(3) services, CMS must approve a state's request for authority under subsection 1915(b)(3) in conjunction with either subsection 1915(b)(1) and/or (b)(4).[16]

Section 1915(c) waivers do not allow capitated managed care arrangements, but have been used since the 1980s to provide home and community services not covered in the Medicaid State Plan. Thus, concurrent use of §1915(b) and §1915(c) waivers allows states to cover both State Plan services (e.g., home health, personal care, and rehabilitative services) and non-State Plan home and community services (e.g. homemaker services, adult day health services, and assistive technology) in their managed care programs' capitation rate for individuals eligible for §1915(c) waivers. States may also include home and community services in their §1915(b) waivers as §1915(b)(3) services.

The §1915(c) authority also allows states to use institutional financial eligibility criteria, which, as discussed above, expands income eligibility criteria to 300 percent of the Federal SSI benefit; applies spousal impoverishment rules; does not deem parental income for dependent children; and allows exclusions from countable income when determining financial eligibility for services. By using these two authorities concurrently, states can create an MLTC program, as has New Mexico. See Table 8-3.

Table 8-2. Arizona Long-term Care System (ALTCS)

Start Date	1988–89
Target Group	Older persons, persons with physical disabilities, or persons with intellectual or other developmental disabilities, all of whom must be clinically certified to need an institutional level of care. Enrollment is mandatory. However, dually eligible persons continue to receive their Medicare benefits through the fee-for-service system, a Medicare Advantage Plan, or a Special Needs Plan.
Service Area	Statewide
Scope of Medicaid Capitation	All Medicaid services, including primary and acute health care, long-term care services (institutional and HCBS), and behavioral services.[15]
Authorities	**Section 1115 waiver.** Arizona has operated its entire Medicaid program under a §1115 waiver from its inception in 1982. ALTCS was truly experimental when it was implemented in 1988—no state had undertaken any significant MLTC, and Arizona was proposing it statewide on a mandatory basis. The population is similar to that served in §1915(c) waiver programs. If ALTCS were proposed today, a §1915(b) and (c) waiver combination would likely be considered.

More information is available at: http://www.azahcccs.gov/reporting/default.aspx

Section 1915(a)

The §1915(a) authority allows states to create voluntary managed care programs without a waiver or a Medicaid State Plan amendment. It does not allow selective contracting, which means that states cannot engage in competitive procurement of contractors under this authority. The state may, however, define the contractors' qualifications and offer contracts to all who meet them, and participating contractors may limit specific providers when they create their networks. This authority can also be used to waive comparability and to limit a program geographically.

This authority alone is not sufficient to create an MLTC initiative because without a concurrent §1915(c) waiver or a §1915(i) State Plan benefit, it limits the state to offering existing State Plan services and using regular State Medicaid Plan financial eligibility criteria. However, §1915(c) waiver services can count as services offered under the State Plan.[17] Services not expressly contained in the approved §1915(c) waiver or in the §1915(i) State Plan amendment for which payment is made under the contract, may be provided as "in lieu of" services at the state's election.[18]

Thus, states that offer many long-term services through their State Plan or existing §1915(c) waivers may find this authority adequate for establishing an MLTC program—as does Pennsylvania, which uses the §1915(a) authority to operate a program for adults with autism. See Table 8-4 for an example of the use of this authority.

Table 8-3.	New Mexico Coordination of Long-Term Services (CoLTS)
Start Date	2008
Target Group	Older persons and persons with physical disabilities. Enrollment is mandatory.
Service Area	Statewide
Scope of Medicaid Capitation	Most Medicaid services, including primary and acute health care and long-term care services (institutional and HCBS). Behavioral services are carved out to a separate managed care organization.
Authorities	**Concurrent §1915(b) and (c) waivers.** New Mexico is the latest state to implement an MLTC program, and has used the (b)(c) combination to create a mandatory, statewide program that includes primary and acute health care and long-term services in one package.

More information is available at: http://www.nmaging.state.nm.us/COLTS_overview.html.

Table 8-4.	Pennsylvania Adult Community Autism Program (ACAP)
Start Date	2009
Target Group	Adults (age 21+) with Autism Spectrum Disorder who require an Intermediate Care Facility (ICF) level of services, but can live in a community setting. Enrollment is voluntary.
Service Area	Four counties.
Scope of Medicaid Capitation	Primary care, ICF level of services in the community, and behavioral services. Acute care and pharmacy are carved out.
Authorities	Section 1915(a) authority. Pennsylvania operates this program without waivers. Although the §1915(a) authority does not authorize selective contracting, only one contractor to date has met the required qualifications and is the sole vendor.

More information is available at: http://www.dpw.state.pa.us/ServicesPrograms/Autism/.

Section 1932(a)

Section 1932(a) was enacted as part of the Balanced Budget Act of 1997. As previously discussed, the BBA recognized that Medicaid managed care had become the service delivery mode for more than half of all Medicaid beneficiaries by the late 1990s, and made mandatory managed care a State Plan option under certain conditions. Section 1932(a) is basically the same as the §1915(a) authority with the exception that it allows mandatory enrollment—except for dually eligible persons and children with special needs. However, these populations can be included on a voluntary basis. It can be used to create a managed care plan for either health care or long-term care or both.

See Table 8-5 for an example of a program that uses §1932(a) in combination with a §1915(c) waiver and Medicare Special Needs Plan authority to create a voluntary MLTC program for dually eligible adults of all ages with disabilities.

Table 8-5.	Wisconsin Family Care Partnership (FC-P)
Start Date	1996
Target Group	Older persons and persons under age 65 with physical disabilities who are clinically certified to need institutional level of care. Enrollment is voluntary.[19]
Service Area	16 counties, with expansion underway.
Scope of Medicaid Capitation	All Medicaid services, including primary and acute health care, long-term care services (HCBS and institutional), and behavioral services. (Medicare services are also fully capitated in a separate payment that FC-P receives from the Medicare program.)
Authorities	Section 1915(c) waiver and §1932(a) State Plan amendment. Wisconsin borrowed from the PACE model to create a program that includes all Medicaid and all Medicare services in one package for dually eligible persons. (But FC-P does not require enrollees to be dually eligible.) Because the program deviates substantially from PACE (e.g., it includes persons under 55 years of age), it could not use the §1934 PACE authority. Instead, it combined a §1915(c) HCBS waiver with the State Plan managed care option of §1932(a). Section 1932(a) is usually used for mandatory managed care programs, but it can also be used with exempt populations (e.g., dually eligible persons) on a voluntary basis. Medicare services are provided using the Medicare Special Needs Plan authority.

More information is available at: http://dhs.wisconsin.gov/wipartnership/.

Section 1934

Section 1934 was also enacted as part of the BBA, making PACE a Medicaid State Plan optional benefit. In combination with Medicare statutory authority in Title XVIII, this authority makes PACE a non-waiver option for fully capitated Medicare and Medicaid managed care for dually eligible persons. Enrollment is voluntary. The major limitation is that the authority applies specifically to the PACE model and may not be used to authorize an MLTC program that does not adhere to the model. See Table 8-6 for a description of PACE.

