

the  
**National**  
Association  
of **People**  
with  
**AIDS**

**MAKING**  
**An Action Plan**  
**MEDICAID**  
**for People**  
**MANAGED**  
**Living**  
**CARE**  
**with HIV**  
**WORK**

**SECOND EDITION**

# MAKING MEDICAID MANAGED CARE WORK

**An Action Plan**

**for People**

PRODUCED BY

The National Association  
of People with AIDS

WRITTEN BY

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WITH THE GENEROUS SUPPORT OF

The Henry J. Kaiser Family Foundation

SECOND EDITION

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**Living with HIV**

## ACKNOWLEDGMENTS

NAPWA developed this second edition of our Medicaid managed care action plan because, more than three years after the release of the first edition, we continue to receive requests for it—and because many people have told us that this action plan has been an important tool for helping individuals to understand changes in Medicaid and for becoming involved in working to improve the health care system in their own community. NAPWA believes that this is due to the contributions and wisdom of our diverse advisory committee and the numerous people who helped us produce the first edition of the action plan. In July 1996, NAPWA convened a meeting in Seattle, Washington consisting of 15 Medicaid beneficiaries living with HIV who came from 11 states and 24 others representing a broad range of perspectives including federal and state policy makers, advocates, and health policy experts.

Once again, we thank the following people who participated in our advisory meeting or contributed significantly in preparing the first edition of this action plan: John Manuel Andriote, A. Cornelius Baker, George Beaulieu, Ronald Brunner, Jackie Bulczak, Frank Burgos, Donald Chamberlain, Mark Cloutier, Paul Di Donato, Susan Dooha, Tony Dreyfus, Brian Eastep, Brett Paul Evans, Tamora Ferrell, Kathy Foley, Grace Gines, Tracey Gooding, Joan Holloway, Ernest Hopkins, Wayne Howard, Beri Hull, Steve Johnson, Neva Kaye, Everett Kinney, Mari Kitahata, Brian Knowles, Christine Lubinski, Miguelina Maldonado, Tim Menard, Donald Minor, Dr. Joseph O’Neill, Pat Philbin, Mark Randolph, Mike Shriver, Christa Singleton, Jeff Stryker, Timothy Westmoreland, Craig Wilkinson, Terry Winter, and Art Zerbe. NAPWA also thanks Joe Nickens and Terje Anderson who provided critical assistance in revising the draft and preparing the second edition, and Christine Lubinski for reviewing the second edition.

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## EXECUTIVE SUMMARY

**In February 1997,** the National Association of People with AIDS (NAPWA) released the first edition of *Making Medicaid Managed Care Work: An Action Plan for People Living with HIV*. This action plan was produced with the belief that much change was taking place in Medicaid programs all across the nation that directly impacts people living with HIV—who have an important role in shaping the outcome of state efforts to transform fee-for-service Medicaid into managed care programs. NAPWA also believes that in the midst of so much change, consumer advocates (people living with HIV and those who advocate on their behalf) need help in setting priorities and giving a focus to their advocacy around Medicaid managed care.

Since the first edition of this action plan was released, much has changed and many states have moved significantly further in implementing Medicaid managed care for people living with HIV. The second edition of this report has been updated to give readers information about some of the major policy and political activities that have taken place in recent years. At the same time, the central organization of this action plan has remained unchanged. The action plan elaborates on nine consensus recommendations from our Advisory Committee. NAPWA believes that these points are as relevant now as they were in the past.

As consumer advocates work to improve health care delivery in their own states and communities, we urge them to be mindful of the following principles:

1. Medicaid managed care is increasingly a reality for people living with HIV. To protect high quality health care, it is necessary to accept that managed care is here to stay.
2. Consumers must be partners with Medicaid programs and managed care providers in the development and monitoring of managed care systems serving people living with HIV.
3. There is a huge need to educate consumers about managed care. This education should address the unique needs of people living with HIV and the challenges posed by managing HIV care.

4. People living with HIV, and their advocates, need to take action at the state level.
5. The HIV epidemic disproportionately impacts many so-called special populations. To successfully meet the needs of people living with HIV, the requirements of people of color, gay men and lesbians, substance users, people with hemophilia, persons in need of mental health services, and individuals from traditionally underserved communities must be an important component of any managed care program serving these individuals.
6. People living with HIV, and their advocates, must push Medicaid programs to more effectively monitor and evaluate managed care plans. This includes using outcome measures related to HIV care and working to establish feedback loops to enable managed care providers to learn about and correct problems in the delivery of health care.
7. People living with HIV must be active in setting priorities for the design of managed health care systems.
8. People living with HIV should strive to work with state Medicaid programs and managed care plans to create incentives that reward the beneficiary, the provider and the managed care plan for improved health.
9. People living with HIV, and their advocates, must advocate for managed care programs that provide high quality care uniformly, despite barriers to accessing care such as language, geography and disability status.

This report describes how to translate these principles into meaningful action on behalf of people living with HIV. It also provides factual information about Medicaid and managed HIV care, as well as a glossary of terms and a resource listing of organizations conducting policy or advocacy work related to Medicaid managed care for people living with HIV.

Individual copies of this report may be obtained free of charge by calling the Kaiser Family Foundation Publication Request Line at (800) 656-4KFF. Additionally, the report may be downloaded from NAPWA's website at [www.napwa.org](http://www.napwa.org) or at the Kaiser Family Foundation website at [www.kff.org](http://www.kff.org).

NAPWA and the Kaiser Family Foundation have also produced other materials to help individuals get good care in Medicaid managed care programs and to help consumer advocates work for improved health care systems. If you have questions about the contents of this report or would like more information about other NAPWA materials, contact NAPWA's Information and Referral Service at (202) 898-0414 or via e-mail at [Information@napwa.org](mailto:Information@napwa.org). To learn more about the Kaiser Family Foundation's materials, contact the Publication Request Line and ask for a Publications Catalog or visit their website at [www.kff.org](http://www.kff.org).

## Medicaid is the largest form of public support for people living with HIV.

Roughly half of all adults living with advanced HIV disease (commonly known as AIDS) and more than ninety percent of children living with AIDS depend on Medicaid during some stage of their illness. Until recently, however, the AIDS community did not devote much attention to advocating for Medicaid. In some regards, Medicaid is a program that people living with HIV “love to hate.” The eligibility requirements are such that most adults living with HIV do not qualify for benefits until they have been impoverished by AIDS-related costs and have met the Social Security Administration's criteria for being considered disabled. Although a significant number of people qualify for Medicaid on the basis of meeting AFDC income and resource standards, thousands of people living with HIV are left without access to health care early in the course of their illness when they do not yet meet the Social Security eligibility requirements. (Note: See page 23 for more information about efforts underway to expand Medicaid eligibility to people living with HIV who are not considered disabled.)

Over the past few years, people living with HIV and their advocates have received a wake-up call. Reforms have been proposed at the federal level with the potential to fundamentally alter the structure of the Medicaid program. Some proposals would have removed the current federally-defined individual entitlement to services for all who meet the program's eligibility requirements. This would have been replaced by a fixed federal block grant payment to the states. Other proposals would have redefined eligibility standards in such a way that even fewer people living with HIV would qualify for Medicaid. While the most harmful proposals were not enacted, Congress did enact the most sweeping changes to the Medicaid program since it was established more than thirty years ago. With the passage of the Balanced Budget Act of 1997 (BBA), the Congress responded to state calls for greater flexibility in operating their Medicaid programs. At the same time, the Congress also responded to concerns from consumers that Medicaid beneficiaries were too vulnerable to receiving substandard care (For additional details, see the section on the BBA on page 22). Outside of Washington, states have been racing to catch up to the private sector in implementing managed care as a cost-containment strategy. Several states are also considering taking advantage of new flexibility that resulted from the BBA.

**Managed care** is a way of providing health care that seeks to integrate the medical care delivery system (including doctors, nurses, hospitals, laboratories, and other providers of health care services) with the insurance system that finances health care. Managed care seeks to limit increases in health care costs by making consumers and providers sensitive to, and jointly responsible for, health care costs.

Medicaid managed care has the promise of providing very good models for the management of HIV disease that rival the quality of care that most people receive in the fee-for-service system. Indeed, well-established managed care organizations such as Group Health Cooperative of Puget Sound and Harvard Community Health Plan have reputations for providing excellent HIV care. Furthermore, several states such as New York and organizations such as the Community Medical Alliance in Boston, Massachusetts and the Johns Hopkins University are now experimenting with new models for the delivery of HIV care within a Medicaid managed care setting. Ideally, managed care will stress prevention and health promotion as a strategy for avoiding hospital stays and other high-cost health care services. This would translate into the aggressive use of prophylactic treatments resulting in an improved quality of life for many individuals. Managed care organizations also have been more willing than many fee-for-service plans to offer a continuum of coordinated benefits and comprehensive services.

