

# MEDICAID & HIV/AIDS POLICY

A B A S I C P R I M E R

THE HENRY J.  
KAISER  
FAMILY  
FOUNDATION

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**Federal Legislation Clinic of**  
**Georgetown University Law Center**

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Prepared for The Henry J. Kaiser  
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July 1999



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# PREFACE

Medicaid is the largest source of financing for HIV/AIDS care in the United States. While its significance was largely unrecognized in the first decade of the epidemic, it has always served as the general safety net under the specific safety nets for people living with HIV and AIDS.

Medicaid is, however, extremely complicated. The Federal law (which provides at least half of the funds for any program) contains detailed requirements and limitations on eligibility, services and financing. State law (which forms the basis for the actual implementation of any program) varies widely across the Nation and is in nearly constant flux. With the addition of the movement away from the traditional fee-for-service model and toward the managed-care model, Medicaid policy is, at best, extremely difficult to follow.

This is particularly so for people with HIV/AIDS. The disease, its treatments, and its epidemiology are changing rapidly. Finding the intersection between these trends and the trends of Medicaid is a daily challenge.

That is why we have compiled this primer. People who work on HIV/AIDS need to understand Medicaid for at least two reasons. First, they must be able to help every person with HIV/AIDS, and every provider who serves these people, understand the current system and obtain the services and payments for which they are eligible. Second, they must be able to work to improve the current program for those who will need it in the future.

The tasks of understanding and improving Medicaid are not easy for a variety of reasons:

- Medicaid is a complicated series of programs with seemingly endless variations. Answering questions as basic as “Who is eligible?” and “What are they eligible for?” in an easily understood form is enormously difficult. This primer is not intended to cover details, but rather to provide a general understanding of the basic facts.
- Medicaid is changing. Even while this primer was being written, the program itself was being rewritten by Congress, the Health Care Financing Administration, the States, the State Medicaid directors, and the courts. Beyond changes in law, waivers from the requirements of the law are being developed, reviewed, implemented, and amended in almost every State.
- Medicaid is expensive. The program is projected to cost Federal and State governments almost \$191.5 billion in 1999 and \$207.7 billion in 2000. Limiting the cost of the program is a major concern for policymakers at all levels of government.

Finally, it should be noted that Medicaid serves as a health care safety net for all people in the United States. It was created long before the HIV/AIDS epidemic began and people with HIV/AIDS have been the beneficiaries of many dedicated advocates for health care for low-income people. It now falls to HIV/AIDS advocates to carry on this tradition and further this legacy, both for the people they represent and for all people in need of health care.

## *Acknowledgements*

This primer is the product of joint efforts by many people including: Katie Corrigan, Mason Emmett, Chai Feldblum, Kristen Ebeler Fennel, Scott Foster, Althea Gregory, Heather Lowry, Sharon Perley Masling, David Rapallo, Leah Stevralia, Michael Beauvais, Jessica Busan, Christine Debry, Jason Dillinger, Doug Griffin, Tni LeBlanc, Elizabeth Miller, Jeffrey Miller, and Jennifer Tomchin.

It could not have been produced without the help of at least the following people, whom I thank: Amy Anderson, Joan Alker, Violet Baxter, Patrick Brannen, Burnell Britton, Bruce Campbell, Lisa Carr, Howard Cohen, Jeff Crowley, Sharon Daly, Marcus Darnley, Trish Devine, Ellen Doneski, Jack Ebeler, Barry Eigen, Judy Feder, Ruth Finkelstein, Dennis Gallagher, Anne Graham, Edmond Glomsky, Randy Graydon, Mike Greenberg, Melody Harned, Mike Hash, Jane Horvath, Nan Hunter, Sean Hurley, Mike Isbell, Azar Kattan, Ruth Katz, Neva Kaye, Earline Killgrow, Mike King, Janet Klein, Jennifer Klein, John Klemm, Richard Kogan, Jeff Levi, Anne Lewis, Gary Martin, Trish McTaggart, Karen Nelson, Teel Oliver, Nancy Olsen, Tina Perkins, Trish Riley, Sara Rosenbaum, Robin Rudowitz, Lou Schiro, Andy Schneider, Sam Shekar, Bob Shelbourne, Harry Simon, Lisa Smith, Richard Sorian, Albert Spivey, Craig Street, Marty Svolos, Bridgett Taylor, and Sandy Wise.

I also greatly appreciate the support of The Henry J. Kaiser Family Foundation and its staff.

Tim Westmoreland

# CHAPTER 1: BRIEF OVERVIEW





# CHAPTER 1

## BRIEF OVERVIEW

**[T]here has developed a degree of complexity in the Social Security Act and particularly the regulations which makes them unintelligible to the uninitiated...Such unintelligibility is doubly unfortunate in the case of a statute dealing with the rights of low-income people.**

*Friedman v. Berger, 547 F. 2d 724 (1976)*

Medicaid is the largest source of money for AIDS health care services in the United States. In 1999, Medicaid is estimated to pay \$3.9 billion for such care. This amount accounts for half of all public spending on AIDS medical care.<sup>1</sup> Fifty percent of all adults with AIDS and ninety percent of all children with AIDS depend on Medicaid to pay for their care.<sup>2</sup>

For people living with HIV/AIDS and for those who provide their care, Medicaid serves as a valuable safety net. Often the only source of financial assistance for health care, Medicaid plays a critical role for people living with HIV/AIDS in providing coverage and access to care.

Despite its importance however, the structure of the Medicaid program is often ill-matched to the needs of people with HIV/AIDS. Limits on who can receive Medicaid coverage and what services are covered can undermine early diagnosis and the potential benefits of the recent advances in treatment. Legislative and administrative attempts to improve these limits have so far been generally unsuccessful.

The increase in the number of persons living with HIV/AIDS, as mortality rates have dropped, and the continued growth in the population of persons with HIV/AIDS from low-income communities call for improving Medicaid's role in financing coverage for people with HIV/AIDS.

The financing and delivery of services under the Medicaid program is undergoing rapid transformation. The managed care revolution that has swept through many private health plans is now sweeping broadly through Medicaid. The rise in managed care has significant implications for Medicaid beneficiaries with HIV/AIDS and for the providers who serve them. While the benefits of managed care can include coordinated cost-effective care, the risk of underservice is also significant. These concerns are particularly important because of the high cost of treatment for HIV/AIDS, compared with the average cost of otherwise healthy Medicaid beneficiaries. Unless special payment arrangements are made, many managed care organizations (MCOs) will

have strong financial incentives to avoid enrolling people with HIV/AIDS or to limit the amount of care provided.

This primer is an introduction to Medicaid and a reference for HIV/AIDS advocates who need to know or refer to the basics. Its purpose is to describe how Medicaid works, including who is eligible and what services are covered; to examine how the program is being transformed through the increasing use of managed care; and to identify opportunities and future challenges for advocacy. The following discussion highlights these issues, while subsequent chapters explore these subjects in greater detail.

## ***Medicaid Today***

The Medicaid program is jointly administered and financed by the federal and state governments. The program has certain minimum federal standards that each state must meet before the federal matching payments will be paid. On top of these minimum standards, states have built many different variations. Some vary as to people served, some vary as to services provided, and some vary as to payment and enforcement mechanisms.

### **Eligibility and Services**

Contrary to popular belief, Medicaid is not available to anyone who is low-income. While someone seeking Medicaid must be low-income, that alone is not enough to qualify. Applicants must also meet one or more standards of categorical eligibility. Most persons with HIV/AIDS gain Medicaid coverage because they have become disabled as a result of their illness or because they meet the program's categorical and financial tests for low-income women and children.

If a person is eligible to be a Medicaid beneficiary, he or she is entitled to a range of services, including all medically necessary services within a state's benefits package, which must include hospital, physician, and clinic services. Depending on state law, a Medicaid beneficiary may also be eligible for a range of optional services, including prescription drugs, hospice, and case management services.

### **Reimbursement**

Payment for Medicaid services varies widely and is changing rapidly. In the traditional model (which is rapidly disappearing), physicians and other professionals are reimbursed on the basis of services provided and most hospital services are paid on a prospective, capitated basis. Community health centers and other clinics, were once reimbursed on the basis of their costs, but that practice is being phased out. Prescription drugs are purchased for Medicaid beneficiaries at a significant discount.

## Managed Care

Although the fee-for-service model of care is often regarded as traditional American insurance, the managed care model is increasingly common in Medicaid just as it is in the private sector. Fee-for-service health care is widely acknowledged to have produced incentives for significant increases in health costs, and the managed care movement has grown in response. Indeed, as of the fall of 1997, states can require that Medicaid beneficiaries enroll in Managed Care Organizations (MCOs).

There are many types of MCOs in Medicaid, and the term has come to mean almost any payment and delivery system designed to plan and provide health care services in a cost-conscious and coordinated manner. Managed care itself, however, is also widely criticized as providing incentives for under-service.

The managed care model is especially problematic when applied to services for Medicaid beneficiaries with HIV/AIDS. Most managed care experience has been with healthy, employed people in the private sector. Most Medicaid experience with managed care has been with generally healthy women and children. The challenge of adapting this cost-containing system to people with long-term health care needs, high expenses, and frequent innovations in therapy is significant.

## Waivers

Although there generally are federal minimum standards for state Medicaid programs, states can request that such standards be waived. In the past, waivers were sought primarily to allow a state to compel beneficiaries to enroll in managed care; such waivers are no longer necessary, because states may now do so without federal permission. However, waivers remain a feature of the Medicaid program and may be used by states for other innovations or experiments in the delivery of health care.

## Enforcement

The Medicaid program contains within it some means for beneficiaries and providers to enforce the guarantees of the program. In addition to administrative remedies, such as the right to a fair hearing and the requirement for internal grievance procedures, Medicaid beneficiaries and providers can seek judicial enforcement through private lawsuits.

## State and Local Advocacy

Within the changing terms of Medicaid and the changing nature of the epidemic, much remains to be reconciled between needed services and actual delivery. In recent years, HIV/AIDS advocates have focused attention on federal policymakers for Medicaid change. With the advent of widespread managed care and the subtleties of managed care contracting, such advocacy should be directed to state and local policy makers as well.

## *Future Challenges*

Perhaps the most obvious problem facing HIV/AIDS advocates today is the limited eligibility for Medicaid available to childless adults. Virtually the only avenue of eligibility for these people, no matter how poor they are, is through total disability and Supplemental Security Income (SSI). Yet, the requirement that people wait for help until they are disabled by AIDS deprives low-income people of the benefits of many of the research advances in HIV therapy, which might prevent the decline of the immune system and the resulting infections and cancers that accompany that decline.

In addition, there are a number of difficult issues regarding the repercussions of the recent repeal of minimum payments to many organizations that have served people with HIV/AIDS. Both community clinics and public hospitals have lost their guarantee of minimum Medicaid payments, depriving them of a steady stream of cross-subsidies for uninsured patients and leaving them to face the near certainty that the care of Medicaid patients will be reimbursed at levels significantly below these institutions' actual costs.

Medicaid managed care plans also face challenges in ensuring adequate payment to care for Medicaid beneficiaries, particularly those with HIV/AIDS. Lower capitation payments may reduce access to services and jeopardize the viability of MCOs that serve Medicaid beneficiaries exclusively.

Medicaid is a vital part of the nation's ability to care for people with HIV/AIDS. HIV/AIDS advocates and program administrators have much to learn from each other. This primer is intended to be a first step.

1 Foster, Scott, et al. *Federal HIV/AIDS Spending: A Budget Chartbook*. The Henry J. Kaiser Family Foundation (July 1999 in press).

2 *Medicaid's Role for People with AIDS*. Fact sheet. Kaiser Commission on the Future of Medicaid (December 1996).

CHAPTER 2:  
MEDICAID  
ELIGIBILITY

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# CHAPTER 2

## MEDICAID ELIGIBILITY

### I. Overview

Medicaid standards of eligibility have categorical requirements (beneficiaries must fall within certain prescribed categories of people—e.g., persons with disabilities, children, etc.) and income and assets requirements (beneficiaries must have income and assets below certain statutorily defined levels—e.g., an annual income below 100% of the federal poverty level).<sup>1</sup>

Groups of people eligible for Medicaid under current law include:

- beneficiaries of Supplemental Security Income (SSI), a federal cash assistance program that provides assistance to low-income persons who are aged, blind, or disabled; (including individuals who have been eligible for SSI but who become ineligible solely because of increased earnings);
- low-income parents and children who currently meet the income and resources standards that were in effect on July 16, 1996, for Aid to Families with Dependent Children (AFDC) (the former cash assistance or welfare program for low-income families);
- certain other low-income pregnant women and children;
- certain other low-income individuals who are participants in other federal programs (i.e., qualified Medicare beneficiaries, special low-income Medicare beneficiaries, qualified individuals, qualified disabled and working individuals, certain Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) insurance continuation beneficiaries); and
- the “medically needy” (persons who do not meet the financial standards for cash assistance programs, but do meet the categorical standards and have income and resources within special “medically needy” limits established by the states).

This chapter discusses each of these eligible groups. Most persons with HIV/AIDS gain Medicaid coverage through one of two distinct paths of coverage. First, many people with HIV/AIDS become disabled as a result of their illness. They deplete any resources they may have, and then either become

eligible for SSI payments and, consequently, eligible for Medicaid, or become eligible for Medicaid as people who are medically needy.

Second, people with HIV/AIDS may qualify for Medicaid for reasons unrelated to their illness by meeting the usual categorical and financial tests for Medicaid eligibility. These are generally believed to be low-income women and children.

As the number of HIV/AIDS cases increases among populations that are more frequently uninsured and low-income, the second group may grow. These individuals may receive benefits earlier in the course of their illness before they become sufficiently disabled to qualify for SSI.

At the same time, however, the number of people with HIV who qualify for SSI (and thus Medicaid) may decline, inasmuch as people who take combinations of antiviral drugs do not appear to become disabled at the same rate as people with AIDS who took earlier drugs. This is both good and bad news: it is, of course, good news that they remain relatively healthy; it is bad news that because they do remain relatively healthy, many of them cannot qualify for Medicaid at all and will have no source of payment for the expensive drugs that are necessary to keep them healthy.

## II. Supplemental Security Income Beneficiaries

Supplemental Security Income (SSI) is a federal program that provides cash assistance to persons who

- are aged, blind, or disabled, and
- have little or no income or resources.

SSI beneficiaries are automatically eligible for Medicaid in 38 states (see Table 2-1). The other states have different standards for eligibility either as a 209(b) state (discussed below) or a waiver state (discussed in Chapter 6). For a detailed breakdown, see Table 2-1, and its accompanying footnotes.

It is important to note that SSI differs from the Social Security Disability Insurance (SSDI) program. SSDI is provided to individuals who have a qualifying disability and who have paid into the Social Security system during their working years. Recipients of SSDI are not necessarily individuals with low incomes and assets, and receipt of SSDI payments does not automatically qualify an individual for Medicaid coverage. (Recipients of SSDI may qualify for Medicare; that process is beyond the scope of this primer (see fn. 11).)

### A. Disability

Persons with HIV/AIDS who qualify for SSI generally do so because they are deemed “disabled.” For purposes of SSI eligibility, a person with a disability is someone who is:

*unable to engage in any substantial gainful activity by reason of a medically determined physical or mental impairment expected to result in death, or that has lasted or can be expected to last for a continuous period of at least 12 months.<sup>2</sup>*

State	Pregnant Women, Infants and Children (Effective October 1997)				Other Eligibility Categories		
	Pregnant Women and Infants	Children Under Age Six	Children Ages Six and Older	Upper Age Limit	Supplemental Security Income, 1996	Max. AFDC Payments (7/16/96)	Medically Needy, 1996
	(Percent of Federal Poverty Level)				(Percent of Federal Poverty Level)		
Alabama	133	133	100	14	75	15	N/A
Alaska	133	133	100	14	75	76	N/A
Arizona	140	133	100	14	75	32	N/A
Arkansas (a)	(133) (200)	200	200	17	75	19	25
California	200	133	100	14	75	56	86
Colorado (b)	133	133	100	14	75	39	N/A
Connecticut	185	185	185	16	75	81	71
Delaware	185	133	100	18	75	31	N/A
District of Columbia	N/A	N/A	N/A	N/A	75	N/A	N/A
Florida	185	133	100	14	75	28	28
Georgia	185	133	100	19	75	39	35
Hawaii (c,d)	300	300	300	19	67	57	57
Idaho	133	133	100	14	75	29	N/A
Illinois (c)	133	133	100	14	48	35	45
Indiana (c,e)	150	133	100	18	73	27	N/A
Iowa	185	133	100	14	75	39	52
Kansas	150	133	100	17	75	40	44
Kentucky	185	133	100	14	75	49	28
Louisiana	133	133	100	18	75	18	N/A
Maine	185	133	125	19	75	51	42
Maryland (d)	185	185	185	14	75	34	40
Massachusetts	185	133	133	17	75	52	72
Michigan	185	150	150	16	75	45	52
Minnesota (c,d)	275	275	275	20	71	49	66
Mississippi	185	133	100	14	75	34	N/A
Missouri (c)	185	133	100	18	71	27	N/A
Montana	133	133	100	14	75	41	46
Nebraska	150	133	100	14	75	34	45
Nevada	133	133	100	14	75	32	N/A
New Hampshire (c)	185	185	185	19	74	51	60
New Jersey	185	133	100	14	75	41	52
New Mexico	185	185	185	19	75	36	N/A
New York (f)	185	133	100	14	75	61	76
North Carolina (c)	185	133	100	18	41	50	34
North Dakota (c)	133	133	100	18	62	40	47
Ohio (c)	133	133	100	14	63	32	N/A
Oklahoma	150	133	100	14	75	28	42
Oregon	133	133	100	19	75	43	57
Pennsylvania	185	133	100	14	75	39	43
Rhode Island (d)	250	250	250	17	75	51	69
South Carolina	185	150	150	18	75	18	N/A
South Dakota	133	133	100	19	75	47	N/A
Tennessee (d)	400	400	400	17	75	54	23
Texas	185	133	100	14	75	17	25
Utah	133	133	100	18	75	53	53
Vermont (g)	(200) (225)	225	225	17	75	59	81
Virginia	133	133	100	19	75	22	33
Washington (g)	(185) (200)	200	200	19	75	50	62
West Virginia	150	133	100	19	75	24	27
Wisconsin	185	185	100	14	75	48	64
Wyoming	133	133	100	14	75	55	N/A

*Source: National Governors' Association, Washington, DC. 1996 and 1997.*  
N/A Not applicable.  
Note: The 1997 Federal poverty guideline for a family of three was \$13,330; for Alaska \$16,670 and Hawaii \$15,330.  
(a) In Arkansas pregnant women are covered up to 133 percent and infants are covered up to 200 percent of poverty.  
(b) Colorado has dropped the assets test for pregnant women only.  
(c) Indicates state with a 209 (b) waiver, which permits it to have different eligibility criteria for the Supplemental Security Income program.  
(d) Hawaii, Maryland, Minnesota, Rhode Island, and Tennessee operate under 1115 waivers. Some populations receive fully subsidized premiums while others are required to pay a portion of the premium and may have a different benefits package.  
(e) Indiana is planning to reinstate the assets test for pregnant women.  
(f) Payment standards in New York state vary among counties. The figures shown are for New York City.  
(g) In Vermont pregnant women are covered up to 200 percent of poverty and infants are covered to 225 percent of poverty. In Washington, pregnant women are covered up to 185 percent of poverty and infants to 200 percent of poverty.

**Table 2-2: Symptoms Associated with HIV Infection Sufficient to Meet the Social Security Administration (SSA) Standard for Presumptive Disability**

A. Bacterial Infections	B. Fungal Infections	C. Protozoan or Helminthic Infections	D. Viral Infections	E. Malignant Neoplasms	F. Conditions of the skin or mucous membranes*	G. Hematologic Abnormalities
<p>1) Mycobacterial infection at a site other than the lungs, skin, or cervical or hilar lymph nodes or pulmonary tuberculosis resistant to treatment or</p> <p>2) Nocardiosis or</p> <p>3) Salmonella bacteremia, recurrent non-typhoid or</p> <p>4) Syphilis or neurosyphilis evaluate sequelae under the criteria for the affected body system or</p> <p>5) Multiple or recurrent bacterial infection(s), including pelvic inflammatory disease, requiring hospitalization or intravenous antibiotic treatment 3 or more times in 1 year.</p>	<p>1) Aspergillosis or</p> <p>2) Candidiasis, at a site other than the skin, urinary tract, intestinal tract, or oral or vulvovaginal mucous membranes; or candidiasis involving the esophagus, trachea, bronchi, or lungs or</p> <p>3) Coccidioidomycosis, at a site other than the lungs or lymph nodes; or</p> <p>4) Cryptococcosis, at a site other than the lungs; or</p> <p>5) Histoplasmosis, at a site other than the lungs or lymph nodes or</p> <p>6) Mucormycosis.</p>	<p>1) Cryptosporidiosis, isoporiasis, or microsporidiosis, with diarrhea lasting for 1 month or longer or</p> <p>2) Pneumocystis carinii pneumonia or extrapulmonary pneumocystis carinii infection or</p> <p>3) Strongyloidiasis, extra-intestinal or</p> <p>4) Toxoplasmosis of an organ other than the liver, spleen, or lymph nodes.</p>	<p>1) Cytomegalovirus disease at a site other than the liver, spleen, or lymph nodes or</p> <p>2) Herpes simplex virus causing:</p> <p>a) mucocutaneous infection lasting 1 month or longer or</p> <p>b) infection at a site other than the skin or mucous membranes or</p> <p>c) disseminated infection or</p> <p>3) Herpes zoster, either disseminated or with multidermatomal eruptions that are resistant to treatment or</p> <p>4) Progressive multifocal leukoencephalopathy or</p> <p>5) Hepatitis, as described under the criteria in [20 C.F.R. Pt. 404, Subpt. P, App. 1, Sec. 4.00 ff or 11.04]</p>	<p>1) Carcinoma of the cervix, invasive, FIGO stage II and beyond or</p> <p>2) Kaposi's sarcoma with</p> <p>a) extensive oral lesions or</p> <p>b) involvement of the gastrointestinal tract, lungs, or other visceral organs or</p> <p>c) involvement of the skin or mucous membranes or</p> <p>3) Lymphoma or</p> <p>4) Squamous cell carcinoma of the anus.</p>	<p>*with extensive fungating or ulcerating lesions not responding to treatment.</p>	<p>1) Anemia or</p> <p>2) Granulocytopenia or</p> <p>3) Thrombocytopenia.</p>
<p><b>H. Neurological Abnormalities</b></p>	<p><b>I. HIV Wasting Syndrome*</b></p>	<p><b>J. Diarrhea*</b></p>	<p><b>K. Cardiomyopathy</b></p>	<p><b>L. Nephropathy</b></p>	<p><b>M. One or more of the following infections*</b></p>	<p><b>N. Repeated manifestations of HIV infection*</b></p>
<p>1) HIV encephalopathy characterized by cognitive or motor dysfunction that limits function and progresses; or</p> <p>2) Other neurological manifestations of HIV infection (e.g., peripheral neuropathy).</p>	<p>*characterized by involuntary weight loss of 10% or more of baseline and, in absence of a concurrent illness that could explain the findings, either:</p> <p>1) Chronic diarrhea with two or more loose stools daily lasting for 1 month or longer or</p> <p>2) Chronic weakness and documented fever greater than 100.4 degrees F for the majority of one month or longer.</p>	<p>*lasting for 1 month or longer, resistant to treatment, and requiring intravenous hydration, intravenous alimentation, or tube feeding.</p>	<p>as described under the criteria in [20 C.F.R. Pt. 404, Subpt. P, App. 1, Sec. 4.00 or 11.04]</p>	<p>as described under the criteria in [20 C.F.R. Pt. 404, Subpt. P, App. 1, Sec. 6.00 ff]</p>	<p>*other than those described in this chart, requiring hospitalization or intravenous treatment 3 or more times in 1 year:</p> <p>1) Sepsis or</p> <p>2) Meningitis or</p> <p>3) Pneumonia or</p> <p>4) Septic arthritis or</p> <p>5) Endocarditis or</p> <p>6) Radiographically documented sinusitis.</p>	<p>*resulting in significant, documented symptoms or signs, (e.g., fatigue, fever, malaise, weight loss, pain, night sweats) and one of the following:</p> <p>1) Restriction of activities of daily living or</p> <p>2) Difficulties in maintaining social functioning or</p> <p>3) Difficulties in completing tasks in a timely manner due to deficiencies in concentration, persistence, or pace.</p>

Source: 20 C.F.R. Pt. 404, Subpt. P, App. 1, Sec. 14.08 (as of June 4, 1998)

“Substantial gainful activity” is interpreted as work that earns more than \$500 of countable income per month (effective July 1, 1999, \$700).<sup>3</sup>

HIV-infected persons with certain opportunistic illnesses are presumed to have met this disability standard.<sup>4</sup> The applicant must provide medical documentation that he or she is infected with HIV and has one or more of the opportunistic infections, cancers, or conditions that defines “HIV infection” for the purpose of SSI (see Table 2-2). The applicant automatically becomes eligible for SSI and Medicaid benefits while the government makes a final determination of whether he or she is disabled. A person with HIV infection and associated symptoms is almost always found to be disabled and, consequently, eligible for SSI.

The SSI definition of disability differs from the 1990 Centers for Disease Control and Prevention (CDC) definition of AIDS, in that a person must have a manifest symptom of HIV-infection and not just a T-cell count of less than 200. This definition means that persons with asymptomatic HIV infection are not eligible for Medicaid through SSI. Therefore, low-income persons with HIV infection who do not fit into another eligibility category often have no access to preventive medical care that could prevent the onset of opportunistic illness or, in the case of new pharmaceuticals, could prevent the decline of the immune system itself. (See Chapter 9 for further discussion.)

## **B. Income and Assets**

### **1. Income**

To be eligible for SSI, a person must not only be elderly, blind, or disabled, but also must have income (and assets, which are discussed next) that is below federally defined levels (see Table 2-3). Income is defined as anything received that can be used to meet the needs for food, clothing, or shelter. For purposes of SSI eligibility, income includes wages, net earnings from self-employment, Social Security benefits, workers’ or veterans’ compensation, pensions, and interest.

The federal maximum income level for SSI eligibility is set at about 75% of the poverty level.<sup>5</sup> In 1998, this was determined to be \$494 per month in countable income for an individual.<sup>6</sup> Emphasis is placed on countable income because the government does not consider all income in determining an individual’s eligibility for SSI.<sup>7</sup> States may also use alternative methods for calculating income.

Advocates for persons with HIV/AIDS must remember, however, that to be eligible for SSI because of disability, an individual must not be able to engage in “substantial gainful activity,” which is defined as an activity that earns more than \$500 per month (effective July 1, 1999, \$700). Accordingly, when applying for SSI, an individual who applies on the basis of disability cannot earn more than \$500 of countable income per month (effective July 1, 1999, \$700).

Once an individual is already receiving SSI, however, he or she may do some work that would constitute a substantial gainful activity (i.e., earning more than \$500 of countable income per month (effective July 1, 1999, \$700) provided that the individual’s disability has not improved and the total countable income (after the appropriate earned income disregards are

taken into account) does not rise above the income cap of eligibility for SSI. In other words, once an individual begins receiving SSI, he/she is allowed some flexibility regarding the disability definition (to allow people to work) as long as the low-income requirement continues to be met. It should be noted that as a person's earned income increases, the amount he or she receives in SSI cash assistance decreases proportionally (although Medicaid eligibility is maintained in full).

<b>Table 2-3: Individuals with Disabilities Who Are or Were Eligible to Receive SSI Are Eligible to Receive Medicaid.*</b>			
<b>Categorical Requirement</b>	<b>Definition of Category</b>	<b>Income Requirement</b>	<b>Assets Requirement</b>
Individuals with disabilities.	Under SSI, a disabled individual is a person who is: 1) unable to engage in work that earns more than \$500/month (\$700/month as of July 1, 1999) by reason of 2) a medically determined physical or mental impairment expected to result in death, or that has lasted or can be expected to last continuously for 12 months.	When applying for SSI, an individual cannot earn more than \$500/month (\$700/month as of July 1, 1999) in countable income.  Once receiving SSI, an individual may earn more than \$500/month (\$700/month as of July 1, 1999), as long as the disability has not improved and total countable income does not rise above the income cap of eligibility for SSI.**	Countable assets cannot exceed \$2000 (or \$3000 for married couples).
Qualified severely impaired individuals	Once received SSI, now ineligible because of earnings; still has physical or mental impairment	Less than amount needed to provide reasonable equivalent of SSI, Medicaid, and any publicly funded attendant care (varies by State)	Same as SSI

\* Does not apply to 209(b) states

\*\* May vary for states with medically needy programs

Moreover, in some circumstances, federal Medicaid law requires that states continue to provide Medicaid coverage to individuals who have received SSI but who earn too much to continue to qualify for it. Such coverage for a “qualified severely impaired individual” is required if he or she

- “continues to have the disabling physical or mental impairment on the basis of which he [or she] was found to be under a disability and, except for his [or her] earnings, continues to meet all non-disability-related requirements for eligibility for benefits [under SSI],”<sup>8</sup>
- His or her unearned income is not above the SSI threshold,
- “the lack of eligibility for [Medicaid] would seriously inhibit his [or her] ability to continue or obtain employment,” and
- His or her earnings are not sufficient to provide “a reasonable equivalent” of the previous SSI benefits, Medicaid, and publicly funded attendant care services (including personal care assistance) that would be available in the absence of such earnings.

