

Meeting the Needs  
of Children, Youth, and  
Families Affected by  
HIV and AIDS Through  
Medicaid Managed Care

AIDS Policy Center for  
Children, Youth & Families  
Washington, D.C.

## **Acknowledgements**

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## Executive Summary

The Medicaid program is a vitally important source of health care financing for Americans living with HIV disease, 53 percent of whom rely on Medicaid for their health care. Among children living with HIV and AIDS, Medicaid is a true lifeline—over 90 percent depend on Medicaid for access to care (HCFA, 1995). Medicaid provides these children with a comprehensive continuum of medical care and developmental support services.

As an increasing number of states seek to control health care costs by moving Medicaid beneficiaries into managed care, it is essential that Medicaid officials, health care providers, advocates, and families work together to develop managed care plans that provide the continuum of high-quality care that children, youth, and families living with HIV/AIDS need. Because key Medicaid managed care decisions are being made at the state level, young people and families, health care providers, and advocates have an opportunity to influence the quality and availability of care for people with HIV and AIDS by working with state Medicaid officials and managed care organizations. AIDS Policy Center for Children, Youth & Families developed this document to guide and assist these stakeholders in Medicaid managed care.

Based on our experience working with families, health care providers, and policy makers, AIDS Policy Center has developed the following key questions for consideration when evaluating Medicaid managed care systems serving children, youth, and families affected by HIV and AIDS. We hope they will be a useful guide for young people, families, and care providers.

### *Quality*

- **Does the managed care plan provide the highest quality care to all enrollees, with special consideration to the needs of children, youth, and families affected by HIV/AIDS?**
- **Are care and benefit packages based on clinical standards set by independent professional organizations or government bodies?**
- **Are clinical standards continually updated to include new and evolving HIV/AIDS treatment knowledge and technology?**

- Does the managed care plan include consumer-friendly grievance and appeals procedures that enable enrollees to challenge decisions to deny care, including experimental treatment?
- Does the managed care plan track the care needs of children, youth, and families affected by HIV/AIDS as a way to ensure that all needed care and services are offered by the plan?

### *Choice*

- Does the managed care plan ensure that youth and families have a choice of qualified health care professionals with expertise in HIV/AIDS treatment?
- Are youth and families affected by HIV/AIDS able to choose a primary care provider with HIV/AIDS expertise, including a specialist to serve as the primary care physician (e.g., an OB-GYN or pediatrician) if necessary?
- Does the managed care plan's network of providers include physicians and other health care providers with expertise in HIV/AIDS treatment or permit unlimited out-of-plan use of such providers?
- Does the managed care plan provide affordable options for youth and families to seek out-of-network health care when necessary?

### *Access*

- Does the managed care plan offer youth and families living with HIV/AIDS convenient and timely access to the care they need?
- Does the managed care plan contract with essential community providers who care for youth and families affected by HIV/AIDS, including Ryan White Title IV community providers?
- Does the managed care plan offer access within a reasonable travel time to a full range of primary care providers, specialists, and specialty care centers?

- Does the managed care plan make non-emergency services available on evenings and weekends?

### *Cultural Competence*

- Does the managed care plan provide a full choice of culturally appropriate benefits and providers, including community-based facilities?
- Does the managed care plan ensure that its provider network reflects the cultural, religious, and demographic makeup of the communities the plan serves?
- Does the managed care plan ensure that culturally competent care is available to all enrollees?

### *Non-Discrimination*

- Does the managed care plan ensure that no consumer or provider is discriminated against in enrollment, access to care, or quality of care?
- Is the managed care plan—in marketing, enrollment, and the provision of services—free from discrimination based on current or anticipated mental or physical health status, race, gender, income, age, geography, or other factors?
- Is the managed care plan free from discrimination against providers based on their—or their patients’—mental or physical health status, race, gender, sexual orientation, religious beliefs, income, age, or other factors?



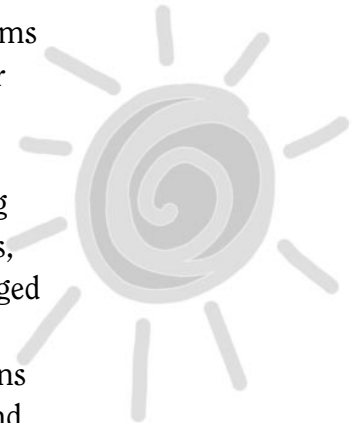
## Introduction and Overview

The Medicaid program is a vitally important source of health care financing for Americans living with HIV disease, 53 percent of whom rely on Medicaid for their health care. Among children living with HIV and AIDS, Medicaid is a true lifeline—over 90 percent depend on Medicaid for access to care (HCFA, 1995). Medicaid provides these children with a comprehensive continuum of medical care and developmental support services.

Because so many children and young people living with HIV and their families receive care through Medicaid, changes to the program have the potential to significantly benefit or harm this vulnerable population. This is nowhere more apparent than with the trend to enroll Medicaid beneficiaries, including people with HIV/AIDS and other disabilities, into managed care systems. Although the appropriateness of managed care for people with HIV/AIDS is still a matter of intense debate, managed care is rapidly becoming the norm in state Medicaid programs. The task before us is to ensure that Medicaid managed care programs meet the complex needs of children and youth living with HIV/AIDS and their families.

As an increasing number of states seek to control health care costs by moving Medicaid beneficiaries into managed care, it is essential that Medicaid officials, health care providers, advocates, and families work together to develop managed care plans that provide the continuum of high-quality care that this group of children and young people need. Because key Medicaid managed care decisions are being made at the state level, youth and families, health care providers, and advocates have an opportunity to influence the quality and availability of care for people living with HIV and AIDS by working with state Medicaid officials and managed care organizations. AIDS Policy Center for Children, Youth & Families developed this document to guide and assist these stakeholders in Medicaid managed care.