Managed care, by placing providers at risk for the costs of providing health care and often also lowering their payment rates, has shifted many of the financial incentives in the health care system. The experience of some, and the fear of many, is that managed care creates incentives simply to deny access to care or to inappropriately limit services needed by sick people. For people living with HIV, this is quite literally a matter of life and death. It is unlikely that the average Medicaid beneficiary (who already experiences many barriers to receiving high quality care in the fee-for-service system) will easily adapt to this new and even more complex health care environment. Educating people about how to survive in this new system is imperative.

Existing protections in the Medicaid law are insufficient because their enforcement relies on the federal government's oversight of state Medicaid programs. While this relationship remains important, it does not address the very critical relationship between a state Medicaid program and the managed care organizations with whom it contracts to provide health care services. Indeed, it is through working with state Medicaid programs to influence the contracting process and to monitor the implementation of managed care contracts that people living with HIV can have the greatest impact on protecting high quality health care.

People living with HIV, and their advocates, can be proud of their history of activism in fighting for access to health care. We have shown a willingness to be vocal on Capitol Hill and in the streets to get our community's health care needs met. With all of its shortcomings and limitations, we must value Medicaid as the main source of health care for most people with AIDS; we must continue the legacy of direct

involvement of consumers of health care services with policy makers and health care providers to work toward an improved health care system; and we must rely on the history and experience of people living with HIV to devise managed care systems that provide people living with HIV and other beneficiaries with high quality health care.

## MEDICAID OVERVIEW

Medicaid is our nation's primary health care safety net for low-income individuals. It is a program that was established in 1965 under Title XIX of the Social Security Act. Unlike Medicare, which is operated solely by the federal government, Medicaid is a federal-state program administered separately in each state. The federal government contributes a matching percentage of state Medicaid outlays, paying a minimum of 50% of health care costs and in some cases paying up to 83% of costs, depending on the state.

In 1997, approximately 40.6 million Americans (more than one in seven) received health care benefits from Medicaid. In that same year, the total estimated operating cost for the Medicaid program was \$161.2 billion.

Medicaid beneficiaries fall into four main categories: low-income children who generally receive cash assistance benefits, certain parents of children receiving cash assistance benefits, low-income elderly individuals who require long-term care, and blind and disabled individuals. Elderly, blind and disabled beneficiaries comprise the smallest categories of beneficiaries, yet they account for a large proportion of Medicaid's costs. Most adults living with HIV/AIDS qualify for Medicaid on the basis of meeting the income require-

ments and being disabled. Most children living with HIV qualify for benefits as recipients of cash-assistance benefits. (AFDC was a federal cash assistance program for low-income families that Congress eliminated in 1996 when it established a new program called Temporary Assistance for Needy Families, or TANF. Before 1996, low-income families receiving AFDC automatically were covered by Medicaid. When AFDC was eliminated, however, Congress protected Medicaid eligibility for these individuals. Currently, receiving Medicaid is not tied to TANF, but low-income families meeting AFDC's eligibility, income and resource standards can still get Medicaid.)

Medicaid covers a range of mandatory services that all states must provide, and an additional range of optional services that states can elect to provide. Mandatory services include inpatient and outpatient hospital, physician, laboratory, x-ray, nursing home and home health services. Optional services include prescription drug benefits (which all Medicaid programs currently elect to provide), clinic services, and prosthetic devices.

SOURCES: *Medicaid Facts: The Medicaid Program at a Glance*, The Kaiser Commission on Medicaid and the Uninsured, 1999.

In examining issues related to Medicaid managed care, agreement was reached on nine key consensus points that can serve to guide the actions of people living with HIV:

1

**Medicaid managed care is increasingly a reality for people living with HIV. To protect high quality health care, it is necessary to accept that managed care is here to stay.**

In talking about managed care for people living with HIV, it is very easy to focus only on the problems that many people face in getting the services they need. It is understandable that some people respond to this by advocating against managed care. By looking at the factors that have caused public and private health care programs to embrace managed care, it is difficult to believe that any level of advocacy will prevent health care from being managed. Over the past few decades, health costs have increased at a rate of inflation greater than that of other goods and services. Our nation spends a growing portion of its resources (when measured as a percentage of the gross domestic product) on health care, and we already spend far more for health care per capita than any other nation.

We do not believe that working against managed care is a useful strategy for protecting high-quality health care for people living with HIV. Instead, we believe that people living with HIV, and their advocates, should recognize the legitimate problem of unconstrained cost increases that managed care is meant to address while also working strenuously to highlight the problems of access to care that are often made worse by managed care. We believe that people living with HIV and all Medicaid recipients benefit when real improvements are made in the efficient delivery of health care services, and resources are reinvested in expanding or improving health care services.

Accepting managed care as a reality does not mean that people living with HIV must accept poor quality or inadequate care. Rather, it means that the efforts of people living with HIV, and their advocates, should be focused on learning how managed care works and on seeking ways to improve managed care programs. This should include efforts to develop financing mechanisms that support the continued viability of many of our current AIDS service organizations and the AIDS care infrastructure that our community

has worked to build for nearly two decades. People living with HIV need to become sophisticated participants in managed care programs in order to hold state Medicaid programs and Medicaid managed care plans accountable for providing optimal quality care.

**MEDICAID AND AIDS CARE**

Medicaid is the single most important health care program for people living with HIV. The Health Care Financing Administration estimates that in 1998, 55% of adults with AIDS and 90% of children with AIDS were beneficiaries of the Medicaid program.

Based on estimates by the Centers for Disease Control and Prevention (CDC) that 271,245 people were living with AIDS in the United States in 1998, more than 163,000 people with AIDS receive health care through Medicaid.

Despite the clear dependence of the AIDS community on Medicaid, people living with HIV comprise fewer than 1% of all Medicaid beneficiaries and they are responsible for approximately only 2% of total Medicaid costs.

The cost of treating people living with HIV can vary greatly depending on a number of factors. In recent years, the availability of highly active anti-retroviral therapy (HAART) has demonstrated an ability to significantly reduce HIV-related health care costs.

Co-morbid conditions such as mental illness and substance abuse can also contribute to varia-

tions in total costs for treating people living with HIV.

The Johns Hopkins AIDS Service has operated a Medicaid managed care program for people with AIDS, called the Moore Options Program, since 1997. In their experience, a person's CD4 count is the most effective predictor of changes in health care costs. For people with AIDS with fewer than 50 CD4/mm<sup>3</sup>, the average cost was \$2,500-\$2,600 per member per month. For people with AIDS with a CD4 count between 50 and 200, the average cost was about \$1,600 per member per month. For people with CD4 count greater than 200 (i.e., people with HIV, but not AIDS), the costs were between \$1,150-\$1,300 per member per month. These costs are associated with treating the urban Baltimore population—a population with significant co-morbidities, especially substance abuse and mental illness.

SOURCE: The Health Care Financing Administration and the Johns Hopkins AIDS Program, website: [www.hopkins-aids.edu/manage/index\\_manage.html](http://www.hopkins-aids.edu/manage/index_manage.html).

2

**Consumers must be partners with Medicaid programs and managed care providers in the development and monitoring of managed care systems serving people living with HIV.**

Since the early years of the HIV epidemic, people living with HIV, and their advocates, have fought for access to health care and have challenged the notion that patients are merely passive recipients of health care. Rather, we have pushed to help set the nation's research agenda; we have created agencies and structures within our own communities to provide health care; and within Ryan White CARE Act programs, we have insisted upon formalized roles for consumer involvement. In order for Medicaid managed care to

meet the needs of people living with HIV, beneficiaries of managed care programs must be involved in all aspects of the design, implementation and monitoring of managed care programs.

Some managed care organizations have historically included beneficiaries on governing bodies or on their boards of directors. Through participating in the governance of organizations, people living with HIV have worked in partnership with managed care organizations. Consumer boards are another way for health care plans to gain input from consumers or to receive technical assistance in analyzing issues. For these boards to work effectively, however, they must be structured to expand their role beyond simply advising and they must be given decision-making authority. In the Medicaid context, given that all beneficiaries have low incomes, it is necessary for the managed care organizations to pay for the costs of beneficiaries to participate on governing or consumer boards.

Consumer boards alone, however, are insufficient. Managed care programs must have well-articulated grievance processes that allow beneficiaries to challenge denials of service or to complain about inappropriate care. Additionally, states must monitor grievance patterns in order to identify and correct ongoing problems reported by consumers. States must also support ombuds programs or consumer advocacy initiatives in order to monitor trends or identify and address newly arising access or treatment-related concerns.

Furthermore, it is important to recognize that issues related to parity, inclusion and representation of people living with HIV disease are often difficult to adequately address. A lack of understanding of the diversity of HIV-affected communities can make it challenging for the mainstream health care system to successfully address the needs of people living with HIV. This is complicated by the difficulties associated with seeking the participation of individuals whose health status frequently changes. People living with HIV must insist upon being partners with state Medicaid agencies and managed care plans. Widespread participation of the HIV-affected communities and other beneficiaries must be a part of all decision-making processes regarding Medicaid managed care programs.