In determining this last point, the cost of a “reasonable equivalent” of these benefits, the Social Security Administration has set a general threshold amount for each state; in some special cases, individual determinations can also be made.<sup>9</sup>

This provision may prove important to people with AIDS who, because of treatment, are improved but are still in need of medical assistance. The overall value of Medicaid to many PWAs is high, and a substantial equivalent to that value may be hard to find or afford.

Finally, under the Balanced Budget Act of 1997, states may also offer buy-in coverage (allowing individuals to purchase Medicaid as their health insurance) to a disabled worker (who is not receiving SSI) with an income at or below 250% of the poverty level if that individual would have received SSI except for his/her excess earnings. The premium for such coverage is based on a sliding scale.<sup>10</sup>

## 2. Assets

SSI eligibility is restricted to qualified persons who have countable assets not exceeding \$2,000 for individuals or \$3,000 for married couples. Assets include savings accounts, real estate investments, and personal belongings worth more than \$2,000. Countable assets do not include a home, a car, life insurance policies with a total face value of less than \$1,500, burial plots, wedding rings, and a few other statutorily defined exceptions.

### C. 209(b) States: The Exceptions

States are not required to extend Medicaid coverage to all individuals who receive SSI payments. States that used a more restrictive standard for Medicaid eligibility than the standard imposed when SSI was implemented in 1972 may continue to use their old standards, rather than the federal eligibility standards discussed above. These states are commonly referred to as “209(b) states,” because section 209(b) of the Social Security Amendments Act of 1972 provides for this exception. 209(b) state standards may include

more restrictive definitions of “disability,” as well as lower income and assets standards. Eleven states currently exercise the 209(b) option.<sup>11</sup>

### **III. Persons Meeting Standards for Aid to Families with Dependent Children**

Prior to August 1996, beneficiaries of the federal welfare program Aid to Families with Dependent Children (AFDC) were automatically eligible for Medicaid. Thus, adults and children who did not meet the SSI disability definition, but who received federal welfare assistance, had another means by which to be assured Medicaid coverage. On August 22, 1996, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (the Welfare Act) was signed into law. The Act eliminated the AFDC program entirely and replaced it with a new program involving block grants to the states, called the Temporary Assistance for Needy Families (TANF) program. Nevertheless, Congress preserved Medicaid eligibility for certain low-income families, even for those individuals who will not receive cash assistance under TANF. This section discusses how families used to qualify for AFDC and, consequently, Medicaid, and how families now qualify for Medicaid after the Welfare Act.

#### **A. AFDC as It Previously Existed**

AFDC was a cash assistance program for low-income families. It was available to individuals in families with dependent children under age 18 if the family met income and assets standards established by the states, and if one parent was (a) continuously absent from the home, (b) incapacitated, (c) unemployed, or (d) deceased. The dependent child had to be living in his or her parent’s home (or a relative’s home), be a resident of the state where the family was seeking benefits, and be a United States citizen or an immigrant permanently and lawfully residing in the United States.

The AFDC income standard varied among states, and was based on each state’s determination of how much money was needed to live in that particular state. In 1999, the average annual income eligibility level for a family of three was \$5,413, or 39.1% of the federal poverty level.

AFDC also had an assets standard. Federal law required that a family unit not have more than \$1,000 in assets (not including the family home, up to \$1,500 of equity in a car, burial plots, and a few other statutory exceptions), but states were allowed to set lower assets standards for AFDC. AFDC beneficiaries automatically qualified for Medicaid in all states.

#### **B. Medicaid Eligibility after the Welfare Act**

Although AFDC has been eliminated, most families who currently meet the AFDC income and resources standards as they existed in the state on July 16, 1996, are still eligible for Medicaid,<sup>12</sup> even if they are denied cash assistance under TANF<sup>13</sup> (see Table 2-4). In essence, the AFDC income and assets standards that were in existence on July 16, 1996, have been established as a floor for state Medicaid eligibility standards. Families and children who fall within these standards are entitled to Medicaid coverage.

Under the Welfare Act, individuals receiving TANF may lose their cash assistance if they refuse to work. States also have the option of terminating

Medicaid coverage, based on refusal to work, for individuals receiving TANF; however, there are certain groups who are exceptions to this general rule. Among these exceptions are pregnant women whose income is at or below certain poverty thresholds (e.g., 133% of the federal poverty level). Most children meeting certain poverty levels must also remain eligible for Medicaid, even if their parents refuse to work.

Finally, if a family receives Medicaid because its income and assets are below the state's former AFDC standards, but the family's earnings increase, thereby terminating its Medicaid eligibility, the family is guaranteed "transitional" Medicaid coverage for up to 12 months as long as the family reports its earnings every quarter. Similarly, if a family's income rises above the cut-off standard because of increased child or spousal support payments, Medicaid payments are guaranteed for four months.

#### IV. Pregnant Women and Children

States are required to provide Medicaid coverage to all pregnant women, infants, and children up to age six with family incomes at or below 133% of the federal poverty level (see Table 2-5). In 1999, 133% of the poverty level was \$18,460 for a family of three.

States may, at their option, select a Medicaid eligibility income standard of up to 185% of the poverty level for pregnant women and infants up to age one (see Table 2-5). In 1999, 185% of the poverty level was \$25,678 for a family of three. States may also use alternative methodologies for calculating income. This can, in effect, result in Medicaid eligibility for individuals with higher income; for example, Vermont has used calculation methods that

**Table 2-4: Persons Who Currently Meet the July 16, 1996 Standards for AFDC Are Eligible to Receive Medicaid.**

Categorical Requirement	Definition of Category	Income Requirement*	Assets Requirement
Persons who currently meet the July 16, 1996 AFDC standards (may also be required to meet TANF work standards).	Families with dependent children under age 18 in which one parent is: 1) absent from home continuously 2) incapacitated 3) unemployed or 4) deceased.	Income requirements vary from state to state based on how much money is needed to live in the particular state. In 1999, the income eligibility level for a family of three averaged \$5,413 or 39.1% of the poverty level.	A family unit cannot have more than \$1,000 in countable assets excluding statutory exceptions.

\*Under TANF, a state may modify these requirements in three ways: 1) a state may lower its income standard below the level of July 16, 1996, but not below the level stipulated in its AFDC plan as of May 1, 1998; 2) a state may increase its income and assets standard above the level of July 16, 1996, but not by a percentage greater than the Consumer Price Index; or 3) a state may use income and assets methodologies that are less restrictive than the methodologies used under the state plan as of July 16, 1996.

allow coverage of persons whose income would be routinely assessed as 225% of poverty.

States also have the option of applying a Medicaid eligibility assets standard. For pregnant women, the assets standard set by a state may be no more restrictive than the standard used for SSI. For infants and children, the assets standard may be no more restrictive than what was used under the former AFDC program.

The provision of Medicaid to pregnant women is especially important for women infected with HIV. These women will be able to receive expensive anti-viral treatments, such as AZT and other new drugs, that not only slow the progression of HIV disease in the women, but also decrease the risk of HIV transmission to their newborns.

States also must provide Medicaid coverage to children who were born after September 30, 1983, and whose family income is at or below 100% of the poverty level (see Table 2-5). This group of beneficiaries will grow over time, resulting in coverage of all low-income children under age 19 by the year 2002. This rule provides another source of Medicaid coverage for HIV-infected children who do not qualify for SSI or meet the former AFDC standards.

Some states have used other options to provide Medicaid coverage to all or some children under age 19 with family income in excess of 100% of the poverty level, and some as high as 300% of the poverty level (see Table 2-5).

In addition, the Balanced Budget Act of 1997 established a new program, the State Children's Health Insurance Program (CHIP). CHIP is designed to provide enhanced, matching federal funds to the states so they can provide health insurance to uninsured, low-income children up to age 19 (see Table 2-5). Under CHIP, a state may expand its coverage for children through its Medicaid program, a separate children's health insurance program, or a combination of both.

States can choose to expand their Medicaid coverage through CHIP to include targeted low-income children who do not qualify for Medicaid under the state plans in effect on April 15, 1997. Targeted low-income children are those children whose family income is at or below 200% of the poverty line for that size family or whose family income exceeds the income level specified in a state's Medicaid plan as of June 1, 1997, by no more than 50%. States may also accelerate the Medicaid coverage of such children, allowing coverage of children who were born before September 30, 1983. This would effectively make older children eligible sooner than required.

States can also use CHIP funds to create or expand a separate children's health insurance program, subject to cost-sharing and benefit rules. (If they do so, the resource tests can be more restrictive than the former AFDC program.) As part of the application process, states must assess whether children are eligible for Medicaid and, if so, ensure that the children are enrolled in Medicaid.

Finally, states may choose to implement a combination of the Medicaid expansion and the separate children's health insurance options.

The Balanced Budget Act of 1997 also allows states to presume Medicaid eligibility for children based on family income information. In this way, chil-

**Table 2-5: Certain Low-Income Women and Children Who Are Not Receiving Federal Cash Assistance Are Still Eligible to Receive Medicaid.**

Categorical Requirement	Definition of Category	Income Requirement	Optional Assets Test
<i>States <b>must</b> provide Medicaid coverage to:</i>	1) Pregnant women	Family income at or below 133% of the poverty level. In 1999, this was \$18,460 for a family of three.	No more restrictive than SSI.
	2) Children up to age 6	Family income at or below 133% of the poverty level. In 1999, this was \$18,460 for a family of three.	No more restrictive than former AFDC program.
	3) Children born after September 30, 1983.	Family income at or below 100% of the poverty level. In 1999, this was \$13,880 for a family of three.	No more restrictive than former AFDC program.
	4) Disabled children who were receiving SSI on August 22, 1996, but lost their Medicaid eligibility due to restrictions placed on SSI child disability standards on that date.	See Table 2-3.	See Table 2-3.
<i>States <b>may</b>, at their option, provide coverage to:</i>	1) Pregnant women	Family income at or below 185% of the poverty level. In 1999, this was \$25,678 for a family of three.	No more restrictive than SSI.
	2) Infants up to age 1	Family income at or below 185% of the poverty level. In 1999, this was \$25,678 for a family of three.	No more restrictive than former AFDC program.
	3) Children under age 19	Family income at or below 200% of the poverty level (\$27,760 for a family of three in 1999) or family income exceeding Medicaid's applicable income level by no more than 50%. States may also accelerate the coverage described in this category, making older children eligible sooner than required. Under the Balanced Budget Act of 1997, states may guarantee 12 months of continuous eligibility despite family income changes that would render the child ineligible.	No more restrictive than former AFDC program.

dren can be enrolled immediately while eligibility under the state plan is determined.

Furthermore, under the Balanced Budget Act of 1997, states must continue to provide Medicaid coverage for disabled children who were receiving SSI on August 22, 1996, but lost their Medicaid eligibility because of restrictions placed on SSI child disability standards in the 1996 Welfare Act (see Tables 2-2, 2-3, and 2-5).

The Balanced Budget Act of 1997 also gives states the option to guarantee 12 months of continuous eligibility for Medicaid for children, regardless of changes in a child's family income or other circumstances that would make a child ineligible during the 12-month period.

## **V. Low-Income Individuals in Other Federal Programs**

Medicaid provides partial coverage for five population groups: qualified Medicare beneficiaries (QMBs), specified low-income Medicare beneficiaries (SLIMBs), qualified individuals (QIs), qualified disabled and working individuals (QDWIs), and certain COBRA continuation beneficiaries (see Table 2-6). Individuals who fall within these categories are not eligible for the full range of Medicaid benefits. Instead, Medicaid provides specific benefits on their behalf. Coverage of these five groups entitles people with HIV/AIDS to Medicaid benefits they would not otherwise receive.

### **A. Qualified Medicare Beneficiaries (QMBs)**

A qualified Medicare beneficiary (QMB) is a person who is aged or disabled, receives Medicare,<sup>14</sup> has an income at or below 100% of the federal poverty level, and has assets at or below 200% of the SSI assets level. Federal law requires the state Medicaid program to pay the Medicare Part A and Part B premiums,<sup>15</sup> deductibles, and cost-sharing charges for these individuals. A QMB is entitled to Medicaid coverage only for these Medicare benefits, unless he or she is otherwise additionally eligible for Medicaid benefits, on another basis.

### **B. Specified Low-Income Medicare Beneficiaries (SLIMBs)**

Medicaid programs are required to pay the Part B monthly Medicare premium for individuals who are entitled to receive Medicare, and who have incomes between 100% and 120% of the national poverty level, but whose resources are at or below 200% of the SSI resource level. For such specified Low-Income Medicare Beneficiaries, Medicaid coverage is limited to payment of the Part B Medicare premium.

### **C. Qualified Individuals (QIs)**

Under the Balanced Budget Act of 1997, Medicaid coverage has been expanded for State SLIMBs. States must now pay Medicare Part B premiums, selecting eligible beneficiaries on a first-come, first-served basis. An individual would be eligible for this coverage if he or she would be a QMB but for

**Table 2-6: Certain Individuals Who Qualify for Medicare Are Eligible to Receive Partial Medicaid Coverage.**

Categorical Requirement	Definition of Category	Income Requirement	Assets requirement
Qualified Medicare Beneficiaries (QMBs)	An individual who is aged or disabled, and receiving Medicare.	Income must be at or below 100% of the federal poverty level. In 1999, this was \$8,240 for an individual.	Countable assets cannot exceed \$4,000 (or \$6,000 for married couples).
Specified Low-Income Medicare Beneficiaries (SLIMBs)	An individual who meets the QMB criteria, except for income.	Income must be between 100% and 120% of the federal poverty level. In 1999, this was between \$8,240 and \$9,888 for an individual.	Countable assets cannot exceed \$4,000 (or \$6,000 for married couples).
Qualified Individuals (QIs)	An individual who meets the QMB criteria, except for income.	Income must be at least 120%, but less than 135%, of the federal poverty level for full coverage of Medicare Part B premiums. Income must be at least 135%, but less than 175%, of the federal poverty level for partial coverage of Medicare Part B premiums. In 1999, 120% of the federal poverty level was \$9,888 for an individual, 135% was \$11,124, and 175% was \$14,420.	Countable assets cannot exceed \$4,000 (or \$6,000 for married couples).
Qualified Disabled and Working Individuals (QDWIs)	An individual who: 1) has been eligible for Medicare under Part A on the basis of his/her disability and, 2) has lost his/her Medicare entitlements based on earnings from work and, 3) continues to have a disabling condition.	Income must be at or below 200% of the federal poverty level. In 1999, this was \$16,480 for an individual.	Countable assets cannot exceed \$4,000 (or \$6,000 for married couples).
COBRA Continuation Beneficiaries	An individual who has the option of continuing insurance coverage under his/her former employer's group health plan.	Income must be below 100% of the federal poverty level. In 1999, this was \$8,240 for an individual.	Countable assets cannot exceed \$4,000 (or \$6,000 for married couples).

his or her income exceeding the established level, and his or her income is at least 120%, but less than 135%, of the poverty level. Partial coverage of Part B premiums must be available for individuals with incomes of at least 135%, but less than 175%, of the poverty level, at the state's option. Again, states may choose to cover a more limited group.

#### **D. Qualified Disabled and Working Individuals (QDWIs)**

Qualified disabled and working individuals (QDWIs) are people who were previously entitled to Medicare Part A on the basis of their disabilities, who lost their entitlements because of increased earnings from work, but who continue to have disabling conditions. Medicaid is required to pay the Medicare Part A premium for QDWIs, provided their income is below 200% of the poverty level, their assets are below 200% of the SSI limit, and they are not otherwise eligible for Medicaid. For such individuals, Medicaid coverage is limited to payment of the Part A premium.

#### **E. Consolidated Omnibus Budget Reconciliation Act (COBRA) Continuation Beneficiaries**

Under a federal law separate from Medicaid, commonly called the Consolidated Omnibus Budget Reconciliation Act (COBRA) insurance continuation requirement, employers of 50 or more employees, that offer a group health plan, are required to offer employees the option of paying for continuation of their insurance coverage themselves after their employment ends. This continuation extends for 18 months if the employee is not disabled at the time such coverage begins. If the employee is disabled at the time COBRA coverage begins, or is determined to be disabled at any time during the original coverage period, the continuation extends for 29 months from the determination of disability.

State Medicaid programs have the option of paying the COBRA continuation payments for individuals with incomes below the poverty level and with assets below 200% of the SSI limit. Medicaid may make these payments, however, only if the state determines that the cost of the COBRA premium is likely to be less than the Medicaid expenditure for an equivalent set of services. Unless the beneficiary is eligible for the Medicaid program on another basis, such as disability, Medicaid benefits are limited to payment of COBRA premiums.

### **VI. Medically Needy Persons**

Another means by which persons with HIV/AIDS may qualify for Medicaid is through the medically needy program. States have the option, but are not required, to create such a program (see Table 2-7).

Medicaid law defines the medically needy as individuals:

- (1) who, except for income and resources, fall into one of the categories covered by the state (i.e., the aged, blind, and disabled, pregnant women, and children), and*

- (2) *whose income and/or assets are generally in excess of the standards for categorically needy coverage, but below state-established “medically needy standards.”*

Currently, approximately 34 states have medically needy programs.<sup>16</sup> The medically needy program is a significant source of Medicaid eligibility for people with HIV/AIDS.

States are given the authority to determine their own medically needy income levels. However, the level may not exceed 133.5% of the state’s former AFDC payment standard.<sup>17</sup> The qualifying income standards for the medically needy vary from state to state. In 1992, Tennessee established its income level at \$250 a month for a family of three, while California’s monthly standard was more than \$900.

Individuals qualifying as medically needy must also meet state-specified assets criteria. Although the income standards for the medically needy are similar to the former AFDC standards, assets criteria for this group vary considerably by state and by family size. The assets limit under AFDC was \$1,000 per family unit, while the average assets limit of the medically needy programs among the states is \$3,760 for a family of three.<sup>18</sup>

Finally, individuals who have incomes above the medically needy standard, but who fall below that standard once their medical expenses are factored in, may also qualify for Medicaid. These medical expenditures are

**Table 2-7: States May, at Their Option, Grant Medicaid Eligibility to the Medically Needy.**

Categorical Requirement	Definition of Category	Income Requirement	Assets Requirement
Medically needy	A medically needy individual: <ol style="list-style-type: none"> <li>1) falls into one of the eligibility categories covered by the state’s Medicaid program (i.e. aged, blind, disabled, low-income pregnant women, etc.) and</li> <li>2) has an income above the standard for Medicaid but below the state established medically needy standard.</li> </ol>	<ol style="list-style-type: none"> <li>1) States determine medically needy income levels, but they cannot exceed 133% of the state’s former AFDC payment standard. On average, standards for medically needy are set at \$6,293 for a family of three.</li> <li>2) Individuals whose income is above the medically needy standard, but who would fall below the standard once their medical expenses are factored in, also may qualify for Medicaid.</li> </ol>	State determines assets criteria.

known as “spend-downs,” because individuals spend down to Medicaid eligibility levels. For example, a low-income woman with HIV who is not pregnant might not be eligible for Medicaid because her income exceeds the income standard for AFDC eligibility as it existed on July 16, 1996. However, she would qualify for the state’s medically needy program, even though her income is \$300 greater than the medically needy standard, if she incurs medical expenses of at least \$300 during the relevant period. Medicaid law allows her to spend down to the medically needy income standard—i.e., it allows her to qualify for Medicaid after spending \$300 in medical expenses.

## VII. Non-Citizens

The Welfare Act created new restrictions and requirements for non-citizen residents of the United States that affect their eligibility for Medicaid and other programs through which they receive treatment for HIV/AIDS. Although some of these restrictions were revisited in the Balanced Budget Act of 1997, the overall result has been a significant reduction in the opportunities for HIV-infected immigrants to be treated using federal and state benefit programs.

The Welfare Act distinguishes among different types of benefits, immigrant status, and government entities. In determining eligibility for government benefits, non-emergency Medicaid benefits are perhaps the most important in terms of scope and scale. The Welfare Act establishes an extremely complex scheme for determining eligibility under this program. Although aliens, like citizens, must first meet the eligibility requirements set forth in the Medicaid statute, aliens may need to meet additional requirements set forth in the Welfare Act, depending on their alien status.

First, if they are otherwise eligible under the Medicaid statute, permanent resident aliens with 40 qualifying quarters of work, certain Native Indians born in Canada, veterans of the U.S. military, active-duty members of the U.S. armed forces, and spouses and unmarried dependent children of veterans or active-duty service members retain their Medicaid eligibility.

Those granted asylum, refugees, aliens whose deportation is being withheld, Cuban and Haitian entrants, and Amerasian refugees who are otherwise eligible for Medicaid will not be barred from receiving coverage because of their immigration status for seven years from the date they enter the country. After this seven-year period, states have the discretion to determine eligibility. However, if these immigrants arrived prior to August 22, 1996, the date the Welfare Act was signed into law, they retain eligibility for Medicaid if that eligibility is obtained through the receipt of SSI. If these aliens do not qualify for Medicaid through SSI, they are subject to the seven-year limit, after which states may determine their eligibility for Medicaid.

Immigrants who entered the U.S. after August 22, 1996, are barred from receiving Medicaid benefits for a period of five years from the date they enter the country unless they are permanent resident aliens with 40 or more qualifying quarters of work, are paroled into the U.S. for one year, are granted conditional entry, or are in need of benefits because of spousal battery. After this five-year bar, states retain discretion to determine Medicaid eligibility. If these immigrants, like those listed in the preceding paragraph, arrived prior to the Welfare Act, they too retain eligibility for Medicaid if they were eligible

through SSI. If they entered the United States prior to the Welfare Act and did not qualify for Medicaid through SSI, their Medicaid eligibility is at the discretion of the states. Although states have the option of denying Medicaid coverage to certain categories of immigrants listed above, so far only two states, Wyoming and Louisiana, are using this option.

Finally, aliens who are not qualified under the Welfare Act (i.e., are not listed in any category above), including aliens who are paroled into the United States for less than one year and aliens who are not lawfully present in the United States, are not eligible, except in certain narrow circumstances (listed in Table 2-8), for benefits under the Medicaid program.

In addition to these restrictions on Medicaid benefits, the Welfare Act also establishes new deeming requirements regarding income and assets. For purposes of determining eligibility for Medicaid coverage, the income and resources of all legal immigrants entering the United States after enactment of the Act will be deemed to include the income and resources of their sponsors and their sponsors' spouses. (Sponsors are adult citizens or nationals who petition for the admission of an immigrant family member.) Sponsors of immigrants who enter after enactment are required to sign legally enforceable affidavits of support obligating them to reimburse the state and federal governments for Medicaid expenditures (other than for treatment of emergency medical conditions) made on behalf of the legal immigrants they are sponsoring. These deeming provisions will make it extremely difficult for immigrants to qualify as low-income enough for Medicaid.

There are several exceptions to these general rules, two of which may be important to immigrants infected with HIV/AIDS. The first essentially allows all immigrants, regardless of when they enter the country or whether their entry was legal, to receive emergency medical services. Immigrants are not eligible for such services, however, until their condition rises to the level of an emergency.

**Table 2-8: Health Services Available to All Non-Citizens Regardless of Status**

- Emergency medical assistance through Medicaid other than organ transplants
- Public health assistance (other than Medicaid) for immunizations, and for testing and treatment of symptoms of communicable diseases
- Short-term, non-cash, in-kind emergency disaster relief
- Assistance in the form of in-kind services at the community level that are necessary for the protection of life or safety (e.g., soup kitchens, crisis counseling and intervention, and short-term shelters)
- Certain programs for housing or community development assistance, or financial assistance

The congressional report accompanying the Welfare Act defines the term “emergency” extremely narrowly. For example, routine labor and delivery are not considered emergencies. There is a question, however, as to whether such routine labor and delivery could constitute an emergency medical service in certain circumstances. Specifically, an argument could be made that, for an HIV-infected mother, labor and delivery is an emergency medical service and, therefore, should be covered under Welfare Act provisions.

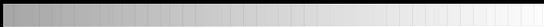
The second exception, which relates to communicable diseases, appears to allow people with HIV to receive treatment for their symptoms. The bill report discourages such an interpretation, however, stating that this exception applies only where absolutely necessary to prevent the spread of such diseases. Accordingly, this may be only a stop-gap measure until applicants are deported (deportation would not apply to legal immigrants), and is not intended to provide authority for continued treatment of such diseases for a long period of time.

Perhaps most important, the communicable disease exception does not apply to Medicaid. Such programs include AIDS health services (e.g. Ryan White), CDC AIDS prevention programs, community health centers, migrant health centers, Healthy Start, maternal and child health block grant, rural health services, community services block grant, and homeless and public housing health centers. These sites can continue to serve immigrants for this category of benefits.

- 1 This eligibility criterion does not apply in 209(b) states (see Chapter 2, Section C).
- 2 “Federal Old Age Survivors and Disability Insurance” 20 CFR 404.1574, 416.97.
- 3 Federal Register, April 15, 1999 Volume 64, Number 72, pages 18566-18571.
- 4 A person with a disability must present medical evidence to the Social Security Administration indicating that he or she has a physical or mental impairment that has rendered him or her unable to work. The government’s determination of whether someone falls within the SSI definition of disability is made on a case-by-case basis, and the paperwork and waiting time for a determination are often quite lengthy. Prior to the Social Security Administration finding that AIDS was a presumptive disability (issued in 1985), many persons with AIDS died before their case-by-case determination was completed.
- 5 Some states allow for higher levels of income and supplement the payment of the federal SSI payment with additional state money. This varies somewhat by state.
- 6 SSA “1998 Supplemental Security Income Report” (May 29, 1998).
- 7 In general, the government counts all of an individual’s unearned income (benefits, interest, etc.) less \$20, plus a little less than half an individual’s earned income, in determining SSI eligibility.
- 8 Section 1905(q) of the Social Security Act.
- 9 “The amount of income this represents varies from State to State and year to year, but is much higher than the income standards normally applied to Medicaid. The range is from about \$12,000 to over \$32,000 a year. However, individualized calculations can be made in certain instances.” Richardson, S., State Medicaid Director Letter — Working Disabled (November 24, 1997) at <http://www.hcfa.gov/medicaid/bbawkdis.htm>.
- 10 See generally, Richardson, S., State Medicaid Director Letter — Working Disabled (November 24, 1997) at <http://www.hcfa.gov/medicaid/bbawkdis.htm>. As of early 1999, only Oregon has chosen to provide such eligibility.
- 11 States using the 209(b) option for Medicaid eligibility (as of May, 1999) are: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.
- 12 The following discussion does not apply to immigrants. The Welfare Act’s impact on immigrants’ eligibility for Medicaid is discussed below in section VII.
- 13 Under TANF, each state receives a block grant to provide time-limited cash assistance for needy families. TANF relies on state law and regulation of eligibility and benefits.
- 14 Medicare is a federal program that provides health care coverage for elderly and disabled people who have paid into the Social Security fund during their working years. Medicare eligibility for the non-elderly is limited to people who have worked a minimum period in jobs through which they paid Social Security tax and who have been disabled for a period of 29 months or more. Medicare is an increasing source of health care for people with HIV/AIDS, but a full discussion of the program is beyond the scope of this document.
- 15 Medicare Part A provides coverage for inpatient hospital care; Part B covers physician services. Medicare generally does not cover prescription drugs.
- 16 This figure was obtained through informal phone interviews with each Health Care Financing Administration (HCFA) regional office. Unfortunately, HCFA does not maintain a comprehensive list of states that operate medically needy programs. The following states do not operate such programs: Alabama, Alaska, Arizona, Colorado, Delaware, District of Columbia, Idaho, Indiana, Louisiana, Mississippi, Missouri, Nevada, New Mexico, Ohio, South Carolina, South Dakota, and Wyoming.
- 17 States may, at their discretion, adjust this standard in the manner described in section IV above. In addition, states may adjust this level upward by an amount equal to the annual consumer price index.
- 18 The assets criteria vary considerably among the states, ranging from \$1,000 in Texas to \$10,000 in Iowa in 1992.



CHAPTER 3:  
MEDICAID SERVICES





# CHAPTER 3

## MEDICAID SERVICES

### I. Overview

Medicaid is the largest single public payor of medical services for persons with HIV/AIDS, paying more than two-thirds of the Federal expenditures for such care. In 1999, Medicaid is projected to pay approximately \$3.9 billion in federal and state funds for medical services provided to this group of beneficiaries.<sup>1</sup> There is, however, considerable variation among the state benefit packages concerning the types of services covered and the amount of care provided. These variations are discussed below.

Federal Medicaid law distinguishes between services states are required to cover if they want to receive federal Medicaid matching funds (generally referred to as “mandatory services”) and those that states may, at their option, include in their benefits package and receive federal matching funds toward their costs (generally referred to as “optional services”). Federal Medicaid law further distinguishes between the scope of services states must provide to the categorically needy (beneficiaries of SSI; families with children who currently meet the state’s July 16, 1996, AFDC eligibility standards, and pregnant women and children entitled to poverty-related Medicaid coverage) and the scope of services they must provide to the medically needy, if they choose to have a medically needy program.<sup>2</sup> More services must be provided to the categorically needy than to the medically needy.

States also may provide optional services to both the categorically needy and the medically needy, and may choose to provide services to the categorically needy that they do not also provide to the medically needy. States may not, however, provide services to the medically needy that they do not also provide to the categorically needy.