*Meeting the Needs of Children, Youth, and Families Affected by HIV and AIDS Through Medicaid Managed Care* provides basic information about managed care and Medicaid and offers key questions for youth and families, health care providers, and advocates to consider in developing or evaluating Medicaid managed care plans. Specifically, the document discusses:



- an overview of the Medicaid program, including funding, eligibility, and delivery of care;
- basic information about managed care, including a glossary of terms in the Appendices;
- a summary of how managed care is increasingly being used to deliver and finance health care for Medicaid beneficiaries;
- some fundamental challenges to health care access under Medicaid managed care; and
- ways youth and families affected by HIV and AIDS can get involved in the development of Medicaid managed care systems.

## The Current Picture

**M**edicaid began in 1965 as a public health insurance program for poor Americans without other access to care. The advent of the AIDS epidemic made Medicaid an essential safety net for a majority of Americans who are living with HIV and AIDS. Many came to depend on publicly financed care only after they became impoverished by AIDS. They lost their private workplace-based insurance when they became too sick to work, spent down their assets to pay for care, and eventually turned to Medicaid.

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Many other Medicaid recipients with HIV/AIDS, particularly women, children, and youth, never had private health insurance or other access to private care. Medicaid is their lifeline to care, and many also depend on a shrinking patchwork of other federal and state assistance for the basic necessities of life. As control of essential programs for food, shelter, and health care shift from federal to state and local government, this vulnerable group of Medicaid beneficiaries have a new opportunity to form partnerships with their care providers and advocates in order to shape the programs that they will use, especially Medicaid managed care plans. AIDS Policy Center encourages them to do so, and we urge their health care providers to work with them as supporters and advocates.

The increasing importance of Medicaid as a safety net for children, youth, and families affected by HIV disease emphasizes long-standing barriers to health care

access, including race and gender. Recently, for the first time in the epidemic, the Centers for Disease Control and Prevention (CDC) reported a decrease in the AIDS death rate. Among women with HIV/AIDS—the great majority of whom are African American or Latino—and among people of color in general, the decrease in death rates was much smaller, most likely because of their relative lack of access to state-of-the-art HIV/AIDS care. In light of such continuing inequities, Medicaid will remain a critical resource for women and children living with HIV and AIDS.

Also of critical importance to the health of children, youth, and families living with HIV and AIDS is Title IV of the Ryan White CARE Act. Title IV projects, which make up the core of AIDS Policy Center membership, provide comprehensive family-centered, culturally competent care and support to women, children, young people, and families affected by HIV and AIDS. These Title IV programs encompass 350 care centers in 27 states, the District of Columbia, and Puerto Rico. The great majority of children, youth, and families served through Title IV are also enrolled in Medicaid and rely on the Medicaid program for a broad array of health care and support services. As of mid-1996, according to the Maternal and Child Health Bureau (AIDS Policy Center for Children, Youth & Families, 1997), about one-third of Title IV clients who are Medicaid beneficiaries are enrolled in managed care.

## About the Medicaid Safety Net

**F**or more than 30 years, the Medicaid program has provided access to health care for low-income and disabled Americans. For eligible children and adolescents, Medicaid offers a comprehensive set of benefits that includes a full range of health, mental health, and developmental services. Availability of this continuum of care through Medicaid is especially important because poor children typically have more health problems than affluent children (The Kaiser Commission on the Future of Medicaid, 1997). Today, one out of four American children receives health care paid for by Medicaid.

Medicaid is a joint federal and state entitlement program, which is administered by the states. The cost of Medicaid is split between the federal government and each state, with the federal government paying between 50 to 80 percent of the cost, and the state paying the rest. Currently, the federal government requires

that all states cover certain eligible groups of people, but 44 percent of poor Americans remain ineligible for Medicaid (The Kaiser Commission on the Future of Medicaid, 1996a). Even so, Medicaid helps pay for health care for 37 million Americans—about one in 10.

As an entitlement program, Medicaid guarantees that individuals who meet the eligibility requirements will receive Medicaid services and benefits. Therefore, federal and state spending for Medicaid is not limited to a fixed amount, and Medicaid benefits are not limited to a fixed number of beneficiaries. The entitlement ensures that the Medicaid program can respond to actual need, rather than limit enrollment to an arbitrary number of people. The entitlement also guarantees that each state dollar paid for Medicaid-eligible individuals will be matched by the federal government at a rate defined in law. The matching payment rate, known as the Federal Medical Assistance Percentage (FMAP), is based on state average per capita income levels compared to the national average, with wealthier states contributing more toward overall Medicaid costs than poorer states.

In order to receive federal matching funds, states must meet certain requirements concerning Medicaid eligibility and benefits. Since state and federal dollars finance the Medicaid program, these requirements ensure some uniformity in the Medicaid entitlement. The entitlement status of the Medicaid program guarantees that every state Medicaid program will offer a minimum package of benefits to certain eligible populations. Federal Medicaid law includes minimum eligibility and benefit criteria that states must meet in the administration of the program. Beyond these minimum criteria, states are also allowed to offer other optional eligibility categories and benefits within certain guidelines. This means that some states have more generous Medicaid programs than other states.



### *Who Is Eligible?*

Not all poor Americans are eligible for Medicaid, only those who fall into certain eligibility categories. The general rule for Medicaid eligibility, requires that individuals meet two criteria in order to qualify for the program: income eligibility and categorical eligibility. The groups for which states are required to provide coverage are called "mandatory categorically needy groups." For children, youth, and families affected by HIV/AIDS, the most important of the mandatory categorically needy groups are:

- pregnant women and their children up to age six who have income below 133 percent of the federal poverty level;
- individuals who meet the former AID to Families with Dependent Children (AFDC) program criteria; and individuals receiving Supplemental Security Income (SSI).