**WHAT IS MANAGED CARE?**

Managed care involves the integration of the health care delivery system (which includes doctors, nurses, hospitals, laboratories and other health care providers) with the insurance system that finances health care.

Managed care is a health care delivery system that frequently utilizes per capita (or capitated) payment arrangements to physicians, hospitals and other providers in order to conserve health care resources.

**3**

**There is a huge need to educate consumers about managed care. This education should address the unique needs of people living with HIV and the challenges posed by managing HIV care.**

In order for people living with HIV to maximize the benefits of managed care, it is important that they understand how this system works. Consumer education is needed to achieve the following five goals:

- **Create informed beneficiaries.** It is necessary to educate consumers about the features of managed care and how best to interact with the system to get their needs met. This should cover basic concepts such as how to select a health plan, how to select a health care provider, when and how to seek out-of-network care, and how to grieve or complain about inadequate care or the denial of health care benefits.
- **Develop strong advocates.** This goal involves educating people living with HIV, and their advocates, about how the Medicaid program works and how managed care programs work. Advocates must understand basic facts about the structure of Medicaid, including ways in which states can require beneficiaries to enroll in managed care through authority granted by the BBA or by seeking a federal “waiver.” Advocates must also learn about the Medicaid system in their state, including identifying the key health care players such as federal, state, and local officials and legislators, as well as other advocates.
- **Clarify the distinctions between managed care and fee-for-service health care and among managed care plans.** Consumers must gain a better understanding of basic principles of our insurance system. Consumers need information on how to function in a new Medicaid environment. A part of this includes giving consumers information about how to navigate through the system when experiencing difficulties with a provider or a managed care organization, as well as how to make choices when competing benefits are available from various health plans.
- **Improve the evaluation and monitoring of Medicaid managed care plans.** Under the fee-for-service system, a key role for Medicaid advocates was to monitor the federal oversight of state Medicaid programs. If consumers were not receiving the health care services they needed, if poor quality care was being provided, or if eligible individuals were being denied Medicaid benefits, pressuring the federal government to exercise its oversight authority on state Medicaid programs often led to improvements. In the managed care environment, understanding the relationship between the state Medicaid program and numerous managed care organizations has become at least as important in order to protect high quality care. People living with HIV need to understand how this new system

works and how they can push states to write strong and enforceable contracts with managed care organizations. Once contracts are signed, people living with HIV, and their advocates, need to become active in the monitoring and enforcement of the contracts.

- **Encourage people living with HIV to form coalitions with other Medicaid beneficiaries.** Success at protecting Medicaid for people living with HIV requires people living with HIV to form broadly based coalitions. A managed care plan that is designed to meet the complex needs of people living with HIV should also be designed to provide high quality care to other beneficiaries. Additionally, people living with HIV should remember that Medicaid is our nation’s primary health care safety net, and through our strong and consistent advocacy, we have the power to make this program better for all who depend on it.

4

**People living with HIV, and their advocates, need to take action at the state level.**

In the past, problems with Medicaid could often be addressed at the federal level. As Medicaid programs adopt managed care systems, the importance of influencing the development of contracts between state Medicaid programs and individual managed care providers (and monitoring their enforcement) shifts much of the action to the state level. To protect the quality of their health care, people living with HIV should take the following actions:

1. Identify and join state-level coalitions or create new coalitions of people with disabilities, advocates for children, the elderly and others organized at the state level who depend on Medicaid for their health care.
2. Critically examine the status of Medicaid in a particular state, and set clear and specific priorities for consumer involvement.
3. Learn who the key players are in a particular state and develop relationships with them.

ABOUT CAPITATION

What is Capitation?

The basis for most current managed care programs involves paying for health care services with capitated payments, as opposed to paying for health care on a fee-for-service basis. This financing change marks a fundamental shift in the relationships between consumers, payers and providers of health care. Under fee-for-service, the payer (in the Medicaid context, this would be the state Medicaid agency) is largely responsible for all financial risk should a beneficiary become ill. Capitated managed care seeks to save the payer money by utilizing the capitated payment to transfer some of the risk for health care costs from the payer to the health plan or the individual health care provider. Paying for health care involves risk because there is no way of knowing in advance how much health care an individual will require over a given time period.

How Does Capitation Work?

A capitated payment is a payment made to a health plan or provider on a per-member, per-month basis. This means that Medicaid may pay a health plan, or a health plan may pay a physician or other provider a payment every month for every patient they have in that managed care plan, whether or not the patient uses any health care services. In agreeing to accept this payment, the provider is agreeing to assume responsibility for the health of her or his patients. The capitated payment from one patient may not be sufficient to cover the health care costs of that individual patient. By pooling the capitated payments from every patient, it is anticipated that the provider can pay for all necessary health care expenses, as well as receive a fair compensation for their own services.

Theoretical Basis for Capitation

Ideally, capitation will give the provider the freedom to make health care decisions in the best interest of the patient. If a patient would like a service that the provider does not believe is medically necessary, the provider’s own financial risk creates an incentive to deny the patient the service. However, since a provider’s costs increase if the patient becomes sick and requires more extensive or more expensive health care services, it should not be in the interest of the provider to deny necessary services. This system presumes that the provider is experienced and knowledgeable about all types of illness, and is capable of judging when health care services can be denied without inflicting adverse effects on the patient.

Concerns with Capitation

A real problem with capitation for people living with HIV is that too many practitioners are extremely inexperienced with providing HIV care, and are in no position to rationally weigh when a particular service is, or is not, needed. This problem is made worse in managed care organizations where non-health care personnel are involved in authorizing treatment. In many cases, the inexperience of providers within a plan also creates incentives for people living with HIV to switch their enrollment to another plan, as this may be their only way to gain access to an experienced specialist practitioner. Because the provider’s own profit declines with every new service that a sick person needs, the fear is that capitation will only lead to the underservice of people living with HIV. This issue is compounded by exceptionally low Medicaid payment rates in some states.

Minimizing Incentives to Deny Care

Some state Medicaid programs, and some private philanthropic organizations are currently experimenting with risk adjustment procedures that seek to compensate both managed care organizations and individual providers with a high caseload of people with AIDS. Additionally, others are experimenting with stop loss insurance, risk corridors, and other mechanisms that are designed to limit the financial risk of a provider for an individual patient who has very extensive health care needs.

Finally, some Medicaid programs “carve out” some services such as pharmaceuticals, which they pay for on a fee-for-service basis or contract with a pharmacy benefit management firm to manage access to this benefit.

The capitated payment is a critical element of most current managed care programs.

- 4. Develop and disseminate a brief guide of the Medicaid managed care issues to be addressed. This can be used to encourage other partners to form a common agenda and can foster cooperation among groups of advocates.
- 5. Devise an advocacy strategy that will support specific goals and priorities. This strategy may involve lobbying state legislators, working with state Medicaid programs, writing letters to public officials, and using the media to raise public awareness of specific goals.

**TYPES OF MANAGED CARE ORGANIZATIONS**

Many types and variations of managed care organizations currently exist. While structure may vary, one of the key distinguishing factors among managed care organizations is the level of risk they assume for providing health care services.

No Risk: Primary Care Case Management Organizations (PCCMs) often contract directly with a state Medicaid program to serve as the gatekeeper. They monitor and approve virtually all covered services, and are paid on a fee-for-service basis. They generally assume no risk for the provision of health care services.

Risk-Based Plans: Under a fully capitated plan, a health plan is paid on a capitated basis (i.e., the health plan receives a fixed fee per enrollee and assumes full risk for the delivery of a comprehensive range of services. Some plans contract on a more limited basis (i.e., ambulatory care only).

SOURCE: *Medicaid and Managed Care*, The Kaiser Commission on Medicaid and the Uninsured, 1999.

**5**

**The HIV epidemic disproportionately impacts many so-called special populations. To successfully meet the needs of people living with HIV, the requirements of people of color, gay men and lesbians, substance users, people with hemophilia, persons in need of mental health services, and individuals from traditionally underserved communities must be an important component of any managed care program serving these individuals.**

Communities hardest hit by the HIV epidemic often have been labeled as “special populations.” However, these so-called special populations are in fact our neighbors, our families, our friends, our clients, and even ourselves.

Too often, the needs of specific groups of people have been treated as an afterthought by many health care plans. In other words, after health care plans have established their core set of benefits, they then tack on a supplementary (and often inadequate) package of programs to provide mental health, substance abuse treatment, transportation, and other supposedly ancillary services. In reality, these services are essential to the health and well-being of people living with HIV.

These supplementary programs are problematic because the services offered are often underfunded or barriers are erected to limit the use of these services. They are usually not made equally available to all beneficiaries who need them. Generally, the services are also not coordinated sufficiently with other benefits.