Table 8-6.	Program of All-inclusive Care for the Elderly (PACE)
Start Date	1983 at On Lok in California; 1990 in replication sites.
Target Group	Persons 55 or older who ae clinically certified to need a nursing facility level of care.
Service Area	72 PACE providers operate programs in 30 states, as of September 2009.
Scope of Medicaid Capitation	All Medicaid services, including primary and acute health care, long-term care services (HCBS and institutional), and behavioral services. (Medicare services are also fully capitated in a separate payment that the PACE program receives from the Medicare program.)
Authorities	Section 1934 State Plan amendment. After several years operating under a §1115 waiver, the Balanced Budget Act of 1997 made PACE a State Plan option. The authority may only be used to establish a PACE program, which is a specific model of care that features an Interdisciplinary Team, adult day health centers where members receive primary health care, and staff model care networks that include physicians who work for the PACE provider organization. Parallel Medicare authority is contained in Title XVIII of the Act at §1894.

For more information: http://www.npaonline.org/website/article.asp?id=4/.

Medicare Special Needs Plans

Because such a high proportion of individuals who need long-term services are dually eligible for Medicaid and Medicare, some states offering MLTC have contracted with Medicare Special Needs Plans to create integrated programs for dually eligible persons. Special Needs Plans are authorized under the Medicare Advantage managed care program. Unlike regular Medicare Advantage plans, Special Needs Plans may limit enrollment to one of three authorized groups: dually eligible persons, beneficiaries requiring institutional level of care, or beneficiaries with specified chronic conditions.[20]

A state uses the appropriate Medicaid authorities to craft a managed Medicaid program and contracts with a Special Needs Plan, which has a separate contract with CMS to deliver Medicare managed care services. The two are combined at the plan level to create an integrated Medicaid and Medicare program for dually eligible persons. Because no authority exists for mandatory Medicare enrollment, integrated plans must be voluntary. See Table 8-7 for an example of contracting with Special Needs Plans to create integrated Medicare-Medicaid programs.

As noted above, §1934, which authorizes PACE programs, is the other authority that may be used to offer integrated Medicare-Medicaid programs.

Table 8-7.	Minnesota Senior Health Options
Start Date	1997
Target Group	Older persons (65+) who are dually eligible for Medicaid and Medicare, whether or not they have long-term care needs. Enrollment is voluntary.
Service Area	Nearly statewide
Scope of Medicaid Capitation	All Medicaid services, including primary and acute health care, HCBS, and up to 180 days of institutional long-term care services. Behavioral services are also included. (Medicare services are fully capitated in a separate payment to Minnesota Senior Health Options from the Medicare program.)
Authorities	**Section1915(a) authority and §1915(c) waiver.** When this program began in 1997, it was an experimental model to combine Medicaid and Medicare and integrate financing for primary and acute health services and long-term care services under a §1115 waiver. By renewal time, other states had developed combination approaches without a §1115 waiver and its difficult budget test, and Minnesota agreed to change to the (a)(c) combination at that time. Medicare authority also shifted over time, from special payment authority and variances under the Medicare statute, to Medicare Special Needs Plan authority.

More information is available at: http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&dDocName=id_006271&RevisionSelectionMethod=LatestReleased

Section 1915(i)

Section 1915(i) was enacted as part of the DRA of 2005 and amended by the Affordable Care Act. This authority allows states to offer HCBS under their Medicaid State Plan to individuals eligible for Medicaid under an eligibility group covered by the State Plan. Unlike the §1915(c) waiver authority, the §1915(i) authority does not tie the provision of HCBS to people who require an institutional level of care, unless the state uses the 300 percent of SSI income rule to determine financial eligibility. This authority also does not by itself allow managed care approaches, and would need to be used in combination with another authority to implement an MLTC program.[21]

All Quality and Other Requirements of Each Authority Must Be Met

For many states, combining two waivers or a waiver and a State Plan amendment will be an effective way to create the program desired while avoiding the greater burdens associated with a §1115 waiver. However, states must be prepared to meet the requirements of each authority they invoke (e.g., a program that combines managed care authority and HCBS authority must meet all the requirements of both). In addition, if partnering with a Medicare Special Needs Plan to create a program for dually eligible persons, the Special Needs Plan will be accountable to CMS for all Medicare managed care requirements.

In the area of quality, for example, a program under the authority of §1915(a), §1915(b), or §1932(a) must meet continuous quality improvement requirements for Medicaid managed care, including performance improvement projects for health status and outcomes. The state must also provide for an External Quality Review Organization to evaluate outcomes and access to care. In addition, for the first two renewals of a §1915(b) waiver, the state must provide to CMS an independent assessment on access and quality requirements. Under §1915(c), states must meet CMS quality requirements in several areas, including safeguarding waiver participants' health and welfare.[22] (See the Appendix for an overview of CMS requirements for quality management and improvement systems.)

Resources

Since the Primer was first published in 2000, numerous reports and other resources have become available on the Internet. This section includes key resources relevant to Medicaid managed care authorities. Most of the publications cite additional resources and the websites also have links to other sources of information.

Publications

Bella, M., and Palmer, L. (2009). *Supporting Integrated Care for Dual Eligibles: Policy Options*. Baltimore, MD: Center for Health Care Strategies.

This policy brief addresses opportunities for integrating care for this high-cost, high-need population. The brief outlines the rationale for integrating care for dually eligible persons, reasons why integration has been slow to progress, and emerging vehicles to accelerate the adoption of fully integrated care models. A companion resource paper provides additional details on promising integrated care models and the challenges and opportunities for supporting integrated approaches.

Available at http://www.chcs.org/publications3960/publications_show.htm?doc_id=982564

CMS (2009). *Providing Long Term Services and Supports in a Managed Care Delivery System. Enrollment Authorities and Rate Setting Techniques: Strategies States May Employ to Offer Managed HCBS, CMS Review Processes and Quality Requirements.*

CMS has developed a brief technical assistance paper that outlines the enrollment authorities that states may consider when designing managed HCBS programs, the CMS review and approval process for each, and rate setting techniques that may be useful. This resource is the product of a CMS central and regional workgroup with expertise in managed care and HCBS, which reflects the progressive efforts underway in a number of states.

Available at http://www.cms.hhs.gov/CommunityServices/Downloads/ManagedLTSS.pdf

CMS State Medicaid Director Letter. May 20, 2010. *Community Living Initiative*.

This letter provides some basic information on the Patient Protection and Affordable Care Act, P.L. 111-148, enacted March 23, 2010, and the Health Care and Education Reconciliation Act of 2010, P.L. 111-152, enacted March 30, 2010, (together referred to as the Affordable Care Act), and includes a link to the online technical assistance guide entitled Long Term Services and Supports in a Managed Care Delivery System.

Available at http://www.cms.gov/smdl/downloads/SMD10008.pdf

Saucier, P., Kasten, J., and Burwell, B. (2009). *Federal Authority for Medicare Special Needs Plans and Their Relationship to State Medicaid Programs.* Prepared by Thomson Reuters for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.