States also can provide Medicaid for certain "optional categorically needy" groups, allowing states to receive federal matching payments for extending coverage to more people. The optional eligibility groups tend to have more flexible eligibility requirements as compared to the mandatory groups. Federal law defines the parameters of optional categorically needy eligibility by the range of income allowed and allowable population groups. Many states use this option to cover individuals who meet the categorical eligibility criteria for mandatory eligibility, but have incomes higher than allowed under mandatory eligibility.

Examples of optional categorically needy groups include:

- pregnant women and infants up to age one with income between 133 percent and 185 percent of the federal poverty level, with states choosing the actual percentage; and
- some adults who are disabled, blind, or elderly with incomes above the mandatory eligibility requirements but below the federal poverty level.

The "medically needy" option permits states to offer Medicaid eligibility to certain individuals with incomes above both the mandatory and optional eligibility criteria. The medically needy option allows individuals (such as adults disabled by AIDS) who meet certain categorical eligibility criteria to "spend down" their assets to meet Medicaid income eligibility by incurring medical expenses, thereby reducing their income to meet the state Medicaid eligibility requirements. Some states also allow families to use the medically needy option to "pay in" to the Medicaid program. These families pay a premium equal to the difference between their income and the Medicaid income eligibility requirements. Currently, 36 states offer medically needy programs. This option has been very important for many people living with HIV/AIDS, particularly certain adult males, individuals who do not qualify under the AFDC criteria, and families with incomes above the Medicaid income requirements.

## *Eligibility Challenges Facing Children, Youth, and Families Affected by HIV/AIDS*

Medicaid eligibility has historically been linked to a number of important government assistance programs. This linking has allowed individuals who met eligibility requirements for programs such as AFDC and SSI to be automatically eligible for Medicaid coverage. For women and children living with HIV/AIDS, automatic eligibility through AFDC has been critical to ensuring access to health care.

**SSI.** With the notable exception of women and children, the majority of people with HIV/AIDS on Medicaid are eligible through meeting disability requirements and qualifying for SSI assistance. To qualify for the SSI program, which provides income assistance to people with serious disabilities, individuals must be disabled as defined by the Social Security Administration (SSA). In the case of HIV/AIDS, this usually means that only individuals who have an HIV symptomatic medical diagnosis can qualify. New clinical practice standards for HIV/AIDS recommend early treatment, before HIV has devastated the immune system. The SSI eligibility criteria requiring "full blown" AIDS disability contradict these clinical standards, and advocates are concerned that the SSA disability definition is preventing many HIV-positive people who are not yet sick enough to qualify for Medicaid from having early access to life-saving treatments.

**AFDC.** For over 60 years, the AFDC program has provided vital financial assistance to needy children and other family members through a joint federal/state partnership. The AFDC program has traditionally been linked to the Medicaid program, ensuring that these needy individuals have access to medical and other essential health services. Until recently, women and children who were eligible for the AFDC program were automatically eligible for Medicaid coverage, and the majority of women and children affected by HIV disease on Medicaid have accessed the Medicaid program this way.

In 1996, the AFDC program was abolished by the enactment of new welfare legislation, the Personal Responsibility and Work Opportunity Act of 1996. The Act replaced AFDC with a program called Temporary Assistance to Needy Families (TANF), and there is no automatic link between TANF eligibility and Medicaid eligibility as there was with AFDC. This means that many women and children who previously qualified for AFDC may not qualify for the TANF program, ultimately jeopardizing their access to Medicaid. The Act does retain the former AFDC eligi-

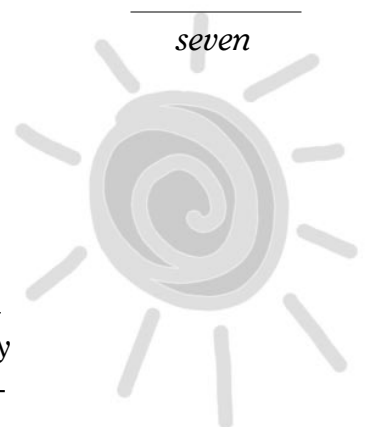
bility criteria as the trigger for Medicaid eligibility. However, advocates are concerned that families that do not qualify for the new TANF program may not know that they could still gain access to Medicaid if they meet the former AFDC criteria.

**Youth.** Medicaid eligibility for adolescents is also of particular concern to families and advocates for people living with HIV and AIDS, because HIV infection is rising alarmingly among young people, who, as a group, are more likely to be uninsured than children or older adults. Two Americans under the age of 20 become HIV infected every hour of every day, and youth between the ages of 13 and 20 account for an estimated one-quarter of all new HIV infections in the U.S. (Office of National AIDS Policy, 1996).

Currently states are required to provide Medicaid coverage for adolescents ages 14 to 19 if the family meets the AFDC eligibility criteria, with the average state qualifying income being 41 percent of the federal poverty level (The Kaiser Commission on the Future of Medicaid, 1997). This leaves millions of poor youth uninsured. A Congressionally mandated "phase in" of coverage for adolescents living below the poverty line, which is scheduled to be complete in 2002, is periodically threatened by Congressional efforts to restructure Medicaid (English, in press). In 1995, for example, the proposed block grants would have eliminated the mandatory phase in. The good news is that some states are taking an active stance on behalf of young people. At least 23 states have expanded coverage for adolescents, using Medicaid options to go beyond the requirements of the mandatory phase in (English, in press).

## About Managed Care

**M**edicaid is a major expense in state budgets. In 1994, for example, states spent \$59 billion for Medicaid, while the federal government spent \$79 billion. Faced with rising health care costs, states are seeking new ways to cut Medicaid program expenditures. Increasingly, states are turning to managed care as a way to control Medicaid program costs. Nationally, 40 percent of all Medicaid beneficiaries are enrolled in managed care programs (The Kaiser Commission on the Future of Medicaid, 1997). This represents a sharp rise from 1993, when only 14 percent of people covered by Medicaid were in managed care (The Kaiser Commission on the Future of Medicaid, 1995).