In providing HIV care, it is important to understand that all people have some sort of special need. Only plans that seek to coordinate all services, including non-traditional health care services and enabling services, such as transportation, will be able to effectively serve people living with HIV.

LISTENING TO THE CONSUMER

*The ability of managed care to succeed in serving people living with HIV is dependent upon its ability to listen to and respond to the need of its beneficiaries.*

Donald Minor can't wait for care.

As a person living with HIV who is also a person with hemophilia, he has experienced utilization review (a practice of managed care organizations such as requiring prior approval before they will pay for a procedure or service) and other managed care practices that can lead to a delay or denial of care. "I'm really what is called a moderate to mild [person with hemophilia]. But when I have an episode, it can't wait for a 10-day clearance, because I could die waiting for somebody to pick up the telephone to say, 'You've got the okay, go ahead and get your medicine.' I have to have my medicine with me ALL of the time. When I start to bleed, I have got to treat it immediately or I suffer the consequences."

Grace Gines knows how important it is to have educated health care practitioners.

As a woman living with HIV, she recalls the challenges she has faced in getting adequate gynecological care. She recounts that she was in a managed care program where she received most of her primary care in an infectious disease clinic, but was referred out for specialty care, including routine gynecological care. She recalls facing discrimination from the gynecologists because many did not want to treat her. Then, when she was treated, she received routine care (such as a pap smear) that was inadequate. "The doctor said I was fine, and she gave me a referral for another appointment in a year. I know that a woman with HIV should have a pap smear every six months. I didn't really confront her. I didn't have the energy. I didn't feel like educating her." Grace did go back to her nurse practitioner, who was her primary care provider, and explained the problem. Thereafter, her nurse practitioner arranged for a pap smear every six months. Grace highlights the importance of regular pap smears and other screenings for women with HIV. Pelvic inflammatory disease (PID) and other gynecological problems are far more common in women living with HIV than in other women. Like most Medicaid beneficiaries, Grace didn't know the best way to complain or take action.

Historically, managed care health maintenance organizations (HMOs) have serviced largely healthy populations. Grace's experience also highlights the problem that many managed care organizations have not contracted with a broad enough range of specialist providers to meet the needs of people living with HIV who have very complex health care needs.

Beri Hull is worried that her doctors will not know what to do to help her stay in recovery.

Beri is a former heroin user who is in recovery and living with HIV. She has concerns that existing barriers to people simply entering the health care system will become worse under managed care, and she worries that substance users who take the first step to recovery will be prevented from getting the care they need by being kept on waiting lists to receive treatment. More than ten years ago, Beri was an active substance user in Chicago. She was on Medicaid, but she didn't even know which health care services she was entitled to receive. "I got on general assistance. I wanted the \$150 a month that they gave us. We called it a green card back then. I was barely aware that I had health care services along with this. I was a person who avoided doctors and establishments if I possibly could."

Beri tells of becoming sick and needing to be hospitalized. Because she was concerned that people would come after her for payment, she gave a false name. She explains that she was so distrustful of doctors and hospitals that she never thought about seeking information on services she could receive. "I think my experience is not unique. So I want to know how managed care is going to affect a person who may not even know they're on managed care."

Beri's experience illustrates the need for managed care organizations to expand their capacity to provide substance abuse treatment. It also shows how important it is to have a provider who understands her perceptions of doctors and the health care system in order to help get her health care needs met.

George Beaulieu is concerned about access to care.

George lives in rural Minnesota. He has found it difficult to locate an experienced HIV practitioner who is geographically accessible. The nearest doctor is 40 miles away, but this provider is not knowledgeable of HIV care. Out of desperation, George has resorted to traveling to Minneapolis, more than 200 miles away, to receive his health care. There, the Hennepin County Medicaid program provides him with comprehensive services.

George's problem in finding an experienced HIV provider is shared by many persons living in rural areas. It also underscores the importance of Medicaid managed care organizations developing mechanisms for obtaining out-of-network, specialty care that do not impose additional cost-sharing burdens on the beneficiary.

LISTENING TO THE CONSUMER

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**People living with HIV, and their advocates, must push Medicaid programs to more effectively monitor and evaluate managed care plans. This includes using outcome measures related to HIV care and working to establish feedback loops to enable managed care providers to learn about and correct problems in the delivery of health care.**

As managed care organizations focus increasingly on cost containment, people living with HIV need to be at the forefront of efforts to create new monitoring systems and enforcement mechanisms to ensure that individuals receive a broad range of services. Consumer surveys and practitioner surveys are important tools that managed care organizations should use to gain information about positive and negative aspects of their health care delivery program.

A key priority for people living with HIV is the identification of Medicaid beneficiaries with HIV/AIDS and the development of specific health outcomes that can be used to measure the quality of health care within a plan. Unfortunately, one of the problems experienced by many Medicaid managed care programs is that the states' own information systems are often antiquated. As a result, state Medicaid programs do not even ask for the type of information that is needed to identify and monitor beneficiaries with HIV/AIDS in order to compare the performance of health plans or to identify problems in the delivery of health care. This problem is exacerbated by gaps in data provided by plans and lack of sufficient infrastructure, including staff and resources, to review data that managed care organizations provide to state Medicaid agencies.

**MANDATORY MANAGED CARE IS INCREASINGLY BEING IMPLEMENTED**

Across the nation, states are transitioning their Medicaid programs from fee-for-service into mandatory managed care programs. Prior to the enactment of the Balanced Budget Act of 1997 (BBA), states were required to seek a federal waiver (exemption from parts of Title XIX, the federal Medicaid statute) to mandatorily enroll Medicaid beneficiaries into managed care. Now that the BBA is law, it is anticipated that even more states will develop mandatory managed care programs.

As of June 30, 1998, 44 states (including the District of Columbia) reported enrolling people living with HIV and AIDS in risk-based Medicaid managed care programs. This does not include the four states (Arkansas, Idaho, Louisiana, and South Dakota) that operate only primary care case management (PCCM) programs. Further, 35 of these

states mandate that at least some populations (including people living with HIV) enroll in managed care programs.

Additionally, roughly 1.6 million persons with disabilities (including people with AIDS) are enrolled in Medicaid managed care programs. Roughly two-thirds of all persons with disabilities enrolled in Medicaid managed care programs are in capitated programs, with the remaining third in primary care case management (PCCM) programs.

SOURCES: *Trends in Serving People with HIV/AIDS through Medicaid Managed Care*, National Academy for State Health Policy, 1999; and *Medicaid Managed Care for Persons with Disabilities: State Profiles*, Regenstein and Schroer, Economic and Social Research Institute, 1998.

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**People living with HIV must be active in setting priorities for the design of managed health care systems.**

In order for any managed care program to provide high quality HIV care, it must have in place structures that enable it to articulate what should be happening in the delivery of health care, assess what is really happening, and fix any problems.

Putting in place strong **access standards and clinical guidelines** is an important way to tell the managed care organization what it should be doing with regard to HIV care. Access standards should cover issues such as waiting times for an appointment, the maximum distance a beneficiary must travel to seek care, standards for the number of in-network specialists over a broad range of medical disciplines that a plan must keep as a proportion of the enrolled population, and time limitations within which a plan must resolve any outstanding consumer grievances.

The standard for high quality HIV care is changing rapidly. New treatments and treatment protocols are becoming available every few months, and each new day brings an increased understanding of how to use drugs and other therapeutic tools to maintain health. Access standards define what kind of care a plan must deliver. These standards must be seen as an evolving floor, or a minimum level of care that a managed care organization is expected to provide. People living with HIV, and their advocates, should always work to raise both the ceiling of what level of HIV care is optimally possible and the floor of what minimum level of care is expected for everyone.

**CLINICAL PRACTICE GUIDELINES HAVE ESTABLISHED A MINIMUM STANDARD OF CARE**

Frequently, consumer advocates and health professionals call for the development of clinical practice guidelines for conditions where none exist or where existing guidelines lack credibility within the affected communities. The HIV community, however, is fortunate to have clinical practice guidelines that cover numerous prevention and care issues related to HIV and which were developed with broad community input.

Among the most critical clinical practice guidelines are the *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* issued jointly by the Department of Health and Human Services and the Kaiser Family Foundation and which were developed and are revised on an ongoing basis by an expert panel that includes leading physicians and researchers, as well as treatment advocates and other community leaders.

The corresponding guidelines for children living with HIV are *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*.

Another important set of practice guidelines are the *Guidelines for the Prevention of Opportunistic Infections in Persons Infected with the Human Immunodeficiency Virus* first issued by the US Public Health Services and the Infectious Disease Society of America (IDSA) in 1997.

FOR MORE INFORMATION: Visit the HIV/AIDS Treatment Information Service at [www.hivatis.org](http://www.hivatis.org) for the most recent guidelines. If you do not have Internet access, contact NAPWA's Information and Referral Service to request a copy of the guidelines.