This brief, the first in a series of three, reviews the history and current status of the Federal Medicare Special Needs Plan authority, with particular attention to provisions of interest to state Medicaid programs.

Available at http://aspe.hhs.gov/daltcp/reports/2009/leghist.htm

Saucier, P., Burwell, B., and Gerst, K. (2005). *The Past, Present and Future of Managed Long-Term Care.* Prepared by Thomson Reuters and the University of Southern Maine Muskie School for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.

The focus of this study is Medicaid-financed long-term care, though the discussion includes Medicare since most Medicaid long-term care beneficiaries are dually eligible. Thus the study includes both Medicaid-only programs and integrated programs that manage both Medicaid and Medicare benefits. The study focuses on older persons and persons with physical disabilities, and excludes programs that are primarily targeted to persons with developmental disabilities or serious and persistent mental illness.

Available at http://aspe.hhs.gov/daltcp/reports/mltc.htm#section1

Saucier, P., and Fox-Grage, W. (2005). *Medicaid Managed Long-Term Care.* Washington, DC: AARP, Public Policy Institute.

This issue brief reviews the limited but important experience of states that had implemented Medicaid managed long-term care programs at the time of publication, identifies key policy issues, and assesses the likelihood of future growth in these programs.

Available at http://www.aarp.org/health/medicare-insurance/info-2005/ib79_mmltc.html

Websites

Centers for Medicare & Medicaid Services

The following site provides information about combining §1915(b) and §1915(c) authorities to provide a continuum of services to disabled and/or elderly populations. By combining these authorities, states can provide long-term care services in a managed care environment or use a limited pool of providers.

Web address: http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/06_Combined1915bc.asp

The following site provides a list of resources that are currently available to provide information and assistance when developing integrated Medicare and Medicaid models of care.

Web address: http://www.cms.hhs.gov/IntegratedCareInt/2_Integrated_Care_Roadmap.asp

The following site provides an Overview of Special Needs Plans and includes several downloadable resources.

Web address: http://www.cms.hhs.gov/specialneedsplans/

National PACE Association

The National PACE Association works with CMS staff and members of Congress who work on policy issues affecting PACE organizations. Because PACE organizations are innovative programs that work with both the Medicare and Medicaid programs, the model has its own regulations that govern its operation. Information about Federal and state policy can be found at the following sites, respectively.

Web address: http://www.npaonline.org/website/article.asp?id=730and http://www.npaonline.org/website/article.asp?id=731

Center for Health Care Strategies (CHCS)

The Center for Health Care Strategies is a nonprofit health policy resource center dedicated to improving health care quality for low-income children and adults, people with chronic illnesses and disabilities, frail elders, and racially and ethnically diverse populations experiencing disparities in care. CHCS works with state and Federal agencies, health plans, providers, and consumer groups to develop innovative programs that better serve people with complex and high-cost health care needs. The following website includes numerous publications and other resources about dually eligible persons and integrated care.

Web address: http://www.chcs.org/info-url_nocat5108/info-url_nocat_list.htm?attrib_id=8408

In particular, the website has two links that are directly relevant to this chapter:

http://www.chcs.org/publications3960/publications_show.htm?doc_id=747565

This webinar explored progress that states have made in integrating care for dually eligible populations via Special Needs Plans, the challenges for integrating care, as well as new non-Special Needs Plan alternatives for states to consider.

http://www.chcs.org/publications3960/publications_show.htm?doc_id=504045

Download resources from this webinar, which featured state and health plan best practices for managing the long-term care of Medicaid beneficiaries, and integrating acute and long-term care for adults solely covered by Medicaid or dually eligible for Medicaid and Medicare.

Endnotes: Citations, Additional Information, and Web Addresses

[1] Paul Saucier is the author of this chapter.

[2] Categorical groups eligible for SSI include those age 65 or older, and children and adults under age 65 who meet SSI disability criteria.

[3] Kaye, N. (2005). Medicaid Managed Care: Looking Forward, Looking Back. Portland, ME: National Academy for State Health Policy.

[4] Saucier, P., Burwell, B., and Gerst, K. (2005). The Past, Present and Future of Managed Long-Term Care. Prepared by Thomson Reuters and the University of Southern Maine Muskie School for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. Available at http://aspe.hhs.gov/daltcp/reports/mltc.htm#section1.

[5] CMS. National Summary of Medicaid Managed Care Programs and Enrollment as of June 30, 2008. Available at http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/downloads/08Trends508.pdf.

[6] CMS. Number of Managed Care Entity Enrollees by State as of June 30, 2008. Available at http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/downloads/08MCE-%20Enrolleesf508.pdf.

[7] Kaye, N. (2005), op. cit.

[8] The 11 states operating MLTC outside of PACE are Arizona, California, Florida, Hawai'i, Massachusetts, Minnesota, New Mexico, New York, Texas, Washington, and Wisconsin. Tennessee has received Federal permission to implement an initiative scheduled to begin in 2010.

[9] Evaluations of early MLTC programs have found consistently that hospital and nursing home use decreases and community services increase. For a review of the literature, see Saucier, P., Burwell, B., and Gerst, K. (2005), op. cit.

[10] Saucier, P., and Fox-Grage, W. (2005). Medicaid Managed Long-Term Care. Washington, DC: AARP, Public Policy Institute. Available at http://www.aarp.org/health/medicare-insurance/info-2005/ib79_mmltc.html.

[11] If a state has made the policy decision to cover persons who meet certain financial or other criteria, capping enrollment could upset advocates and raise valid issues related to equity. If a state can get Federal financial participation for all eligible persons, they would of course prefer this, but because the Office of Management and Budget puts an overall cap on expenditures, the state must either cap enrollment or pay costs only with state dollars once the expenditure limit is reached.

[12] The requirements for a §1115 waiver can lead to enrollment caps, which are politically difficult and can strain relations with contractors. Capping per person costs can be done easily by setting the capitation rate to not exceed the per person cap.

[13] For more on Medicaid rate setting in PACE, see National PACE Association (2009). Pace Medicaid Rate-Setting: Issues and Considerations for States and PACE Organizations. Available at http://www.npaonline.org/website/navdispatch.asp?id=2871.

[14] The Affordable Care Act amended §1915(h) of the Social Security Act.

[15] Behavioral services include mental health and substance abuse services.

[16] CMS. (2009). Providing Long Term Services and Supports in a Managed Care Delivery System. Enrollment Authorities and Rate Setting Techniques: Strategies States May Employ to Offer Managed HCBS, CMS Review Processes and Quality Requirements. Available at http://www.cms.hhs.gov/Community-Services/Downloads/ManagedLTSS.pdf.