While they are afforded great flexibility in designing their benefits packages, states must meet four general federal requirements. States must ensure that:

- each covered service is sufficient in amount, duration, and scope (ADS) to reasonably achieve its purpose;
- the services available to any categorically needy person are comparable to the services available to any other categorically needy person,

- regardless of how he or she qualifies for Medicaid and regardless of his or her illness (“comparability”);
- coverage is the same statewide (“statewideness”); and
- with significant exceptions, Medicaid beneficiaries have the freedom to choose their health care providers, as long as the provider accepts Medicaid patients (“freedom-of-choice”).<sup>3</sup>

Finally, any understanding of the requirements of Medicaid’s covered services must include not just the material in this chapter, but also that in Chapter 5, Medicaid Managed Care. While states may not fail to provide mandatory services because of a managed care arrangement, managed care contracts divide the immediate responsibilities among the state, the plan, and the providers and sometimes contain restrictive definitions of services.

## II. Mandatory Services

In order to receive Federal matching payments, all States are required to provide a core set of services (referred to as “mandatory services”) to the categorically needy. These services include physician and hospital services (inpatient and outpatient), laboratory and X-ray services, prenatal care, and preventive services for children. Table 3-1 provides a complete list of mandatory services. (HCFA has specifically concluded that HIV counseling and testing must be reimbursed when provided to a pregnant woman).

Mandatory services include most services provided at Federally Qualified Health Centers (FQHCs), which include federally assisted community health centers, migrant health centers, and health care centers for the homeless.<sup>4</sup> The Medicaid program will reimburse the clinic for any covered services provided to Medicaid beneficiaries; this reimbursement allows the clinic to conserve its public and private grant funding for people who have no health insurance.<sup>5</sup>

Medicaid law also places certain requirements on those states that have opted to have a medically needy program. States must provide to the medically needy, at a minimum: prenatal and delivery services for pregnant women, home health services for individuals entitled to nursing facility care, ambulatory services for children, and ambulatory services for any medically needy adult entitled to inpatient services at a hospital or nursing facility.<sup>6</sup> States may choose to offer some or all of the mandatory services offered to the categorically needy to the medically needy as well.

**Table 3-1: Mandatory Services**

States must provide this core set of services to the categorically needy to qualify for federal matching payments.

Hospital services (inpatient and outpatient)

Physicians' services

Laboratory and X-ray services

Early and periodic screening, diagnosis, and treatment (EPSDT) services (for individuals under age 21)

Federally qualified health center (FQHC) services

Rural health clinic services

Family planning services

Nursing facility (NF) services (for individuals age 21 or older)

Home health services (for individuals entitled to NF care)

Nurse-midwife services

Certified pediatric nurse practitioner or family nurse practitioner services

Source: *Medicaid Source Book: Background Data and Analysis, 1993*

### III. Selected Optional Services

States may choose to provide a host of other services, referred to as optional services, for which the states will receive federal matching payments. Some of these are offered by virtually every state; others are rarely included in benefit packages. Table 3-2 outlines Medicaid's optional services, the number of states that offer the services to the categorically needy only, and the number of states that offer the services to both the categorically and the medically needy. The following are a few of the optional services of greatest importance to persons with HIV/AIDS.

#### A. Prescription Drugs

Perhaps the most important benefit to persons with HIV/AIDS is prescription drugs, an optional service that all states have chosen to provide. Thirteen of the states provide this benefit to categorically needy persons only, while 27 states and the District of Columbia provide prescription drug coverage to both the categorically and the medically needy<sup>7</sup> (see Table 3-3).

**Table 3-2: Optional Services**

States may provide payment for any of these services to categorically needy and medically needy.

Service	States offering to both categorically and medically needy	States offering to categorically needy	Section 1115 demonstration project	Total*
Prescribed drugs	32	14	10	56
Clinic services	33	13	9	55
Transportation services	32	13	10	55
Prosthetic devices	31	14	10	55
Rehabilitative services	31	13	9	53
Nursing facility services (under age 21)	26	16	10	52
Intermediate care facilities for the mentally retarded	22	18	10	50
Optometrists' services	28	11	10	49
Eyeglasses	27	12	9	48
Case management services	27	11	8	46
Podiatrists' services	27	9	10	46
Dental services	26	11	9	46
Physical therapy	29	10	6	45
Emergency hospital services	25	11	8	44
Speech, hearing and language disorders	26	11	5	42
Inpatient psychiatric services (under age 21)	21	12	9	42
Inpatient hospital services (for 65 or older in institutions for mental diseases)	21	12	9	42
Dentures	25	7	6	38
Hospice care services	22	8	8	38
Occupational therapy	24	6	6	36
Diagnostic services	22	5	7	34
Screening services	20	5	7	32
Preventive services	20	6	6	32
Psychologists' services	20	6	6	32
Nursing facility services (for 65 or older in institutions for mental diseases)	17	9	6	32
Personal care services	18	7	6	31
Nurse anesthetists' services	16	8	5	29
Chiropractors' services	20	4	4	28
Private duty nursing	16	4	6	26
Respiratory care services	9	2	3	14
Christian Science sanitoriums	7	3	4	14
Medical social workers' services	6	1	3	10
Tuberculosis-related services	5	1	3	9
Christian science nurses	2	1	1	4

\* Source: HCEA Pub. No. 02155-97: Medicaid Services State by State (Oct. 1, 1996). Fifty states, five U.S. territories, and Washington, D.C. are included in this table.

Only to categorically needy	Alabama, Alaska, Colorado, Idaho, Indiana, Mississippi, Missouri, Nevada, New Mexico, Pennsylvania,** South Carolina, South Dakota, and Wyoming.
Both to categorically and medically needy	Arkansas, California, Connecticut, District of Columbia, Florida, Georgia, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Texas, Utah, Virginia, Washington, West Virginia, Wisconsin.

\* States operating under Section 1115 waiver authority are not included in this chart. The extent of the coverage of prescription drugs in such demonstrations varies state by state.

\*\* Pennsylvania is the only state with a medically needy program that does not provide prescription drugs as a covered benefit.

To be covered by Medicaid, prescription drugs must be: (1) made by a manufacturer that has entered into a pricing agreement with HHS, (2) prescribed by a physician or other state-licensed practitioner approved by the Medicaid program, and (3) dispensed by a pharmacist or other licensed practitioner approved by the Medicaid program.<sup>8</sup>

State Medicaid programs generally cover only drugs that have been approved by the Food and Drug Administration (FDA), including both brand-name drugs and generics. The programs may also cover, at state discretion, experimental drugs. Thus, the decision to cover experimental drugs varies by state and by drug.

States are not required to provide unlimited access to prescription drugs. Medicaid law allows states to restrict access, and thus contain costs, through the creation of drug formularies (lists of drugs that the programs will cover). A drug may be excluded from the formulary, however, only if it has no significant therapeutic advantage over a drug already in the formulary (e.g., a brand-name drug may be excluded from the formulary if the generic version of the drug is in the formulary). In addition, Medicaid must continue to cover a non-formulary drug for a particular beneficiary if his or her physician demonstrates that the drug is medically necessary.

Because protease inhibitors are so expensive, there has been some question about whether they are covered by Medicaid. In June 1996, HCFA issued a letter to state Medicaid directors in which it explained that states are required to cover FDA-approved protease inhibitors. The letter stated that “[w]hile States have discretion to establish certain limitations on the provision of drugs, . . . States should examine their drug benefits to ensure that limitations do not excessively or unreasonably restrict coverage of effective treatments (including FDA-approved combination therapy) for HIV/AIDS-infected individuals.” In addition, the letter explained that if a state includes drugs and covers the HIV/AIDS population in managed care plans, protease inhibitors must be available in managed care formularies. As an alternative, states have the option to “carve out” the prescription of, and payment for, drugs

used in the treatment of HIV/AIDS from its managed care contracts, and may pay for these drugs under its standard drug benefit policy. For further discussion of prescription drugs in a managed care setting, see Chapter 5.

## **B. Hospice Services**

Under Medicaid, the term “hospice” generally refers to a network of care provided in the home to a terminally ill patient with a life expectancy of six months or less. Patients in nursing facilities may also receive hospice services.<sup>9</sup>

Medicaid-covered hospice services include nursing care, home health aide services, counseling, homemaker services, medical supplies, and prescription drugs. Fewer than one-fifth of the states offer hospice services only to the categorically needy. Almost half the states offer hospice care coverage to both the categorically and the medically needy.

To receive Medicaid coverage for hospice services, a beneficiary must choose hospice coverage, thereby waiving his or her right to coverage for other services. Specifically, a patient may not receive coverage for any treatment services for the terminal condition for which he or she elected hospice care, nor may the patient receive coverage for any hospice-type services rendered by providers outside his or her designated hospice (or provider) network. If the patient receives hospice services while living in a nursing facility, he or she may also receive Medicaid coverage for room and board.

A patient may revoke election of hospice services and resume Medicaid coverage of the benefits waived during the time the patient received hospice care. If eligible, the patient may elect to receive hospice care again in the future.

Since hospice services, by definition, provide palliative care to terminally ill patients, prescription drugs intended to prolong the life of or cure the patient are not covered by Medicaid once a patient chooses to enter a hospice plan. Prescription drugs for pain and symptom relief, however, continue to be covered. Thus, a person with HIV/AIDS who elects to enter a hospice would probably no longer be eligible under Medicaid for anti-viral drugs, such as AZT or protease inhibitors, but would continue to be eligible for drugs such as those that treat skin ulcers, acute diarrhea, vomiting, and pain.

The Center for Medicaid and State Operations (formerly known as the Medicaid Bureau) recently proposed that hospice plans also cover intravenous treatment of lesions and blindness associated with cytomegalovirus (CMV), as such treatment relieves the intense pain associated with the condition and allows the patient to maintain normal daily activities. Traditionally, state hospices have been reluctant to provide intravenous CMV treatment due to its high cost. Therefore, the center is also recommending that treatment be considered an add-on to the daily reimbursement rate for hospice care. Consequently, hospices should be partially reimbursed for the treatment by Medicaid, with the state covering the remainder.

## **C. Case Management Services**

Case management services are defined as services that assist eligible individuals in gaining access to medical, social, educational, and other services, and typically include needs assessments, development of a plan of care, assistance in accessing services, and follow-up and monitoring of individuals.

Under Section 1915(g) of the Social Security Act, states may provide case management services to categorically needy beneficiaries without regard to the statutory requirements of comparability and statewideness. However, case management services may not duplicate activities that are furnished by other Medicaid services. At a state's option, case management may be limited to any specific group, such as individuals with HIV/AIDS, with chronic mental illness, etc.

Case management services may be particularly important to people with HIV/AIDS, who often need assistance through the patchwork of public and private benefits available to them. Such services are offered by approximately half of the states to both the categorically and medically needy.

#### **IV. Utilization Controls and Service Limitations**

Even though states are required to offer mandatory services to all categorically needy individuals, they may limit the duration and frequency of use of these services. These limitations are designed to curtail payments for inappropriate or medically unnecessary services, but they are often used simply to control costs.

States have wide discretion and varying policies in this area. Many have an annual limit on the number of days of inpatient hospital care for which an individual may be covered. Many states also have placed a limit on the number of prescriptions an individual may receive per month or a dollar-amount limit on what the state will pay for prescription drugs per month. Others have limited the number of times an individual may visit his or her physician during a specified time period. In certain cases, extensions may be granted by the states based on a beneficiary's documentation of medical necessity. Table 3-4 lists some of the Medicaid benefit limitations in states with large AIDS populations.

States may not limit services without restraint. In theory, their ability to create ceilings on how much they will cover is limited by a federal floor, the minimum that must be provided for a state to remain in compliance with the federal statute. The most important parts of this floor are the requirements that states provide all medically necessary services within the states' benefits packages and that each service provided must be sufficient in its amount, duration, and scope. (See the next section, and examples in Chapter 7 on enforcement.)

#### **V. Requirements Applicable to All Covered Services**

Federal standards govern the minimum amounts and types of services a state must provide, making up a minimum benefits package. A state must design its benefits package in accordance with four basic coverage rules:

- *Amount, Duration, and Scope (ADS) of covered benefits*
- *Comparability of benefits*
- *Statewideness of benefits*
- *Freedom of choice for patients to choose providers*

<b>Table 3-4: Medicaid Benefits Limitations in High AIDS Incidence States in Fee-for-Service Settings</b>			
<b>State</b>	<b>Prescription Drug Limitations</b>	<b>Hospital Inpatient Limitations</b>	<b>Physician Visit Limitations</b>
California	More than 6 prescriptions/month requires prior authorization.	Prior authorization required for elective procedures.	No limit, but more than 6 visits in a given month will cause beneficiary's utilization to be monitored.
Georgia	For persons under 21, more than 6 prescriptions/month requires prior authorization; for others, more than 5 prescriptions/month requires prior authorization.	Psychiatric inpatient care limited to 30 days/year, but may be exceeded if medically necessary.	12 visits/recipient/year; may be exceeded if medically necessary.
Illinois	no limit if medically necessary	Pre-operation stay limited to one day	1 visit/day/physician; otherwise, no limit if medically necessary
New Jersey	no limit if medically necessary	no limit if medically necessary	no limit if medically necessary
New York	no limit if medically necessary	no limit if medically necessary	no limit if medically necessary
Pennsylvania	6 prescriptions/month	no limit if medically necessary	18 visits/year; may be exceeded if medically necessary, but no physician may bill for more than one visit per day.
Texas	3 prescriptions/month. No regulatory limitation for managed care or nursing facility patients; may be governed by managed care contracts.	30 days per illness with yearly limit of \$200,000 per recipient. Does not apply to persons under 21 — TX State law prohibits limiting medically necessary services to this group.	no limit
Washington, DC	no limit if medically necessary	no limit if medically necessary	no limit if medically necessary

Source: Phone conversations with staff of HCEA Regional Offices July 2, 1996

### **A. Amount, Duration, and Scope (ADS)**

The ADS standard requires that each covered service be sufficient in the amount of the service provided (e.g., a sufficient supply of a medication to treat a condition), the duration of time for which the service is provided (e.g., an appropriate number of days of inpatient hospital care for a particular condition), and the scope of the treatment provided (e.g., provision of outpatient follow-up care after surgery). Each service must be sufficient to reasonably achieve the purpose of the service. In other words, states may not limit services so strictly that the treatment is rendered ineffective.<sup>10</sup>

### **B. Comparability**

The comparability standard requires that services available to one categorically needy person be equal in amount, duration, and scope to those available to any other categorically needy person. In the same vein, services available to any person in a medically needy group must be comparable to those available to any other person in that group. States are not permitted to discriminate in the provision of services on the basis of age, gender, or diagnosis. For example, a state may not provide unlimited physician visits to SSI beneficiaries who use wheelchairs, but provide only 20 physician visits per year to children with HIV/AIDS.

### **C. Statewideness**

The statewideness standard requires that the amount, duration, and scope of services be uniform throughout the state. For example, a state may not deliver different sets of services to rural areas and urban areas, or to individuals in different urban areas. Therefore, if a state covers all medically necessary prescription drugs for the categorically needy in a rural area, it must also do so in an urban area.

### **D. Freedom of Choice**

The freedom-of-choice standard requires that beneficiaries be free to obtain services from any individual practitioner, institution, agency, pharmacy, or organization that agrees to provide Medicaid services and is qualified to perform them. In recent years, most states have sought federal waivers of these basic rules of service from the Secretary of the Department of Health and Human Services (HHS). For instance, a waiver of the freedom-of-choice standard was necessary for a state to require that all Medicaid beneficiaries enroll in managed care plans.

The Balanced Budget Act of 1997 changed this rule. States are now permitted to require Medicaid beneficiaries to enroll in a managed care organization without first seeking a waiver of the freedom-of-choice standard. Chapter 6 discusses such waivers and the effect of the Balanced Budget Act of 1997.

## Chapter 3

- 1 Foster, Scott, et al. Federal HIV/AIDS Spending: A Budget Chartbook. The Henry J. Kaiser Family Foundation (June 1999 in press).
- 2 As explained in Chapter 2, states are required to provide Medicaid to the categorically needy as a condition of receiving federal matching funds. States have the option, but are not required to extend Medicaid coverage to the medically needy. Thirty-four states have established medically needy programs.
- 3 As discussed in Chapter 6, these requirements may be waived under certain circumstances. In addition, the Balanced Budget Act of 1997 expands the ability of states to require most Medicaid beneficiaries to enroll in managed care organizations.
- 4 People with HIV/AIDS may receive services at these federally assisted clinics even if they are not eligible for Medicaid, with charges (if any) based on the individual's ability to pay.
- 5 Medicaid is a particularly important source of revenue for federally qualified health centers (FQHCs) because states must reimburse them at 100% of the reasonable costs of delivering the service to Medicaid beneficiaries. Although the Balanced Budget Act of 1997 will phase out this percentage over the next five years, it currently remains substantially higher than the amount that non-FQHC clinics generally receive for Medicaid services. (This issue is discussed further in Chapter 4.)
- 6 Note that while these services are mandatory for the medically needy, only those services that must be provided to the categorically eligible are customarily called "mandatory services," probably because the entire category of medically needy coverage exists solely at the option of the state.
- 7 A number of other states (Arizona, Delaware, Hawaii, Minnesota, Ohio, Oklahoma, Oregon, Rhode Island, Tennessee, and Vermont) control access to prescription drug coverage through Section 1115 waivers. (See Chapter 6 for more information on waivers.)
- 8 Virtually every manufacturer has entered into such an agreement. (See Chapter 4.)
- 9 It should be explicitly noted that Medicaid will continue to provide coverage for hospice services if the patient remains terminally ill beyond his or her six-month life expectancy period. If, however, a provider makes hospice referrals frequently for patients who live longer than the six-month limit, audit questions may be raised.
- 10 With the widespread use of managed care arrangements in Medicaid, a related issue has arisen regarding restrictive plan definitions of the phrase "medical necessity." (See Chapters 5 and 7.)

CHAPTER 4:  
MEDICAID PROVIDER  
REIMBURSEMENT

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# CHAPTER 4

## MEDICAID PROVIDER REIMBURSEMENT

### I. Overview

The Medicaid program gives states considerable freedom to create various methods and standards for reimbursing health care providers for Medicaid services. There are, however, three basic federal reimbursement requirements designed to ensure that beneficiaries have access to care and that payment rates to providers are adequate.<sup>1</sup> These three requirements apply to all types of covered services:

- Providers generally may not bill patients for any charges beyond Medicaid's payment, and must accept Medicaid reimbursement as payment in full for services rendered.<sup>2</sup>
- Methods and procedures for making Medicaid payments must ensure that payments will be consistent with efficiency, economy, and quality of care.
- State payment rates must be adequate to attract a sufficient number of providers so that covered services will be as available to Medicaid beneficiaries as they are to the general population.

Within the framework established by these basic requirements, states have developed a wide range of payment systems. This chapter discusses the legal requirements governing Medicaid reimbursement for providers of the services most often used by persons with HIV/AIDS (see Table 4-1). Some states may have been granted a waiver of some federal requirements, usually in order for the states to provide services through a managed care arrangement. Since the passage of the Balanced Budget Act of 1997, such mandatory managed care programs no longer require a federal waiver and will doubtless become even more commonplace. In such states, payment systems may be very different from those discussed here. Some of these specialized plans are described in Chapters 5 (regarding managed care) and 6 (regarding waivers).

<b>Type of Provider</b>	<b>Type of Reimbursement</b>
Hospital inpatient care	Public rate-setting process
Individual health care practitioners	Lesser of: actual charge or fee schedule rate
Prescription drugs	Drug rebate program
Hospice care	Fixed daily rate (optional service)
Federally qualified health centers	Reasonable cost payment system (being phased out beginning in FY 2000 and completely repealed on Oct. 1, 2003.)

## II. Reimbursements for Particular Providers

### A. Hospital Inpatient Care

Nearly all states currently reimburse hospitals for inpatient care based on a prospective payment system. In other words, payment amounts are determined in advance, either on the basis of diagnosis (case rate—e.g., a higher rate for a hospital stay for AIDS treatment than one for tonsillitis), or on the basis of a negotiated flat rate per hospital day, regardless of diagnosis (per diem rate). Hospitals receive a set rate for services provided, regardless of the actual costs for an individual patient. If the cost for an individual Medicaid beneficiary is higher than the set rate, the hospital absorbs the loss; if it is lower than the set rate, the hospital keeps the difference (and, in many cases, uses the profit to help cover the financial loss from other Medicaid patients and from uninsured patients). (Note that different rules apply to Medicaid beneficiaries in managed care systems, described in Chapter 5.)

Until the fall of 1997, the Boren Amendment to the Medicaid statute required that Medicaid payment rates set by States for hospitals and nursing homes be reasonable and “adequate to meet the costs incurred by efficiently and economically operated facilities.”<sup>3</sup> In addition, hospital care rates had to be sufficient to ensure Medicaid beneficiaries reasonable access to services.<sup>4</sup> However, the Balanced Budget Act repealed the Boren Amendment for hospitals for services furnished on or after October 1, 1997, and established a state public rate-setting process under which proposed rates, methodologies underlying the rates, and justifications for such rates are published and subject to public review and comment.<sup>5</sup>

## B. Individual Health Care Practitioners

Medicaid payment rates for physicians and other individual practitioners must be sufficient to ensure Medicaid beneficiaries access to services. Specifically, Medicaid payments for individual provider services are usually the lesser of the provider's actual charge for the service, or the maximum allowable charge determined by the state.

Reimbursement for physicians differs among states. While all states rely on a fee schedule that provides higher fees for complex care than for simple office visits, these schedules vary significantly: a physician in one state may be reimbursed for an office visit at 10 times the level of a similarly qualified physician in another state. Regardless of these variations, however, virtually all Medicaid physician reimbursement rates are lower than Medicare reimbursement rates for comparable services and are much lower than reimbursement rates under private health insurance.

This comparatively low payment has often resulted in few physicians being willing to accept Medicaid patients. In an effort to address this problem, the Medicaid statute requires that state reimbursement rates be set at a level that will make Medicaid services available to beneficiaries (although this requirement has met with mixed success).

## C. Prescription Drugs

In general, Medicaid covers all FDA-approved drugs. The only exceptions are drugs made by a manufacturer that has not signed a discount/rebate agreement with the Federal government.<sup>6</sup>

Under the Medicaid Drug Rebate program, for a pharmaceutical manufacturer to have its drugs paid for by Medicaid, the manufacturer must give the state a set discount.<sup>7</sup> Failure to agree to this policy results in a complete ban on sales of the company's drugs, not only to all Medicaid beneficiaries, but also to all beneficiaries of the Department of Veterans Affairs (VA) health care system and to all clients of a range of federally assisted health clinics (including clinics receiving Ryan White CARE Act funds). Agreement to this policy ensures that all drugs manufactured by that company will be available to all such beneficiaries and clients, without additional restriction by the state Medicaid plan (or, respectively, by the VA or the public clinics). Such discount requirements also may apply to non-prescription drugs (e.g., aspirin) if non-prescription or over-the-counter drugs are covered in the state's Medicaid plan.

Prescription drug providers are reimbursed for the purchase of the drugs and the cost of dispensing them to Medicaid beneficiaries. To encourage the use of generic drugs (multiple-source drugs), HCFA sets a price limit for each drug based on the wholesale cost of the least expensive generic version. Because the purchase cost of such drugs is determined by the least expensive version, providers have a monetary incentive to dispense generic equivalents whenever possible.

## **D. Hospice Care**

As discussed above, hospice care is an optional Medicaid benefit. If a state chooses to include hospice services in its plan, hospices are reimbursed at a fixed daily rate, according to the nature of the care provided (e.g., inpatient respite care, routine home care, etc.), which must be at least as much as the comparable Medicare rate. Average payments per patient are subject to a capped amount, set annually by the Secretary of HHS. A hospice's costs of administering prescription drugs are not reimbursed separately; rather, they are included in the daily rate. This combined reimbursement policy makes it extremely costly for hospices to provide drugs for palliative care for HIV/AIDS-related conditions.<sup>8</sup>

## **E. Federally Qualified Health Centers**

A federally qualified health center (FQHC) is a facility that receives federal grant funding—e.g., a community health center (including a health center for the homeless, a migrant health center, or a center that meets other federal grant eligibility requirements). Prior to 1997, states were required to pay FQHCs 100% of the facilities' reasonable costs for furnishing services to a Medicaid beneficiary. Enactment of this minimum payment resulted in substantial increases in most states' payments to FQHCs. Medicaid patients no longer represented a financial loss for these facilities, so FQHCs were able to reserve most of their grant funds to serve the uninsured.

The Balanced Budget Act of 1997 enacted a phase-out of this reimbursement system, reducing the percentage of reimbursement beginning in FY 2000 (states must continue to pay 100% in FY 1998 and 1999; states are permitted to pay only 95% in FY 2000, 90% in FY 2001, 85% in FY 2002, and 70% in FY 2003, with the payment requirement completely repealed by October 1, 2003).

The Balanced Budget Act of 1997 also established a new system for FQHCs that have contracts with managed care organizations. States must provide these FQHCs with supplemental payments for the reasonable cost of services minus the amounts FQHCs receive under their contracts with managed care organizations.

## **F. Managed Care Organizations (MCOs)**

The payments to managed care organizations are discussed more fully in Chapter 5. Such payments must be made on an actuarially sound basis. As discussed later, this provision of the Medicaid law could be used to help ensure that MCOs receive sufficient payment to allow them to provide adequate care for Medicaid beneficiaries, especially those with chronic or expensive conditions.

- 1 In addition to these basic requirements, there is an important general federal restriction: Medicaid reimburses for health care services only if the patient has no other source of payment. If a beneficiary has any other means of payment, such as private health insurance, workers compensation, automobile or liability insurance, or another third-party source, that source must pay for the services.
- 2 States may, however, require certain beneficiaries to pay for a portion of their health care services as cost-sharing. While cost-sharing was not permitted previously for managed care organizations, the Balanced Budget Act of 1997 allows cost-sharing in managed care organizations to the same extent as in fee-for-service programs. When cost-sharing is allowed, it may only be a nominal charge (usually \$2 or less). It should be noted that, as a statutory matter, participating providers may not withhold covered services from beneficiaries unable to pay the required cost-sharing.
- 3 A number of lawsuits against states used this language successfully to require an increase in reimbursement rates.
- 4 Special rules apply to hospitals that serve a disproportionate share of Medicaid beneficiaries (and are designated as such). These extremely complex rules were recently altered in the Balanced Budget Act of 1997. These rules are beyond the scope of this primer.
- 5 See Rosenbaum, Sara and Darnell, Julie, A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 (P.L. 105-33) with Prior Law (September 1997) (prepared for the Kaiser Commission on the Future of Medicaid).
- 6 In addition, some experts argue that managed care organizations serving Medicaid patients may further restrict access to drugs through the use of formularies, although the policy and law in this area are unclear. If the MCO does restrict access, the State still bears the responsibility to ensure a patient has a needed drug.
- 7 In most cases of drug purchase, a pharmacy is paid full price by Medicaid and the discount is given to the state by the manufacturer in the form of a retroactive rebate. It is easier to think of the policy as a discount. HIV/AIDS advocates should note that, because of other laws independent of the Medicaid statute, these discounts are also available to non-Medicaid eligible people with HIV/AIDS served under the Ryan White program, either through a clinic or through the state's AIDS Drug Assistance Program (ADAP), as well as through community health centers.
- 8 See discussion of CMV drugs in Chapter 3, p. 40.



CHAPTER 5:  
MEDICAID  
MANAGED CARE

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# CHAPTER 5

## MEDICAID MANAGED CARE

### I. Overview

Over the past decade, managed care has swept across the American health care system, leaving practically no individual or provider untouched. Although Medicaid was somewhat behind private health insurance in this revolution, it is now making up for lost time, with the percentage of Medicaid beneficiaries who are members of a managed care plan having quintupled between 1991 and 1997.<sup>1</sup> This change is widespread: As of July 1, 1997, thirteen states currently operate comprehensive statewide health care reform demonstrations<sup>2</sup> and 48 States have at least some form of managed care providing coverage to Medicaid beneficiaries.<sup>3</sup> As a result of the Balanced Budget Act of 1997, these numbers will certainly continue to increase and may accelerate.

To date, most Medicaid managed care programs have enrolled principally low-income women and children. Fewer of these managed care plans have served Medicaid beneficiaries who have disabilities, the usual eligibility category by which people with AIDS enter Medicaid.

But this, too, is changing rapidly. One recent report concluded that “[a]pproximately one in four non-elderly persons with disabilities in the Medicaid program is enrolled in managed care, and it is likely that these numbers will grow over the next several years.”<sup>4</sup>

All of this means that managed care is coming to people with HIV/AIDS who are served by Medicaid. Given this impending and inevitable evolution in the delivery of health care, both managed care designers and HIV/AIDS policy advocates have to learn new concepts and address new issues. With a few notable exceptions, managed care plans have not developed the specialized approaches necessary to serve people with chronic or disabling diseases. Correspondingly, and again with some notable exceptions, HIV/AIDS advocates have not developed a clear understanding of how to adapt managed care to meet the needs of people with HIV/AIDS.

This chapter is intended to help HIV/AIDS advocates so they can enter the debate over the design and improvement of Medicaid managed care, rather than remaining solely in the debate over whether to have such plans at all. It is meant to provide a basic understanding of managed care in general, in Medicaid, and in HIV/AIDS care.