Clinical guidelines are specific recommendations that a plan makes to a provider regarding what constitutes high quality HIV care. They include recommendations for assessing when it is necessary to refer an individual to a specialist, when a provider should recommend prophylaxis for opportunistic infections, when to offer antiretroviral therapy, when to switch regimens, and when to provide diagnostic services such as viral load testing.

In order to know what is actually happening within a managed care organization, sophisticated **management information systems** are necessary. Management information systems involve setting up record keeping systems that enable a managed care organization to track the composition of its beneficiaries, the services they are receiving, which services are costing the most money, and assess the ultimate impact on the health of the beneficiaries of various treatment options.

Once a monitoring system has been developed, and expectations have been established for what a managed care organization should be doing, **process and outcome measures** help to track what is happening. Process measures look at issues such as how often a beneficiary is offered a specific

service. For example, pneumocystis carinii pneumonia (PCP) is one of the most common opportunistic illnesses experienced by people living with HIV, despite the fact that most cases of PCP are easily preventable with low-cost antibiotics. An important process measure that can shed light on the quality of HIV care within a plan involves how often or when an HIV positive beneficiary is offered PCP prophylaxis. These types of measures are useful in indicating whether or not appropriate services are being routinely provided.

Outcome measures are more difficult to assess, but are often more useful than process measures. They are designed to indicate if the health care intervention has resulted in improved health. An example of an outcome measure in the case of PCP would be information that tracks how many people living with HIV within a health plan are hospitalized for PCP. A managed care plan that can show that its HIV-positive beneficiaries are hospitalized with PCP less frequently than beneficiaries in another plan (at a comparable stage of disease progression) may be able to use this to argue that it is providing higher quality care. This type of measure is also useful for indicating the relative effectiveness of different types of interventions.

**A MODEL PROGRAM: MARYLAND MEDICAID AND THE JOHNS HOPKINS MOORE OPTIONS PROGRAM**

In late 1996, the Maryland Medicaid Program received an 1115 waiver from the Health Care Financing Administration. Beginning in June 1997, the waiver allowed the state to mandate that all of its Medicaid beneficiaries enroll in a Medicaid managed care program (with limited exceptions for special needs children). Maryland's program contains certain features that are intended to address many of the structural problems with other Medicaid managed care programs. From the perspective of people living with AIDS, critical features of Maryland's managed care plan are:

**Risk-adjusted payments for people with AIDS**

As discussed previously, paying a flat capitated payment for all beneficiaries when people with HIV/AIDS (and some other conditions) have predictably higher health care costs creates enormous incentives to underserved people with HIV/AIDS. Further, most people with HIV/AIDS in a given community get their HIV care from a limited number of providers. If these HIV providers are not paid an enhanced rate to cover their high HIV-related costs, it is often impossible for them to survive financially.

Maryland's Medicaid managed care program pays a special AIDS rate (capitated payment). Maryland set its AIDS rate by calculating the average cost of care for people with AIDS in 1994 and 1995, and then subtracting 10%. The capitated payment for Medicaid beneficiaries in the general Medicaid population is in the range of \$200-350 per member per

month. The capitated payment for people with AIDS in Baltimore City is \$2,111 per member per month, and for people with AIDS in Maryland outside of Baltimore City, the capitated payment is \$1,770 per member per month.

**Specialists as the Primary Care Provider**

In the past, many experts in the delivery of HIV care thought that the best way to improve the quality of care received by all people with HIV was to train all primary care providers to serve people with HIV and AIDS. In recent years, with the availability of antiretroviral therapy and the ongoing rapid changes in the standard of HIV care, most experts have abandoned this philosophy. Now, it is thought that the best way to ensure that people with HIV and AIDS get high quality care is to ensure that individuals can access specialist providers—with experience in treating people with HIV/AIDS.

The Maryland managed care program permits a specialist to serve as the primary care provider. This means that infectious disease and other specialists who people see for their HIV care can be the individual's main doctor.

**New Technologies Purchased on a Fee-for-Service Basis**

The basis for a capitated payment is that health plans are expected to manage predictable health care expenses. This is difficult to do for expenses which you cannot anticipate. In a

very short time (starting in 1996), health plans and Medicaid programs have had to manage to make protease inhibitors and antiretroviral therapy available to virtually all of their HIV-infected patients. Given that the cost of this therapy is in excess of \$10,000 annually for each member, this is a challenge for health plans that negotiated how much they would get paid from the Medicaid program without factoring in the costs of these drugs. In the future, other new technologies will be developed that will contribute significantly to improving the quality of care for people with HIV/AIDS.

Maryland has addressed the issue of making new technologies available by simply exempting these costs (i.e., carving them out) from the capitated payment. The state Medicaid program pays for such technologies on a fee-for-service basis. This has the advantage of not penalizing health plans that did not negotiate their payment rate with the technology in mind. It has the huge advantage for Medicaid beneficiaries in that it takes away any reason for the health plan to not make the technology available. Some other states have taken a similar approach by simply exempting all prescription drugs from their capitated payment.

**Johns Hopkins Moore Options Program**

The Johns Hopkins Moore Options Program is the managed care program of the Johns Hopkins University Health System. It is not the only HIV/AIDS provider in the Maryland Medicaid managed care program, but it is the largest. Johns

Hopkins Hospital and the Johns Hopkins Medical School have been consistently ranked as among the very best in the nation—which gives it immense resources for providing high quality HIV/AIDS care.

The Johns Hopkins Moore Options Program has several components, including an inpatient unit at the Johns Hopkins Hospital, a social work program that provides case management and other services, a chronic care facility at the Johns Hopkins-Bayview Medical Center, a clinical research program, and the Moore Clinic database to collect and analyze information regarding the use of resources and the associated costs. The centerpiece of the Johns Hopkins Moore Options Program is the Moore Clinic, an outpatient clinic that currently monitors more than 2,000 patients in various states of HIV infection (a portion of whom are Medicaid beneficiaries). The program also has a network of other providers that includes the two STD clinics operated by the Baltimore City Health Department, and ten county health departments.

The Johns Hopkins Moore Options Program spent ten years negotiating with Maryland Medicaid before it established its Medicaid managed care program. The program has been at the forefront of advocacy efforts around risk-adjusted payments and other efforts to ensure the financial sustainability of specialized HIV care programs.

SOURCE: The Johns Hopkins AIDS Program website: [www.hopkins-aids.edu/manage/index\\_manage.html](http://www.hopkins-aids.edu/manage/index_manage.html).

Once a comparison is made between what should be happening in a managed care plan and what actually is happening, it becomes necessary to change practices and procedures. Filing a grievance is one important way for an individual consumer to address shortcomings in the delivery of their health care. A grievance is a formal complaint that a beneficiary may file with a managed care organization or with the state Medicaid agency.

For example, if a beneficiary has been told that the managed care organization will not pay for them to receive viral load testing, the beneficiary may argue that this test is necessary to establish a baseline of their immune functioning from which to monitor the progression of their illness and the effectiveness of treatment. They can look for studies to show that such a test is the current state of the art in assessing disease progression. Complaining can force the managed care organization to review its decision not to provide the viral load test. In many cases, this can lead to a reversal of the previous denial of the service.

Another approach to solving problems in the managed care system is to establish an **ombuds program**. An ombudsperson is someone either inside or outside of the managed care organization (preferably outside of the organization so that they are completely independent of the health plan) who receives grievances and attempts to work with both parties to resolve a grievance. In many models, the ombudsperson often functions as a beneficiary advocate. Many advocates have recently shown a renewed interest in ombuds programs.

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**People living with HIV should strive to work with state Medicaid programs and managed care plans to create incentives that reward the beneficiary, the provider and the managed care plan for improved health.**

We are currently living in a time of cautious optimism that our nation's investment in biomedical research has begun to pay off with a series of new drugs (protease inhibitors and other antiretrovirals) that show great promise in successfully treating HIV disease. This has caused many people living with HIV to consider a whole range of new possibilities. Improved health due to these therapies could even permit some people who were previously disabled to return to work, or enter the workforce for the first time.

Due to the nature of our publicly funded health care system, and the fact that most adults with HIV/AIDS only become qualified for Medicaid coverage once they are too ill to be "gainfully employed", the new treatments could be so effective in restoring health that they may make the individual no longer eligible for Medicaid. This could threaten access to the drugs that are necessary to maintain their newfound health. Recently enacted legislation (the Work Incentives Improvement Act of 1999) is designed to address this "catch-22" by ensuring continued access to health care coverage even after a person's health has benefited from treatment.

One of the main features of managed care is that physicians and other providers who receive a capitated payment are at risk for the cost of their patient's health care. An important advocacy goal must be to ensure that Medicaid managed care programs are designed such that people living with HIV, their health care providers, and their managed care organizations all benefit from the individual becoming healthier.

AN ADVOCATE'S LIST

With so many things going on, as people living with HIV/AIDS are moved into managed care programs, it can sometimes be difficult to set priorities. The following list of key issues is one perspective on specific battles consumer advocates should fight in order to protect health care for people living with HIV/AIDS.