[17] Ibid. CMS may consider the inclusion of HCBS in a stand-alone §1915(a) contract in those cases where the state operates an approved section §1915(c) waiver or §1915(i) State Plan benefit for the same population served through the contract, in the same geographic region as the contract, containing the same services offered through the contract, and the costs of such services may be included in contract payments. These HCBS would be expressly contained in the managed care contract, and the individual need not be enrolled in a §1915(c) HCBS waiver or be receiving services through a §1915(i) HCBS State Plan program. Because this is a voluntary vehicle, an individual must be able to have the option to receive the services through another Medicaid approved authority in the state (i.e., State Plan or HCBS waiver).

[18] Ibid.

[19] Adults age 17 years, 9 months and older are eligible.

[20] For an overview of the Federal Special Needs Plan authority, see Saucier, P., Kasten, J., and Burwell, B. (2009). Federal Authority for Medicare Special Needs Plans and their Relationship to State Medicaid Programs. Prepared by Thomson Reuters for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. Available at http://aspe.hhs.gov/daltcp/reports/2009/leghist.htm.

[21] To date, there are no known MLTC programs invoking this authority.

[22] 42 CFR 441.302. Available at http://law.justia.com:80/us/cfr/title42/42-3.0.1.1.10.7.html.

Guide to Appendix

Introduction 233
An Evidence-Based Approach to Quality Monitoring 233
Continuous Quality Improvement (CQI) Model 234
Continuous Quality Improvement: Design 234
Continuous Quality Improvement: Discovery 236
Crafting Performance Measures 236
Continuous Quality Improvement: Remediation 240
Continuous Quality Improvement: Improvement 242
Beyond Assurance-Based CQI 244
The CMS Review Process 244
Technical Assistance for Medicaid HCBS Quality 245
Resources 246
Endnotes: Citations, Additional Information, and Web Addresses 248

Appendix
Medicaid HCBS Quality

Introduction

Under Federal statute, the Centers for Medicare & Medicaid Services (CMS) have the authority to oversee and regulate states' approaches to quality assurance for Section (§)1915(c) home and community-based services (HCBS) waiver programs (hereafter called HCBS waiver programs). Over the last 10 years, CMS has mounted a vigorous initiative to promote and enhance quality oversight of HCBS waiver programs, an initiative that has required changes by the states and CMS.

Until 2004, Federal oversight of HCBS waiver program consisted of periodic reviews focusing on whether programmatic requirements had been met. During this period, CMS did not collect representative data on waiver system performance, nor did it require the states to collect such information for use in quality monitoring and improvement activities. Moreover, there was appreciable variation in how CMS Regional Offices conducted quality reviews.

A major impetus for increased Federal attention to quality in the HCBS waiver programs was a 2003 Government Accountability Office (GAO) report.
The report cited as problematic the minimal information required in the waiver application about a state's approach to monitoring quality, as well as the absence of a minimum level of routine reporting from the states to CMS. The GAO urged greater oversight by CMS and the provision of increased guidance to the states on waiver monitoring practices.

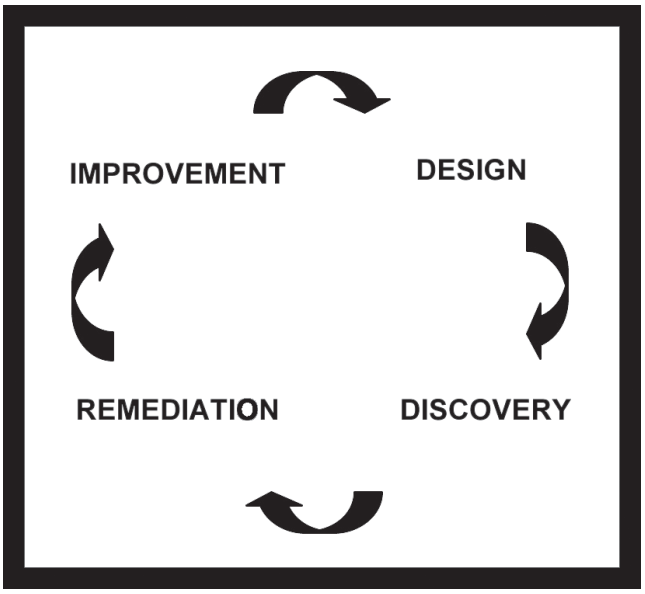
An Evidence-Based Approach to Quality Monitoring

In response to the GAO report, CMS designed and adopted an evidence-based approach to HCBS waiver program quality. The evidence-based approach is premised on the expectation that states have first-line responsibility for program monitoring to ensure the waiver operates as it was designed (i.e., as specified in the approved waiver application) and that program participants' health and welfare are safeguarded. States, on a periodic basis, must provide CMS with evidence that the program is indeed operating as specified in the approved waiver and that participants' health and welfare are safeguarded. The evidence CMS requires is related to the six statutory assurances that states make to CMS as a condition of approval of a waiver. CMS's role is to review the evidence the state submits, along with other information about the waiver's performance, and render a determination about the waiver's compliance with the Federal assurances.

Continuous Quality Improvement (CQI) Model

CMS's evidenced-based approach, while new to the Medicaid HCBS enterprise, is based on a well-established management tool known as Continuous Quality Improvement—or CQI. The CQI concept is generally credited to W. Edwards Deming, a statistician who pioneered this approach in his work with manufacturers in Japan in the late 1940s. At the heart of the CQI model is the use of empirical information—that is, evidence—to drive continuous, cyclical improvement. CMS has embodied the CQI principles in its Design, Discovery, Remediation, Improvement (DDRI) model. The DDRI model has been the operative framework for HCBS waivers since the early 2000s and is the common vocabulary that links CMS's expectations and state quality efforts. CQI is best envisioned as a cyclical process, one component feeding into the next.

Figure 1. The DDRI Model



It is CMS's expectation that Medicaid HCBS programs embrace the CQI approach and nurture a culture of quality improvement.

Continuous Quality Improvement: Design

"Design" refers to a state's plan for how it will monitor a waiver program and make improvements when systemic problems are detected. States must describe this plan in the waiver application. In 2005, CMS issued a new waiver application format, which elicits specific information about a state's design of its quality monitoring and improvement strategy. In the waiver application, a state must describe how it will "discover" when the assurances have not been met, its plans for monitoring whether the individual problems it uncovers are "remediated" or fixed, and how it will engage in system "improvement" activities when it discovers that there are systemic problems responsible for an accumulation of individual problems. A state's CQI design must be organized around the Federal assurances, described in Table 1.

Each assurance embodies more than one programmatic expectation. In the waiver application, CMS has articulated many subassurances—in order to operationalize the six assurances in concrete terms in accordance with CMS policy. CMS's articulation of subassurances seeks to ensure that states monitor the aspects of the program CMS deems fundamental. A few examples of subassurances are presented in Table 2. A full listing of the subassurances may be found in the most current version of the §1915(c) waiver

Table 1. Section 1915(c) Federal Assurances	
Level of Care	Persons enrolled in the waiver have needs consistent with an institutional level of care.
Service Plan	Participants have a service plan that is appropriate to their needs and preferences, and receive the services/supports specified in the service plan.
Provider Qualifications	Waiver providers are qualified to deliver services/supports.
Health and Welfare	Participants' health and welfare are safeguarded.
Financial Accountability	Claims for waiver services are paid according to state payment methodologies specified in the approved waiver.
Administrative Authority	The state Medicaid agency is actively involved in the oversight of the waiver, and is ultimately responsible for all facets of the waiver program.