The chapter necessarily is not comprehensive and may not be current by the time it is read; the field of managed care is in constant flux, with new combinations and arrangements being developed every day. Nor is this chapter designed to be prescriptive; there is no universally right mixture of risk, cost containment, quality assessment, and free choice.

Rather, this chapter introduces the basic concepts of managed care, contrasted with traditional insurance, and describes a few of the most common models and structures. Then it discusses some of the newest developments in Medicaid managed care for people with HIV/AIDS and highlights some problems that must be addressed to ensure high-quality health care services for them.

## II. For Comparison: The Basic Fee-for-Service Model

Medicaid traditionally was—and, for many people with disabilities, still is—a fee-for-service plan. Therefore, only by understanding the concepts and workings of fee-for-service plans can one understand the changes brought about by managed care. This is a very brief overview for comparison purposes (see Table 5-1).

<b>Fee-For-Service Plans</b>	<b>Risk-Bearing Managed Care Plans</b>
Plan at risk for health care costs	Plan and providers share risk of health care costs
Fee-for-service payments to providers	Capitated payments to most providers (per-member on periodic basis)
Risk of overutilization	Little risk of overutilization
Little incentive to control costs	Incentive to control costs
Little risk of underservice	Risk of underservice
No specification of participating providers	Access to providers limited (or additional cost-sharing required for non-participating providers)
Access to services unlimited (as long as fees are adequate)	Limited access to services

## A. In General

Fee-for-service plans are thought of as traditional American health insurance. Under a fee-for-service plan, the patient (or the patient's family or employer) pays an insurance company a monthly premium to take the financial risk that the patient might need health care services at some point during the year. Those health care services that are insured are defined as covered benefits.

In return, the insurance company pays the bills for any hospital or physician services that the insured person actually uses during that year within those benefits. Insurance companies combine the premiums from a large number of such people into a pool. Some people will need no health care services at all, so the pool will pay no expenses on their behalf. Others will have major health care problems, so the pool will reimburse the doctors and hospitals for services rendered. (In virtually every insurance plan, there will also be some cost-sharing for the patient to pay.<sup>5</sup>) If the premium charged to everyone who participates in the pool is adequate, the insurance company will keep any leftover funds in the pool for overhead and profit, along with the profits made from investing the money from the pool until payments are needed.

Both private and Medicaid fee-for-service plans produce an inherent incentive for costs to increase. Individual providers are paid more if they see more patients and see them more often. Hospitals are paid more if they admit patients more often or if they admit patients when outpatient care might suffice. Pharmacies are paid more if they provide more and more expensive drugs. Except for cost-sharing, patients have no short-term incentive to save money and may seek out more expensive or more frequent services, even when these services provide little or no additional value to their health.

## B. Fee-for-Service and Medicaid

Under the traditional Medicaid fee-for-service program, the system is similar to a private plan, except that the federal and state governments serve as both payors and insurance companies. In other words, the government uses its own money to reimburse providers for any covered health care services given to Medicaid patients. Cost-sharing by the patient is limited to nominal amounts.

The core problem of health care cost increases under a fee-for-service model is also an issue under Medicaid. Health care costs under Medicaid have risen dramatically over the past two decades.<sup>6</sup> Some analysts argue that providers who participate in Medicaid make up for the low reimbursement rate by increasing the volume of services provided and the number of office visits. In addition, Medicaid is obliged to provide all medically necessary services within a state's benefits package, including increasingly expensive technologies and medications.

### C. Fee-for-Service and People with HIV/AIDS

With respect to people with HIV/AIDS, the advantages of the traditional Medicaid fee-for-service plan are familiar. Traditional Medicaid plans allow people with HIV/AIDS and other beneficiaries the freedom to choose their physician, hospital, and/or clinic. The beneficiary need not receive clearance prior to seeking a particular service. To the extent state Medicaid plans limit the amount, duration, and scope of the services available, these decisions are made publicly by a state agency and are subject to state and federal regulation.<sup>7</sup> In addition, as discussed in Chapter 3, any limitation a state plan places on the amount, duration, and scope of a particular service can be overcome by documentation of medical necessity.

The traditional Medicaid fee-for-service plan is not a panacea for people with HIV/AIDS. There is often a shortage of Medicaid providers and a lack of coordination in the provision of health care. Because most state Medicaid plans provide such low reimbursement rates for physicians, clinics, and hospitals, people with HIV/AIDS often have difficulty finding providers. Consequently, their theoretical freedom of choice among providers may be severely limited in practice. When they do find willing providers, people with HIV/AIDS generally must schedule and coordinate the services of their primary care physicians with their specialists, find physicians who use the same hospital (and ensure that the hospital takes Medicaid patients), and check for possible interactions and side effects of their prescription drugs, all without administrative assistance.

## III. The Basic Managed Care Model

### A. In General

The creation and implementation of managed care systems have become a widespread response to uncontrolled costs under fee-for-service plans, and such systems have been advocated as a potential tool for improving efficiency and coordinating services. Indeed, the term “managed care” has come to refer to almost any payment and delivery system that is designed to plan and provide health care services in a cost-conscious and coordinated manner. In general, managed care plans provide health care providers and patients with a variety of incentives and rules to accomplish three basic goals:

- Limit the use of health care generally and encourage prevention (e.g., diseases should be treated before surgery is needed, and surgery should be the option of last resort).
- Limit the type of care provided to the simplest and least expensive appropriate care (e.g., surgery should be performed on an outpatient basis, rather than inpatient, whenever possible).
- Restrict patients’ choice of providers to those who provide care in a cost-effective manner.

The flow of payments in managed care plans initially resembles that in fee-for-service plans. Someone (usually the patient, patient’s family, or patient’s employer) pays the plan a monthly premium to assume the risk of

expensive health care and increased costs. In return, the plan is responsible for either arranging and paying for, or actually providing, the needed hospital, physician, or other health care services.

There are many different approaches to managing and sharing the costs of such services. Some managed care plans own hospitals and employ physicians; whenever a member of the plan needs health care services, he or she must seek treatment from the plan's providers. Some managed care plans make contractual agreements with hospitals and physicians to serve their members at a discount, and members of that plan may use only those providers (or incur significant cost-sharing to see any other provider). Some plans hire physicians as employees, but enter into contracts with hospitals for services. Some plans hire primary care physicians, but contract with specialists. The varieties are endless.<sup>8</sup> Almost all managed care plans, however, place some limits on whom a patient may see for covered services.

Many plans pay providers on a capitated basis. In other words, they make a predetermined payment per-month, per-member, regardless of the amount of health care services actually used by each member. Capitated rates are the monthly fees the plan pays providers in exchange for the providers bearing some of the risk of expensive health care during the designated period. These providers can include hospitals, clinics, physician groups, and individual physicians.

Some people mistakenly believe that the premium or the capitated rate is a limit on the amount of services that may be received by each covered patient. In other words, if either the monthly premium or the capitated rate is \$300, they assume the patient is allowed to receive only \$300 per month in services. This belief is incorrect. While there may be overall limits on a plan's liability per patient (such as \$1 million over a lifetime), the premium and capitated rate are not limits. Rather, the monthly premium is paid by (or on behalf of) the patient to the plan in exchange for the plan agreeing to provide all the covered health care services that the patient needs during that month.

Unlike fee-for-service plans, however, most managed care health plans share the profits and losses of medical expense with some or all of their employees and contractors, the health care providers. Often, hospitals, primary care physicians, specialists, and pharmacies are, themselves, given a capitated rate or a total budget. If they exceed the budget, they suffer a loss; if they stay under the budget, they keep the profit.

In all of these instances, the hospitals, physicians, pharmacies, and case managers have a financial relationship with the plan that is separate from their relationship with the patient. Thus, practically everyone who is in a position to make a decision about how much health care to provide (and at what price) may also risk losing money if he or she provides "too much care." This is intended to provide incentives for efficiency and coordination of care. However, it also provides incentives for inappropriately limiting access to, duration of, or quality of needed services.

In eliminating the problematic lack of incentives to control costs inherent in fee-for-service plans, managed care models create a new problem: a lack of internal incentives to provide all necessary, appropriate, and high-quality care. In other words, they create an incentive to underserve patients. In the most extreme example, the managed care model may encourage plans to

underserve patients who have very expensive conditions from which they are unlikely to recover, rather than to provide such patients with the services they need. (As discussed below, these problems are exacerbated in Medicaid plans.)

One factor mitigating against underserving patients with expensive conditions is the professionalism of health care providers. Most health care professionals have taken oaths regarding their responsibility to protect their patients and are diligent in abiding by these oaths. Many decisions in health care, however, are judgment calls, subject to subtleties of impression and persuasion.<sup>9</sup> When providers, themselves, are at risk for employment discipline or financial loss, such professionalism may not carry as much weight as when decisions are independent of budgetary concerns.<sup>10</sup>

In response to these troublesome incentives to underserve patients, public and private entities have devised strategies to encourage managed care plans to provide all appropriate care to their beneficiaries. For example, some health plans use patient satisfaction ratings, some states use report card measures, and various quality-of-care measures are required in contracts.

In the private sector, marketplace considerations also may act as a countervailing financial interest against underserving patients. A patient may be able to leave one plan and join another if he or she is dissatisfied with the care provided,<sup>11</sup> or employers may cancel their contract with one plan and seek another if they believe their employees are not being served adequately. It should be noted, however, that in many areas such marketplace incentives may not be applicable because employees are offered only one managed care plan.

## **B. Managed Care and Medicaid**

Medicaid beneficiaries may be enrolled in managed care plans on a voluntary or mandatory basis. In some states, the state contracts with a managed care plan (or plans) and the state's beneficiaries have the option of joining the plan(s). In other states, Medicaid beneficiaries are required to join the managed care plan (or plans) with which the state contracts. Until the fall of 1997, before a state Medicaid program could require beneficiaries to join a plan, the state had to have received a waiver from some aspect of the federal requirements concerning comparability, statewideness, freedom of choice, and/or amount, duration and scope. (Chapter 6 discusses such waivers.) As a result of the Balanced Budget Act of 1997, such waivers are no longer required for a state to operate mandatory managed care programs under Medicaid.<sup>12</sup>

When a state contracts with a managed care program, the state Medicaid program pays the plan a set per capita rate on a monthly or yearly basis. This rate, negotiated in advance, is based on the number (and, in some instances, the eligibility group or specific diagnosis) of the Medicaid beneficiaries who will be enrolled in the plan. Under the terms of the contract, the plan is responsible for paying for or providing all the covered health services needed by a beneficiary during the designated period. The plan, rather than the state, negotiates with health care providers, perhaps hiring some providers for Medicaid work only, perhaps receiving discounts from some providers, or perhaps generally spreading the payments and costs among

providers. The contract between the state and the plan determines what is required, allowed, and forbidden in the health care delivery system.

It is important to note that states cannot eliminate the basic requirements of a state plan simply by contracting with a managed care plan. The state must also ensure that appropriate services are actually provided. If the plan fails to provide mandatory benefits (e.g., family planning services), the state must make alternate arrangements for Medicaid beneficiaries to receive them. By this reasoning, because HCFA has told all states that their prescription drug benefit must include all protease inhibitors (a position described in Chapter 3), the failure of a managed care plan to provide any of these drugs to a Medicaid beneficiary would force the state to make other arrangements to provide them.

While marketplace incentives in commercial settings may help to maintain quality against incentives to underserve, such incentives rarely function effectively in the Medicaid program. Medicaid beneficiaries are often unable or unaware of how to protect their interests. As a practical matter, they often have a limited number of managed care plans from which to choose. In addition, lack of geographic access, especially in medically underserved areas, may effectively limit a beneficiary's ability to change plans.

Indeed, the Balanced Budget Act of 1997 allows states to limit individuals to a choice between two managed care entities. In rural areas, states may limit enrollment to a single managed care entity as long as that entity allows individuals to receive assistance through at least two physicians or case managers within the managed care entity. The 1997 law also alters the rules for disenrollment from managed care entities, essentially allowing managed care entities to lock in beneficiaries unless they can demonstrate a substantive reason why they should be released from the plan. The Act also repealed the requirement that managed care entities receiving federal Medicaid funds must maintain enrollment of less than 75% Medicaid and Medicare enrollees, a rule that was designed to ensure that the level of services for Medicaid beneficiaries was at least comparable to that of the privately insured.

Finally, there are few incentives for plans to compete to serve costly patients for inadequate payments. Quite to the contrary, there is a clear incentive for plans not to market to such persons and to disenroll them whenever possible. Without a strongly competitive market and carefully calibrated payment scales, there are few incentives to maintain standards of care in such settings.

If the managed care market in an area is competitive, there may be pressures for a plan to underestimate costs or deliberately underbid to receive a contract from the state. Such underestimation or underbidding may occur as plans negotiate with Medicaid, or it may occur as plans prepare to provide services and negotiate to shift part of the risk to contractors. Over time, such underestimation or deliberate underbidding raises the likelihood that people with expensive conditions such as HIV/AIDS will not receive adequate care.

Vigorous oversight by regulators has traditionally served as an alternative to market-based incentives. However, many state Medicaid agencies, which have only overseen fee-for-service programs, are not prepared to regulate managed care quality assurance.

Finally, the general difficulty in developing adequate capitated rates of payment is made worse with respect to Medicaid capitation rates. Those who actually calculate health care costs and risks often are not the ones who set Medicaid capitation rates. Rather, the rates are heavily influenced by the Congress, the President, the state legislature, or the governor, whose sole goal may be a budget target. Even if sophisticated actuarial calculations suggest that a higher capitated rate is necessary to serve Medicaid beneficiaries adequately, politicians may demand a lower rate. Even the best managed care plan cannot provide good care under such circumstances.

### **C. Managed Care and People with HIV/AIDS**

As mentioned earlier, there is not much experience with Medicaid managed care for people with HIV/AIDS. In theory, however, managed care eliminates many of the problems associated with Medicaid fee-for-service systems. Managed care offers the potential of coordinated and comprehensive medical care. The beneficiary's primary physician, rather than the patient, can work with other providers in the managed care plan to ensure that the person with HIV/AIDS receives adequate and comprehensive care. Moreover, there is the potential for guaranteed access; under a Medicaid managed care plan, people with HIV/AIDS are theoretically assured access to physicians and hospitals who will serve them.

However, Medicaid managed care plans may not have arrangements with appropriate specialists (such as infectious disease specialists) and may not provide full access to the prescription drugs that are necessary for prevention and treatment of both immune system decline and opportunistic infections. Moreover, many primary care providers are unaccustomed to treating people with HIV/AIDS.

Conversely, health care providers who have long been serving people with HIV/AIDS may be denied reimbursement for certain health care services unless they enter into a contract with the state or the managed care plans serving Medicaid beneficiaries in the area. This elimination of a steady stream of Medicaid payments may damage HIV/AIDS health care providers in at least two ways. First, those who have legal or ethical obligations to serve all patients may care for Medicaid patients without being reimbursed for that care. Second, those providers who do not have a Medicaid contract may be left with only patients who have no source of payment and, thus, a burden of bad debts that will be difficult to finance without receiving payment from some patients with Medicaid.

In addition, there are few financial incentives in managed care systems to provide people with HIV/AIDS on Medicaid with the highest-quality health care. In an attempt to keep costs down, plans may be more inclined to provide the least costly treatment rather than the most effective one.

Moreover, most managed care models and rates have been developed from experience with the employed and relatively healthy population. As discussed above, rate-setting is difficult as a general matter. This difficulty is exacerbated when dealing with Medicaid in general and with people with HIV/AIDS in particular. Many analysts believe that the health care needs of low-income people as a group are different from (and greater than) those who are more affluent. Furthermore, to the extent that Medicaid managed

care experience and data exist, they deal almost exclusively with low-income HIV-negative women and children whose needs are better understood and less medically complex than those of people with chronic illnesses and disabilities, such as people with HIV/AIDS.

The relatively recent development of managed care organizations (MCOs) that serve only Medicaid beneficiaries has also created a new financing problem that will be particularly difficult when dealing with people with HIV/AIDS and other chronic or expensive conditions. In most MCOs and fee-for-service plans, one group may be charged extra to make up for the expected shortfall in payment for another group. The classic example of such cross-subsidies is the extra cost that insurers pay for hospital care to make up for the hospital's serving some people whose payment is inadequate or non-existent. In a Medicaid-only MCO, in which Medicaid pays for every covered person, the possibility of this cross-subsidy is virtually eliminated. This means that payment rates must be calculated even more exactly or there will be insufficient funds to provide care.

HIV/AIDS also crystallizes the current difficulties in estimating costs and, in turn, developing capitation rates that arise because of inadequate information systems, lack of data on the incidence and prevalence of the disease, and costs from inflation and innovation in treatment. Private sector managed care systems have only partial data on people with HIV/AIDS and the cost of their care. The epidemic has changed course and continues to do so, both epidemiologically and geographically. In addition, there has been much innovation in HIV/AIDS treatment, often resulting in higher and more unpredictable treatment costs.

These complexities are not just a problem for providers, but for people with HIV/AIDS as well. Medicaid payment systems that fail to consider the special needs of these beneficiaries will underestimate the cost of care, making it difficult for managed care plans to provide such care. Even the best-intentioned and best-structured plan cannot provide adequate services if it cannot pay its employees and contractors. Thus, HIV/AIDS advocates must work to ensure that Medicaid makes adequate payments to the health plan so that it can provide high-quality care to its beneficiaries.

#### **IV. Varieties of and Variations on Managed Care**

Few health care delivery systems in the United States are purely either fee-for-service or managed care. For example, most fee-for-service systems (including basic Medicaid plans) now pay hospitals at pre-set rates based on the patient's diagnosis. Many managed care plans, in turn, enable their members to see providers who do not participate in the plan and still receive at least some payment for the care. Others have mixed-and-matched capitated payment for some providers with fee-for-service payment for others. Both fee-for-service and managed care systems have made extensive use of case management services.

This section briefly describes a few of the most basic forms and variations of managed care. HIV/AIDS advocates should understand, however, that these forms mutate at an astonishing rate and that any one plan or contract will likely be very different from any other.

### **A. Managed Care Organizations (MCOs)**

The term managed care organization (MCO) is a generic one, referring to a managed care plan of almost any configuration. A Medicaid MCO usually refers to any sort of managed care plan under the Medicaid system.<sup>13</sup> The Balanced Budget Act of 1997 has also established a statutory definition for the term. Under the Act, a Medicaid MCO may be any public or private organization, such as an HMO, an eligible organization with a Medicare risk contract, a Medicare+Choice organization with a Medicare contract, or a provider-sponsored organization.

### **B. Health Maintenance Organizations (HMOs)**

Health maintenance organizations (HMOs) are the original form of managed care, although the structure has evolved into a variety of different plans that all call themselves HMOs. The basic feature of an HMO is that it provides both inpatient and outpatient health care services to its members for a pre-paid, per capita rate. Most HMOs use gatekeepers to coordinate care and lower costs. Variations among HMOs generally involve differences in how they employ or contract with groups of health care providers and whether the providers serve only the HMO's patients or other patients as well.

For example, a staff-model HMO usually owns hospitals and employs physicians and other health care staff. Group-model and network-model HMOs contract with a specific group or groups of physicians and health care providers, which may exist solely to serve the HMO's members. An independent-practice-association-model (IPA) HMO usually contracts with groups of providers who share financial risk.

### **C. Preferred Provider Organizations (PPOs)**

Preferred provider organizations (PPOs) are plans that contract with a limited number of physicians and other providers to provide services to the plans' members. These network providers render services to the plan beneficiaries at a discounted charge. Although PPOs do not usually limit patients strictly to the plans' providers, patients usually pay a significantly larger share of the costs if they receive services from a provider outside the network.

### **D. Primary Care Case Management Systems (PCCMs)**

Medicaid considers primary care case management systems (PCCMs) to be a form of managed care, so this primer treats them as such. In general, however, PCCMs are hybrid systems, best characterized either as an attempt to organize and arrange care under a fee-for-service plan or as a managed care coordinator that carries no risk of profit or loss. They are common in Medicaid.

The primary distinguishing characteristic of a PCCM is the gatekeeper, a person or group of persons responsible for reviewing and approving all health care services a patient seeks or receives. The gatekeeper is usually, but not always, the patient's primary care physician. The gatekeeper monitors the patient's health, ensures that the patient is using appropriate services (such

as office or clinic visits, rather than emergency room treatment), and directs or refers the patient to other providers, as appropriate.

In PCCMs based on a fee-for-service model, the gatekeeper acts, in essence, as a utilization reviewer, approving, modifying, or rejecting each service request made by a beneficiary. A PCCM plan (or an insurance plan that contracts with a PCCM) will still reimburse the health care provider on a fee-for-service basis plus a monthly fee, but the gatekeeper ensures that services are provided only when necessary and in the most cost-effective manner possible.

Independent PCCMs that contract with a managed care plan generally do not have a stake in the profit or loss in the costs of health care services and have no individual incentive to ration care. These PCCMs perform the gatekeeping (i.e., they decide whether and what services should be provided), but the managed care plan takes the ultimate loss if health care costs exceed capitated rates for plan members.

Like fee-for-service and managed care plans, PCCMs have advantages and disadvantages for people with HIV/AIDS. Under the PCCM model, the gatekeeper is both a friend and foe. As a friend, the gatekeeper coordinates the beneficiary's care. He or she directs or refers the patient to other providers, as appropriate. The gatekeeper may even, in some instances, act as a case manager, helping the patient through the maze of available services and assistance programs, and aiding in the completion of accompanying paperwork and eligibility tests.

Gatekeepers are not, however, patient advocates. While PCCM gatekeepers and their staff may perform functions similar to those performed by case managers funded through the Ryan White CARE Act or HIV/AIDS volunteer agencies, they perform these functions within the context of medical services only, and they receive a payment from the insurer or the plan to do so. In extreme cases, to limit costs, PCCM gatekeepers may sometimes close the gate, preventing a person with HIV/AIDS from receiving necessary care. The limited budgets afforded to many state Medicaid programs may force such a result.

The Balanced Budget Act of 1997 created a statutory definition of a PCCM. Under this definition, PCCM services are case management-related services provided by a physician, a physician group practice, an entity having arrangements with physicians to provide such services, a nurse practitioner, a certified nurse-midwife, or a physician assistant. The case management services must be provided under a contract with the state requiring the case manager to provide services that have reasonable and adequate hours of operation, are accessible to patients, have adequate availability of health care providers, do not discriminate based on health status, allow termination of enrollment under certain circumstances, and meet other general requirements related to a state's option to use managed care.

## **E. Point of Service (POS) Options**

A point of service (POS) option is a provision in a managed care plan that allows patients to use non-participating providers. POS is an option that many patients use to see a specific provider for a specific purpose, while receiving most other services inside the plan. For instance, some people with

HIV/AIDS may prefer to continue to receive diagnostic or treatment care from the doctor they saw before they became health plan beneficiaries; others may wish to receive care at sites with greater familiarity with HIV/AIDS (such as university clinics), rather than from the plan's providers. The POS option usually requires a significant amount of patient cost-sharing.

POS options are not currently available in most Medicaid managed care plans, and few Medicaid beneficiaries are able to pay for out-of-network services. In the last few years, HIV/AIDS advocates have begun to seek such options.

If a managed care plan cannot provide sufficient services for its beneficiaries, it is almost always legally obligated to arrange for these services through other channels without additional cost-sharing to the patient. Under Medicaid, the state remains obligated to provide all medically necessary services within the state's benefits package if its MCO does not.

### **F. Contracts with Community Providers**

In addition to POS options, some managed care plans enter into contractual arrangements with clinics (such as community health centers) and other providers in their locality. The terms of such contracts vary, but, in essence, they allow these providers to continue to serve plan members and to receive payment from the plan for doing so.

### **G. Carve-Outs and Exemptions**

A carve-out refers to a plan exception in which certain types of care or groups of patients are not covered or are treated differently by the managed care plan. Some plans, for instance, do not provide risk-based coverage for mental health or drug-abuse treatment. Some proposals have suggested that people with HIV/AIDS should be exempted from mandatory Medicaid managed care plans and, instead, be treated under a fee-for-service system or under a specialized managed care plan with different providers, services, and reimbursement rates.

### **H. Pharmaceutical Benefits Management (PBM)**

Pharmaceutical benefits management (PBM) is a managed care approach to prescription drugs. A PBM may be part of an overall managed care plan, or it may be a separate service, provided through a contract with a fee-for-service plan, a managed care plan, or the payor (employer or Medicaid program) directly. PBMs ensure that the least expensive appropriate drugs are used, often requiring the substitution of generic drugs for brand-name products.<sup>14</sup> They may also negotiate discount prices and provide drugs at a much lower price than retail pharmacies. Furthermore, PBMs sometimes take on the additional responsibility of ensuring that each individual patient's prescriptions are coordinated by checking for drug interactions and side effects.<sup>15</sup>

### **I. Prepaid Health Plans (PHPs)**

Prepaid health plan (PHP) is a term used almost exclusively in the Medicaid program. It refers to Medicaid managed care plans that bear the

risk of profit or loss for the provision of a limited range of health care services, rather than the full range of such services. Some PHPs provide outpatient services but not hospital care. Others assume the risk of a narrower group of services, such as mental health benefits. These specialized plans typically contract with a larger MCO to provide a specific set of services to the larger plan's members. For example, a group of physicians may form a PHP and contract with a Medicaid agency to provide only outpatient physician services to Medicaid beneficiaries.

## V. Financing Issues in Medicaid Managed Care

As states move to require people with HIV/AIDS to enroll in managed care plans, a number of new financing issues will arise. (For a discussion of other issues related to managed care, see Chapter 9.) The crux of these concerns is the high cost of treatment for HIV/AIDS compared with the average cost of an otherwise healthy Medicaid beneficiary. Unless special payment arrangements are made, many MCOs will have strong financial incentives to avoid enrolling people with HIV/AIDS at best and to serve them poorly at worst. (It should be noted that many other diagnoses require more expensive care than HIV/AIDS e.g., those requiring cardiac surgery. These diagnoses might also merit special payment arrangements).

Although the cost of care is changing almost daily, the average annual medical costs of a person with AIDS may be \$25,000 to \$120,000 or more. These expenses are especially daunting when compared with the average annual medical cost of \$2,000 for other individuals between ages 18 and 44.

Managed care plans are usually paid a flat rate to provide care, and, since that rate is much lower than the cost of HIV/AIDS care, MCOs can expect to take a financial loss on most people with HIV/AIDS. Thus, the capitated reimbursement that is at the heart of managed care may dissuade plans from enrolling people with HIV/AIDS. In response, some plans may limit enrollment (usually covertly, since discrimination of this sort may be illegal, depending on the circumstances). Others may place restrictions on access to HIV/AIDS-related health care services, which will deter people with HIV/AIDS from enrolling and cut costs for patients who are enrolled. (This, too, may be illegal in some circumstances). Consequently, the financial responsibility for HIV/AIDS care will be unevenly distributed among health plans, and the quality and choice of care for people with HIV/AIDS will be compromised.

In an effort to avoid these unwanted side effects of managed care for this segment of the population, some analysts and a few health plans are experimenting with various strategies to make the provision of care for people with HIV/AIDS financially neutral for the plan. These strategies include risk adjustment, reinsurance and stop-loss, and risk corridors.

Whatever approach is considered, it should be noted that there is a federal requirement that Medicaid payment to MCOs be made on an "actuarially sound" basis. This provision should provide a strong tool for advocates and plans to work together to ensure that the state's payment for services is sufficient to provide quality care.

## A. Risk Adjustment

Generally, risk adjustment raises or lowers the amount of premiums or capitated payments according to a prediction of the likely health care expenses associated with different individuals. State Medicaid programs could perform a statistical analysis of clinical and cost data to determine different capitated payments for different managed care plans, based on the demographics and relative health of their beneficiaries. Plans that predictably provide more care or more expensive care, such as those plans that have more enrollees with HIV/AIDS, would receive higher compensation.

Some have argued that the statutory requirement that MCOs be reimbursed by Medicaid on an actuarially sound basis effectively requires that such a risk adjustment be done when states contract with MCOs serving people with HIV/AIDS or other expensive conditions. At this time, no regulation to that effect has been issued by HCFA.

The challenge of risk adjustment lies in the logistics of defining the special population and determining the appropriate payments. Regarding beneficiaries with HIV/AIDS, risk adjustment options include a single HIV/AIDS rate based on a uniform standard for diagnosis, or multiple rates that attempt to account for cost differences within the broader category. Multiple rates might be based on, for example, the stage of the illness (e.g., asymptomatic HIV infection versus advanced AIDS), or the beneficiary's residence as a proxy for social factors (e.g., poverty, homelessness, and social support) that may require additional health care or support services.<sup>16</sup> Medicaid programs are likely to continue experimenting with these and other methods of risk adjustment to reflect the varying health care needs of beneficiaries enrolled in managed care plans.

## B. Reinsurance and Stop-Loss

Reinsurance is generally any insurance acquired by a health plan (either fee-for-service or MCO) from a third-party insurer or the government. A reinsurance arrangement protects the plan itself from any resulting financial loss if the plan or a few beneficiaries incur extremely high health care expenses. For example, reinsurance may take over financial responsibility for the plan if the plan experiences more than a designated amount of overall loss.

Stop-loss is a type of reinsurance that protects the plan from medical expenses above a threshold amount for an individual during a specified time period. For example, a plan may have a stop-loss insurance policy for one year for cases over \$100,000. After the plan pays \$100,000 for an individual beneficiary, the stop-loss insurer reimburses the plan for its additional expenses for that individual for the remainder of the year. Both reinsurance and stop-loss are common.