Managed care is a system for financing, delivering, and evaluating health care within a limited network of providers for a fixed, usually prepaid cost. Care is typically coordinated through a primary care physician, who determines what care is needed, including making decisions about when it is necessary to see a specialist.

Ideally, managed care provides people living with HIV and AIDS with much-needed care coordination, ensuring that the right care is provided at the right time and in the right amount—no more, no less (Koyanagi, 1997, p. 2), and several notable managed care plans offer state-of-the-art HIV/AIDS care to their enrollees.

Managed care can present risks, however, if access to specialists skilled in HIV care is limited or unavailable or if medically necessary services are not provided. Managed care has an uneven track record in dealing with people who are disabled or chronically ill, including those living with HIV/AIDS. Aseltyne and his colleagues (1995) identified a major concern with the wholesale assignment of people with HIV/AIDS to managed care: "HIV disease, with a rapidly changing standard of care, may not fit neatly into the financing structures of managed care because providers may have difficulty controlling or even predicting the costs of care" p. s11.

The need to control and predict costs, essential elements of managed care, make people living with HIV and AIDS unattractive prospects for many managed care plans. There is no question that HIV-positive Medicaid recipients, like many other people with serious disabilities, are relatively high users of medical care and consequently more costly to cover. Although people with HIV/AIDS made up only 0.3 percent of Medicaid beneficiaries in 1994, they accounted for two percent of Medicaid spending that year (The Kaiser Commission on the Future of Medicaid, 1996b). Families and advocates are concerned that the relative high cost per beneficiary of Medicaid recipients with HIV/AIDS will lead managed care plans to avoid enrolling them or to deny them necessary care once enrolled.

Regardless of the fit between managed care and quality HIV/AIDS care, the massive shift toward managed care in Medicaid clearly will continue. The challenge facing state Medicaid officials, managed care organizations, consumers, health care providers, and advocates is to design managed care plans that meet the complex needs of children, youth, and families living with HIV and AIDS.

### *Financing—Fee-For-Service vs. Capitation*

Under the traditional Medicaid program, the financing and delivery of care are separate. Payment for services is handled through a fee-for-service payment arrangement, in which physicians and other care providers charge a fee for each service or procedure and are reimbursed accordingly by the Medicaid program. Critics of the fee-for-service system argue that providers have incentives to perform costly and frequent interventions because they are guaranteed payment. The fee-for-service system also has been criticized for lacking coordination and promoting duplication of services, both of which burden people living with HIV and AIDS. Many states view the fee-for-service system as partially responsible for skyrocketing costs in the health care industry in general and in the Medicaid program in particular. Through managed care, states hope to gain some control over Medicaid spending by limiting the payment of health care services per beneficiary and by coordinating the delivery and financing of care. Additionally, some families receiving care through the Medicaid fee-for-service system have difficulty finding physicians and other health care providers who accept Medicaid patients.

Under managed care, health care financing and delivery are merged. The managed care environment is a capitated system, in which managed care organizations, or plans, are paid a set fee for each person they agree to serve. The capitated rate is paid per beneficiary, regardless of the care or services actually delivered. A capitated rate builds in an incentive for managed care plans to control the utilization and costs of services—the less care used, the higher the profit. Managed care plans control utilization and costs through a variety of mechanisms, including coordination, utilization review, and physician incentives.

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### *Care Coordination—The Primary Care Provider*

Coordination is a key component of managed care. The goals of care coordination are to achieve cost savings and improve health outcomes. Managed care plans use primary care providers—generally family practitioners, pediatricians, and other primary care physicians—to coordinate patient care and service utilization. One of the functions of the primary care provider is to control the access that patients have to specialized care. Generally, managed care enrollees must receive a referral from their primary care provider in order to see a specialist. This referral requirement can be burdensome for children, youth, and fami-

lies living with HIV/AIDS or other disabilities, who typically require care from an array of specialists and subspecialists. Managed care plans in many states are modifying the referral requirement for people with chronic illnesses as a way to improve access to care.

Because the state of HIV/AIDS care is changing so rapidly, primary care providers also may not have adequate training in the treatment of HIV disease to effectively coordinate care for people who are HIV infected. This lack of expertise can result in people living with HIV/AIDS being denied access to needed specialty care.

### *Physician Incentive Programs*

Managed care plans use physician incentives to control the overutilization of services often present in the fee-for-service system. Managed care plans track the number of referrals and specialized, costly services that physicians authorize. Physician incentive programs financially reward physicians who limit access to costly services, including referrals to specialized care. Therefore, physicians who have a high number of referrals to specialists and who authorize access to costly services will be affected negatively by not receiving financial bonuses or other payments. At a minimum, such arrangements can make people living with HIV/AIDS unattractive patients for many managed care physicians. In the worst case, physician incentives can act to limit access to necessary specialty care.

### *Utilization Review*

Utilization review is used by managed care plans to evaluate the necessity, appropriateness, and efficiency of the care delivered to beneficiaries. Plans compare data on the actual delivery of care with established criteria and standards.

Managed care plans often use utilization review data to determine what services they will cover and how these services will be delivered. Since the goal of utilization review is ultimately cost savings, it favors tried and true, inexpensive treatments. For people living with HIV/AIDS, utilization review data has been used to limit access to effective treatments and clinical trials on the basis of cost and experimental status. This is a particular danger for pregnant women, children, and youth, for whom many HIV/AIDS treatments are considered experimental.