Table 2. Examples of Subassurances (Version 3.5 of the §1915(c) Waiver Application)	
Level of Care	The levels of care of enrolled participants are reevaluated at least annually or as specified in the approved waiver
Service Plan	Service plans are updated/revised at least annually or when warranted by changes in the waiver participant's needs
Service Plan	Services are delivered in accordance with the service plan, including in the type, scope, amount, and frequency specified in the service plan.
Service Plan	Participants are afforded choice: between waiver services and institutional care; and between/among waiver services and providers.
Provider Qualifications	The state verifies that providers initially and continually meet required licensure and/or certification standards and adhere to other state standards prior to their furnishing waiver services.

application. (See the Resources section of this appendix for a link to the application.)

Continuous Quality Improvement: Discovery

Discovery refers to the monitoring process states use to uncover deviations from program design in a timely fashion. Discovery allows states to know when program processes are not being followed and when the assurances (subassurances) are not being met. The discovery monitoring process requires a state to establish performance measures that enable it to assess whether—and the extent to which—it is complying with each of the Federal assurances.

In the waiver application, a state must specify one or more performance measures for each subassurance. In addition, it must provide information on (1) the data source(s) for each performance measure; (2) how the representativeness of the data will be ensured; (3) information on the party or parties responsible for collecting, reviewing, and using the data to manage the program; and (4) how frequently summary (i.e., aggregated) reports will be generated and reviewed.

Crafting Performance Measures

Most importantly, performance measures should be actionable. Because their purpose is to help the state evaluate its program and the health and welfare of program participants, the measures should be able to identify when a subassurance is not being met, so that actions can be taken to bring the program into compliance. Performance measures must also meet four criteria (see Box).

Criteria for Crafting Performance Measures

- Be measurable and stated as a metric
- Have face validity
- Be based on the correct unit of analysis
- Be representative

The first criterion is that the performance measure be measurable and stated as a metric. This means that the performance measures must be able to take on different values. States frequently make the mistake of describing a process for monitoring a subassurance, rather than focusing on the outcome of the monitoring reported in the form of a metric. Typically, assurance-based performance measures are stated in the form of a percentage. The performance measure data must also be able to be aggregated across individual waiver participants, providers, or claims—depending on the unit of analysis (discussed below). Aggregating performance measure data allows the state to generate reports on a specific aspect (subassurance) for the program as a whole, assess the operation of the program on that given aspect, and determine the level of compliance.

A Performance Measure Should Be a Metric

Acceptable: Percent of waiver participants whose service plans were reviewed and updated annually. (Outcome)

Unacceptable: The Division of Aging conducts record reviews to assess whether services plans of waiver participants are reviewed and updated annually. (Process)

The second criterion is face validity, the property of a performance measure that reflects whether it will indeed measure what it has been designed to measure—in this case, a subassurance. To meet this criterion, state staff have to ask the following: Does the performance measure truly capture and measure the essence of a specific subassurance? "On the face of it" does it track with the subassurance? A performance measure with face validity will enable a state to monitor its performance on a given subassurance, and for CMS to judge the state's demonstration of compliance with the subassurance. If a performance measure lacks face validity, the state runs the risk of collecting potentially useless information, wasting resources, losing the ability to monitor one aspect of its program, and not demonstrating compliance to CMS. States should be careful to not use performance measures that are stated as a metric but are lacking face validity vis-à-vis a given subassurance.

A Performance Measure Should Have Face Validity

Service Plan Subassurance: Service plans address all participants' assessed needs (including health and safety risk factors) and personal goals, either by the provision of waiver services or through other means.

Unacceptable: Mean risk fall score for waiver participants.

- Metric, but lacks face validity.
- Does not tell you to what extent risks were addressed in service plan.
- May be a good assessment item, but is not a performance measure with face validity for the subassurance.

Acceptable: Percent of participants' service plans that address their risk.

- Metric.
- Has face validity vis-à-vis the subassurance.

The third criterion is the correct unit of analysis. Choosing the correct unit of analysis for a performance measure is crucial. The unit of analysis refers to the group/entity which the performance measure references. Typically, the unit of analysis for Level of Care, Service Plan, and Health and Welfare subassurances is the waiver participant; for Provider Qualification subassurances it is providers, and for Financial Accountability it is claims. Data for generating performance measures can come from several sources (administrative data, claims data, reviews of participants' records, automated care coordination systems, critical incident data bases, mortality reviews, etc.), and sometimes from a combination of data sources. Whatever the data source, it is key to make sure that the unit of analysis is appropriate to the subassurance that the performance measure will be used to monitor.

A Performance Measure (PM) Should Use the Correct Unit of Analysis

Service Plan Subassurance: Service plans are updated/revised at least annually.

Incorrect Unit of Analysis: Percent of Supports Coordination Agencies that updated/revised annual service plans on time.

- PM focuses on Supports Coordination Agencies (provider) rather than waiver participants.
- May be a more appropriate measure for a Provider Qualifications PM.

Correct Unit of Analysis: Percent of waiver participants who received an annual updated/revised service plan.

The fourth criterion is representativeness. When monitoring a waiver, CMS is interested in knowing how the waiver as a whole is performing on any given subassurance. If the performance measure data are not representative of the waiver population (or of providers or claims), neither the state nor CMS can be confident that the resulting measure accurately portrays the waiver's performance.

By definition, the data for generating a performance measure are representative if they derive from the entire population (e.g., service plans of ALL waiver participants, reviews of ALL providers, reports on ALL claims). However, collecting data from the entire population can be very costly—particularly for larger waiver programs. Thus, performance measures frequently are based on data taken from a sample (i.e., a subset of the population). The estimates derived from a sample can represent the entire population, as long as random selection is used in drawing the sample.

CMS expects performance measure data to be representative because if not, then the state cannot assert with confidence that the data represent the waiver as a whole, and CMS cannot conclude compliance due to insufficient evidence.

CMS elicits information about the state's plan for generating representative data for its performance measures within the quality section of the waiver application labeled "Sampling Approach." These sections require states to specify whether a performance measure will be based on population data or whether the state will use a sampling approach. If the state opts for sampling, CMS does not require the state to specify the size of the sample, but rather asks the state to specify the sampling parameters that will be used to determine sample size. CMS has certain expectations about the values these parameters must take on for the resultant sample to be considered representative (see Box.)

Using Sampling Parameters to Determine a Representative Sample

Three parameters must be set to determine sample size: (1) Confidence Level, (2) Confidence Interval (also called the Margin of Error), and (3) Distribution (of the variable) in the Population. CMS considers a sample to be sufficiently representative if the Confidence Level is .95 or larger and the Confidence Interval (Margin of Error) is +/– 5 percent or less. A Confidence Level of 95 percent ensures that one can be 95 percent certain that the estimate derived from the sample is accurate. A Confidence Interval of +/– 5 percent ensures that the actual population value is within +/– 5 percent points of the estimate provided by the sample. A Distribution value of .5 is always acceptable (discussed in more detail below.)