Note that, although reinsurance and stop-loss plans protect MCOs from extreme or unusual costs, they provide little protection from losses that may result from large numbers of beneficiaries with consistently above-average health care needs. Accordingly, these approaches have a more limited potential for Medicaid managed care for people with HIV/AIDS than does risk adjustment of capitated payments. However, risk adjustment can only account for predictable risk levels, whereas reinsurance and stop-loss protect the plan from unexpected extreme expenses.

### **C. Risk Corridors**

A risk corridor is an arrangement by which Medicaid and a managed care plan would share the risk of providing health care services. Such contractual agreements protect the plan by incorporating stop-loss provisions, and protect Medicaid by limiting the plan's potential profits. If an MCO's costs prove unexpectedly high, Medicaid would become a reinsurer; vice versa, if an MCO's costs are unexpectedly low, Medicaid could share profits. Accordingly, risk corridors share the risk of both losses and profits, based on the combined expenses of all beneficiaries.

By limiting the large gains that plans may reap from zealous and potentially inappropriate enrollment selection strategies and cost-cutting through underservice, risk corridors redirect the focus to the more gradual gains possible from innovation and improved efficiency. Some have argued that one drawback of risk corridors is that Medicaid and the plan need to agree to limit the expenditures from which the plan may profit. Consequently, they argue, such arrangements may compromise the incentives and flexibility of managed care plans. Others respond that potential profits and losses in a risk corridor are still adequate to attract competition but without the risk of underservice.

### **D. Exemptions/Carve-Outs**

Under the Balanced Budget Act of 1997, Medicaid beneficiaries who are children with special needs cannot be required to enroll in managed care. Children with HIV/AIDS were specifically discussed under this exemption. This exemption was a much-debated issue, and it was ultimately agreed to, in part, because of the many and varied specialty services needed by such children.

Some have suggested that such an exemption would be appropriate for all people with HIV/AIDS. Such action would allow Medicaid beneficiaries with HIV/AIDS to remain in a fee-for-service model of care. As discussed above, there are potential advantages and disadvantages to each system. The true advantage for people with HIV/AIDS in this proposal is that they would be allowed to choose which system in their state would serve them better and they could, potentially, leave one system for the other on the basis of their care.

Others have discussed the creation of managed care plans solely for people with HIV/AIDS, providing a clear package of services at a clearly estimated rate. Such plans might contract directly with the state Medicaid plan or subcontract with a more general MCO that provides services to Medicaid beneficiaries.

These are only a few possibilities for dealing with the problems posed by placing people with HIV and other chronically ill and disabled people in MCOs. As Medicaid continues to incorporate managed care, states will continue to experiment with these and other strategies for serving people with HIV/AIDS to determine a manner that is fair to Medicaid, plans, and beneficiaries.

- 1 Health Care Financing Administration, "National Summary of Medicaid Managed Care Programs and Enrollment," (June 30, 1997), [www.hcfa.gov/medicaid/1115dm97.html](http://www.hcfa.gov/medicaid/1115dm97.html).
- 2 HCFA, "States with Comprehensive Statewide Health Care Reform Demonstrations" (June 30, 1997), [www.hcfa.gov/medicaid/1115dm97.html](http://www.hcfa.gov/medicaid/1115dm97.html).
- 3 Regenstein, M. and Schroer, C., "Medicaid Managed Care for Persons with Disabilities," Kaiser Commission on Medicaid and the Uninsured (December 1998).
- 4 Regenstein, M. and Schroer, C., "Medicaid Managed Care for Persons with Disabilities," Kaiser Commission on Medicaid and the Uninsured (December 1998).
- 5 "Cost-sharing" refers to the amount, in addition to the premium, paid by the beneficiary for the receipt of health care services. These amounts include, for example, co-payments, co-insurance, and deductibles.
- 6 Overall Medicaid costs have risen in the past for many reasons, some more significant than the increasing cost of services. Such reasons include the aging of the population, the rising proportion of Americans in poverty, the costs of disproportionate share hospital (DSH) payments to states, and artificial financing schemes. Some recent projections estimate that the previously steep rate of increase is slowing down much more quickly than expected, perhaps because of new controls on DSH and state financing.
- 7 For example, as discussed in Chapter 7, a Medicaid beneficiary who has been denied a particular service is entitled to a fair hearing before the state Medicaid agency. Both beneficiaries and providers are provided a private right of action in federal court under 42 U.S.C. §1983. (See Chapter 7 on enforcement.) Furthermore, laws like the Americans with Disabilities Act prohibit discrimination on the basis of disability (including HIV/AIDS) by state and local governments and agencies.
- 8 A number of these approaches are discussed below and in Chapter 6.
- 9 In one study, 79% of physicians surveyed stated that the cost of medical services sometimes or frequently affects their patient care decisions. "More Than 1100 Young Doctors Reveal What They Like—And Don't Like—About Medicine," *California Physician's Magazine*, December 1995, p. 22.
- 10 Legislative proposals to address part of this problem have recently been enacted by the Congress and state legislatures. For example, one new federal provision prohibits plans from restricting physicians' advice to patients about costly or uncovered treatment options.
- 11 Of course, if these are expensive patients, the plan may not regret their departure. Indeed, there would appear to be an incentive not to market the plan to such patients, to discourage their enrollment (directly or indirectly), and to encourage their departure.
- 12 Mandatory enrollment in managed care is still not permitted in the cases of children with special needs (which usually includes those with HIV/AIDS), Native Americans, and persons eligible for Medicare.
- 13 To get an idea of the level of complexity and confusion that has taken over health care finance, consider one reference work's definition of MCO: "Managed care organization. A generic term applied to a managed care plan. Some people prefer it to the term 'HMO' because it encompasses plans that do not conform exactly to the strict definition of an HMO (although that definition has itself loosened considerably). May also apply to a PPO, EPO, IDS, or OWA." In turn, this same work defines OWA to mean: "Other weird arrangement. A general acronym that applies to any new and bizarre managed care plan that has thought up a new twist." Kongstvedt, Peter R., *The Managed Care Handbook*, 3rd edition, 1996, pp. 505-506.
- 14 If, however, PBMs do not provide a specific drug, that decision may be appealed. If the PBM does not provide a specific drug for which there is a therapeutic justification, the state Medicaid plan must make alternative arrangements to do so. See the discussion in Chapter 3 on this point and, specifically, on protease inhibitors.
- 15 Some PBM plans are owned and operated by pharmaceutical manufacturing companies. Such business relationships have resulted in allegations that a PBM may steer plans toward products made by the owner of the plan.
- 16 For more information, see Dreyfus, Tony, et al., *Using Payment to Promote Better Medicaid Managed Care for People with AIDS* (July 1997).

CHAPTER 6:  
MEDICAID  
WAIVERS

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# CHAPTER 6

## MEDICAID WAIVERS

### I. Overview<sup>1</sup>

Under the Medicaid program, states must submit plans that explain how they intend to operate their Medicaid programs and conform to the requirements set forth in the statute and regulations. States are required to submit these plans to the Health Care Financing Administration (HCFA) for approval. Under a statutory system of waivers, however, states may ask HCFA for approval to design plans that deviate from the usual law.

One of the primary goals for which states sought Medicaid waivers has now become attainable without going through the waiver process. The Balanced Budget Act of 1997 eliminated the federal review process entirely for large portions of Medicaid beneficiaries. For exceptions to the freedom-of-choice requirements, in particular, Medicaid now permits states to require most beneficiaries to enroll in managed care organizations without the states having to go through a federal waiver determination process. The Balanced Budget Act of 1997 also permits states with existing waivers to continue operating under these waivers.

Some programs implemented under the waiver system have resulted in positive efforts to coordinate health care services, ensuring beneficiaries access to care in a comprehensive manner and covering individuals who were previously ineligible for Medicaid. Waivers were often requested and implemented, however, as part of a state effort to control the costs of the Medicaid program. In most cases, they attempted to replace fee-for-service systems with managed care systems, which many viewed as increasing the risk of reduced services for beneficiaries.<sup>2</sup>

### II. Types of Waivers

In general, there are two types of waivers: program waivers and research and demonstration waivers. Program waivers are divided into two subgroups: freedom-of-choice waivers and home- and community-based services (HCBS) waivers, both of which are generally narrow in scope. In contrast, research and demonstration waivers are generally broader and allow states to pursue large-scale, new initiatives in financing and delivering care to Medicaid beneficiaries on a statewide basis. In recent years, a growing number of states

have sought these research and demonstration waivers to enable them to restructure their Medicaid programs within a managed care framework.

### III. Program Waivers

#### A. Freedom-of-Choice Waivers (*Section 1915(b)*)

##### 1. In General

Prior to the Balanced Budget Act of 1997, freedom-of-choice waivers (authorized by Section 1915(b) of the Social Security Act), waived the federal requirement that states must give Medicaid beneficiaries the freedom to choose their health care providers. In principle, states were provided this flexibility to improve access to care through enrollment in a comprehensive network, such as a managed care organization (MCO), that operates in a cost-efficient manner. Such waivers also made possible more systematic monitoring of the quality of services rendered.

As mentioned above, the Balanced Budget Act of 1997 eliminated the necessity for a Section 1915(b) waiver in most circumstances. The Act grants states the authority to require that beneficiaries enroll with MCOs or primary care case managers as a condition of receiving Medicaid assistance. In the past, Section 1915(b) waivers could not waive the requirement that managed care entities have at least 25% private enrollees (although Section 1115 waivers, discussed below, could waive this requirement). With the Balanced Budget Act of 1997's repeal of the 75/25 rule, this is no longer an issue.

The Act has narrow exceptions, however, that may leave some need for the freedom-of-choice waiver. First, children with special needs are exempt from this grant of state authority to require beneficiaries to enroll in MCOs and states must still seek a freedom of choice waiver to do so. Children with special needs include those who are eligible for supplemental security income (SSI), have special health care needs, are mentally retarded and require care in a hospital or intermediate care facility, are receiving foster care or adoption assistance, or are in foster care or otherwise in an out-of-home placement. States may require these children to enroll in managed care systems only if they obtain waivers through the process described below. Since children with AIDS will almost always be considered to have special needs, this waiver will continue to be important to people involved in HIV/AIDS care.

The second group exempted from this provision includes various Medicaid populations that qualify for Medicare, such as dual enrollees, qualified Medicare beneficiaries (QMBs) and specified low-income Medicare beneficiaries (SLIMBs).

Finally, states may not require Native Americans to enroll in a managed care entity unless it is the Indian Health Service, a tribal health program with a contract with the Indian Health Service, or an urban Indian health program operated pursuant to a grant or contract with the Indian Health Service.

These exemptions are important for people who live with an AIDS diagnosis long enough to qualify for SSDI and Medicare, for elderly people with HIV, and for Native Americans with HIV.

HCFA approves freedom-of-choice waivers for an initial two-year period, and may grant extensions for additional two-year terms.

## 2. Statutory Requirements Waived and Requirements for Approval

Under Section 1915(b), the Secretary of HHS may waive the following:

- the statewideness requirement so that services provided do not necessarily have to be available throughout the state;
- the requirement that covered services be comparable; and
- the freedom of choice requirement so that states may prohibit beneficiaries from selecting their own Medicaid providers.

In its waiver request, a state must satisfy several documentation requirements. First, it must demonstrate the budget neutrality of the project. HCFA does not require that each waiver proposal meet rigid pre-determined fiscal standards; instead, the agency reviews each waiver request individually. Even with this flexibility, however, states have found it difficult to meet the documentation requirements for budget neutrality. To do so, a state must demonstrate that the costs of the project will not exceed what Medicaid would have paid under the state plan for comparable services furnished to the same beneficiaries in the absence of the waiver. In addition, the state must provide a comparison of Medicaid costs with and without the waiver to predict the impact of the waiver on the state's Medicaid program.

The second documentation requirement is that the state provide assurances that the restrictions established by the waiver will not impair beneficiaries' access to medically necessary services of adequate quality. Third, the state must provide an assurance that restrictions on free choice of providers do not apply to family planning services. Finally, the state must include basic information about its Medicaid program, such as the purpose of the waiver, services to be provided, and types of participating providers. Specifically, the state must specify what Section 1915(b) action it intends to take (e.g., implementing a PCCM system or designating a locality to act as a broker) and, depending on the action to be taken, may have to submit additional information.

### B. Home- and Community-Based Services (HCBS) Waivers

#### 1. In General (*Section 1915(c)*)

States have used home- and community-based services waivers (HCBS waivers, often referred to as Section 1915(c) waivers) to offer services not otherwise directly available under the Medicaid program. Previously unavailable services, such as case management, adult day health care, and hospice care, may help to reduce dependence on nursing facility care, thus maximizing independence for persons with HIV/AIDS on Medicaid and increasing efficiency within the health care system.

HCBS waivers allow states to bypass certain federal requirements that limit the development of Medicaid-financed, community-based treatment alternatives. These waiver programs allow many individuals who might otherwise have been placed in medical facilities to be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher (and often lower) than that of institutional care.

Section 1915(c) lists seven services that may be provided in HCBS waiver programs:

- case management
- homemaker services
- home health aide services
- personal care services
- adult day health care
- basic living skills and vocational training, and
- respite care

States may also request and, subject to HCFA approval, provide at Medicaid's expense other services necessary to enable waiver participants to avoid being placed in a medical facility (such as transportation, in-home support services, meal services, special communication services, minor home modifications, and adult day care). Section 1915(c) waivers give states the flexibility to provide any one or a combination of services authorized by law, and to provide these services in the amount they determine to be necessary.

States may make HCBSs available to beneficiaries who would otherwise need inpatient care in a hospital, nursing facility, or intermediate care facility for the mentally retarded (ICF/MR), which would be reimbursable under the state plan. Traditionally, states have provided services to elderly or disabled persons at risk of needing nursing home care, and to persons with mental retardation and developmental disabilities. States may also target persons with specific illnesses and conditions, such as people with HIV/AIDS or technology-dependent children.

The first HCBS waiver program was established in 1981. Currently more than 200 HCBS waiver programs serve more than 250,000 people. At present fifteen states plus the District of Columbia have elected to use such programs to provide people with HIV/AIDS with cost-effective alternatives to placement in a medical facility and to provide expanded services as optional services through HCBS waiver programs.<sup>3</sup> (See Table 6-1.)

HCBS waiver programs are approved by HCFA for an initial period of three years and may be extended for additional five-year terms. HCBS waiver programs are currently the responsibility of the Center for Medicaid and State Operations' Office of Long-Term Care Services within HCFA. For waivers targeting people living with HIV/AIDS, states may avail themselves of a streamlined application process that eases the states' administrative burdens and speeds up the timing of approval.

**Table 6-1: Home- and Community-Based Waivers Targeted Specifically to Persons with AIDS**

State	Case Management	Skilled Nursing	Respite	Home-Based Services and Attendant Care	Food Services	Foster Care	Other Services
<b>California*</b>	Case Management	Skilled Nursing	Respite	Homemaker; minor home adaptations; attendant care	Home-delivered meals; nutritional supplements; nutritional counseling to individuals with HIV/AIDS or children under 13 with HIV/AIDS with category A, B, or C class	Medi-Cal supplements for infants and foster care children	Psychosocial counseling; special medical equipment and supplies; transportation
<b>Colorado</b>	Case Management	Private-duty nursing		Home health		Hospice and intensive supervision of foster care children with HIV/AIDS	Personal care; adult day care
<b>Delaware*</b>	Case Management	Private-duty nursing	Respite	Homemaker		Intensive supervision and supplemental payments for children and adults in foster care to PWAs and HIV-related disease	Adult medical day care; mental health
<b>District of Columbia*</b>	Case Management		Respite		Home-delivered meals		Personal care
<b>Florida</b>	Case Management	Skilled nursing	Respite	Homemaker; chore services; home-based substance abuse treatment, education, and support to AIDS patients with adult live-in care	Home-delivered meals	Foster care	Personal care; day health care; massage therapy; health assessment; special medical equipment and supplies; physical therapy and respiratory therapy; environmental modifications
<b>Hawaii**</b>		Skilled nursing; Private-duty nursing	Respite	Home maintenance to AIDS/ARC patients	Home-delivered meals		Personal care; EARS; counseling/training; transportation; moving assistance; day health care
<b>Illinois*</b>			Respite	Homemaker; home health; emergency home response system		Foster care supplemental payment	Personal care; environmental modifications
<b>Iowa*</b>		Nursing care	Respite	Homemaker; Home health aide			Counseling
<b>Missouri*</b>		Private-duty nursing					Personal care attendant; supplies; transportation

Source: Health Care Financing Administration

\*Services available to persons with AIDS or HIV.

\*\*Services available to persons with AIDS or AIDS-related complex (ARC).

\*\*\*Services available to individuals with AIDS or children up to age 13 with HIV.

<b>Table 6-1 continued</b>							
<b>State</b>	<b>Case Management</b>	<b>Skilled Nursing</b>	<b>Respite</b>	<b>Home-Based Services and Attendant Care</b>	<b>Food Services</b>	<b>Foster Care</b>	<b>Other Services</b>
<b>New Jersey***</b>	Case Management	Private-duty nursing				Special DYFS Foster care; special group foster care to individuals w/AIDS or children who are HIV positive	Personal care; medical day care; hospice; certain narcotic and drug-abuse treatment
<b>New Mexico*</b>	Case Management	Private-duty nursing		Homemaker/personal care			
<b>North Carolina*</b>	Case Management		Respite	In-home aide; supplies and home mobility aides	Preparation and delivery of meals		Adult day health; personal emergency response system
<b>Pennsylvania*</b>				Extended home health	Nutritional supplements; Nutritional consultation		Specialized medical equipment
<b>South Carolina*</b>	Case Management	Private-duty nursing		In-home counseling; home management; attendant care			Personal care aide; environmental access adaptations; medical supplies (nutritional supplements; diapers/pads); extended prescription drugs
<b>Virginia*</b>	Case Management	Skilled nursing; Private-duty nursing	Respite		Nutritional supplements		Personal care
<b>Washington</b>		Skilled nursing; Private-duty nursing	Respite	Assisted living to people with HIV/AIDS disabling condition	Home-delivered meals; nutrition counseling		Psychological counseling; transportation; adult day health care

Source: Health Care Financing Administration

\*Services available to persons with AIDS or HIV.

\*\*Services available to persons with AIDS or AIDS-related complex (ARC).

\*\*\*Services available to individuals with AIDS or children up to age 13 with HIV.

## 2. Boarder Baby Waivers (*Section 1915(e)*)

In 1988, Congress established another HCBS waiver program targeted at so-called boarder babies—children under age five who are infected with HIV or are drug-dependent at birth, and who may remain in hospitals indefinitely because of difficulties finding foster placement in the community. This waiver program, embodied in Section 1915(e) of the Medicaid law, covers children who are receiving or are expected to receive federally funded adoption or foster care assistance. A state may use this waiver program to provide nursing care, physician services, respite care, prescription drugs, medical devices and supplies, transportation, or any other services requested by the state and approved by the Secretary of HHS.

To date, HCFA has not approved any Section 1915(e) waivers for states seeking to provide services to boarder babies. Instead, states have used Section 1915(c) to cover these children. States may have decided to use the latter authority to allow for the possibility that the natural parents want to resume custody of their children in the future, in which case the children would no longer be eligible for foster assistance and would not be covered under a Section 1915(e) waiver.

## 3. Statutory Requirements Waived and Requirements for Approval

Under Section 1915(c) and (e) of the Social Security Act, the Secretary of HHS may waive the Medicaid statewideness requirement so that states may cover HCBS care in only a portion of the state, rather than in the entire state. The Secretary may also waive the requirement that covered services be comparable for all categorically needy Medicaid beneficiaries in particular eligibility groups. This allows states to limit coverage of HCBS care to certain specified individuals. Finally, the Secretary may permit states to waive some of the restrictive financial eligibility standards that apply to persons living in the community and, instead, to use the somewhat more liberal financial standards used for persons needing institutional care for the designated individuals covered by the waiver.<sup>4</sup>

These waiver programs require prior approval; they do not provide general authority for states to provide HCBS care as mandatory or optional services for which federal Medicaid matching funds are available. Rather, states must make special applications to the Secretary, who must review and approve the programs before HCBSs become eligible for federal matching payments. The state must make a number of assurances before HCFA will grant the waiver.

First, a state must demonstrate budget neutrality—that is, that the estimated average per capita expenditures for persons receiving HCBS waivers will not exceed the cost of care that such individuals would have incurred in the absence of a waiver. Second, a state must provide assurances that there will be safeguards in place to protect the health and welfare of the beneficiaries, and that the state Medicaid agency will be able to evaluate and

determine potential waiver participants' need for institutional care. Finally, individuals determined to be eligible for community-based services must be given a choice of waiver services or institutional care.

### **C. Public Participation in the Waiver Process**

Waivers are deemed granted unless the Secretary denies the request within 90 days or requests additional information within 90 days of the application date. HCFA is required to monitor the implementation of approved waivers to ensure that waiver requirements are satisfied. Violations of these requirements can result in termination of the waiver.

A state's waiver request must be submitted to HCFA by the governor, the head of the state Medicaid agency or an authorized designee, or the state cabinet members responsible for state Medicaid agency activities. Therefore, the primary opportunities for public participation will be at the state level. State officials should be able to provide interested parties with information about potential waivers or pending applications. While HCFA cannot require public notification of Section 1915(b) or (c) waivers, the agency strongly encourages states that are considering applying for a waiver to allow public input through public meetings or other forms of notification.

## **IV. Research and Demonstration Waivers (*Section 1115*)**

The research and demonstration authority provided by Section 1115 is a far-reaching tool that allows states to experiment with how their Medicaid programs cover and deliver acute care services by sidestepping many of the usual Medicaid requirements. In return for this greater flexibility, states must agree to have such policies and procedures formally evaluated.

Research and demonstration waivers are increasingly being used to enact a broad variety of changes at the state level, ranging from small-scale pilot projects testing new benefits and financing mechanisms to major restructuring of state Medicaid programs. States also used Section 1115 waivers for welfare reform projects, but following the enactment of the Welfare Act of 1996 such a waiver is now redundant. A number of states are still operating the programs they ran under their prior Section 1115 waivers, but are now doing so under a TANF block grant created by that Act.

### **A. Types of Demonstration Waiver Projects**

Although each waiver program is state-specific, the demonstration programs that have been approved share common themes. Many states use Section 1115 waivers to establish pre-determined, per capita payments in the context of a managed care plan in place of the traditional fee-for-service method of paying for hospital, physician, and other acute care services. Such a program pays the plan a fixed amount for each beneficiary enrolled. These programs restrict the beneficiaries' choice of providers to those who contract with the plan, but allow beneficiaries to choose among plans.

Some states use Section 1115 waivers to modify eligibility standards to expand coverage to certain low-income uninsured populations. It is estimated that, of the 5.5 million beneficiaries currently enrolled in Section 1115

demonstration projects, more than 2 million would not be eligible for Medicaid under current general federal standards.<sup>5</sup>

A third common use of the Section 1115 waiver authority is to enable the state to maintain levels of federal matching funds for payments to hospitals that serve a disproportionate number of low-income patients with special needs (disproportionate share hospitals or DSHs), but to redirect these funds away from the DSHs and toward other aspects of the demonstration project, such as coverage of previously ineligible individuals.

Section 1115 waivers have been used to establish capitated programs such as the statewide Arizona Health Care Cost Containment System and the Minnesota Prepaid Medicaid Demonstration Project, both of which were launched in 1982 and remain in operation today. Currently, eighteen states have received approval for statewide health reform projects under Section 1115 waivers, and another nine states and the District of Columbia are developing such projects.

*As of June 1997, the states operating comprehensive health care reform demonstration projects are: Alabama, Arizona, Colorado, Delaware, District of Columbia, Hawaii, Minnesota, Ohio, Oklahoma, Oregon, Rhode Island, Tennessee, and Vermont.*<sup>6</sup>

## **B. Statutory Requirements Waived and Requirements for Approval**

The Section 1115 waiver provision permits a state, subject to HCFA approval, to waive broad requirements of the Medicaid program (and indeed other parts of the Social Security Act) if such a waiver is likely to assist in promoting the objectives of the program. Because of this broad and flexible standard, states have been able to revise substantially their Medicaid programs by obtaining Section 1115 waivers.

Section 1115 waivers have been particularly important to states in the managed care context. Before the passage of the Balanced Budget Act of 1997, states had to obtain a waiver to initiate Medicaid-only managed care programs. For example, the 75/25 rule prohibited states from contracting with managed care plans whose public enrollment (i.e., Medicaid and Medicare beneficiaries) constituted more than 75% of the total enrollment. In addition, federal law gave Medicaid beneficiaries the option to disenroll from a plan without cause after the first 30 days of membership. Although these requirements protected Medicaid beneficiaries from poor-quality care and denial of services, they also prevented states from experimenting with new health care delivery systems, including managed care programs to serve Medicaid beneficiaries. Other statutory requirements that could be waived under Section 1115 included the federal standards for managed care entities and the freedom-of-choice provisions for family planning services.<sup>7</sup>

Although research and demonstration waivers are quite broad, a state does not qualify for such a waiver simply by meeting established criteria, as it does to qualify for Section 1915(b) and Section 1915(c) waivers. HCFA scrutinizes research and demonstration waivers more carefully; therefore,

they are more difficult to obtain. Because such waivers are intended for research purposes, projects must usually include a formal research or experimental methodology and provide for an independent evaluation.

In addition to illustrating a proposed program's research value, states must assure the Secretary that the demonstration program will be budget-neutral. Specifically, such programs, even if they expand coverage to include individuals who would otherwise not be eligible, cannot cost more than the Medicaid program would have spent in that time.

Traditionally, HCFA has been reluctant to waive Medicaid provisions that restrict a state's ability to charge Medicaid beneficiaries premiums. HCFA has been equally reluctant to waive the requirement that MCOs demonstrate an acceptable level of solvency.

Research and demonstration waiver authority is normally granted for a period of up to five years. States are allowed to extend their Section 1115 demonstration waivers through an expedited process for up to three years. In fact, states may have an incentive to do so: states continuing the use of MCOs through demonstrations are exempt from the new consumer protection requirements established by the Balanced Budget Act of 1997.

### **C. Public Participation in the Waiver Process**

Before obtaining a Section 1115 waiver, a state must have its proposal approved by HCFA. In 1993, the Clinton administration expressed a willingness to approve mandatory Medicaid managed care programs and directed the Secretary of HHS to revise substantially the Department's approval process for Section 1115 waivers. As a result, HHS streamlined its policies for evaluating state waiver requests.

First, HCFA will provide guidance to states prior to submission of an application. Once a state decides it is going to pursue a waiver, it may submit a concept paper to HCFA. HCFA encourages states to include, as part of this concept paper, a process for public involvement and input in the development of the proposed demonstration project. The agency will accept any process of public comment that includes public hearings; uses a commission or similar process; results from enactment by the state legislature; provides formal notice and comment; publishes a notice of intent to submit demonstration proposals in newspapers; or includes another similar process that allows for public input in the decision-making process prior to the time an application is submitted. HCFA will notify the state within 15 days whether its public participation procedure is adequate.

States are not required to submit their public participation procedures before submitting their formal waiver proposals. However, HCFA publishes new and pending Section 1115 proposals each month in the Federal Register. The agency does not act on a waiver application for 30 days following submission of the proposal. During this time, interested parties have the opportunity to comment on the proposed demonstration project. In addition, if HCFA finds that a state public participation process was inadequate, the state is required to post a notice in a general circulation newspaper describing the proposal and how parties can comment. In this circumstance, the comment period is limited to 30 days. An organization can request that HCFA notify it when a waiver proposal has been received, prior to publication of the proposal in the Federal Register.

Finally, once a demonstration waiver is granted, HCFA may engage in periodic evaluations of the program. The agency has the authority to review and investigate documented complaints that the state is failing to comply with the terms and conditions of the waiver. Advocates should monitor the state's compliance with these requirements and report to HCFA when the state fails to fulfill its responsibilities. Furthermore, many Section 1115 programs also have external evaluators who can be useful sources of information while working on an evaluation.

## V. Waiver Process at the Federal Level

Waivers are deemed granted unless the Secretary denies the request within 90 days or requests additional information within 90 days of the application date. Freedom-of-choice waivers are currently approved for two-year periods and may be renewed at two-year intervals. HCFA is required to monitor the implementation of approved waivers to ensure that waiver requirements are satisfied. Violations of these requirements can result in termination of the waiver.