1. Make sure managed care organizations get paid enough. While it may seem counter-intuitive to worry about how much a for-profit health care plan gets paid, this may be the best way to ensure that people living with HIV get the care they need. We believe we can get managed care organizations to provide high qual-

ity care if we make sure that Medicaid is paying them for high quality care.

2. Protect existing categorical eligibility. The best health care system is worthless unless people can get in the door. Therefore, an important goal of any advocacy effort must be to ensure that the current federal definition of disability is maintained as a floor, and that other eligibility categories are protected.

3. Make sure that the managed care contract covers the right set of benefits. We live in an era of cost constraint and growing limitations on covered health care services. Therefore, an important

issue for people living with HIV regards priorities for covered services. Many people with HIV recognize the prime importance of prescription drug benefits. Beyond drug benefits, consumers and advocates need to set priorities to make sure that managed care contracts cover the services that people really need.

4. Work for tough quality assurance standards, including the use of outcome measures. The best health care program, on paper, will not help people in the real world unless strong quality assurance systems are in place. This requires managed care organizations to set goals for quality improvement and it also

entails a strong data collection and evaluation program to assess what is, and is not, working. Outcome measures that look for improved health are an important way for managed care organizations to show that they are providing high quality health care.

5. Make sure that enforcement mechanisms exist to ensure that beneficiaries receive the care for which they qualify. Enforcement of the Medicaid law and enforcement of the managed care contract are two critical elements of a well functioning Medicaid program. Without strong enforcement structures, beneficiaries will not receive the care they need.

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**People living with HIV, and their advocates, must advocate for managed care programs that provide high quality care uniformly, despite barriers to accessing care such as language, geography and disability status.**

A concern about Medicaid managed care is that not all beneficiaries are situated to speak up when they experience difficulties in getting the care they need. Because of the ways in which managed care changes many of the financial incentives in the health care system, Medicaid must strengthen the existing mechanisms to ensure that all beneficiaries are treated uniformly and fairly.

Under current Medicaid law, all Medicaid services must be provided without regard to the disease status of the beneficiary. Other provisions of the law require all services to be provided statewide and insist that the services that one type of beneficiary receives must be comparable to those that another receives. Still other provisions of the Medicaid law guarantee beneficiaries all medically necessary services.

It is important to recognize that great variations in language, culture, geography, and other factors exist that have the potential to divide the AIDS community. However, high quality health care for any beneficiary is threatened unless high quality health care is ensured for all beneficiaries. Therefore, an important goal of our advocacy must be to ensure that all people are treated fairly in Medicaid managed care programs and that all people receive the high quality health care that everyone deserves.

**A CRITICAL ISSUE: FOCUSING ON THE MANAGED CARE CONTRACT**

Neva Kaye is the Operations Manager at the National Academy for State Health Policy, an organization that provides technical assistance to state Medicaid programs. Previously, she has also worked in the Medicaid Administration in Wisconsin.

Neva believes that the development of a strong Medicaid managed care program for people living with HIV depends on having an enforceable contract with clear and measurable responsibilities between a state Medicaid agency and the managed care organization. While the following is not an exhaustive list, she stresses that any contract must:

1. Define medical necessity and describe the circumstances when the plan is required to provide all medically necessary services.
2. Provide for a broad range of covered services.
3. Address how a managed care organization will ensure that all covered beneficiaries are able to access health care services.
4. Articulate permissible and impermissible marketing activities and enrollment procedures.
5. Outline quality assurance activities that a plan must undertake.
6. Define the grievance and appeals process.
7. Specify the types of data that a managed care organization must report to the state. This should include data collection requirements pertaining to the utilization of health care services, health care outcomes, and financial operations of the managed care organization.
8. Define the geographic service area of the managed care plan.

9. Describe how and when a beneficiary may select a primary care provider. This should describe the circumstances when a beneficiary may insist that a specialist provider be designated the primary care provider.
10. Outline and limit cost-sharing requirements for beneficiaries.
11. Prohibit discrimination, and provide for specific civil rights protections for beneficiaries.
12. Describe and limit permissible utilization review techniques.
13. Define and disclose information about relationships with providers.
14. Describe enforcement of the contract and provide for sanctions for non-compliance.
15. Define the term of the contract and provide conditions for termination.

16. Address issues related to beneficiary confidentiality and confidentiality of medical records.

*Note:* As a companion document to this consumer action plan, NAPWA has developed a guide, *Building Strong Medicaid Managed Care Programs: A Guide to Help Consumer Advocates Participate in Strengthening HIV/AIDS Provisions in Managed Care Contracts*. Copies may be ordered free-of-charge by contacting the Kaiser Publication Request Line at (800) 656-4KFF or it may be downloaded from NAPWA's website: [www.napwa.org](http://www.napwa.org) or the Foundation's website: [www.kff.org](http://www.kff.org).

This guide was based, in part, on *Sample Purchasing Specifications for Services for HIV Infection, AIDS and HIV-Related Conditions*, developed by the Center for Health Services Research and Policy at the George Washington University. This document may be downloaded from the Center's website: [www.gwu.edu/~chsrp/](http://www.gwu.edu/~chsrp/).

**Since the first edition** of this action plan was published, states have moved forward to implement managed care programs for an increasing proportion of the Medicaid population. As we have seen in the past, the transition to managed care works better in some states than in others. We have also seen, however, that consumer advocacy is making a difference. Opinion polls and other surveys consistently show that the public is concerned about managed care. Further, many states have also responded to many of the concerns raised by consumer advocates.

A few of the critical changes that have taken place since the first edition of this action plan was published include:

#### **Balanced Budget Act of 1997 (BBA)**

In the Summer of 1997, the Congress enacted and the President signed into law the Balanced Budget Act of 1997 (BBA). This law included the federal budget for fiscal year 1998, but also included a spending framework for the federal government for five years that was projected to produce a balanced budget. As part of this law, Congress enacted the most significant changes to Medicaid since the program was created in 1965.

Boiled down to a sound bite, the BBA did two things to the Medicaid program. First, it gave states even greater flexibility in mandating enrollment in managed care programs. In fact, in many circumstances, states no longer have to seek federal permission (through a waiver) to create mandatory managed care programs. Second, Congress enacted new consumer protections for Medicaid beneficiaries. Among other protections, the BBA: requires that all Medicaid beneficiaries in non-rural areas be given a choice of at least two health plans; allows beneficiaries to change health plans or case managers for any reason in the first ninety days after enrollment; prohibits door-to-door marketing by health plans and other practices that have confused beneficiaries or have caused some beneficiaries to be coerced into enrolling in particular plans; and requires states to operate grievance processes for appealing coverage decisions. The BBA also called on the Secretary of the Department of Health and

Human Services to conduct a study to determine what safeguards are necessary to protect people with special needs in Medicaid managed care programs.

#### **Presidential Commission on Consumer Protections**

In response to widespread public concerns about changes in our national health care system, the President appointed an Advisory Commission on Consumer Protection and Quality in the Health Care Industry in 1996. This panel consisted of a diversity of stakeholders including health plan officials, employers, labor representatives, and consumers. One of the key actions of the Commission was to develop a Consumer Bill of Rights and Responsibilities.

Many consumer advocates were ambivalent regarding the value of such a “Bill of Rights” because the diversity of stakeholders prevented a consensus from developing that would truly protect America’s health care consumers. At the same time, most advocates were appreciative of the President’s leadership for simply keeping managed care reform on the public agenda. Since the release of the Bill of Rights by the Commission, many Members of Congress have drafted legislation that they believe mirrors the principles embodied in the Bill of Rights. Some proposals have been introduced that enjoy the enthusiastic support of the consumer advocacy community. Unfortunately, none of these consensus principles has been enacted into law, and the whole issue has become deeply partisan. In an election year, the prospects for legislation to be signed into law are uncertain. Nonetheless, the President has issued an Executive Order that requires all federal agencies to implement the Consumer Bill of Rights and Responsibilities for all public programs, including Medicaid, to the extent authorized by law.

#### **Access to Medicaid for People with HIV/AIDS**

The HIV community has always recognized the shortcomings of the Medicaid program, including its limits on eligibility for most adults with HIV until their illness has progressed to AIDS. The advent of

## Glossary of Terms

effective combination therapies to treat HIV infection, beginning in 1996, however, was a watershed event that magnified the importance of expanding Medicaid to include persons living with HIV who do not have AIDS.

Under current law, most people living with HIV are stuck in a catch-22. New therapies are available, and it is recommended that persons consider beginning therapy early in the course of HIV disease progression. For many people on highly active antiretroviral therapy (HAART), especially persons who had not previously taken AZT and other antiretroviral therapies, combination therapies can reduce HIV viral load (the amount of HIV virus circulating in the bloodstream) to undetectable levels. These therapies appear to be able to forestall the progression of HIV disease to AIDS. The catch is that many people living with HIV do not have private health insurance or their current insurance is inadequate, and even if they meet Medicaid's income requirements (which demands that persons have a very low income), they cannot qualify for Medicaid until they are considered disabled, which usually means they have AIDS.