For most states, determining a credible sample size will involve using a sample size calculator. Many calculators may be found online by searching the term "sample size calculator." These calculators will prompt the user for values for Population Size, Confidence Level, and Confidence Interval (Margin of Error).

Many calculators will not prompt the user for a value for the Distribution (of the variable) in the Population, but will assume a .5 value. The best calculators, however, will allow the user to specify the Distribution value. It is not possible here to delve into the conceptual underpinnings of this parameter; suffice it to say that under certain conditions states may vary this parameter (from .5), thereby lowering the recommended sample size, and still have a sample that is considered large enough to be representative. There is a rule of thumb states may follow in varying the Distribution parameter: If the state is drawing a sample for the first time in order to collect data for a performance measure(s), it must assume a 50-50 Distribution and use the .5 value.

However, if the state has collected data on a given performance measure(s) previously, and derived the estimate from the entire population or a representative sample, they may alter the distribution to reflect that previous experience. For example, in Year 1 of data collection the state discovered that 90 percent of service plans addressed participants' needs, but 10 percent did not. In Year 2, they would be justified in using a 90–10 split (.9 Distribution value) in the sample size calculator. To illustrate the difference in sample size that altering the Distribution can make, let us use the example of a waiver with 3,000 participants. With a Distribution value of .5, the recommended sample size is 341, but with a Distribution of .9 (or .1, its reciprocal), the recommended sample is 133.[5]

If a state can justify using a Distribution other than the standard .5, it can decrease sample size while simultaneously generating performance measure estimates that are credible and representative.

One error states should avoid is simply choosing sample size based on a percentage of the population (e.g., 10 percent of all waiver participants). This approach will often either yield a sample that is not large enough to deliver credible results or will specify a sample that is larger than necessary. Sample size should always be calculated by specifying the sampling parameters discussed above.

Sample Stratification. Sometimes states are interested in obtaining information on how various subgroups—or strata—are performing. For example, a state may want to monitor the performance of care coordination agencies in their responsibility for conducting timely annual level-of-care determination. So, the state decides to "stratify" its record review sample by care coordination agency. However, before doing so, states need to consider several implications of a stratification approach. First, if there is a desire to compare subgroups, then it is important that the sample for each subgroup be large enough to be representative of each subgroup. In general, the more subgroups, or strata, the larger the overall sample size will need to be. The state must balance its need for information on subgroups with available resources.

Although CMS elicits information from states on the waiver application about stratification, stratification is not a CMS requirement; it is entirely at the state's discretion whether to stratify. However, if stratification is used, it is important that the data be "re-weighted" so that they represent the entire population; a simple averaging of results from the various strata will not produce a valid estimate.[6] A statistician or someone with expertise in sampling statistics should be consulted. Technical assistance is also available from CMS as described later in this appendix.

When states use the same quality improvement strategy (QIS) across multiple waivers or across waivers and state-funded HCBS programs (sometimes referred to as a "Global QIS"), they may be tempted to draw one sample for all the waivers and programs combined. However, CMS requires that evidence be reported for each waiver separately, and that the samples for each waiver be large enough, on their own, to be representative of a given waiver's population/providers. In this context, one might hear the issue referred to as "stratifying" by waiver. If the state wants to sample across multiple programs, it will have to stratify by program and ensure that the sample size for each program is large enough to be representative.

Continuous Quality Improvement: Remediation

The purpose of discovery activities is to identify instances where the program is not operating as intended and is out of compliance with the Federal assurances. Discovery activities, however, are not an end in themselves but rather (and most importantly) a means to identifying problems so that they can be addressed. In the CQI waiver cycle this is called Remediation. The focus of remediation is to address and resolve all individual problems uncovered in the course of discovery.

The rate of compliance is measured through the performance measures as discussed above. CMS expects states to be in compliance with the statutory assurances. If a performance measure indicates that the state achieved less than 100 percent compliance, the state must remediate all instances of non-compliance discovered. While a state may not be in compliance initially, it may come into compliance by taking remedial actions. Compliance can occur by appropriately addressing all detected problems. It is clearly preferable, however, for the state to achieve compliance by preventing problems in the first place (i.e., having a high level of performance initially).

As states design their quality strategies they must build in systematic mechanisms for addressing problems as they are uncovered. In the waiver application, states are required to specify these methods. States should have policies and procedures describing (1) who is responsible for monitoring remediation activities and verifying that problems are appropriately addressed, (2) the explicit expectations for timeframes within which problems should be resolved, and (3) what sanctions may be imposed in the event that corrective action is not taken by the responsible party. It is also important that remediation methods be appropriate to the problems uncovered. Corrective actions will differ depending upon the assurance, subassurance, and/or performance measure for which non-compliance was discovered.

Like discovery evidence, states should also be able to aggregate remediation evidence. The aggregation of remedial activities is a state's way of summarizing the types and numbers of actions taken in response to non-compliance with regard to a given performance measure. Aggregated data about remediation actions, in the form of remediation reports, provide the evidence CMS requires to ensure that the state has addressed instances of non-compliance. Remediation reports can also be used by the state, along with discovery reports, to identify and analyze trends related to non-compliance. Table 3 illustrates what a summary discovery and remediation report might look like for one level-of-care subassurance. The discovery and remediation reports are linked because the number and types of remediation actions necessarily follow from the instances of non-compliance uncovered through the state's discovery activities. In this example, over the course of one calendar year, the state uncovered 30 instances where a reevaluation to determine the level of care was not conducted on time (Discovery Results).

Table 3. Fictitious State Waiver Quality Monitoring Report, Generated 1-1-2009 Period of Performance: January 1, 2008 through December 31, 2008

Performance Measure: Number and percent of waiver participants who received an annual re-determination of eligibility within 12 months of their initial level-of-care evaluation or within 12 months of their last annual level-of-care re-determination.

Discovery Results

	Compliance Rate	Sample
Compliance	91%	300
Non-compliance	9%	30
Total	100%	330

Remediation Actions

Actions	Number of Actions
Reevaluation conducted, still eligible	25
Reevaluation conducted, not eligible	4
Referred to state-funded program	4
Claims from period of ineligibility excluded from Federal Financial Participation(FFP)	4
# of remediations completed in < 30 days	26
# of remediations completed in 31-60 days	2
# of remediations completed in > 60	1
Outstanding remediation actions	1*
Total instances of non-compliance addressed	29

** In a record review on 12/22/08, a person was discovered to be 35 days overdue for a re-determination. Due to the holidays, the re-determination had not occurred at the time this report was generated.*

Twenty-nine of the 30 instances were addressed through the state conducting a reevaluation on each tardy re-determination (Remediation Actions). In 25 of the 30, the person was found to still be eligible at reevaluation and thus no further action was necessary. However, in 4 cases the person re-evaluated was deemed ineligible for the waiver, and in these instances the state took further actions to refer these individuals to the state-funded program and to ensure that no FFP was claimed for waiver services provided during the period of ineligibility.