- 1 This chapter is derived in part from more extensive discussions of the waiver programs contained in Medicaid Waivers (July 12, 1996), a publication of the Health Care Financing Administration; Medicaid Source Book: Background and Analysis (1993 update), a publication of the U.S. House of Representatives prepared by the Congressional Research Service; and Kaiser Commission on the Future of Medicaid, Policy Brief: Restructuring Medicaid: Key Elements and Issues in Section 1115 Demonstration Waivers (May 1997).
- 2 "In contrast to fee-for-service care-where the incentive is to oversupply services to increase revenues-capitated managed care, with its fixed payment system, contains incentives to provide fewer services to maximize short-term profits." GAO, Medicaid Managed Care: Challenge of Holding Plans Accountable Requires Greater State Effort, (May 1997), p. 7. See also Chapter 5 on managed care.
- 3 Department of Health and Human Service, Medicaid Bureau, "Fact Sheet" (June 1996).
- 4 Generally, the income of a person living in the community will be deemed to include the income and resources of the person's spouse. By contrast, after the first month of institutionalization, only the individual's own income and resources are considered for purposes of eligibility.
- 5 HCFA. "1997 Medicaid Managed Care Enrollment Report." (March 1998).
- 6 HCFA, "States with Comprehensive Statewide Health Care Reform Demonstrations" (June 30, 1997), <http://www.hcfa.gov/medicaid/1115dm97.html>.
- 7 As noted in the introduction, the Balanced Budget Act of 1997 eliminated the federal review process for large portions of Medicaid beneficiaries and, as a result, Medicaid now permits states to enroll most beneficiaries in "Medicaid-only" managed care plans without seeking a waiver of federal requirements. However, states must still seek Section 1115 waivers of federal requirements to enroll children with special needs, Medicare beneficiaries, and Native Americans in managed care plans.



CHAPTER 7:  
ENFORCEMENT  
MECHANISMS  
FOR MEDICAID

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# CHAPTER 7

## ENFORCEMENT MECHANISMS FOR MEDICAID

### I. Overview

The Medicaid program is a voluntary, cooperative federal-state partnership in which states agree to pay for health care services to certain groups of low-income persons in exchange for federal matching funds. If a state fails to cover a Medicaid-required service or to interpret a policy consistently with federal law, individual beneficiaries and service providers have several possible remedies, including obtaining a hearing before a state agency and bringing suit in federal court.

### II. Medicaid Fair Hearing

Federal law provides that a Medicaid beneficiary who has been denied a service is entitled to a fair hearing. Each state must provide for either (a) a hearing before the state Medicaid agency or (b) an evidentiary hearing at the local level, with a right of appeal to the state agency.

The state's hearing system need not be in the form of a judicial or quasi-judicial trial, but it must provide the Medicaid beneficiary with a full administrative review. Due process requires that the hearing be at a reasonable time, date, and place; that the beneficiary have timely and adequate notice describing the reason for the denial of benefits; and that the beneficiary have the opportunity to question adverse witnesses and present orally his or her own evidence and arguments.

In most states, the agency's final determination may be appealed in state court. The appeal rate, however, is very low; typically, fewer than 5% of fair hearings are appealed.<sup>1</sup> If appealed, the state attorney general usually provides representation for the agency. Although two states<sup>2</sup> have expressed concern that the right to appeal creates an unreasonable burden for their Medicaid agencies, most regard the ability to appeal as a right of due process and treat appeals as an alert to their agencies of potential problems and a need to clarify interpretations of law.

### **III. Managed Care Programs and Enforcement**

#### **A. Internal Grievance Procedures**

The Balanced Budget Act of 1997 requires Medicaid managed care organizations (MCOs) to establish internal grievance procedures. Although in the past federal law imposed a requirement that risk contractors provide for prompt resolution of grievances, it is unclear exactly what type of grievance mechanisms will satisfy the new federal provisions. Whatever form the grievance procedures take, however, they must allow Medicaid beneficiaries or their health care providers to challenge the failure of an MCO to cover a certain service or provide appropriate medical assistance. As states use their new authority to enroll Medicaid beneficiaries in mandatory managed care, grievance procedures may evolve to address the most significant beneficiary concerns. However, because more federal guarantees have been removed, it is more likely that grievance procedures will be an issue of contention.

#### **B. State Enforcement Mechanisms**

The Balanced Budget Act of 1997 also grants states the authority to levy intermediate sanctions against MCOs that fail to provide the medically necessary items and services guaranteed under their contracts with states. These intermediate sanctions include suspension of new enrollment; suspension of capitation payments; imposition of civil money penalties; and permission for beneficiaries to disenroll without cause. Although the sanctions are clearly spelled out in the statute, it is less obvious what level or degree of violation will trigger state action against an MCO. Presumably, each state will monitor each MCO's performance and penalize MCOs with poor quality of care, but no federal statutory standard triggers these penalties. In addition to the intermediate penalties, states may terminate a managed care contract as long as the MCO has received notice of the termination and a hearing.

### **IV. HCFA Enforcement Mechanisms**

HCFA may use several mechanisms to ensure state compliance with federal Medicaid requirements, including disallowance and compliance actions. (These actions are not common and may be very political in nature.)

#### **A. Disallowance Actions**

The method generally chosen to address a state's noncompliance with federal requirements is the disallowance action, pursuant to which HCFA retrospectively disallows (or retracts) federal matching payments for state expenditures that do not meet federal guidelines. Typically, disallowance actions are brought against a state for specific misspent amounts. Thus, these actions are not necessarily indicative of a systemic problem in the state's application of Medicaid law. The HHS Inspector General is responsible for conducting audits of state expenditures, which may reveal improper payments subject to disallowance actions.

## B. Compliance Actions

While disallowance actions apply retrospectively to misspent funds, compliance actions are meant to produce the changes necessary to bring a state's actions under Medicaid into line with federal requirements. In a compliance action, HCFA may withhold federal funds, in whole or in part, if it determines that the state plan, or the administration of a portion of the plan, no longer complies with federal requirements. Thus, compliance actions strive to change a state's general application of Medicaid law and, consequently, involve broader policy issues than most disallowance actions.

Compliance actions are pursued through a lengthy, multi-stage process, designed to encourage states to meet federal requirements. The first stage involves an informal notice to the state that it is not complying with Medicaid law. If the state does not demonstrate a good faith effort to achieve compliance, the regional HCFA office puts it on a compliance report. Subsequent stages involve a conference between the Center for Medicaid and State Operations and the state agency, which may be followed by a recommendation by the Center Director to the HCFA administrator for an administrative hearing.

The pace of this process is deliberately slow in order to provide states with an opportunity to come into compliance. Termination of a state's federal funding for its program as a whole, or that portion of the program found not to be in compliance, is the theoretical ultimate result of the compliance process. However, no state has ever had its entire funding withheld as a result of this process.

## V. Private Right of Action

An individual may also enforce the federal guarantees of Medicaid by bringing a lawsuit against a state in federal court. This accountability mechanism—a private right of action—is not created by the Medicaid statute itself, but, rather, is found in another federal statute—42 U.S.C. Section 1983. This provision states that an individual who has been deprived of a federal right by someone acting on behalf of a state may bring an action in court to enforce that right.<sup>3</sup>

Essentially, Section 1983 is a general enforcement mechanism that prohibits anyone acting on behalf of a State from depriving an individual of any rights guaranteed in any federal law, which includes the guarantees set forth in the Medicaid program. Parties bringing Section 1983 claims may sue in federal or state court, and have a full range of legal and equitable remedies available to them.

### A. Scope of Section 1983 Claims

For an individual to use the Section 1983 enforcement mechanism, Congress must have created a substantive right that can be judicially enforced. Although there have been several elaborate arguments about whether a statute sets forth a substantive right, the issue was clarified in 1990 when the Supreme Court decided *Wilder v. Virginia Hospital Association*.<sup>4</sup> In that case, the Court set forth three questions for analyzing

whether a statutory right may be judicially enforced (see Table 7-1). Using this test, courts have determined that the Medicaid statute provides a host of judicially enforceable rights.

### **B. Cases Interpreting the Enforcement Provision**

The private right of action is merely an enforcement mechanism, not a substantive right itself. The substantive right is identified first by Congress, and then, if necessary, recognized judicially. The current Medicaid statute contains several substantive rights that may be, and have been, enforced through Section 1983 claims. These include the right to an adequate amount, duration, and scope of medical treatment; the right to all medically necessary treatment within the states' benefits packages; and the right of reasonable reimbursement to providers. Many cases have been settled out of court because plaintiffs withdraw their actions after defendants, faced with the prospect of litigation, correct their behavior. (Appendix E lists some of the cases recognizing substantive rights within the Medicaid program.)

**Table 7-1: *Wilder v. Virginia Hospital Association* Test to Determine Whether a Statutory Right May Be Judicially Enforced**

**1. *Is the provision in question intended to benefit the plaintiff?***

Courts have broadly construed the Medicaid provisions of the Social Security Act to allow claims by a wide variety of plaintiffs, including beneficiaries, providers, associations representing beneficiaries and/or providers, and any combination of the above.

**2. *Does the provision create binding obligations on the state (or other governmental unit), rather than merely expressing a congressional preference?***

Courts typically find that the Medicaid provisions are mandatory, and that they must meet the “binding obligations” test. Although courts have found that the Medicaid statute as a whole creates binding obligations on states (and other governmental entities), courts also separately analyze each provision alleged to have been violated. Plaintiffs typically bring claims alleging that several provisions of the Medicaid statute have been violated by a state, rather than one provision.

**3. *Is the interest the plaintiff asserts specific enough to be enforced judicially, rather than being “vague and amorphous?”***

Claims brought under Section 1983 typically meet this part of the test. Even provisions of the Medicaid statute that merely require “reasonableness” or “reasonable efforts” have been construed as specific enough to be enforced by courts.

### C. Section 1983 and HIV/AIDS

For people with HIV/AIDS, the Section 1983 enforcement mechanism has been essential in obtaining necessary treatment under Medicaid. Perhaps the most influential case for people infected with HIV is *Weaver v. Reagan*, 886 F.2d 194 (8th Cir. 1989). That case challenged a rule promulgated by the Missouri Department of Social Services that limited Medicaid coverage for zidovudine (AZT) to only those individuals with specific medical conditions. To be eligible to receive AZT under Missouri's program, the Medicaid beneficiary needed a diagnosis of AIDS, and either a history of *Pneumocystis carinii pneumonia* (PCP) or a T-cell count of less than 200. The appellate court ruled that Missouri's Medicaid plan could not deny AZT coverage to AIDS patients who are eligible for Medicaid and whose physicians determine that AZT is a medically necessary treatment.

### D. Potential Changes to the Enforcement System

The private right of action provided by Section 1983 is among several provisions in the Medicaid debate that many have sought to have repealed. (Chapter 9 discusses these efforts in more detail.) According to some critics, this private right of action inappropriately allows judges, who may be unconnected from the fiscal realities of state finance, to decide what is reasonable.

Supporters of Section 1983 argue that, if the private right of action is eliminated as a result of Medicaid legislative change, beneficiaries and providers will not be able to hold states accountable for complying with their federal obligations under the Medicaid program. In other words, even if Congress mandates that Medicaid beneficiaries should have certain substantive rights, the removal of a private right of action would effectively eliminate those guarantees. They also argue that it is appropriate to have decision-makers who may be unconnected with state finance in order to provide a forum without conflicts of interest.

- 1 However, in some states the appeal rate can be quite high. For example, there is a 20% appeal rate in Tennessee.
- 2 The states that have expressed concerns are New Jersey (which concedes that judicial review acts as a quality control policy and regulator) and Minnesota (which believes the right to appeal has an adverse impact on the agency).
- 3 Although Section 1983 was originally intended to address the constitutional problems of states discriminating against African-Americans, the Supreme Court, in 1980, officially recognized that Section 1983 also provides the authority for suit against anyone acting on behalf of a state or local government who infringes on federal statutory rights.
- 4 *Wilder v. Virginia Hospital Association*, 496 U.S. 498 (1990).



CHAPTER 8:  
STATE AND LOCAL  
ADVOCACY

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# CHAPTER 8

## STATE AND LOCAL ADVOCACY

### I. Overview

Traditionally, state and local advocacy initiatives to affect Medicaid programs were directed at federal policymakers. However, the Balanced Budget Act of 1997 added significantly to the states' ability to require enrollment in managed care, leaving the federal government with less direct control over implementation of the Medicaid program. As more and more states opt to implement Medicaid managed care programs in place of the traditional fee-for-service system, advocates working to influence Medicaid policy need to reevaluate their strategies. This is not to say that there is no longer a role for federal advocacy. Particularly in those states already operating large waiver programs, HCFA and the Inspector General of HHS will play significant roles in oversight and renewal. State and local advocates should work with their counterparts in Washington, D.C. to develop working relationships with these agencies.

While community organizing, lobbying, and media advocacy directed toward Washington are still essential tools for people concerned with HIV/AIDS, it is also important to consider new ways to work with states to ensure that Medicaid managed care programs are responsive to the needs of beneficiaries with HIV/AIDS. Although there are ways to influence state policy and managed care programs by working at the federal level, much of the important and meaningful advocacy work will take place in each individual state. This chapter is intended to help state and local advocates in the development of effective strategies to shape Medicaid law and enforce its terms.

### II. Developing State Managed Care Plans

With the advent of the managed care system, states are playing a new role in the delivery of health care. Unlike fee-for-service programs, where the state is the primary insurer and, as such, is often at odds with its beneficiaries, managed care programs put the state in the position of both purchaser and consumer. In these roles, the state has an interest in getting full value for its money and gathering as much information as it can about the performance of its service providers. If a state implements a managed care program, advocates may need to go beyond the role of watchdog at the state

level and participate in the negotiating process between the state and the providers. By working with the state, advocates can help set the terms of contracts with service providers and alert state officials to lapses in service to beneficiaries.

It is particularly important for advocates to be involved in managed care contract negotiations in light of the Balanced Budget Act of 1997 provision that allows states to limit the number of contracting managed care organizations (MCOs). Under the previous system, numerous MCOs submitted bids to the state Medicaid agency, and the state awarded contracts to any company that met the federal requirements. With several MCOs providing Medicaid benefits, beneficiaries could choose from a range of quality of care and accessible services. Now, after enactment of the Balanced Budget Act of 1997, states may limit managed care contract awards to two MCOs in each urban area and one MCO in each rural area. Under this new system, state agencies will have the power to bestow lucrative managed care contracts on a few companies. As a result, instead of competing for beneficiaries through high-quality services, MCOs may be lobbying for the attention of state legislators and state Medicaid agencies.

However, state government's interests do not always parallel those of Medicaid beneficiaries. States also have an interest in limiting their own financial and litigation exposure and in shifting the politically difficult tasks of making rationing decisions away from state officials to others, including MCOs.

Any number of factors will influence the final outcome of the contract award: amount of the bid, quality of services, or, in the worst case, an MCO's access to state decision makers. Whatever the mix, however, advocates should participate in the negotiations to keep the contracting process open and honest and to guarantee that a broad range of services for people with HIV/AIDS are included in the contract.<sup>1</sup> (The contracting process and incentives are discussed in Chapter 5.)

Opportunities for public input into managed care contracts vary from state to state. Some states, like Ohio, incorporate many of the specific details of their program into administrative rules, and advocates have an opportunity to participate in formal notice and comment procedures. Others, like Washington and Wisconsin, solicit suggestions from advocates, plans, providers, and other state agencies through focus groups, community oversight committees, and written comments. But advocates should be aware that these procedures will change as states use their new authority to implement mandatory managed care under the Balanced Budget Act of 1997.

Before approaching the state, advocates should be prepared to do the following:

- Find out whom you should talk to. Each managed care program is different; do not assume the state Medicaid official is your best contact. Some states hire contract managers to oversee individual service providers while others have adopted an ombudsman system. Identify the contract managers or agencies responsible for HIV/AIDS issues and funding. Consider where your input will have the most impact. (Appendix D contains a list of state Medicaid contacts.)

- Participate in building relationships. Most states do not have a formal public process for arriving at the terms of contracts. Advocates must get inside the state agency and develop relationships with the individuals who negotiate the contracts and enforce their terms. By educating the contract negotiators about the needs of people living with HIV/AIDS, including cutting-edge technologies and new diagnostics and drug treatments, advocates help the state become a more informed purchaser and consumer, better able to negotiate appropriate services and treatments.
- Provide professional assistance. Some state lawyers and contract negotiators have little experience in the legal and business aspects of managed care. Advocates must share their own expertise.
- Document your concerns. Bring real cases to the attention of the state agency, instead of relating informal anecdotes or hypotheticals. By resolving real cases, states can set precedents and develop models that will settle future disputes.
- Come up with solutions and be ready to engage in discussion. Many states are developing or refining their managed care programs, and there is much room for creative thinking. For example, HIV/AIDS advocates and managed care providers might lobby the state jointly to provide reasonable capitation rates to managed care providers so they are not discouraged from offering comprehensive services to people living with HIV/AIDS.

As states assume more control over managed care systems, advocates can no longer rely simply on tough federal regulation. In the managed care world, the devil is in the details of each service provider contract because these documents define the services and drugs that will be readily available to people living with HIV/AIDS. If advocates strike a position of pure opposition to the state officials who are negotiating the contracts, they may be excluded from the process and lose services for their communities.

### **III. Monitoring Contract Implementation**

Once the managed care contract is in place, local advocates need to focus on their more traditional roles as community educators, watchdogs, and consumer advocates. If a state contracts with an MCO, it is not relieved of its obligation to provide the full range of services required under Medicaid. A state cannot contract away its responsibilities under federal law. Advocates need to make sure that the services they worked to include in a managed care contract are actually being delivered to beneficiaries with HIV/AIDS in an appropriate and safe manner. If a contract fails to include necessary services, advocates should expose the failure of the state to fulfill its responsibilities under federal law.

One challenge is to uncover instances in which MCOs deny services guaranteed under the contract. The law provides some consumer protection for Medicaid beneficiaries, but to realize the full benefit of federal protections, beneficiaries need to be active participants in their health care program. For example, under the Balanced Budget Act of 1997, managed care contracts between the state Medicaid agencies and the MCOs must specify what services the MCO will provide to beneficiaries. To find out whether all of the services available under the contract are actually being delivered, a Medicaid beneficiary may, upon request, obtain a list of the services for which an MCO is responsible. The law does not impose a burden on the MCO to disclose publicly the services it will provide people with HIV/AIDS (e.g., a poster in a hospital waiting room or an announcement through the mail); instead, it places the burden on the beneficiary to request the document.

This type of disclosure requirement will be an effective mechanism for exposing poor quality of care only if beneficiaries know to ask for the document and know what services to look for. People with HIV/AIDS rely on complex and rapidly changing treatments, including various drugs and physical therapies. Even with a list of services, beneficiaries might not know they are being denied available treatment. Advocates will have to work closely with beneficiaries to guarantee that people with HIV/AIDS are receiving all of the services specified in the contract.

Another way to monitor quality of care is to analyze the performance reviews of each MCO providing health care to Medicaid beneficiaries. The Balanced Budget Act of 1997 requires states to develop strategies for quality assessment, including standards for access to care, procedures for monitoring quality assurance, and a system for collecting data from the managed care entities. In addition, according to both the Act and pre-existing federal law, each MCO contracting with a state must undergo an annual review of its quality of care by an independent agency. HHS will soon issue federal protocols for quality of care that will provide a uniform standard for the states' performance review. (It is unclear whether the pre-existing federal review requirement will continue to apply after the standard is published.) There are, however, several ways states can exempt MCOs from this review requirement. When exemptions do occur, advocates can look to annual performance reviews and other data collected by the state to publicly expose areas where MCOs fail to meet the terms of the contract or the federal standard for quality of care.<sup>2</sup> However, an important source of information may be lost if MCOs are exempted from the review requirements.

#### **IV. Using Grievance Procedures**

Finally, advocates can challenge a state's Medicaid program on a case-by-case basis by using one of the enforcement mechanisms outlined in Chapter 7. In the past, there was no federal requirement that MCOs establish grievance procedures for Medicaid beneficiaries. The Balanced Budget Act of 1997, however, requires MCOs to establish effective procedures for hearing and resolving grievances with beneficiaries enrolled in the program. Either eligible beneficiaries or their service providers can bring a claim challenging the denial of medical assistance. Even if an MCO does not contract

for a service or denies a claim in the internal grievance process, the state continues to have an obligation to provide medically necessary services to Medicaid beneficiaries under federal law. In addition to establishing internal grievance procedures, the Balanced Budget Act of 1997 retains the fair hearing requirements discussed in Chapter 7.

## V. Participating in the Federal Waiver Process

Despite the recent expansion of state authority, in some instances the waiver process remains relevant to advocacy efforts. First, states are bound to meet the terms of the waivers that are currently in place. Some of these waivers have important provisions for people with HIV/AIDS (such as the availability of specialty services or the effectiveness of grievance procedures).

Second, states may apply for demonstration waivers of Medicaid requirements instead of relying on their new authority to enroll beneficiaries in managed care. Section 1115 waivers continue to provide states the opportunity to waive any federal Medicaid requirement, including eligibility requirements and capitation rates.

Finally, because of certain provisions of the Balanced Budget Act of 1997, states must seek a waiver of federal requirements to enroll children with special needs in a mandatory managed care program. As a result, children who are eligible for Supplemental Security Income or who are in foster care or adoption assistance cannot be forced into a managed care program unless the state has gone through the federal waiver process.

Given that states will continue to have the opportunity and incentive to apply for waivers of federal requirements, advocates should continue to use available administrative procedures to encourage HCFA and the state to include meaningful quality-of-care standards in the waivers and enforce those standards through rigorous federal and state oversight. (See Chapter 6 for an explanation of the waiver process and the opportunities for public input.)

If advocates communicate their concerns to HCFA early in the waiver application process, the agency will have a greater opportunity to present these issues to the states as they negotiate the terms and conditions of the waivers. For example, in New York, the city planned to require 25,000 HIV-positive AFDC recipients to enroll in managed care programs. A study by the Housing Works Women's Advocacy Group showed that 95% of New York's Medicaid MCOs could not refer these individuals to a primary care physician with experience treating HIV. Through their organizing, lobbying, and media efforts, advocates convinced HCFA to delay approval of New York State's waiver until the state could demonstrate that the MCOs would provide accessible and high-quality care for HIV-positive Medicaid beneficiaries.

- 1 The Balanced Budget Act of 1997 also requires the states to implement conflict-of-interest safeguards that would apply to state officers and employees responsible for managed care contracts. These safeguards must be as effective as the federal standards found in Section 27 of the Office of Procurement Policy Act.
- 2 In Florida, investigative journalists from the Sun Sentinel effectively exposed weaknesses in the state's Medicaid managed care program by poring over thousands of reports of Medicaid HMO patient care. For example, of the 29 Medicaid HMOs in the state, 40% could not assure the state's review board that they had provided basic medical services to their beneficiaries. See Schulte, Fred & Bergal, Jenni, "Medicaid Cost Makes Managed Care the Only Option," Sun Sentinel, November 29, 1995, A1.



CHAPTER 9:  
FUTURE CHALLENGES  
FOR PEOPLE WITH  
HIV/AIDS ON MEDICAID

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# CHAPTER 9

## FUTURE CHALLENGES FOR PEOPLE WITH HIV/AIDS ON MEDICAID

### I. Overview

The Welfare Act of 1996, the Immigration Control and Financial Responsibility Act of 1996, and the Balanced Budget Act of 1997 made far-reaching and significant legislative changes to the Medicaid program, many of which have not yet been implemented. Many of the core protections of the program still remain, but much is in flux.

Also waiting in the wings are a number of other problems and proposals. Some are issues for all Medicaid beneficiaries and providers. Some arise only in the context of HIV/AIDS or disability and chronic illness. This chapter briefly describes some of the issues and highlights opportunities for those concerned about health care for low-income individuals with HIV/AIDS.

Each of these issues is controversial, as Medicaid law is pulled back and forth between those wishing to retain an individual entitlement that applies regardless of the state in which an individual lives and those desiring a state-defined, state-administered system. As people live longer with HIV/AIDS because of successful treatment, and as the demographic groups hard hit by the epidemic change and broaden, the health needs of the epidemic that must be financed will also change. To protect these individuals, the goal of advocates should be not merely to defend Medicaid as it currently exists against attack, but, instead, to improve the program and increase the protection and services it affords.

## **II. Eligibility Issues**

### **A. Eligibility of Non-Disabled HIV-Positive Individuals**

The most obvious issue is actually not new, but is one with which many HIV/AIDS advocates are very familiar. Unless a person with HIV is eligible for welfare or SSI, or is a pregnant woman or a child, he or she is not categorically eligible for Medicaid, no matter how low-income the individual may be. Since most people with HIV have been and are childless adults, eligibility has been often narrowed to those who are totally disabled. HIV infection that is not accompanied by one of the AIDS-defining conditions is not sufficient to qualify for Medicaid.

This has been a Catch-22 for people with HIV since the first recommendation for preventive care in the late 1980s. The paradox is essentially this: There are drugs to prevent pneumonia, the most common AIDS-defining illness among people with HIV. With a few exceptions, the only childless adults who are eligible for Medicaid assistance in purchasing the drug (and accompanying care) are those people who have already contracted pneumonia.

This problem has become even more profound with the advent of the triple drug combinations that include protease inhibitors. These drugs are often recommended for use before a person develops full-blown AIDS, but (again, with a few exceptions) the only childless adults who are eligible for Medicaid are those who already have AIDS. Since these drugs and the medical services that must accompany them are quite expensive, this paradox bars many low-income people with HIV from receiving the benefits of these innovative therapies.

Several bills have been introduced in Congress since 1990 to end this paradox and allow Medicaid eligibility for people with immune dysfunction sufficiently severe that it requires treatment. None of the bills has passed.

In April 1997, Vice President Gore announced that he was directing HCFA to develop a plan within 30 days to make it possible for low-income people with HIV to get Medicaid assistance to purchase these new therapies. At the end of 1997, HHS announced that it was no longer pursuing such a plan. Some smaller-scale alternatives are still under discussion.

### **B. Eligible Beneficiaries**

As discussed in Chapter 2, the Medicaid program requires states to provide coverage for certain populations, and permits states to cover additional populations. Some proposals for Medicaid change would eliminate the federal standards for mandatory eligibility for specified categories of individuals who are currently covered. For example, SSI-eligible individuals and low-income families have been identified as groups of current beneficiaries that could be removed from the mandatory eligibility list. Under such proposals, a state, at its option, could provide coverage for individuals in these previously mandatory groups, but it would not be required to do so.

### **C. Definition of Disability**

Under current law, the Social Security Administration (SSA) determines the federal definition of disability,<sup>1</sup> which is, in turn, generally used for determination of categorical eligibility for Medicaid (with the exception of the twelve 209(b) states discussed in Chapter 2). A proposal to allow states to establish their own definitions of disability for purposes of Medicaid has been passed as part of larger legislation in recent years but has never been enacted into law. This proposal would go beyond allowing states to use their eligibility standards from 1972 (the 209(b) option) and would permit them to create their own standards without ties to past laws.

Such a proposal would have serious implications for people with HIV/AIDS. If a state is allowed to decide whether to retain the SSA or 1972 definition or to create its own definition, some people who currently qualify as disabled might not meet a more restrictive state definition and, therefore, would lose eligibility. In short, states could decide that a certain diagnosis does not qualify a person as disabled. (Some have suggested that, if given the discretion, states might expand eligibility for disabled persons. Inasmuch as the authors of this proposal and the Congressional Budget Office predicted the proposal would cut billions of dollars in Medicaid spending, this does not seem likely.)

This prospect is particularly troubling as it applies to AIDS. Crafting a definition of AIDS for purposes of SSI has been a painstaking and difficult effort. For instance, only relatively recently has the definition considered the opportunistic illnesses affecting women and children, and new diagnostic and prognostic techniques have sometimes been included only after extensive discussion. Restructuring the definition of disability in different jurisdictions is likely to result in confusion and inequities. Engaging in this debate within the context of cost-cutting in the Medicaid program may result in loss of coverage for many people with HIV/AIDS who currently qualify for Medicaid. Finally, HIV/AIDS still bears some stigma, and some legislatures may not be as compassionate or fair toward people with HIV/AIDS as people with other disabilities. When this is combined with the financial incentives to limit coverage for expensive illnesses, the possible outcomes are very serious.

## **III. Benefits Issues**

### **A. Required Services and Scope of Services**

During each debate on Medicaid, it has been proposed that federal standards of required services be scaled back and left to state discretion. In deliberations on the Balanced Budget Act of 1997, Congress seriously considered deleting the federal requirement for medically necessary treatment services for children that are now part of Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Supporters of this proposal argued generally that states should not be required to meet a federal standard of treatment, but they were largely unable or unwilling to give specific examples of treatment that should be discontinued.

Similarly, debates have arisen about current federal law mandating that a covered service be sufficient in amount, duration, and scope (ADS) to reasonably achieve its purpose; must be provided statewide; and must be comparable for all beneficiaries. Some proposals for Medicaid change would eliminate these requirements, freeing states to define their own levels of services. States could use this opportunity to diminish or curtail services to people with HIV/AIDS, to other groups by diagnosis, or to all beneficiaries. For example, states could meet the hospital services requirement by providing only one day of hospitalization per year. States also might set different levels of benefits for different medical conditions, granting more services, for example, to a beneficiary with cancer, and fewer services to a beneficiary with AIDS.<sup>2</sup>

Likewise, if the statewideness requirement were deleted, states might offer services in some geographic areas and not in others. For example, states could take funding from expensive urban areas, and divert it to suburban and rural areas; states could also limit coverage for optional benefits to those localities willing to pay for it with local funds. This elimination of statewideness could prove especially problematic in large states like California. If some services were provided in only one location within the state, the state would, in effect, deny those services to beneficiaries who live far away from that location because most Medicaid beneficiaries are too low-income to afford extensive travel.

Also possible would be the elimination of the current Medicaid requirement that services available to any beneficiary under a state program be comparable to those available to any other beneficiary. If such comparability were repealed, a state could offer unlimited physician visits for the aged and restrict the allowed number of physician visits to six per year for people with disabilities. The elimination of the comparability requirement is especially distressing for people with politically unpopular diseases, such as HIV/AIDS, whose services might be cut more drastically than, or even for the benefit of, other Medicaid beneficiaries.