In 1997, the Vice President raised the possibility of expanding Medicaid to cover low-income people with HIV who were not sick enough to qualify for disability status. The Clinton Administration declined to do so, however, after an initial study suggested that the cost would be too high. At the same time, the Administration did express a willingness for the Health Care Financing Administration to consider Medicaid research and demonstration waiver applications from states that were interested in experimenting with various Medicaid expansion options. In February 2000, HCFA approved Maine's application for an HIV waiver, helping to set a precedent for future applications. Several other states (including California, Colorado, the District of Columbia, Florida, Massachusetts, North Carolina and Wisconsin) are considering submission of waiver applications. This issue is critically important to health care provision for people living with HIV. People living with HIV and advocates should monitor the progress of these research and demonstration waivers—and are encouraged to support efforts in their own states to expand Medicaid.

**Balanced Budget Act of 1997 (BBA)** — A federal law enacted in the summer of 1997 that provided for the fiscal year 1998 budget and laid out a five-year plan to balance the federal budget. This legislation implemented the most significant changes to the Medicaid law since the program was established in 1965.

**Beneficiary** — Person who has Medicaid coverage.

**Capitated Payment** — Payment to a health plan, physician, hospital, or other provider made on a per-member (of a health plan) per-month basis, whether or not the individual uses health care services during that month.

**Carve Out** — Practice of excluding specific services from a managed care organization's capitated rate. In some instances, the same provider will still provide the service, but they will be reimbursed on a fee-for-service basis. In other instances, carved out services will be provided by an entirely different provider. Because of great variations in cost from one patient to the next, pharmacy benefits, HIV care, mental health services, and substance abuse treatment are types of services that are often carved out.

**Co-Payment** — A fixed fee that the beneficiary must pay out-of-pocket each and every time they access a particular health care service.

**Deductible** — The amount of out-of-pocket expenses that a beneficiary must pay before the insurance plan will begin to cover its share of the health care costs.

**Fee-for-Service** — The traditional style health delivery system in which a beneficiary can choose their own provider and the insurance company is responsible for paying a specific portion of the fee for each and every service.

**Formulary** — A list of drugs that an insurance company or managed care organization agrees to provide to their beneficiaries, when prescribed by their health care provider. Drugs not on the formulary are not covered by the health plan. The use of formularies is a cost-containment strategy employed by some managed care organizations to limit access to high-cost medications.

**Gag Clause** — A provision of a contract between a managed care organization and a health care provider that restricts the amount of information a provider may share with a beneficiary or that limits the circumstances under which a provider may recommend a specific treatment option.

**Gatekeeper** — A person employed by a managed care organization (generally a primary care physician or a case manager) responsible for monitoring and coordinating a beneficiary's health care. This individual must pre-approve specific services and referrals to specialist providers in order for the managed care organization to accept responsibility for paying for the care provided.

**Grievance** — A complaint about denial of care, inappropriate care, or other problem that is lodged by a beneficiary against their health care plan.

**Group Model HMO** — A type of health maintenance organization that operates a closed network of providers who are generally paid on a salaried basis. Unlike a staff model HMO, all of the health care providers are not located in one facility or clinic and the HMO generally does not own their own health care facilities.

**Health Maintenance Organization (HMO)** — The oldest and most common form of managed care organization in the United States. HMOs are a health care delivery system that accept a pre-paid premium and provide a specific set of benefits and services, generally through a closed network of care providers. (For specific types of health maintenance organizations, see also — Group Model HMO, Independent Practice Association, and Staff Model HMO).

**Independent Practice Association (IPA)** — A type of managed care organization in which beneficiaries may select from among a list of in-network providers. Providers accept an established capitated payment, but are free to accept patients from more than one managed care organization.

**Insurer** — A person or organization who receives a premium in exchange for agreeing to provide a certain set of benefits, should an adverse event (such as illness) occur.

**Managed Care** — An approach to the delivery of health care that seeks to integrate the medical care delivery system (physicians, hospitals and other service providers) with the insurance system that finances health care.

**Managed Care Organization (MCO)** — A health plan that seeks to manage care. Generally, this involves contracting with health care providers to deliver health care services on a capitated (per-member per-month) basis. (For specific types of managed care organizations, see also Group Model HMO, Health Maintenance Organization, Independent Practice Association, and Staff Model HMO).

**Medicaid** — A health care program that is jointly operated between the federal and state governments to provide health care to specific categories of low-income residents — cash assistance recipients, persons with disabilities, and the elderly who require long term care.

Medicaid provides health care benefits to more than 50% of all adults with AIDS in the United States (who generally qualify on the basis of disability). Additionally, more than 90% of all children with HIV disease depend on Medicaid for their health care. Most of these children and their parents qualify for coverage because they also receive cash assistance.

Federal welfare reform legislation was recently enacted that eliminates the Aid to Families with Dependent

Children (AFDC) program and replaces it with a new type of cash assistance program, called Temporary Assistance for Needy Families (TANF). Nonetheless, children and their parents who would have qualified for benefits under the old AFDC program remain eligible for Medicaid benefits.

Another important source of Medicaid coverage for people with AIDS is the medically needy program. Medically needy persons are those individuals who meet the disability requirements for Medicaid, but whose income is too high to automatically qualify for coverage. Persons may also spend down into the medically needy category whereby they spend their own resources to pay for medical care until their income minus their medical expenses would make them eligible for coverage. Although states are not required to operate medically needy programs, 36 states currently do.

**Medicare** — A federal health care program providing benefits to elderly retirees and people with disabilities who have a work history that makes them eligible for benefits. Persons under age 65 must be disabled for a period of 29 months before they qualify for benefits. While this requirement has traditionally limited access to Medicare for people with AIDS, Medicare now pays for more AIDS care than the Ryan White CARE Act. Additionally, as new treatments and other changes increase our ability to manage HIV disease,

Medicare will increase in importance as a source of health care for people with AIDS.

Some people are dually eligible for Medicaid and Medicare.

**Network** — A list of physicians, hospitals and other providers who provide health care services to the beneficiaries of a specific managed care organization.

**Ombudsperson** — A person within a managed care organization or a person outside of the health care system (such as an appointee of the state) who is designated to receive and investigate complaints from beneficiaries about quality of care, inability to access care, discrimination, and other problems that beneficiaries may experience with their managed care organization. This individual often functions as the beneficiary's advocate in pursuing grievances or complaints about denials of care or inappropriate care.

Not all states or health plans currently operate ombuds programs. These programs increasingly are being examined by consumer advocates as a mechanism for protecting the interests of beneficiaries within managed care organizations.

**Open Season** — Period (generally once per year) when persons who have a choice among more than one health plan are permitted to switch enrollment to another plan.

**Out-of-Network Provider** — A health care provider with whom a managed care organization does not have a contract to provide health care services. Because the beneficiary must pay either all of the costs of care from an out-of-network provider or their cost-sharing requirements are greatly increased, out-of-network providers are generally not financially accessible to Medicaid beneficiaries.

**Out-of-Pocket Expense** — Payments that the beneficiary must pay at the time that they access a particular health care service.

**Primary Care Provider** — A type of health care provider who is trained to recognize and treat a broad range of medical problems. Primary care physicians are frequently trained in family medicine or internal medicine.

In the context of managed care, the primary care provider often serves as the gatekeeper who must approve all referrals to specialist providers.

**Private Insurance** — Health insurance that is operated by the private sector. Any health insurance plan not operated by federal, state or local governments. This includes insurance that people obtain from their employer or as a member of a union.

**Re-insurance** — A method of limiting the risk that a provider or managed care organization assumes by purchasing insurance that becomes effective after a set amount of health care services have been reached. This insurance is intended to protect a provider from the extraordinary health care costs that just a few beneficiaries with extremely extensive health care needs may incur. (See also stop-loss insurance).

**Risk Adjustment** — A statistical method of paying managed care organizations different capitated payments based on the composition and relative healthiness of their beneficiaries. This procedure would generally compensate providers of HIV services with a higher capitated payment than providers of other (often less costly) health care services.

**Risk Corridor** — A financial arrangement between a payer of health care services, such as a state Medicaid agency, and a provider, such as a managed care organization, that spreads the risk for providing health care services. Risk corridors protect the provider from excessive care costs for individual beneficiaries by instituting stop-loss protections and they protect the payer by limiting the profits that the provider may earn.

**Risk Sharing** — A financial arrangement between health care providers, managed care organizations and another entity such as a state Medicaid program in order to spread the risk of providing health care services. This type of arrangement is often employed to protect providers and managed care organizations serving chronically ill individuals (such as people living with HIV) from financial insolvency.