In this example, the state had a policy that all remediation actions related to late level-of-care re-determinations must be accomplished within 30 calendar days of discovery; as such, the state is also tracking whether appropriate remedial actions are taken within the specified timeframe. In addition, the remediation report identifies the number of outstanding problems not addressed on the date the report was generated.

The example provided in Table 3 is a summary report for one year and might be the type of report a state would submit to CMS as evidence. However, the state should have a data system capable of generating more frequent reports, to enable performance monitoring as the discovery and remediation results come in. A key component of a quality assurance system is the ability to discover problems close to their occurrence, which then enables a quick response—be it fixing the original problem or uncovering remediation actions that are inappropriate and/or untimely.

Continuous Quality Improvement: Improvement

Fixing individual problems as they occur is an essential component of CQI, but if the same type of problem occurs repeatedly, it would be helpful for the state to step back and assess what systemic causes might be responsible. Having determined the potentially largest contributor(s) to the problem, the state is then in a position to develop an intervention to prevent future occurrences of the problem. Examining summary discovery and remediation data over several months is a good way to determine if there are trends indicating the need to go beyond interventions to address individual problems and initiate those that are more systemic and would result in better performance.

While Remediation focuses on addressing individual problems, Improvement focuses on making adjustments to the system's processes or procedures in order to prevent or minimize future individual problems. When system improvements work, discovery data improve.

Typically, the discovery metrics of the performance measures enable the state to assess whether an improvement action actually resulted in better performance; for example, the state will conduct a "pre-post" analysis using the performance measure data to evaluate the impact of the improvement action. The "pre" data is the performance on a measure(s) prior to the implementation of the improvement intervention, and the "post" data constitutes performance on the same measure(s) in the months following the intervention.

If the improvement action is effective, the state will see improvement in the performance measures. If improvement is not achieved after a reasonable amount of time has passed (i.e., sufficient time to allow for full implementation of the improvement action), the state needs to go back to the drawing board and figure out why the improvement project did not work. One reason why an intervention might not be successful is because the intervention really did not occur as it was designed (e.g., a newly instituted procedure was not followed). The other reason for failure is that the intervention was not the right intervention. If a state does not get the results anticipated, it needs to assess both possible causes. In most instances, states are very astute about targeting the right intervention, and more often than not a new procedure has the intended result.

Example of a Quality Improvement Project

A State was concerned that the compliance rate on its performance measure *"Percent of service plans that address participants' risk"* consistently hovered around an unacceptable 75 percent for several months. The State's waiver manual specifies that risks should be evaluated during an assessment and enumerates the various aspects of risk (i.e., health risks, behavioral risks, cognitive risks, fragility of the informal support system, etc.). Yet, case managers' practice did not always meet the State's expectations as stated in the manual.

When the Quality Unit, as part of their quality monitoring, reviews participants' service plans and discovers that risk has not been addressed, the case manager is required to revise the service plan and then the Quality Unit must follow-up to verify that the service plan has indeed been updated. Continually having to remediate these individual instances of non-compliance are costly to the State (in addition to the lack of compliance possibly jeopardizing the health and welfare of program participants).

To improve the situation, the State decided to reconfigure its assessment form by adding a risk assessment protocol that must be completed by the case manager during every assessment. After reviewing other states' approaches to risk assessment, the Quality Unit and Program Operations staff developed its own protocol, piloted it with a small group of case managers, and revised it based on the pilot's findings. Prior to rollout of the new Risk Assessment Protocol, Program Operations staff conducted multiple training sessions in the use of the new protocol for case managers and supervisory personnel throughout the State. They also assigned one of their staff as a "go to" person to answer questions case managers might have when using the new protocol.

Because the Quality Unit conducts record reviews on an ongoing basis, it was able to assess the effect of the new Risk Assessment Protocol. Three months after the new protocol was implemented, 86 percent of service plans addressed risk, and after 6 months, the compliance rate was at 97 percent; but by month 12 it had fallen back to 90 percent. Upon investigation, the State determined that the decrease was attributed to new case managers who had not received the initial training on the new protocol. In order to sustain a high compliance rate, the State is exploring the development of an online training module that all new case managers must view, combined with close supervision for their first 3 months of employment.

While the State's initial quality improvement project was successful, the success was not sustained. Thus, they continue to fine tune their training processes to achieve their goal of high compliance rates.

CMS expects states to engage in CQI activities, especially if there is consistent non-compliance over a period of several months. States are required to specify in the waiver application the party responsible for assessing the need for, prioritizing, and implementing quality improvement activities, as well as the state's processes for conducting these activities. They also are required to specify how they will assess the impact of the changes they made and whether they resulted in quality improvements. See Box below for an example of a quality improvement project.

Quality improvement is a necessary and essential component in any CQI endeavor, and states should design deliberate processes to ensure that the waiver program's performance undergoes routine evaluation to identify and improve its operation. At least once during the waiver's approved period, and as part of its quality improvement responsibilities, CMS expects a state to
evaluate the effectiveness of its quality monitoring processes (i.e., to determine if the state's monitoring processes work as well as they were intended). This evaluation provides an opportunity for the state to consider exploring more efficient and/or effective approaches to its quality monitoring processes. Appendix H of the waiver application requires states to describe how and when they will conduct this self-review.

Beyond Assurance-Based CQI

While CMS requires states to engage in quality improvement activities related to the assurances and subassurances, many states of their own accord will identify aspects of their program they wish to improve or enhance—aspects that are not directly related to any of the assurances or subassurances. For example, the state may install an automated case management system or decide to upgrade its information technology system. These types of improvements are encouraged by CMS, but they are of a different nature than the improvement activities associated with the assurances and subassurances. States may also choose to track additional aspects of program performance that go beyond the Federal requirements, and CMS is supportive of states taking such initiatives.

The CMS Review Process

On a periodic basis, CMS requires states to submit evidence that demonstrates their active monitoring of their waivers, as well as compliance with the assurances and subassurances. This evidence should consist of summarized findings of the Performance Measures (Discovery Data), and summarized results of all remediation actions taken when the state discovered any non-compliance related to any Performance Measures. Table 3 depicts what summarized evidence might look for one performance measure.

States are also expected to report on any quality improvement actions they have initiated, the reasons for conducting the quality improvement project, the nature of the intervention, and the empirical results of the improvement action (i.e., to what extent it worked, as measured by an improvement in the Performance Measure's compliance rate). Currently, CMS requires states to submit information on waiver quality on an annual basis in a 372 report, a report that is waiver-specific and also includes waiver cost and utilization data.