## **B. Residency**

Some legislators assert that states should be permitted to impose residency requirements that limit the benefits available to individuals who have recently moved to a state. For example, benefits available to a new resident might be limited to the amount, duration, and scope of benefits that were available in the individual's former state of residence. (Note also that a five-year ban on receipt of Medicaid services by legal aliens who entered the United States after August 1996 was enacted as part of the Immigration Act.) Recent correspondence from HCFA indicates that it considers such a residency requirement to be unconstitutional. A recent ruling in a Supreme Court case involving welfare payments also found such requirements to be unconstitutional.<sup>3</sup>

## IV. Reimbursement Issues

### A. Repercussions of the Balanced Budget Act of 1997 Repeal of Minimum Reimbursements

As noted in Chapter 4, the Balanced Budget Act of 1997 eliminated the requirement that states reimburse at a rate of 100% the reasonable costs for services rendered at federally qualified health centers (FQHCs) and rural health clinics. These clinics are generally community health centers, funded by HHS. The reimbursement rate is to be phased out and, in 2004, eliminated altogether.

The diminished reimbursement for Medicaid beneficiaries served at such sites means that these clinics will have less funding for those persons who are ineligible for Medicaid (such as HIV-positive but not yet disabled childless adults, people with AIDS who are not yet sufficiently impoverished to meet the income and assets standards, or now-barred legal and illegal immigrants). These fiscally strained facilities are also increasingly expected to provide the expensive new therapies to individuals who are not Medicaid eligible or those whose Medicaid plans provide insufficient prescription drug benefits. Grant funding for FQHCs is contained within an overall spending cap, which is not expected to rise in sufficient amounts to allow these sites to make up for lost funds. This is compounded by the requirement that most FQHCs treat patients regardless of the patients' ability to pay. Difficult local rationing decisions will be inevitable.

Likewise, the repeal of the Boren Amendment (discussed in Chapter 4) eliminated the guarantee to hospitals and nursing homes that reimbursement would be reasonable and adequate. In its place, the Balanced Budget Act of 1997 requires states to provide a public process for determining rates, methodologies underlying the establishment of such rates, and justifications for the rates proposed. Consequently, providers have no reimbursement standard in federal law and, if experience is any indication, Medicaid reimbursement levels will be far below the amount needed to serve beneficiaries on a break-even basis.

This change may be invisible in states in which most services are provided through managed care because these states were already generally not limited by the Boren Amendment in their contracting with hospitals. But in all states, without the Boren Amendment, providers may now have considerably less leverage as they attempt to protect themselves by negotiating with the states to obtain contracts for reasonable reimbursement. Consequently, such bargaining may not be an adequate substitute for a universal guarantee of reasonableness and adequacy. If these providers are unable to contract with the state managed care organizations (MCOs), and the state plans do not guarantee adequate reimbursement, they may be forced to refuse service to uninsured people and to individuals enrolled in the Medicaid MCO or to reduce the overall level of patient care. This matter is of particular concern to public hospitals and clinics, since these facilities usually have a legal obligation to serve patients regardless of their ability to pay.

## **B. Increased Cost to Beneficiaries**

Some proposed changes to the Medicaid program could result in greater costs for some beneficiaries. For example, such changes might allow more than nominal cost-sharing, whereas the current Medicaid plan pays the entire amount of a medical bill with limited permissible patient costs. Proposals might also allow balance billing, which permits a provider who is dissatisfied with the state reimbursement to bill the beneficiary for the remainder.

The Balanced Budget Act of 1997 takes some steps in this direction. The Act clearly says that states may allow or require some cost-sharing by patients enrolled in MCOs, but only to the extent that such cost-sharing is allowed or required of patients in a fee-for-service setting. States could use cost-sharing for a variety of goals, ranging from discouraging overuse of emergency rooms to encouraging immunizations for children (i.e., if children are not immunized, parents have to pay more). Medicaid providers such as MCOs and their subcontracting providers, however, are prohibited from withholding services from a beneficiary who cannot pay such cost-sharing. HIV/AIDS advocates should ensure that this prohibition is reflected in state risk contracts with MCOs, and in subcontracts between MCOs and providers.

## **V. Managed Care Issues**

The Balanced Budget Act of 1997 contains new provisions allowing states to require virtually all Medicaid beneficiaries to enroll in an MCO. These provisions, when combined with the previous level of Medicaid MCO activity under waivers, mean that HIV/AIDS advocates should be especially attentive to the details of MCO contracting. As HIV/AIDS advocates sort through the acronyms and contracts, there are a few basic issues to watch. The first is the adequacy of payment for managed care services for people with HIV/AIDS. Paradoxical as it may seem, HIV/AIDS advocates must act to ensure that managed care plans and their contractors (which are sometimes the same institutions that underserve people with HIV/AIDS) are paid enough to provide high-quality care. Even good plans cannot provide high-quality care without appropriate payment.

The next issue is limitations on access. Most managed care plans limit patient access to only those providers who enter into contractual arrangements with the plan. Some providers will not agree to participate and others will not be offered the opportunity. Especially in plans in which the capitated rates have been set unrealistically low, good providers may not want, or be financially able, to participate. Consequently, inadequately funded Medicaid plans may simply reinvent the problems encountered by Medicaid fee-for-service patients in finding willing providers.

The final general issue is quality of care. Since much of the managed care model is premised on market forces, and since many of the state Medicaid agencies have traditionally been structured around fee-for-service plans, there are usually only limited procedures in place to assess and ensure the quality of care provided by Medicaid MCOs. Consequently, it will fall to HIV/AIDS and other consumer advocates to monitor the adequacy of services

in these plans, develop and enforce review and grievance procedures within the plan and within the state Medicaid agency, and enforce the basic protections afforded by the law.

Most, if not all, of these issues are covered in the state Medicaid plan and its negotiated contracts with the managed care plan. HIV/AIDS advocates wishing to influence the outcome of a state's Medicaid managed care plan should work early and often with the state Medicaid agency on these two documents. Indeed, some state Medicaid officials have welcomed participation by advocates to highlight, clarify, and decrease the likelihood of potential problems.

In addition, many health plans have community advisory committees that accept comments on patient issues. HIV/AIDS advocates should seek to participate in such committees and maintain open lines of communication with the committee members and health plan staff. Health plans that have enrolled members with HIV/AIDS report that they welcome constructive comment regarding health care delivery to this segment of their beneficiary population.

If issues are not resolved satisfactorily with the state or the health plan during the development of the state plan, advocates should also work closely with federal officials in HCFA. While states now have greatly increased flexibility to structure managed care arrangements, basic federal requirements remain in place.

Finally, HIV/AIDS advocates should work with the Congress and with state legislatures to ensure that the plan in general, and capitated rates in particular, are appropriately structured and adequately funded. Just as the National Institutes of Health (NIH) could not begin good HIV/AIDS research work without adequate financial support, HCFA and the state Medicaid agencies cannot provide good health care for people with HIV/AIDS without adequate resources.

## **VI. Enforcement Issues**

### **A. Private Right of Action**

Although the Balanced Budget Act of 1997 did not limit the general private right of action, this right to enforce the terms of the Medicaid Act is under frequent attack. Under some proposals (some of which passed the Congress but were vetoed), individuals who believe that the state has wrongly denied them benefits would no longer have a right to challenge the state in federal court. Instead, such proposals would require a state plan to provide for a private right of action in state court after a beneficiary exhausts state-determined administrative remedies. They would allow the Secretary of HHS to bring an action in federal court on behalf of individuals or classes of people who believe they have been unlawfully denied benefits. Individuals could not, however, bring a claim in any court against the Secretary based on the Secretary's bringing, or failure to bring, such an action. In addition, because of the large administrative burden that would be shifted to HHS, it is very unlikely that enforcement of individual Medicaid rights would continue as effectively as under the current system, which allows aggrieved

individuals, themselves, to seek redress. (For a more detailed discussion of the use of the private right of action, see Chapter 7.)

## **B. Other Mechanisms Created by the Balanced Budget Act of 1997**

The Balanced Budget Act of 1997 also created a series of new oversight and quality control mechanisms for Medicaid managed care. These mechanisms are not yet implemented, but HIV/AIDS advocates should be aware of their requirements and involved in their establishment and activities.

The Act requires that Medicaid MCO contracts with the state be explicit about the benefits that Medicaid beneficiaries can expect to be covered. While these contracts do not have to be published, this information must be available to enrollees if they request it. This provision is important in two ways. It makes clear what is covered so that enrollees can pursue grievances with the MCO if services are not made available. Equally important, it makes clear what is not covered by the MCO contract. Any mandatory benefits that the contract does not cover are still the responsibility of the state and the state must make such services available to Medicaid beneficiaries in another manner.

The Act also requires MCOs to make available certain information, if requested, including participating providers, enrollee rights and responsibilities, grievance and appeals procedures, comparative information regarding benefits and cost-sharing, the service area, and, to the extent available, quality and performance measures.

While leaving intact the existing fair hearing requirements, the Act specifies that MCOs must also have an internal grievance procedure for enrollees and providers. The Act also sets out requirements for an annual external review of the MCOs regarding the quality of care provided, although many MCOs may be exempt from these requirements. When they occur, the reviews must focus on quality outcomes, timeliness, and access issues for the items and services covered by the MCO contracts. The results of the reviews must be made available to enrollees and potential enrollees of the plans. Federal standards for the reviews will be designed by an independent quality review organization for the Secretary of HHS. Before the Secretary has established such standards, pre-existing federal external independent review requirements will continue to apply.

Under the Act, states are allowed to institute penalties against MCOs that fail to meet their contractual obligations. These new statutory penalties include fining MCOs, appointing temporary management of MCOs, permitting beneficiaries to disenroll from MCOs without cause, suspending enrollment of beneficiaries, and suspending payment to MCOs. Since the Act prevents states from terminating a contract with an MCO without a (potentially lengthy) prior hearing, such intermediate sanctions may present a short-term solution to potential problems.

Finally, the Act ensures that MCOs cannot keep their providers from advising a patient about services the provider believes the patient needs. This was enacted in response to widespread reports that MCOs were preventing their doctors from giving patients their best professional advice.

## VII. Conclusion

Medicaid plays a critical role for people with HIV/AIDS. As the program evolves and the HIV/AIDS epidemic continues to grow, particularly among low-income and vulnerable populations, HIV/AIDS advocates need to be vigilant. Limitations in Medicaid eligibility can deprive low-income people of the benefits of many of the research advances in HIV therapy, that might prevent the decline of the immune system and the resulting infections and cancers that accompany the decline.

For Medicaid beneficiaries with HIV/AIDS, advocates need to work to assure that the implementation of managed care does not create barriers to care because payment rates are too low, providers are excluded from managed care networks, or administrative hurdles are too difficult. It is vital that HIV/AIDS advocates take an active role in understanding how Medicaid works and, in collaboration with federal and state administrators assure the program serves as many people as well as possible.

- 1 This definition is used for Supplemental Security Income (SSI) and the determination of Medicaid eligibility, as well as for Social Security Disability Insurance (SSDI) and the determination of Medicare eligibility.
- 2 It is questionable whether such state plans would pass muster under Title II of the Americans with Disabilities Act, which prohibits discrimination on the basis of a disability by state and local governments.
- 3 *Rita L. Suenz, Director, California Department of Social Services, et al. v. Brenda Roe and Anne Doe* (1999) U.S. LEXIS 3174.



APPENDIX A:  
FREQUENTLY ASKED  
QUESTIONS

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# APPENDIX A:

## FREQUENTLY ASKED QUESTIONS

### **What is Medicaid?**

Medicaid is a means-tested public assistance program that provides payment for medical services for some people who cannot afford them. It is jointly funded by the federal and state governments.

### **How does Medicaid differ from Medicare?**

Medicare is the national social insurance program for health care for older and disabled people. Eligibility is not means-tested but, rather, is based on age or disability and work history. Funding is from employer/employee contributions through Social Security, designated taxes, and general federal revenues.

### **Who is in charge of Medicaid?**

The U.S. Congress and state legislatures shape the Medicaid program. The Health Care Financing Administration (HCFA), an agency within the Department of Health and Human Services (HHS), establishes and enforces federal Medicaid requirements. Individual state Medicaid agencies implement and oversee state programs.

### **Who is eligible for Medicaid?**

The Medicaid eligibility criteria include both categorical requirements and income and assets requirements. Generally, eligible groups include Supplemental Security Income (SSI) beneficiaries; low-income parents and children who currently meet the income and resources standards that were in effect on July 16, 1996, for Aid to Families with Dependent Children (AFDC) (the cash assistance program for low-income families); certain other low-income pregnant woman and children; certain low-income Medicare beneficiaries; and medically needy individuals (at the option of the state). (See Chapter 2 for additional information on eligibility.)

## **Do people with HIV/AIDS automatically qualify for Medicaid?**

HIV accompanied by one or more of the symptoms specified by the Social Security Administration (SSA) is considered a presumptive disability; consequently, in most states people with AIDS who meet the financial requirements can qualify for Medicaid through SSI. (See Table 2-2 for symptoms associated with HIV infection sufficient to meet the SSA standard for presumptive disability.) However, asymptomatic HIV infection is not a presumptive disability. Many HIV-infected individuals are, therefore, unable to receive preventive treatment unless they qualify for Medicaid through another federal program or are considered “medically needy.” (See Chapter 2 for additional information on eligibility.)

## **How many people with AIDS in the United States are covered by Medicaid?**

HCFA estimates that about 50% of adults with AIDS and 90% of the children with AIDS will be covered by Medicaid at some point in their lives.<sup>1</sup>

## **How do I apply for Medicaid?**

Application procedures vary by state. For details, contact your local HIV/AIDS advocacy organization. Such groups are often listed in the yellow pages under “Social Services Organizations.” You may also contact your local Social Security office or local welfare agency. For further reference, Appendix D contains a list of state Medicaid contacts.

## **What is the Medicaid budget?**

An estimated \$191.5 billion will be spent in 1999. The federal share will be approximately \$108.1 billion; the state share will be approximately \$83.3 billion.<sup>2</sup>

## **How many Medicaid dollars are spent on HIV/AIDS-related medical care?**

An estimated \$3.9 billion (or about 2% of the overall Medicaid budget) will be spent on HIV/AIDS-related medical care in 1999.<sup>3</sup>

## **What percentage of HIV/AIDS-related medical care costs is covered by Medicaid?**

Medicaid accounts for approximately 25% of aggregate HIV/AIDS-related medical care costs.<sup>4</sup>

## **How much will I have to pay for Medicaid?**

There is no charge for Medicaid coverage, although once eligible, Medicaid beneficiaries in some states are required to pay for a portion of their health care services. When such cost-sharing is implemented, the charge is generally nominal (usually \$2 or less).

Individuals who meet the categorical requirements, but whose income and assets exceed the established Medicaid criteria in the state, may have to spend down to satisfy eligibility requirements. In other words, the individual may have to spend income on medical care, thereby reducing his or her income to the eligibility standard. (See Chapters 2 and 4 for additional information on eligibility and provider reimbursement, respectively.)

## **What types of services are available through Medicaid?**

Federal Medicaid law distinguishes between mandatory and optional services. Mandatory services include physician and hospital services, laboratory and X-ray services, prenatal care, and preventive services for children. Optional services include prescription drugs (though all states have chosen to provide this benefit), hospice services, and case management services. Generally, all covered services must satisfy basic federal standards: sufficiency of amount, duration, and scope; comparability; and statewideness. (See Chapter 3 for additional information on Medicaid services.)

## **Can I get prescription drugs through Medicaid?**

Yes. All state Medicaid programs include prescription drug coverage, although states may have a variety of restrictions on the number of prescriptions, cost-sharing, and other overall limits. Covered medications include various drugs for prevention and treatment of AIDS-related opportunistic infections and drugs for treatment of primary HIV disease (e.g., reverse transcriptase inhibitors such as AZT, and protease inhibitors). (See Chapter 3 for additional information on Medicaid services.)

## **Are Ryan White services part of Medicaid?**

No. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 provides federal funds to cities, states, and nonprofit clinics for planning, implementing, and evaluating programs to improve the quality and availability of health care and support services for people with HIV/AIDS. Medicaid and the Ryan White CARE Act are separate programs and function independently. Medicaid's \$3.9 billion of HIV/AIDS-related expenditures are more than twice the \$1.4 billion that will be spent under the Ryan White CARE Act.

### **Can I be served in programs receiving Ryan White assistance if I have Medicaid?**

Yes. Most health care services provided at health care clinics that receive financial assistance from the Ryan White program are included in the list of mandatory services that states must provide to receive federal Medicaid funds. These clinics can then bill Medicaid for your care and use their Ryan White grant dollars to serve people without private insurance or Medicaid.

### **Is ADAP part of Medicaid?**

No. AIDS Drug Assistance Programs (ADAPs) are part of the Ryan White CARE Act program. They are separate from Medicaid and function independently. If a Medicaid beneficiary receives ADAP services, ADAP can then bill Medicaid for that beneficiary's care and use Ryan White grant dollars to serve people without private insurance or Medicaid.

### **Does Medicaid address cultural and language needs?**

No. Federal Medicaid standards do not require individual providers or managed care organizations to furnish translators for non-English-speaking beneficiaries. However, many states require that all written materials outlining services offered by the provider be available in languages other than English if the provider serves non-English-speaking beneficiaries. In addition, some states include cultural and linguistic service standards as a prerequisite for managed care organizations bidding for contracts to serve Medicaid populations with a certain percentage of recipients whose primary language is not English. (See Chapter 3 for additional information on Medicaid services.)

### **Can I choose my own physician under Medicaid?**

Sometimes. The federal standards governing Medicaid services include a freedom-of-choice requirement. Consequently, under the general Medicaid program, beneficiaries can obtain services from any individual practitioner, institution, agency, pharmacy, or organization that agrees to provide Medicaid services and is qualified to do so. However, low physician payment rates in some states have led many physicians to refuse to take on Medicaid beneficiaries, resulting in a limited choice of providers.

Under waivers granted to states and under the Balanced Budget Act of 1997, however, states are permitted to require beneficiaries to enroll in MCOs as a condition of receiving Medicaid benefits. Such plans usually limit the beneficiaries' choice of physicians. (See Chapter 5 for additional information on Medicaid managed care.)

## **What can I do if I disagree with how I am treated by the Medicaid program?**

Beneficiaries and service providers have several possible remedies if a state fails to provide a required service or to implement a policy consistently with federal law. First, an aggrieved beneficiary is entitled to a fair hearing either before the state Medicaid agency or at the local level with a right of appeal to the state agency. (It should be noted that such fair hearing protections also apply to applicants to a Medicaid program.) Second, a separate federal statute provides beneficiaries with a private right of legal action and a full range of legal and equitable remedies. In addition, individuals may seek local, state, or federal review of their treatment by the Medicaid program. (See chapters 7 and 8 for additional information on enforcement and local advocacy, respectively.)

## **Is Medicaid changing? Whom do I contact to get involved?**

The Medicaid program is changing and will continue to do so. Generally, changes and proposals reflect changes in the larger U.S. health care system. Specifically, much of the discussion regarding Medicaid focuses on managed care. (See Chapter 5 for additional information on Medicaid managed care). To get involved, contact your local HIV/AIDS advocacy or HIV/AIDS service organization (probably listed under Social Services Organizations in the yellow pages), community health clinics, or public hospitals. For further reference, Appendix D contains a list of state Medicaid contacts.

## **What is a managed care organization?**

The phrase managed care organization (MCO) can refer to almost any health care delivery and payment system designed to plan and provide health care services in a cost-conscious and coordinated manner. It usually refers to an organization that restricts patients' choice of providers to those who provide care in a cost-conscious manner. MCOs are distinguished from fee-for-service Medicaid systems, in which the government pays a premium to a health care provider on behalf of each beneficiary for each covered service. (See, generally, Chapter 5 on Medicaid managed care.)

## **Can a state require Medicaid beneficiaries to enroll in a managed care organization?**

Yes. Under a new federal law passed in the summer of 1997 (the Balanced Budget Act of 1997), states can require Medicaid beneficiaries to enroll in an MCO as a condition of receiving Medicaid benefits. There are exceptions for children with special needs, Native Americans, and Medicare beneficiaries; but even for these people, the state may obtain permission through specific waivers from the federal government to require mandatory enrollment in managed care.

## **How do I find out which services a specific managed care organization provides?**

Medicaid MCOs are required to provide beneficiaries, upon request, with a list of all items and services available to enrollees that are covered directly or through referrals. MCOs are also required to provide information about the identity, locations, qualifications, and availability of health care providers in the organization, as well as information about enrollee rights, enrollee responsibilities, and grievance procedures.

## **What do I do if a managed care organization refuses to provide a service?**

MCOs are required to establish an internal grievance procedure under which an enrollee may challenge the denial of coverage or payment for assistance. All Medicaid beneficiaries are also entitled to a fair hearing before the state Medicaid agency. In addition, beneficiaries can bring a claim in federal court. (See Chapter 7 for more information.) Beneficiaries should try to work with the physician or other provider involved to challenge a denial.

## **What can I do if I don't like the managed care organization in which I'm enrolled?**

States and managed care entities must permit beneficiaries to terminate their enrollment at any time for cause. If beneficiaries do not have cause to disenroll, the MCO can lock in beneficiaries for 12 months at a time. Beneficiaries have 90 days from the date they are initially enrolled to disenroll without cause, although this may not be a meaningful choice for beneficiaries in a rural area with only one managed care organization.

- 1 Kaiser Commission on the Future of Medicaid, Medicaid's Role for Persons with HIV/AIDS (October 1996).
- 2 Foster, Scott, et al. Federal HIV/AIDS Spending: A Budget Chartbook. The Henry J. Kaiser Family Foundation (July 1999) (in press).
- 3 Foster, Scott, et al. Federal HIV/AIDS Spending: A Budget Chartbook. The Henry J. Kaiser Family Foundation (July 1999) (in press).
- 4 Department of Health and Human Services, Medicaid Bureau, "Fact Sheet" (June 1997).

APPENDIX B:  
QUESTIONS TO ASK ABOUT  
MEDICAID MCO CONTRACTS

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# APPENDIX B:

## QUESTIONS TO ASK ABOUT MEDICAID MCO CONTRACTS

These questions were taken from Jane Perkins and Kristi Olson, National Health Law Program, “An Advocate’s Primer on Medicaid Managed Care Contracting,” *Clearinghouse Review* 19 (May/June 1997), and are used here with permission.

### A. Threshold Issues

- Does the implementation schedule allow adequate time for consumers and advocates to review, investigate, and comment on the draft with due diligence?
- Is the request for proposals (RFP) and/or draft contract readily available for consumers and advocates?
- Does the implementation schedule allow adequate time for the MCOs that are awarded contracts to implement the contract provisions?
- Does the implementation schedule allow adequate time for the provisions of the health benefits manager contract to be implemented?
- Are the provisions of the contract mandatory for all subcontracts?

### B. Marketing

- Does the contract prohibit direct (e.g., door-to-door) marketing?
- Is the MCO prohibited from offering financial incentives to induce members to enroll?
- Is the MCO prohibited from engaging in misleading or confusing marketing practices?

### C. Education and Enrollment

- Does the contract describe the responsibility of the MCO and the state for education and outreach?
- Is the MCO required to supply members with an enrollee handbook that contains descriptions of available providers and member rights and responsibilities?

- Is the state required to pre-clear written materials and monitor educational activities undertaken by the MCO?
- Is the MCO required to provide member material orally and in writing, at a reading level set by the state, in the recipient's primary language, and in alternative formats, including (teletypewriter) TTY and telecommunication devices, braille, large print, and cassette?
- Does the contract describe how members who do not select an MCO will be assigned to one?
- Does the contract specify that the state Medicaid agency will be responsible for disenrollment and will prohibit disenrollment by the MCO based on a missed appointment or co-payment or an adverse change in health status, diagnosis or perceived diagnosis, expected or actual treatment costs, or the enrollee's attempt to exercise his or her rights under a grievance or complaint system?

#### **D. Selection of Primary Care Provider**

- Does each enrollee have the freedom to choose a Primary Care Provider (PCP) from among the MCO's participating providers?
- Does each family member have the option to choose his or her Primary Care Provider?
- Does the MCO allow members with disabilities, chronic conditions, or complex conditions to choose a specialist as their Primary Care Provider?
- Does the contract specify time frames for the recipient to select a Primary Care Provider?
- Are members with disabilities given extra time to select a Primary Care Provider?
- Is the MCO required to inform members of the time frames and the consequences for failing to act within that time?
- Does the contract describe how the MCO will assign Primary Care Providers to members who do not choose one?
- Are enrollees permitted to change their Primary Care Provider's without cause at any time?
- Does the contract describe how the MCO will ensure continuity of care if the member's Primary Care Provider leaves the MCO's network?
- Are pregnant women allowed to receive primary care from their current provider, whether or not their current provider is in the MCO's network, until 60 days postpartum?

#### **E. Initial Assessments and Ongoing Care**

- Is the MCO required to honor ongoing plans of care initiated before enrollment until the enrollee is evaluated by his or her Primary Care Provider and a new plan of care is established? And if care is reduced or terminated, does the contract provide for the member to receive a due process notice, including rights to continued benefits?

- Is the MCO required to provide a face-to-face initial health assessment for all new members within the first 60 days of enrollment?
- For members known or appearing to be pregnant, is the MCO required to provide a face-to-face initial health assessment within 15 days of enrollment?

## **F. Specialists**

- Does the MCO allow members with disabilities, chronic conditions, or complex conditions to select a specialist as their Primary Care Provider?
- If the MCO cannot offer a choice of at least two specialists or subspecialists, including pediatric subspecialists, qualified to meet the particular needs of the individual, is the MCO required to pay for the service out of network if the member requests a non-participating specialist?
- Is the MCO required to make access to specialists with pediatric/adolescent expertise available to every child or adolescent who needs and requests specialty care?

## **G. Essential Community Providers and Coordination with Agencies**

- Is the MCO required to subcontract with school-based health clinics, federally qualified health clinics, rural health clinics, traditional mental health care providers, Title Ten providers, local health departments, homeless clinics, teen clinics, migrant health clinics, children's tertiary care facilities?
- Is the MCO required to contract or develop coordination and referral agreements with Women, Infant and Children (WIC) programs, early intervention programs, child welfare programs, state mental health agencies, substance abuse agencies, special education programs, teen pregnancy, and parenting programs?

## **H. Access and Availability Standards**

- Does the contract require the MCO to guarantee 24-hour, seven-days-a-week accessibility to qualified providers?
- Does the contract require a patient to primary care physician ratio that takes into account the physician's participation in several MCOs and the physician's commercial market caseload?
- Is the MCO required to make available a pediatrician/adolescent medicine specialist who meets travel standards for every child or adolescent who requests a pediatric/adolescent medicine specialist as his or her Primary Care Provider?
- Does the contract specify primary care availability standards no more than 20 minutes away for members in urban areas and 30 minutes away for members in rural areas?
- Is routine care available within 10 days?

- Is specialty care available within three weeks?
- Is emergency care available immediately and at the nearest facility, whether or not that facility participates in the MCO's network and whether or not the care has been approved in advance by the MCO?
- Is urgent care available within 24 hours?
- Does the contract specify maximum in-office waiting times?
- Is the MCO responsible for ensuring that members whose primary language is not English and members with special medical needs have access to primary care providers and specialists qualified to meet their needs?

## **I. Scope of Services**

- Does the contract specify that the MCO is responsible for juvenile court-ordered treatment involving covered services?
- Is the responsibility for medical services contained in individualized family service plans and individualized education plans clearly specified?
- Does the contract require case management services to facilitate needed medical, educational, social, and other services?
- Does the contract require coverage of interdisciplinary team treatment?
- Does the contract require coverage of access to clinic studies?
- Does the contract define the following terms consistent with federal/state statutes and regulations: medical necessity, family planning, EPSDT, case management, and transportation?
- Are members able to self-refer for family planning, obstetrical, gynecological, mental health, and substance abuse services?
- Is the MCO prohibited from demanding prior authorization restrictions beyond those allowed under fee-for-service?

## **J. Early and Periodic Screening, Diagnosis, and Treatment**

- Does the contract incorporate federal and state statutes and regulations concerning EPSDT?
- Does the contract incorporate part 5 of the HCFA State Medicaid Manual (which delineates requirements for screens—e.g., lead testing, health education, and age-appropriate laboratory tests)?
- Does the contract clearly delineate whether the state or the MCO is responsible for EPSDT outreach and informing?
- Does the contract prohibit the MCO from placing caps and other quantitative limits on the number of services a child may receive?
- Is the MCO prohibited from requiring prior authorization for EPSDT screens?
- Is the MCO required to meet or exceed 80% EPSDT participation?

- Does the contract require the MCO to meet national professional standards of care as articulated by the American Academy of Pediatrics, Advisory Committee on Immunization Practices, American College of Obstetricians and Gynecologists, American Medical Association Guidelines for Adolescent Preventative Screening, and American Academy of Child and Adolescent Psychiatry’s Work Group on Quality Issues?

## **K. Medical Necessity**

- Is the definition of medical necessity clear in all contracts and subcontracts?
- Is the contract clear on the MCO’s responsibility for providing medically necessary covered services as required by law?
- Does the definition of medical necessity allow the treating physician to determine whether the care is medically necessary?
- Does the contract include a separate definition of medical necessity for behavioral health care that is consistent with federal and state law and that recognizes the role of the member/family, least restrictive treatment settings, and wraparound services?