**Specialty Gatekeeper** — A health care provider within a managed care organization with expertise in HIV care (or a specific area of medicine) who makes decisions regarding referrals to other providers and when it is necessary to provide specific health care services. For persons living with HIV, it is particularly important to have the designated care coordinator experienced and knowledgeable in treating HIV.

**Staff Model HMO** — A type of managed care organization that hires its own doctors as salaried employees, and generally owns its own clinics and health care facilities.

**Standing Referral** — A referral to a specialist provider that covers routine visits to that provider. It is a common practice to permit the gatekeeper to make referrals for only a limited number of visits (often 3 or fewer). In cases where the medical condition requires regular visits to a specialist, this type of referral eliminates the need to return to the gatekeeper each time the initial referral expires.

**Stop-Loss Insurance** — A type of insurance that managed care organizations purchase to protect against excessive costs associated with a few high-cost beneficiaries.

**Utilization Review** — A management technique designed to reduce unnecessary health care costs or to ensure that the least costly care option is provided. Utilization review can include: pre-certification which requires the approval of a managed care organization before a specific health care service is provided; case management which involves designating a nurse or other employee to monitor and coordinate the care that a patient receives; or imposing second opinion requirements in which a second specialist must agree that a specific

health care procedure is necessary before the managed care organization will agree to approve the expense. Various utilization review techniques can take place at different stages in the delivery process (i.e., before, during, and after a service is provided).

**Waiver** — Approval that the Health Care Financing Administration (HCFA, the federal agency that administers the Medicaid program) may grant to state Medicaid programs to exempt them from specific aspects of Title XIX, the federal Medicaid law. Most federal waivers involve loss of freedom of choice regarding which providers beneficiaries may use, exemption from requirements that all Medicaid programs be operated throughout an entire state,

or exemption from requirements that any benefit must be available to all classes of beneficiaries (which enables states to experiment with programs only available to special populations).

The federal government has only granted waivers in cases where the public has had an opportunity to provide input, and where the waivers are designed to protect both access to and quality of care.

Medicaid waivers have been used to allow states to mandatorily enroll Medicaid beneficiaries into managed care. Some of these waivers have used mandatory enrollment into managed care as a means of delivering care more efficiently and expanding Medicaid coverage to uninsured groups of individuals.

## Resources

NAPWA serves as the voice of all people living with HIV. NAPWA conducts policy analysis on Medicaid, Medicare, the Ryan White CARE Act, and the private health insurance market and also operates an information and referral program for individuals seeking information on health care and other services available in their own community. The following organizations are also engaged in various projects and activities related to Medicaid managed care:

### Henry J. Kaiser Family Foundation

2400 Sand Hill Road  
Menlo Park, CA 94025  
PHONE: (650)854-9400  
FAX: (650)854-4800  
WEBSITE: [www.kff.org](http://www.kff.org)  
PUBLICATION REQUEST LINE:  
(800)656-4KFF  
FAX BACK: (888)KFF-AIDS

The Henry J. Kaiser Family Foundation is an independent philanthropy focusing on the major health care issues facing the nation. The Foundation is an independent voice and a source of facts and analysis for policymakers, the media, the health care community, and the general public.

The Kaiser Commission on Medicaid and the Uninsured serves as a policy institute and forum for analyzing health care coverage and access for the low-income population and assessing options for reform. The Commission, established in 1991, strives to bring increased public awareness and expanded analytic effort to the policy debate over health coverage and access, with a special focus on Medicaid and the uninsured. The Commission is a major initiative of the Henry J. Kaiser Family Foundation and is based at the Foundation's Washington, D.C. office.

### AIDS Action Council

1906 Sunderland Place, NW  
Washington, DC 20036  
PHONE: (202)530-8030  
FAX: (202)530-8031  
WEBSITE: [www.aidsaction.org](http://www.aidsaction.org)

AIDS Action provides federal-level advocacy and policy analysis on Medicaid, Medicare, managed care, and other health care access issues for people living with HIV and AIDS.

### AIDS Housing of Washington

2025 First Avenue, Suite 420  
Seattle, WA 98121  
PHONE: (206)448-5242  
FAX: (206)441-9485  
WEBSITE: [www.aidshousing.org](http://www.aidshousing.org)

AIDS Housing of Washington offers technical assistance to AIDS housing and service providers on housing operations and planning issues, licensing, and developing partnerships between housing and service providers.

### AIDS Policy Center for Children, Youth and Families

918 16th Street, NW, Suite 201  
Washington, DC 20006  
PHONE: (202)785-3564  
FAX: (202)785-3579  
WEBSITE: [www.aidspolicycenter.org](http://www.aidspolicycenter.org)

The AIDS Policy Center provides technical assistance on the Medicaid managed care process with special emphasis on issues affecting children with HIV.

### Center on Budget and Policy Priorities

820 First Street, NE, Suite 810  
Washington, DC 20002  
PHONE: (202)408-1080  
FAX: (202)408-1056  
WEBSITE: [www.cbpp.org](http://www.cbpp.org)

The Center on Budget and Policy Priorities provides research and policy analysis on a broad range of budget and policy issues, with an emphasis on those issues affecting low- and moderate-income Americans. The Center has done extensive analysis of the fiscal and policy impact of various proposals for Medicaid reform.

**Families USA**

1334 G Street, NW  
Washington, DC 20005  
PHONE: (202)628-3030  
FAX: (202)347-2417  
E-MAIL: info@familiesusa.org

Families USA provides technical assistance, policy support, media training and organizing support to state-level Medicaid managed care efforts.

**Gay Men's Health Crisis**

129 W. 20th Street  
New York, NY 10011  
PHONE: (212)337-3342  
FAX: (212)337-1220  
E-MAIL: susand@gmhc.org

Gay Men's Health Crisis produces waiver analysis documents, briefing papers on managed care and people with AIDS, consumer education on managed care for people with AIDS, and has helped to draft a Managed Care Bill of Rights.

**Health Care Financing Administration (HCFA)**

7500 Security Boulevard  
Baltimore, MD 21244-1850  
PHONE: (410)786-3000  
E-MAIL: Question@hcfa.gov  
WEBSITE: www.hcfa.gov

HCFA is the federal agency that administers the Medicaid program.

**Managed Care Technical Assistance Center****Health Resources and Services Administration (HRSA)**

c/o John Snow, Inc.  
1555 Wilson Boulevard, Suite 520  
Arlington, VA 22209  
PHONE: (877)832-8635 (toll-free)  
FAX: (703)528-7480  
WEBSITE: www.jsi.com/hrsamctac.gov

HRSA's Center on Managed Care works to ensure that HRSA's programs and the vulnerable populations they serve are active and knowledgeable participants in managed care systems. The Center offers a coordinated program of technical assistance, training, evaluation and interagency collaboration. HRSA HIV/AIDS program staff also review and provide comments on Medicaid waiver applications.

**Housing Works (Albany Office)**

247 Lark Street, First Floor  
Albany, NY 12165  
PHONE: (518)449-4207  
FAX: (518)449-4219  
WEBSITE: www.housingworks.org

Housing Works provides advocacy and policy analysis on Medicaid and managed care issues in New York City and New York State. Special emphasis is placed on articulating the health care needs of homeless and formerly homeless people with AIDS.

**National Academy for State Health Policy**

50 Monument Square, Suite 502  
Portland, ME 04101  
PHONE: (207)874-6524  
FAX: (207)874-6527  
WEBSITE: www.nashp.org

NASHP serves as a technical resource center for states. It acts as a clearinghouse for best practices, as well as providing direct technical assistance to state policymakers.

**National Health Law Program**

2369 South La Cienega Boulevard  
Los Angeles, CA 90034  
PHONE: (310)204-6010  
FAX: (210)204-0891  
WEBSITE: www.healthlaw.org

NHeLP is a national public interest law firm with extensive expertise related to Medicaid and managed care. NHeLP has produced managed care consumer education materials and has analyzed state Medicaid waivers.

**National Minority AIDS Council**

1931 13th Street, NW  
Washington, DC 20009  
PHONE: (202)483-6622  
FAX: (202)483-1135  
WEBSITE: www.nmac.org

NMAC provides policy analysis and advocacy on Medicaid and managed care and its impact on people with HIV.

**Project Inform**

205 13th Street, Suite 2001  
San Francisco, CA 94103  
PHONE: (415)558-8669  
FAX: (415)558-0684  
WEBSITE: www.ProjectInform.org

Project Inform provides information to consumers and advocates for people living with HIV. Project Inform also advocates on issues related to Medicaid and managed care.

**San Francisco AIDS Foundation**

995 Market Street, #2  
San Francisco, CA 94103  
PHONE: (415)487-3000  
FAX: (415)487-3089  
WEBSITE: www.sfaf.org

SFAF engages in San Francisco County-level advocacy on Medicaid and private-sector managed care, as well as advocating on the state and federal levels.

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*NAPWA advocates on behalf of all people living with HIV  
in order to end the pandemic and the human suffering caused by HIV and AIDS.*



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