# STATUS OF STATE MEDICAID WAIVERS

## *Approved & Implemented (15)*

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Alabama	New York
Arizona	Ohio
Arkansas	Oklahoma
Delaware	Oregon
Hawai'i	Rhode Island
Maryland	Tennessee
Massachusetts	Vermont
Minnesota	

## *Approved Pending Implementation (3)*

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Florida  
Illinois  
Kentucky

## *Framework Approved*

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South Carolina

## *Under Review (8)*

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Georgia	New Jersey
Louisiana	Texas
Missouri	Utah
New Hampshire	Washington

## *Disapproved (1)*

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Montana

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## The Medicaid Waiver Process

The shift toward managed care for Medicaid recipients with special health care needs has been taking place primarily through special waiver programs, in which the federal government allows states to experiment with alternative models for providing Medicaid care. States must get permission from a federal agency called the Health Care Financing Administration (HCFA) to make certain kinds of changes in their Medicaid programs. This permission, when granted, is called a "waiver," because it allows states to waive or put aside certain parts of federal Medicaid law.

Currently, 15 states have approved and implemented Medicaid waivers; another three have approved waivers pending implementation; one state has the framework approved; eight have a waiver application under review; and one has had its waiver disapproved (see chart). State Medicaid waiver applications are public documents. Consumers, health care providers, and advocates can get a copy, with a little persistence.

The Medicaid waiver process allows states flexibility to waive a number of requirements that govern the Medicaid program. Among these are provisions that ensure Medicaid beneficiaries:

- comparable access to services regardless of an individual's condition or illness; and
- statewide access to any service provided regardless of where an individual beneficiary lives in the state.

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Provisions like these ensure that higher-cost beneficiaries, including people living with HIV/AIDS, have access to the health care providers and services they need under Medicaid. They also mean that individuals with certain illnesses or disabilities cannot be denied access to care available to other beneficiaries.

Through the Medicaid waiver process, states apply to waive some of these provisions of Medicaid law. In their waiver applications to HCFA, states generally must identify which provisions of Medicaid law they wish to waive, define the population groups they intend to enroll under managed care, and demonstrate that they have sought public/consumer input into the waiver application. States also

must comply with any requests from HCFA for revisions to the application. Most waiver applications include a proposed timeline for implementation of the waiver, including when and how certain portions of the Medicaid populations will be enrolled in managed care.

While many states are looking to managed care to help control Medicaid costs, most states with waivers tend not to enroll their entire Medicaid populations in managed care, at least initially. Usually, states choose to enroll the least costly populations first, including women and children eligible under the AFDC criteria. States can choose to require or offer Medicaid managed care enrollment to portions of their Medicaid populations. In most cases, women and children eligible through AFDC criteria are enrolled mandatorily, meaning they can no longer get care through fee-for-service Medicaid. Under most waivers granted to date, individuals with disabilities have typically been given the choice of voluntarily enrollment in the managed care plan or remaining in fee-for-service.

Recent changes to the Medicaid program eliminate the freedom of choice protection that formerly required states to seek a waiver to enroll Medicaid beneficiaries in managed care. States are now permitted to mandate enrollment of Medicaid recipients in managed care, with a few exceptions. Among the exceptions are children with special health care needs. States may still seek permission to mandate managed care enrollment for these children under Medicaid waiver programs, as well as to make other decisions that will affect the quality and availability of care to children, youth, and families living with HIV and AIDS. For these reasons, consumers, health care providers, and advocates remain important stakeholders in the Medicaid waiver process.

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### *People Living with HIV/AIDS and the Medicaid Waiver Process*

The public input component of the Medicaid waiver process has been critical to protecting consumers, particularly consumers with special needs, in the development and implementation of Medicaid waivers. People living with HIV/AIDS and health advocates have made important contributions to many Medicaid waiver processes—identifying some of the problems with proposed waivers and arguing for the needs of people with HIV/AIDS under managed care, thereby educating HCFA and others about what these needs are. In turn, before granting approval to enroll this population in managed care, HCFA has required

a number of states to revise their waiver applications to demonstrate their ability to adequately address the health care needs of people living with HIV/AIDS.

There are a number of ways that people living with HIV/AIDS, their care providers, and advocates can get involved in the Medicaid waiver process. The following suggestions offer a starting point:

- Get involved with community organizations in your area, including AIDS organizations, health or disability advocacy groups, and local or state medical or nursing associations.
- Call your state legislative representative and ask if the state has plans to submit a Medicaid waiver.
- Participate in public hearings or other opportunities to comment on proposed Medicaid waivers.
- Request information on Medicaid and managed care issues from AIDS advocacy organizations.



## **Challenges for Children, Youth, and Families Affected by HIV and AIDS**

**T**he shift toward Medicaid managed care raises many new challenges to the delivery of health care to children, adolescents, and families living with HIV and AIDS. The managed care model was developed to provide care for healthy, employed people—a population with relatively low health care costs, well-suited to the kind of preventive, cost-effective care that managed care plans emphasize. Managed care can be problematic with a costly, high service utilization population, such as people with HIV/AIDS. In fact, preventive care may not always result in lower health care costs for people living with HIV disease, particularly with expensive new HIV/AIDS treatments such as triple drug combination therapy with protease inhibitors.

Enrollment in Medicaid managed care will not affect all people living with HIV/AIDS equally. Children, adolescents, and families qualifying for Medicaid under the AFDC criteria may end up being enrolled in managed care mandatorily because they are part of the larger AFDC population, whether or not they have

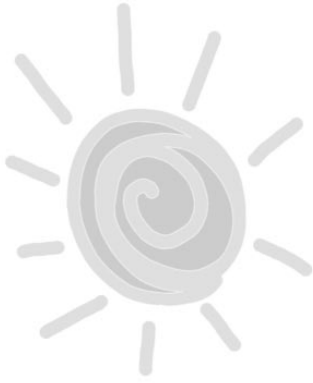
HIV/AIDS. If they do have HIV disease, finding themselves without access to their choice of health care providers could prove disastrous. Although the disabled population, including people with AIDS, are usually given the choice of voluntary enrollment into Medicaid managed care, individuals with HIV/AIDS in the AFDC category, including women, children, and adolescents, have not always been afforded the same voluntary enrollment option as other disabled individuals with HIV.