## **L. Family Planning Services**

- Does the contract allow members to obtain family planning services from any provider, in or out of the network, without a referral?
- Is the MCO required to inform members, including adolescents, of access to family planning services, in or out of network, without a referral?
- Is the MCO required to keep family planning services confidential, even if the patient is a minor?

## **M. Special Needs**

- Does the contract explicitly require the MCO to comply with the Americans with Disabilities Act and Title VI of the Civil Rights Act?
- Does the contract require the MCO to provide information orally and in writing in the recipient’s primary language and alternative formats, including TTY and telecommunications devices, braille, large print, and cassette?
- Does the contract require the MCO to employ multi-cultural and multi-lingual staff, representative of the racial and ethnic diversity of its members?
- Does the contract prevent discrimination on the basis of health status, illness, or perceived needs?
- Is the MCO required to make special accommodations for children in foster care, children in state custody, adopted children, and homeless individuals?
- Does the contract address the ability of minors to consent to medical treatment without parental permission?

## **N. Due Process**

- Are the MCO and its participating providers required to post due process rights in a conspicuous location in the reception area of each provider?
- Is the MCO required to inform members how to obtain assistance in filing a grievance and of the potential availability of free legal services?
- Is the MCO required to notify members of time frames for plan grievance procedures, state fair hearings, and expedited reviews?
- Is the MCO required to inform members of their right to a state fair hearing without exhausting MCO grievance procedures?
- Is the time frame for a plan grievance procedure no more than 30 days?
- Is there an expedited review process, and does it provide for a decision within 72 hours?
- Is the MCO required to provide notice to the member and the member's representative, if applicable, whenever a service is denied, reduced, or terminated?
- Does the required notice explain why service was denied, reduced, or terminated and give the specific legal support for that action?
- Does the required notice explain the right to continued services pending a final decision?
- Does the required notice explain the right to seek a second opinion at the MCO's cost?
- Does the required notice explain due process rights, including the right to a state fair hearing, without exhausting MCO grievance procedures?
- If a service is denied, reduced, or terminated, and the MCO fails to give adequate and timely notice, is the MCO required to provide the complete service (unless the member's primary care provider or specialist, as appropriate, indicates that the service would not be in the member's best interest)?

## **O. Financial and Organizational Requirements**

- Does the contract prohibit financial arrangements between the MCO and its providers that may inappropriately limit care?
- Does the contract prohibit gag clauses in MCO subcontracts?
- Does the contract require the MCO to report administrative costs and profits as separate line items? Place a cap on MCO profits? A cap on administrative costs?
- Does the contract have higher capitation rates for members with more extensive needs?
- Is cost-sharing prescribed?
- Does the contract require the MCO to meet state insurance/licensing certification standards?
- Does the contract require National Committee for Quality Assurance (NCQA) accreditation for MCOs?

- Does the contract require the MCO and its subcontractors to notify members of the incentive plans being used?
- Are the specific conditions and services defined legally and clinically and grouped into actuarially manageable service packages for which prices can be set?
- Will participating plans be required to show that they are investing capital in the improvement of services, treatment protocols, and development of best practices?

## **P. Public Disclosure**

- Is the MCO required to disclose compensation arrangements publicly?
- Is the MCO required to disclose the disenrollment rate from the MCO publicly?
- Is the MCO required to disclose its profit level publicly?
- Is the MCO informed that the results of state consumer satisfaction surveys and external audits will be made public?
- Is the MCO informed that the number, type, and resolution of complaints and formal legal actions will be made public?
- Is the MCO informed that data regarding compliance with performance measures will be made public?

## **Q. Reporting Requirements**

- Are data stratified for gender, race, disability, and age? Do the sampling techniques account for the cultural and linguistic populations serviced by the MCO? For example, if 20% of the MCO enrollment is African-American and the MCO is measuring mammography screening, then 20% of the mammography percentage should be African-American as well.
- Does the contract require focused studies and 100% chart reviews of persons with special health care needs?
- Is the MCO required to adhere to the reporting requirements specified in the Health Plan Employer Data and Information Set (HEDIS) 3.0?

## **R. Quality and Performance Improvement Goals**

- Does the contract include outcome measures and performance goals for EPSDT, emergency room use, cultural competence, and coordination of non-capitated/out-of-MCO services? Do outcome improvements anticipate closing the disparity in health status between white and minority members?
- If mental health and substance abuse services are included, does the contract anticipate improvement in penetration and duration of these services?
- Does the state withhold a percentage of the capitation rate until the MCO demonstrates that minimum performance standards have been met?

- Is the MCO required to implement a quality assurance and improvement plan?
- Is the MCO's contracting status measured against reported HEDIS 3.0 data?
- Does the contract incorporate the quality assurance measures contained in HCFA's quality assurance reform initiative?
- Is the MCO required to review the performance of its contracting providers and ensure correction of any deficiencies?

## **S. Consumer Involvement**

- Does the contract notify the MCO that the state will conduct an annual consumer satisfaction survey?
- Does the contract notify the MCO of the availability of an independent hot line for members to call with problems, questions, and complaints?
- Is the MCO required to provide a consumer relations office for member questions, problems, and complaints?
- Is the MCO required to report complaints to an independent ombudsman program?
- Is the MCO required to hire advocates to assist members?
- Is the MCO required to include consumers in work groups, advisory boards, or other "accountability" loops?
- Does the contract require the MCO's written information and materials to be pre-tested by consumers to ensure that the material is appropriate?
- Is the MCO required to employ Medicaid recipients?

## **T. Enforcement**

- Does the contract explicitly recognize Medicaid recipients as the intended third-party beneficiaries of the contract?
- Does the contract explicitly recognize Medicaid recipients as the intended third-party beneficiaries of subcontracts and provider agreements entered into by the MCO?
- Does the contract broadly specify the state's right to recoup or withhold payments, impose corrective action plans, suspend further enrollment, exact damages, or terminate the contract for noncompliance with the terms of the contract and other legal documents?

## **U. Contracts with Health Benefit Managers**

- Does the health benefit manager (HBM) contract emphasize face-to-face counseling?
- Does the contract require the HBM to maintain and communicate accurate information on the participating and available primary and specialty care providers and their locations and business hours?

- Are benefit counselors required and/or given incentives to have a low default rate?
- Are recipients told how long they have to choose an MCO?
- Are individuals with disabilities given extra time to choose an MCO?
- Does the HBM contract describe the default assignment process?
- Does each family member have the option to choose his or her own MCO?
- Are recipients whose membership in an MCO is terminated due to ineligibility automatically re-enrolled in the same MCO on resumption of eligibility within 90 days, unless the recipient selects a new MCO?
- Is the HBM required to provide information written and orally in the recipient's primary language, at a state-set reading level, and in alternative formats, including TTY and telecommunication devices, braille, large print, and cassette?
- Does the contract specify whether the state or the HBM is responsible for outreach and education to Medicaid-eligible individuals not enrolled in Medicaid, especially children and adolescents?
- Does the contract specify the responsibility of the state and the HBM for EPSDT outreach and education?
- Does the hiring of health benefit counselors reflect the cultural and linguistic population being served?
- Does the contract exclude health benefit counselors from complaint and dispute resolution activities?



APPENDIX C:  
STATE MEDICAID CONTACTS





# APPENDIX C:

## STATE MEDICAID CONTACTS

For information on state programs throughout the U.S.:

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Fax Number (207) 874-6527

Lee Partridge  
American Public Human Services Association  
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Fax Number (202) 289-6555

### Individual State Medicaid Offices:

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***Medicaid Director***  
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#### ALASKA

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**ARKANSAS**

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**CONNECTICUT**

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APPENDIX D:  
SELECTED CASE LAW

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# APPENDIX D:

## SELECTED CASE LAW

- *Hern v. Beye*, 57 F. 3d 906 (10th Cir. 1995)

Federal Guarantee: The Medicaid statute guarantees pregnancy termination services to women who become pregnant as a result of rape or incest.

State Action: Colorado attempted to bypass this requirement by passing a state law permitting Medicaid-funded abortions only to save the life of an expectant mother.

Disposition: A physician brought suit against Colorado and won. The court noted that “the four other circuit courts to confront similar state restrictions on abortion funding under Medicaid have all concluded that such limitations violate the requirements of federal Medicaid law.”

Remedy: The court enjoined Colorado from denying Medicaid funding for abortions to qualified women whose pregnancies are a result of rape or incest.

- *Miller v. Whitburn*, 10 F. 3d 1315 (7th Cir. 1993)

Federal Guarantee: A state’s Medicaid plan must provide treatments that are “medically necessary,” but need not provide treatments considered “experimental.”

State Action: A five-year-old child who was eligible for Medicaid suffered from a condition known as “short-bowel syndrome.” The illness would eventually result in liver deterioration and required that she be fed intravenously through a catheter in her stomach. However, the State of Wisconsin refused to fund a transplant because “the Department [of Health] considered the procedure experimental,” and, therefore, not reimbursable.

Disposition: Although Wisconsin argued that this decision was solely within the discretion of the state, the court disagreed.

Remedy: The court vacated the lower court's order, and ordered the district court to re-examine the propriety of the operation.

- *Visser v. Taylor*, 756 F. Supp. 501 (D. Kan. 1990)

Federal Guarantee: According to Medicaid regulations, a state Medicaid agency “may not arbitrarily deny or reduce the amount, duration or scope of a required service to an otherwise eligible recipient solely because of the diagnosis, type of illness or condition.”

State Action: The Kansas Department of Social and Rehabilitation Services refused to cover under its Medicaid prescription drug program a specific drug for treating schizophrenia, even though the patient's physicians had determined that the drug was medically necessary to treat the patient's condition.

Disposition: The federal district court held that the state acted “arbitrarily, capriciously, and in contravention of the Social Security Act” when it refused to cover the prescribed drug. According to the court, the state violated the regulations, since it reduced the scope of its services solely on the basis of the patient's illness or condition.

Remedy: The court issued a preliminary injunction to require the state to provide Medicaid coverage for the needed drug to the patient, as long as the patient is eligible for Medicaid and the drug is prescribed by her physicians. The court also ordered the state to include the drug in its list of drugs covered by Kansas's Medicaid program.

Other cases of interest:

- *Wilder v. Virginia Hospital Assn.*, 496 U.S. 498 (1990)

Virginia attempted to institute a reimbursement formula for hospitals that provided services to mentally retarded citizens. The hospitals claimed the formula was unreasonable and inadequate and violated the Medicaid guarantee of “reasonable” reimbursements. As a result, Virginia hospitals were not able to provide adequate “hospital services, nursing facility services, and services in an intermediate care facility for the mentally retarded.” A nonprofit corporation of public and private hospitals brought a private cause of action under Section 1983 to recover these reimbursement amounts. The Commonwealth sought summary judgment, arguing that Section 1983 was inapplicable. The Supreme Court held that the Boren Amendment was, indeed, enforceable in a section 1983 action for declaratory and injunctive relief brought by health care providers.

- *Arkansas Medical Society v. Reynolds*, 834 F. Supp. 1097 (E. Dist. Ark. 1992)

In an attempt to “balance Arkansas’ Medicaid budget in fiscal year 1993, the Arkansas Department of Human Services reduced reimbursement rates to various Medicaid providers by 20%...” Numerous examples of Arkansas’s resulting failure to meet federal Medicaid requirements were shown, such as the widespread closing of obstetric and pediatric clinics, the literal abandonment of “hundreds of pregnant women,” the “threat of irreparable harm to the OB Medicaid patients in Garland County,” and the complete refusal by some providers to accept any Medicaid patients at all. The court issued a preliminary injunction when a group of providers and beneficiaries brought a claim demonstrating the violations of federal Medicaid provisions.

Further Action: The United States Court of Appeals, Eighth Circuit, affirmed the District Court opinion in 1993 (*Arkansas Medical Society Inc. v. Reynolds*, 6F.3d519).

- *Matthews v. Coye*, No. C-90-3620 (N. D. Calif.) (stipulation and dismissal, Oct. 17, 1992)

California Medicaid agency was required to implement the federal EPSDT provision calling for a lead blood assessment appropriate for age and risk factors.

- *Grijalva v. Shalala*, 946 F. Supp. 747 (D. Ariz. 1996)

Under the Medicare statute, regulations promulgated by the secretary of HHS, and due process, Medicare beneficiaries are unequivocally entitled to notice and hearing when private provider HMOs deny services based on coverage determinations. In addition, the court held that the secretary violates 42 U.S.C. Section 1995mm(c)(1) by entering into contracts with any HMO that fails to satisfy notice and hearing requirements.

Further Action: The United States Court of Appeals, Ninth Circuit, affirmed the District Court opinion in 1998 (*Grijalva v. Shalala*, (152 F.3d 1115)). In 1999, the Supreme Court granted certiorari, then vacated the judgement and remanded the case to the Ninth Circuit for further consideration in light of *American Manufacturers Mutual Insurance Company v. Sullivan* (526 U.S. 1999); portions of the Balanced Budget Act of 1997; and the Department of Health and Human Services regulations implementing those provisions (1999 U.S. Lexis 3025).



APPENDIX E:  
SUPPLEMENTAL READING





# APPENDIX E:

## SUPPLEMENTAL READING

Advisory Commission on Intergovernmental Relations, Medicaid: Intergovernmental Trends and Options (A-119 August 1992).

Jeffrey S. Crowley, Making Medicaid Managed Care Work: An Action Plan for People Living with HIV (1997).

Scott Foster, Althea Gregory, Piet Niederhausen, David Rapallo and Tim Westmoreland. Federal AIDS Spending: A Budget Chartbook (1998).

Lawrence Gage & William VonOehsen, Managed Care Manual: Medicaid and State Health Reform (1995).

Jane Horvath & Neva Kaye, Medicaid Managed Care: A Guide for the States (1995).

International Retrovirology Association, Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology (Vol. 8, Supplement 1, 1995) (James Kahn, M.D., and Mark D. Smith, M.D., M.B.A., eds.).

Kaiser Commission on the Future of Medicaid, Medicaid and Managed Care: Lessons from the Literature (March 1995).

Kaiser Commission on the Future of Medicaid, Medicaid at the Crossroads (November 1992).

Peter R. Kongstvedt, The Managed Care Handbook (3d ed., 1996).

Office of Disability, Social Security Administration, Red Book on Work Incentives: A Summary Guide to Social Security and Supplemental Security Income Work Incentives for People with Disabilities (SSA Pub. No. 64-030 August 1995).

Sara Rosenbaum & Julie Darnell, A Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 (P.L. 105-33) with Prior Law (September 1997) (prepared for the Kaiser Commission on the Future of Medicaid).

Andy Schneider, Overview of Medicaid Provisions in the Balanced Budget Act of 1997, (December 1997). (prepared for The Kaiser Commission on the Future of Medicaid).

Subcommittee on Health and the Environment, Committee on Energy and Commerce, 103d Cong., 1st Sess., Medicaid Source Book: Background Data and Analysis (1993 update) (Comm. Print 103-A 1993).

Institute of Medicine, National Research Council, *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States* (National Academy Press, 1999).

President's Advisory Commission On Consumer Protection and Quality in the Health Care Industry, *Consumer Bill of Rights and Responsibilities* (1997), [www.hcqualitycommission.gov/press/cbor.html](http://www.hcqualitycommission.gov/press/cbor.html)

J. Rawlings-Sckunda, N. Kaye, *Emerging Practices and Policy in Medicaid Managed Care for People with HIV/AIDS: Case Studies of Six Programs* (August, 1998).

Regenstein, Marsha, Christy Schroer, *Medicaid Managed Care for Persons with Disabilities: State Profiles* (December 1998) (prepared for the Kaiser Commission on Medicaid and the Uninsured).

# APPENDIX F: ACRONYMS





# APPENDIX F:

# ACRONYMS

ADAP	AIDS Drug Assistance Program
ADS	Amount, Duration, and Scope
AFDC	Aid to Families with Dependent Children
AIDS	Acquired Immune Deficiency Syndrome
ARC	AIDS-Related Complex
AZT	Zidovudine
CARE	Comprehensive AIDS Resources Emergency Act (or the Ryan White CARE Act)
CDC	Centers for Disease Control and Prevention
CHIP	Children's Health Insurance Program
CMV	Cytomegalovirus
COBRA	Consolidated Omnibus Budget Reconciliation Act of 1985
DSH	Disproportionate Share Hospital
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
FDA	Food and Drug Administration
FQHC	Federally Qualified Health Center
FR	Federal Register
HBM	Health Benefit Manager
HCBS	Home- and Community-Based Services
HCFA	Health Care Financing Administration
HEDIS	Health Plan Employer Data and Information Set
HHS	Department of Health and Human Services
HIV	Human Immunodeficiency Virus
HMO	Health Maintenance Organization
HRSA	Health Resources and Services Administration
ICF/MR	Intermediate Care Facility for the Mentally Retarded
IPA	Independent Practice Association

MCO	Managed Care Organization
NCQA	National Committee for Quality Assurance
NF	Nursing Facility
NIH	National Institute of Health
PBM	Pharmaceutical Benefits Management
PCP	Primary Care Provider (alternately, when referring to AIDS-related conditions, this acronym stands for <i>Pneumocystis carinii pneumonia</i> )
PCCM	Primary Care Case Management
PHP	Prepaid Health Plan
POS	Point of Service
PPO	Preferred Provider Organization
PWA	Person With AIDS
RFP	Request for Proposals
QDWI	Qualified Disabled and Working Individual
QMB	Qualified Medicare Beneficiary
SLIMB	Specified Low-Income Medicare Beneficiary
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
State SLIMB	State-Specified Low-Income Medicare Beneficiary
TANF	Temporary Assistance for Needy Families
VA	Department of Veterans Affairs
WIC	Women, Infant and Children Programs

APPENDIX G:  
GLOSSARY





# APPENDIX G:

## GLOSSARY

**Aid to Families with Dependent Children (AFDC)**—A federal cash assistance program for low-income families. This entitlement program was eliminated by the Personal Responsibility and Work Opportunity Act of 1996 and was replaced by Temporary Assistance for Needy Families (TANF), which is not an individual entitlement program, but a block grant to states.

**AIDS Drug Assistance Program (ADAP)**—A program funded through the Ryan White CARE Act and, in some states, state funds. This state-administered program is designed to pay for all or some of the cost of HIV-related drugs for low-income people with inadequate private or public health insurance.

**AIDS-Related Complex (ARC)**—A term formerly used to describe a variety of chronic symptoms and physical findings found in HIV-infected people whose conditions did not meet the CDC case surveillance definitions of AIDS. Symptoms included swollen glands, recurrent fevers, unintentional weight loss, chronic diarrhea, lethargy, minor alterations of the immune system, and oral thrush. The term is now considered to be obsolete.

**Amount, duration, and scope (ADS) standard**—The federal minimum standard for Medicaid benefits, requiring that each covered service be sufficient in the amount of the service provided, the duration of time for which the service is provided, and the scope of the treatment provided to reasonably achieve its purpose.

**Azidothymidine (AZT)**—Also known as Zidovudine (ZDV), one of the first drugs successfully used in fighting HIV. Studies have shown that when a pregnant woman with HIV takes AZT, the chances of her passing the virus to her baby decrease significantly.

**Capitated payment (or capitated rate)**—A predetermined payment by a managed care plan to a health care provider, made on a periodic, per-member basis, regardless of the amount of health care services actually used by each member of the plan. Payment is made in exchange for the plan taking responsibility for paying for or providing all the covered health services needed by a beneficiary during a designated period.

**Carve-out**—A managed care plan exception in which certain types of care or groups of patients are not covered or are treated differently by the plan.

**Categorically needy**—Persons who fall into a covered category to receive Medicaid services (e.g., beneficiaries of SSI; those individuals who currently meet a state’s July 16, 1996, standards for AFDC; and pregnant women and children entitled to poverty-related Medicaid coverage). States are required to extend Medicaid coverage to these individuals as a condition of receiving federal matching funds.

**Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) Continuation Benefit**—A federal requirement that employers of 50 or more employees that offer a group health plan must offer employees the option of paying to continue it after their employment ceases for one of several specified reasons. In general, this benefit is available for 18 months after employment ends. If the individual is disabled at the time employment ceases, it is available for 29 months. Individuals must pay full (employer and employee) costs and administrative costs.

**Cost-sharing**—Payments made by the beneficiary of health insurance, in addition to the premium, for the receipt of health care services. These amounts include, for example, co-payments, co-insurance, and deductibles.

**Cytomeglovirus (CMV)**—CMV is one of the herpes viruses. It occurs commonly among children in child care. The virus is in urine, saliva, tears, stools, blood, vaginal secretions, semen and breast milk of infected people. Contact with these body fluids of an infected person is the most likely route of spreading the disease. CMV can damage the fetus of a pregnant woman who gets infected during the first half of her pregnancy. If the fetus is infected, the baby can develop hearing loss, learning disabilities, or, infrequently, more severe disease.

**Department of Health and Human Services (HHS)**—The federal department that includes the Health Care Financing Administration, the Centers for Disease Control and Prevention, the National Institutes of Health, the Food and Drug Administration, and the Health Resources and Services Administration, among others. The primary federal agency for protecting health and providing essential human services.

**Disabled**—For purposes of SSI eligibility, a person is disabled if he or she is unable to engage in any substantial gainful activity by reason of a medically determined physical or mental impairment expected to result in death, or that has lasted or can be expected to last for a continuous period of at least 12 months.

**Drug Rebate Program**—A program under Medicaid and the Department of Veterans Affairs requiring that, in order for a drug manufacturer to have its prescription drugs paid for by Medicaid, the manufacturer must give the government payor a discount in price. Failure to agree to such a policy with the federal government results in a complete ban on sales of the manufacturer’s drugs, not only to all Medicaid beneficiaries, but also to all beneficiaries of the Department of Veterans Affairs health care system and to all clients of a range of federally assisted health clinics. The discount requirements may

also apply to non-prescription drugs if they are covered in the state's Medicaid plan.

**Early Periodic Screening, Diagnosis, and Treatment (EPSDT)**—A package of comprehensive and preventative child health services that states are required to provide to Medicaid-eligible individuals under the age of 21.

**Federally qualified health center (FQHC)**—A facility that receives specific federal grant funding—e.g., federally assisted community health centers (including migrant health centers, and health care centers for the homeless).

**Fee-for-service plan**—The model generally considered to be traditional health insurance, in which the beneficiary pays a monthly fee to the insurer, who will then pay for a designated portion of the cost of any covered health care services used by the beneficiary.

**Gatekeeper**—an entity which is responsible for coordinating and approving all health care services a patient in a health care plan seeks or receives. The gatekeeper is usually, but not always, the patient's primary care physician. The gatekeeper monitors the patient's health, ensures that the patient is using appropriate services, and directs or refers the patient to other providers, as appropriate.

**Group-model HMO**—A type of HMO that contracts with a group of health care providers. The plan pays a negotiated fee to the group for services to be rendered; the group then pays its providers.

**Health Care Financing Administration (HCFA)**—The agency within the Department of Health and Human Services that administers the Medicare program and enforces federal requirements for the Medicaid program.

**Health maintenance organization (HMO)**—A general term used to describe a wide variety of different managed care plans that provide both inpatient and outpatient health care services to its members for a pre-paid, per-capita rate.

**Individual practice association (IPA) HMO**—A type of HMO that contracts with an association of health care providers, paying a negotiated fee for services rendered. The association contracts with individual providers, who may continue to have other patients, to render the services.

**Managed care organization (MCO)**—A general term used to describe a payment and delivery system designed to plan and provide health care services in a cost-conscious and coordinated manner.

**Mandatory services**—Services that states are required to provide to receive federal Medicaid matching payments. These generally include physician and hospital services, laboratory and X-ray services, prenatal care, and preventive services for children.

**Medicaid**—A means-tested public assistance program that provides payment for medical services for some people who cannot afford them. It is jointly funded by the federal and state governments.

**Medicaid MCO**—Generally, any sort of managed care plan under the Medicaid system. The Balanced Budget Act of 1997 has also established a statutory definition for this term—i.e., any public or private organization that maintains certain policies and procedures, including organizations such as an HMO, an eligible organization with a Medicare risk contract, a “Medicare+Choice” organization with a Medicare contract, or a provider-sponsored organization.

**Medically needy**—Persons who, except for income and resources, fall into one of the categories covered by a state and have income and resources within special limits established by the states. States are not required to do so, but may extend Medicaid coverage to these individuals.

**Medicare**—A federal program that provides health care coverage for elderly and disabled people who have paid into the Social Security fund for a minimum number of years.

**National Committee for Quality Assurance (NCQA)**—A private nonprofit organization in Washington, D.C., whose mission is to maintain and improve the quality of care within the managed care environment by holding managed care organizations accountable and providing purchasers of care with information on quality.

**Network-model HMO**—A type of HMO that contracts with multiple groups of health care providers. The plan pays the groups for services to be rendered; the groups then pay their member providers.

**Optional services**—Services that the states are not required to provide but may provide through Medicaid and receive federal matching payments. These include prescription drugs, hospice services, and case management services.

**Pharmaceutical benefits management (PBM)**—A managed care approach to prescription drugs. PBMs may be part of an overall managed care plan or a separate service, provided through a contract with a fee-for-service plan, a managed care plan, or the payor (employer or Medicaid program) directly.

**Point of service (POS)**—An amendment to a typical managed care plan that allows patients to go outside of the plan and use non-participating providers.

**Preferred provider organization (PPO)**—A form of managed care organization that contracts with limited numbers of physicians and other providers to provide services to plan beneficiaries at a discounted charge.

Prepaid health plan (PHP)—A term used almost exclusively in the Medicaid program, it is a managed care plan that bears the risk of profit or loss for the provision of a limited range of health care services, rather than the full range of patient services.

Primary care case management system (PCCM)—Generally, an organization that reviews and approves all health care services a patient is seeking or receives. The Balanced Budget Act of 1997 created a statutory definition for PCCM services; under that definition, case management-related services are provided by a physician, a physician group practice, an entity having arrangements with physicians to provide such services, a nurse practitioner, a certified nurse-midwife, or a physician assistant. Under the Act, the case management services must be provided under a contract with the state wherein the case manager will provide services that have reasonable and adequate hours of operation, are accessible to patients, have adequate availability of health care providers, do not discriminate based on health status, allow for termination of enrollment under certain circumstances, and meet other general requirements related to a state utilizing its option to use managed care.

Qualified Medicare beneficiary (QMB)—A person who is aged or disabled, receives Medicare, has an income at or below 100% of the poverty level, and has assets at or below 200% of the SSI assets level.

Qualified disabled and working individual (QDWI)—A person who was previously entitled to Medicare Part A on the basis of his or her disability, who lost the entitlement due to increased earnings from work, but who continues to have a disabling condition and whose income is at or below 200% of the federal poverty level and whose assets are at or below 200% of the SSI assets level.

Qualified Individual (QI)—A person who would be a qualified Medicare beneficiary but for his or her income exceeding the established level, and whose income is at least 120%, but less than 135%, of the poverty level. The actual percentage-of-poverty level is chosen by the state

Ryan White Comprehensive AIDS Resources Emergency (CARE) Act—A federal law that provides federal funds to cities, states, and non-profit clinics for planning, implementing, and evaluating programs to improve the quality and availability of health care and support services for people with HIV/AIDS.

Section 1983—A provision of federal law (42 U.S.C. Section 1983) stating that an individual who has been deprived of a federal right (such as the guarantees set forth in the Medicaid program) by a person acting on behalf of a state may bring an action in court to enforce that right.

**Social Security Disability Insurance (SSDI)**—This program provides cash assistance to individuals who have a qualifying disability and who have paid into the Social Security system for a minimum number of years.

**Social Security Administration (SSA)**—The federal agency that administers SSI and SSDI, among other programs.

**Specified low-income Medicare beneficiary (SLIMB)**—A person entitled to receive Medicare, who has an income between 100% and 120% of the national poverty level, but whose resources are at or below 200% of the SSI resource level.

**Staff-model HMO**—A type of HMO that usually owns hospitals and employs physicians and other health care staff.

**State Children’s Health Insurance Program (CHIP)**—A federal law to expand coverage to low-income uninsured children. Congress enacted the CHIP as part of the Balanced Budget Act of 1997. This new program allocates \$20.3 billion in federal matching funds over five years to states to expand insurance for children. States can use the money to expand coverage either through a separate state program or by broadening their Medicaid programs—or both.

**Supplemental Security Income (SSI)**—A federal cash assistance program that provides assistance to low-income persons who are aged, blind, or disabled.

**Temporary Assistance for Needy Families (TANF)**—A federal program that gives states block grants to provide time-limited cash assistance for needy families. This program was created by the Personal Responsibility and Work Opportunity Act of 1996, and replaces the AFDC program.

**Waiver**—Discretionary permission from the secretary of HHS to waive certain statutory requirements of Medicaid law when a state wishes to use nontraditional methods to deliver or pay for Medicaid services.

**Women, Infant, and Children Programs (WIC)**—WIC is the Special Supplemental Nutrition Program for Women, Infants, and Children. This is a federally funded nutrition program that provides nutrition education, healthful foods, and health referrals to women, infants, and children who qualify. WIC is for pregnant women, breastfeeding women (up to 1 year after delivery), postpartum women (up to 6 months after delivery), infants and children up to age 5.



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