In addition to the annual reporting, prior to waiver renewal CMS conducts an in-depth review of the waiver program and requires the state to submit evidence on all performance measures covering all discovery, remediation, and improvement activity reports for the first 3 years of the waiver (and for the first 18 months for a new waiver). After reviewing the state's evidence package, CMS issues a Findings Report detailing whether the state met the assurances. For a state that could not demonstrate it met an assurance, the Findings Report will specify what it must do to come into compliance if CMS is to renew the waiver upon its expiration. A state found out of compliance is typically required to submit an action plan to CMS; once approved and the state begins implementation, CMS will monitor the state's progress through state-submitted reports, teleconferences, and on-site visits.

States should also expect to be visited by CMS staff at least once during a waiver cycle. The purpose of these visits is for CMS to verify that the monitoring strategies that the state described in the approved waiver application are actually being implemented, and that monitoring reports are being generated in

the frequency specified in the application and used by the state in operating the waiver. While on site, CMS may (1) interview state staff to better understand the processes and operations associated with the quality improvement strategy, (2) "shadow" quality oversight staff as they conduct monitoring activities, (3) observe the state's quality oversight meetings where performance measure data and remediation reports are reviewed and where quality improvement activities are planned and evaluated, and (4) visit providers to verify that the state is conducting provider reviews as described in the waiver application.

CMS may also visit a state if there are reports about program participants' health and welfare being seriously jeopardized, or in the case of serious provider infractions. Additionally, through-out the waiver's cycle, states should expect an ongoing dialogue with CMS about waiver quality; both state staff and CMS staff are expected to take responsibility for this interchange.

Technical Assistance for Medicaid HCBS Quality

CMS staff, be they Regional Office staff assigned to the waiver and/or staff in the Baltimore Central Office, are available to answer states' questions about Medicaid HCBS quality and to provide guidance. In addition, since 2001 CMS has made available to the states free quality-related technical assistance (TA) through the National Quality Enterprise (NQE). The NQE provides one-on-one TA for states targeted to specific waivers. In addition, the NQE conducts HCBS Quality Training Forums consisting of teleconferences open to all states where topics related to HCBS quality oversight are addressed by CMS, national experts, and state HCBS staff. The NQE also publishes periodic manuscripts on various HCBS quality issues and maintains a website. This site includes links to many CMS documents pertaining to HCBS quality, as well as manuscripts and resources endorsed by CMS. Those joining the website are able to post questions to peers in other states. Also, states may request TA from the NQE through this website. (See the Resources section for a web link to the site.)

Resources

National HCBS Quality Enterprise Website

This website provides information on quality improvement for Medicaid §1915(c) HCBS waivers and the CMS Quality Enterprise project. It also provides state Medicaid quality staff an opportunity to connect with one another and pose questions to Quality Enterprise staff. Visitors must create a member's account to access the full site or can browse using a preview option.

Resources include CMS Quality Communications, technical assistance manuscripts, PowerPoint presentations, and audio-recorded training calls. All of the materials posted on this website have been reviewed and approved by CMS. Material is added to the website on an ongoing basis and interested parties are encouraged to check the website for updates. Below are some examples of material that may be found on the NQE website as of the publication date of this Primer.

Web address: http://www.nationalqualityenterprise.net/

- B. Edwards, CMS Quality Communication #15: Web Based §1915(c) Waiver Application; Instructions and Technical Guide; Resource Documents; 372 Online Form, CMS Disabled and Elderly Programs Group, January 25, 2010.
- S. Galantowicz, Implementing Continuous Quality Improvement (CQI) in Medicaid HCBS Programs, National Quality Enterprise, January 21, 2010.
- B. Jackson, PowerPoint presentation and audio recording: Examples of Performance Measures for the §1915(c) Waiver Assurances (first installment), January 14, 2010.
- B. Jackson, PowerPoint presentation and audio recording: Examples of Performance Measures for the §1915(c) Waiver Assurances (second installment), March 11, 2010.
- G. Arden, CMS Quality Communication #12: Revised Interim Procedural Guidance (IPG) and Technical Assistance Products, CMS Disabled and Elderly Health Programs Group, February 6, 2007.
- R. Freedman and S. Taub, Sampling: A Practical Guide for Quality Management in Medicaid HCBS Waivers, National Quality Contractor, March 2006.
- S. Galantowicz and B. Selig, Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement, National Quality Contractor, February 2005.

Centers for Medicare & Medicaid Services. (2008). ***Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria*****. Baltimore, MD: Department of Health and Human Services.**

This publication contains extensive information concerning Federal policies that apply to the operation of an HCBS waiver. In particular, Appendix G: Quality Improvement, Health and Welfare and Appendix H: System Improvement are relevant to the forgoing discussion on Medicaid HCBS Quality. The instructions include technical guidance to aid states in designing an HCBS waiver, and incorporate the review criteria that CMS uses in order to determine whether a waiver meets applicable statutory, regulatory, and other requirements.

Available at https://www.hcbswaivers.net/CMS/faces/portal.jsp under links and downloads, entitled ***§1915(c) Waiver Application and Accompanying Materials.***

Endnotes: Citations, Additional Information, and Web Addresses

[1] Beth Jackson is the author of this appendix. CMS funded the development of this appendix on quality management systems.

[2] CMS's expectations for state responsibility for quality in Medicaid HCBS programs is most clearly articulated for the §1915(c) waiver programs; however, the agency increasingly is looking to the §1915(c) quality requirements as a model for further articulation of quality requirements for home and community-based services provided under other Medicaid authorities, such as the §1915(a) and §1915(b) authorities and the §1115 demonstration authority.

[3] U.S. Government Accountability Office. Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened. GAO-03-576, June 2003.

[4] Version 3.1 of the waiver application was issued in a Word format in 2005. In November 2006, CMS launched the application in a web-based format under Version 3.4. In January 2008, CMS released Version 3.5 where the quality-related portions were re-designed to elicit even more specific information from the states on quality monitoring and improvement. As of April 1, 2010, use of the web-based application is mandatory.

[5] Assumes a Confidence Level of .95 and a Confidence Interval (Margin of Error) of +/–5.

[6] Typically, stratification violates the simple random sample assumption that every unit within the sample contributes equally. The sample size of the strata are often disproportionate to their representation in the population, and thus the sample must be statistically adjusted so that an estimate of the entire population can be made, and to avoid having members of any one subgroup (strata) contributing more or less than a member of another subgroup.

[7] This quality review process was instituted by CMS in January 2004 when they issued Interim Procedural Guidance. CMS updated aspects of this process in February 2007 with the Revised Interim Procedural Guidance issued under Quality Communication #12 from the Director of the Disabled and Elderly Health Programs Group.

[8] From 2001–2008, the CMS-funded National Quality Contractor provided technical assistance to states. In October 2008, CMS changed the funding mechanism to a grant and renamed it the National Quality Enterprise.

U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation
200 Independence Avenue, Washington, DC 20201

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

RETURN TO:

Office of Disability, Aging and Long-Term Care Policy (DALTCP) Home
[http://aspe.hhs.gov/_/office_specific/daltcp.cfm]

Assistant Secretary for Planning and Evaluation (ASPE) Home
[http://aspe.hhs.gov]

U.S. Department of Health and Human Services Home
[http://www.hhs.gov]