An understanding of the challenges that people living with HIV/AIDS face under managed care can help health care advocates and policy makers develop Medicaid managed care plans that address their special health care needs. The Medicaid waiver process provides a valuable opportunity for families and their health care providers and advocates to raise concerns with state Medicaid officials, HCFA representatives, and managed care organizations. This consumer and provider involvement will help protect access to a comprehensive continuum of high-quality health care for children, youth, and families affected by HIV and AIDS.

## **Key Questions to Consider for Serving Children, Youth, and Families Affected by HIV/AIDS in Managed Care Plans**

**A**IDS Policy Center for Children, Youth & Families has identified five aspects of health care that are of special importance to children, adolescents, and families affected by HIV and AIDS: quality, choice, access, cultural competence, and non-discrimination. The centrality of these concepts has been demonstrated over the last decade by health care providers and families working in partnership to develop systems of pediatric/family HIV/AIDS care, first through the federal Maternal and Child Health Bureau, and now through Title IV Ryan White CARE Act programs.

Based on this experience, we have developed key questions to consider for serving children, youth, and families affected by HIV/AIDS through Medicaid managed care. We hope they will be a useful guide for consumers, health care providers, and advocates interested in working with state Medicaid officials and managed care organizations to develop or evaluate Medicaid managed care plans.



## *Quality*

- ✓ **Does the managed care plan provide the highest quality care to all enrollees, with special consideration to the needs of children, youth, and families affected by HIV/AIDS?**
- ✓ **Are care and benefit packages based on clinical standards set by independent professional organizations or government bodies?**
- ✓ **Are clinical standards continually updated to include new and evolving HIV/AIDS treatment knowledge and technology?**
- ✓ **Does the managed care plan include consumer-friendly grievance and appeals procedures that enable enrollees to challenge decisions to deny care, including experimental treatment?**
- ✓ **Does the managed care plan track the care needs of children, youth, and families affected by HIV/AIDS as a way to ensure that all needed care and services are offered by the plan?**

Managed care plans use clinical standards, utilization review, and quality assurance mechanisms to coordinate the delivery of health care, track the effectiveness of interventions, and develop treatment guidelines and standards. These mechanisms, in principle, provide managed care plans with useful information that can help health care providers use the most cost-effective interventions. However, in practice, these mechanisms can effectively deny access to needed health care for vulnerable groups. For children, adolescents, and families living with HIV disease, there can be grave consequences to such denial of care.

Managed care plans often develop their own clinical practice standards, instead of looking to those developed by independent medical organizations or government bodies. The current rapid-fire pace of change in HIV/AIDS care makes this a bad idea. Even AIDS specialists are struggling to identify best clinical practices. Non-specialists have no chance of doing so.

Clinical practice standards used by managed care plans to guide providers in the treatment and management of patients also tend to rely on the tried and true, rather than new cutting-edge treatments. Limited, conservative clinical standards have resulted in people living with HIV/AIDS essentially being denied

access to life-saving treatments—triple drug combination therapy, for example. Many HIV-positive individuals enrolled in managed care have had difficulty participating in clinical trials because managed care plans often consider such trials as experimental. This is particularly harmful to women, children, and adolescents with HIV disease, because clinical trials have historically ignored these populations, and new opportunities are just now being created for their participation.

Utilization review helps reduce duplication and inefficiency by evaluating the necessity and appropriateness of clinical treatment. One of the problems with using utilization review data in this way is that managed care plans often fail to take into consideration special needs populations, such as children and youth with HIV/AIDS, in the collection and analysis of data. Therefore, utilization review might deem services used by people living with HIV/AIDS or other disabilities—who tend to need more frequent and costly care—as unnecessary and unwarranted, resulting in a denial of essential care.

Managed care plans use utilization review and clinical standards not only to provide effective health care, but also to save money. With cost saving as the bottom line, the needs of vulnerable populations, including people living with HIV/AIDS, may not be adequately addressed. Factoring in the frequent and expensive health care needed by this population and the rapidly evolving treatment standard, it is no wonder that there are concerns about access to high-quality health care for this group of children, young people, and families.

### *Choice*

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- ✓ **Does the managed care plan ensure that youth and families have a choice of qualified health care professionals with expertise in HIV/AIDS treatment?**
- ✓ **Are youth and families affected by HIV/AIDS able to choose a primary care provider with HIV/AIDS expertise, including a specialist to serve as the primary care physician (e.g., an OB-GYN or pediatrician) if necessary?**
- ✓ **Does the managed care plan's network of providers include physicians and other health care providers with expertise in HIV/AIDS treatment or permit unlimited out-of-plan use of such providers?**

✓ **Does the managed care plan provide affordable options for youth and families to seek out-of-network health care when necessary?**

Traditional fee-for-service systems allow patients to see any provider they choose. Critics of this system blame freedom of choice as a factor contributing to runaway health care costs and unnecessary treatment. By creating networks of providers and using primary care providers to coordinate and manage the health care of plan participants, managed care limits the choice of individual patients. Managed care plans further limit choice through controlling access to specialists and certain kinds of care. For individuals with special health care needs, who typically require frequent consultation with specialists and regular diagnostic testing, seeking referrals can become overly burdensome, and limited choice of providers can have negative effects on access to treatment and health outcomes.

Primary care providers can adequately triage and coordinate care for relatively healthy enrollees, but the complex needs of those with HIV disease may pose challenges. Physicians with HIV treatment expertise may be best suited to coordinate the care of HIV-positive patients. According to a recent study (cite, 1996), the single most important indicator of positive health outcomes for people living with HIV and AIDS is the extent of physician experience treating people with HIV disease. In the case of children, youth, and families, the expertise of the primary physician can be even more important, as many physicians with experience treating HIV-positive adult males are unfamiliar with diagnosing and treating HIV disease in women, children, and adolescents.

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As managed care plans set up their networks of physicians, physicians with HIV expertise must be included. Because the health care needs of people living with HIV/AIDS are complex and treatments are rapidly evolving, plans must ensure that access to specialized care is available. Preferably, specialized care should be available within the plan's network of providers. However, if certain specialized care is unavailable within the network, the plan should ensure that out-of-network care is available and affordable.

Individual enrollees also ought to be able to designate a physician with HIV expertise to serve as their primary physician. This means that families affected by HIV should be able to choose a specialist, such as an OB-GYN, to manage their health care, and some private and Medicaid managed care plans do view this as

an effective strategy for managing the complex health care needs of individuals with HIV/AIDS. Plans also are increasingly using "standing referrals" for this purpose, allowing the primary care physician to approve standing referrals that permit enrollees with special health care needs to seek specialized care that they need on a regular basis.

### *Access*

- ✓ **Does the managed care plan offer youth and families living with HIV/AIDS convenient and timely access to the care they need?**
- ✓ **Does the managed care plan contract with essential community providers who care for youth and families affected by HIV/AIDS including Ryan White Title IV community providers?**
- ✓ **Does the managed care plan offer access within a reasonable travel time to a full range of primary care providers, specialists, specialty care centers?**
- ✓ **Does the managed care plan make non-emergency services available on evenings and weekends?**



Barriers to care exist both within fee-for-service and managed care systems. Poor women and people of color are most likely to experience these barriers. Access is further complicated when individuals have complex health care conditions, such as HIV/AIDS. For families, children, and adolescents with HIV/AIDS, community-based care providers, such as the Ryan White Title IV health centers, are essential for ensuring access to appropriate care. Care provided through Title IV is family-centered, planned in partnership with families and addressing the health, social, and psychosocial needs and concerns of the entire family. Managed care plans should include these and other community providers in their provider networks, and Title IV providers should explore the feasibility of entering into contracts under Medicaid managed care to provide the support services needed by families living with HIV disease.

Managed care plans should also take other access issues into consideration when developing networks and plan administrative regulations. Some relatively simple considerations of patient access on the part of managed care plans can actually be cost-effective for plans. Travel distance is a very common barrier to care. If

patients have to travel long distances to seek care, they may forgo seeking needed care and eventually require more costly care. In addition, non-emergency care needs to be available at convenient times. For example, evening and week-end hours for non-emergency services can help avoid the use of costly emergency facilities for routine, non-emergency care.

### *Cultural Competence*

- ✓ **Does the managed care plan provide a full choice of culturally appropriate benefits and providers, including community-based facilities?**
- ✓ **Does the managed care plan ensure that its provider network reflects the cultural, religious, and demographic makeup of the communities the plan serves?**
- ✓ **Does the managed care plan ensure that culturally competent care is available to all enrollees?**

HIV/AIDS can further compound the barriers that poor women and people of color experience in getting Medicaid care, both in fee-for-service and managed care. To overcome these barriers, managed care plans must consider the cultural, religious, and demographic make-up of the communities they serve as they develop provider networks. Contracts with community-based providers, such as Ryan White Title IV providers, also can help managed care plans develop provider networks that better reflect the communities they serve.

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### *Non-Discrimination*

- ✓ **Does the managed care plan ensure that no consumer or provider is discriminated against in enrollment, access to care, or quality of care?**
- ✓ **Is the managed care plan—in marketing, enrollment, and the provision of services—free from discrimination based on current or anticipated mental or physical health status, race, gender, income, age, geography, or other factors?**

✓ **Is the managed care plan free from discrimination against providers based on their—or their patients’—mental or physical health status, race, gender, sexual orientation, religious beliefs, income, age, or other factors?**

Since the beginning of the epidemic, discrimination and stigma have hindered access to care for people living with HIV and AIDS. As more and more Medicaid beneficiaries, including those with HIV/AIDS, are brought into managed care, managed care plans must address these issues. In particular, managed care plans must not be allowed to discriminate in the development of provider networks, marketing of the plan, or delivery of services.

Marketing abuses by managed care plans have been well documented in a number of states enrolling Medicaid populations in managed care. Some plans have used discriminatory marketing techniques to avoid enrolling certain costly population groups, including people with HIV/AIDS and substance abusers. In response to complaints by consumers and health advocates, HCFA has required many states to use independent agencies to enroll Medicaid populations instead of leaving this up to the managed care plans.

When managed care plans do discriminate in the development of provider networks, there can be direct consequences to access to care for children, youth, and families affected by HIV and AIDS. In some instances, physicians who treat large numbers of people with HIV disease or who have HIV/AIDS expertise have been prevented from participating in managed care provider networks. Managed care plans have done this in part to prevent these physicians from bringing a costly client base into the plan. Some plans have prevented physicians from identifying their HIV/AIDS clinical expertise in patient information materials for similar purposes.

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## Using the Key Questions

**A**IDS Policy Center for Children, Youth & Families developed the key questions to be used in a variety of ways to protect and improve Medicaid care for children, youth, and families living with HIV and AIDS—an increasingly vulnerable group. We hope that state Medicaid officials developing or evaluating

managed care plans will find them useful as a guide to help determine a plan's suitability for children, adolescents, and families affected by HIV and AIDS. We hope that managed care organizations will be able to use them as a self-check list of items to consider when they undertake to serve this group of children and families.

We also hope that Title IV Ryan White CARE Act projects will find the introduction to Medicaid and managed care useful in today's rapidly changing health care environment, as an increasing number of people they serve will soon be enrolled in Medicaid managed care. Finally, we hope that families and young people living with HIV/AIDS and their advocates will find the questions to be a handy checklist as they work in partnership with state Medicaid officials and managed care organizations to develop and evaluate the Medicaid managed care plans that will be serving them and their children.

## References

AIDS Action Foundation. (1996, November). *Medicaid reform & managed care: Implications for people with HIV and the organizations that serve them*. Washington, DC: Author.

AIDS Policy Center for Children, Youth & Families. (1997, May). *Title IV projects and managed care: Preliminary summary of 1996 grant proposals—Policy brief*. Washington, DC: Author.

Aseltyne, W.J., Cloutier, M, & Smith, M.D. (1995). HIV disease and managed care: *An overview*. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 8 (supplement 1), S11-S22.

English, A. (in press). Changing health care environments and adolescent health: Legal and policy changes. *Controversies and Issues in Adolescent Health Care*.

HCFA (Health Care Financing Administration). (1995, September). *Medicaid: An overview*. HCFA Pub. No. 10965.

Institute for Family-Centered Care (1996, Summer). Family-centered care and managed care: Are they compatible? *Advances in Family-Centered Care*, 3(1), 2.

The Kaiser Commission on the Future of Medicaid. (1997, May). Medicaid's role for children. *Medicaid Facts*. Washington, DC: Author.

The Kaiser Commission on the Future of Medicaid. (1996a, November). The Medicaid program at a glance. *Medicaid Facts*. Washington, DC: Author.

The Kaiser Commission on the Future of Medicaid. (1996b, October). *Medicaid's role for persons with AIDS*. Washington, DC: Author

The Kaiser Commission on the Future of Medicaid. (1995, March). *Medicaid and managed care: Lessons from the Literature*. Menlo Park, CA: The Henry J. Kaiser Family Foundation.

Koyanagi, C. (1997). Can managed care meet the mental health needs of very young children? *Issue Paper*, Washington, DC: Bazelon Center for Mental Health Law.

Office of National AIDS Policy. (1996, March). *Youth & HIV/AIDS: An American agenda*. Washington, DC: Author.

## Appendix A

### *Glossary—Common Medicaid and Managed Care Terms*

**Aid to Families with Dependent Children (AFDC):** For over 60 years, the nation's primary cash assistance program for poor women and their children. Federal welfare legislation in 1996 replaced AFDC with a program called Temporary Aid to Needy Families, but AFDC criteria are still used to qualify poor children and youth for Medicaid.

**Capitation:** A method of payment in managed care in which a provider is paid a fixed amount per person enrolled in a managed care plan, according to a defined set of benefits, regardless of the kind or amount of care provided.

**Carve Out:** Separation of certain benefits—such as mental health care or prescription drugs—from the basic managed care plan by contracting with outside providers for those services. "Carve out" also refers to the removal of particular services from the capitation rate. For example, under Medicaid managed care, some states have carved out HIV/AIDS drugs from the capitation rate. The drugs continue to be reimbursed by Medicaid under a fee-for-service arrangement.

**Categorically Needy:** A category of Medicaid eligibility that is based on defined income criteria for families with children and pregnant women, and for elderly, blind, or disabled individuals. People not falling into these categories cannot qualify, no matter how low their income. The Medicaid statute defines over 50 distinct population groups as potentially eligible, including those for which coverage is mandatory in all states and those who may be covered at a state's option. Covered services that states must provide to the categorically needy are much broader than services for optional groups.

**Copayment:** An amount of money that a person seeking care pays directly to a provider at the time services are provided. Copayments are intended to control the utilization of services. Even quite small copayments can be problems for individuals who need frequent care, such as people living with HIV/AIDS.

**Fee-for-Service:** The traditional method of paying for care in which health care providers are reimbursed for a particular service (e.g., office visit, medical procedure, prescription) provided, and fees typically differ according to the length and difficulty of the service.

**Formulary:** An approved list of prescription drugs that managed care plans may provide to their enrollees. Some plans restrict prescriptions to those contained on the formulary and others also provide non-formulary prescriptions. Drugs contained on the formulary are generally those that are determined to be cost effective and medically effective. Which drugs are included in a managed care plans formulary is a matter of immense importance to children, youth, and families living with HIV and AIDS.

**Incentives:** Profit sharing arrangements offered by managed care plans that permit physicians and others to share in profits earned from the reduction of referrals to specialists and high cost service usage. Federal fraud and abuse rules currently under consideration may affect the kinds of incentive plans that can be used.

**Managed Care:** A method of organizing, financing, and delivering health care that seeks to control health care costs while coordinating an individual's health care. Managed care plans receive a prepaid rate for each member enrolled in the plan as opposed to being paid for the actual care provided.

**Mandatory Enrollment:** Mandatory enrollment means that Medicaid beneficiaries must choose from a "participating" plan and may no longer get their care from any qualified provider of their choice.

**Medicaid Waiver:** A formal process by which a state can apply to the federal government for a waiver from certain Medicaid program rules.

**Medically Needy:** A category of Medicaid eligibility based not solely on income, but on income less accumulated medical bills. States have the option of offering medically needy programs, and currently, 36 states do so.

**Open Enrollment:** A method for assuring that insurance plans, especially managed care plans, do not select only healthy individuals to participate, eliminating those who might be poor risks. Under an open enrollment requirement, a plan must accept all that apply during a specific period each year.

**Primary Care Provider:** A physician such as a family practitioner, pediatrician, internist, or obstetrician who coordinates care for a plan member, including making referrals for specialists or other non-routine care.

**Referral:** A formal practice of sending a patient to another practitioner or facility for services or consultation that the referring provider is not prepared or qualified to provide.

**SSI (Supplemental Security Income):** A federal income support program for low-income people who are elderly, blind, or disabled. SSI is administered by the Social Security Administration. Eligibility for SSI is usually tied to eligibility for Medicaid.

**Voluntary Enrollment:** Under Medicaid managed care, an arrangement that permits beneficiaries to choose whether to participate in managed care or remain in a fee-for-service arrangement.

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## Sources:

Aids Action Foundation. (1996, November). *Medicaid reform & managed care: Implications for people with HIV and the organizations that serve them*. Washington, DC: Author.

Institute for Family-Centered Care (1996, Summer). Family-centered care and managed care: Are they compatible? *Advances in Family-Centered Care*, 3(1), 2.

